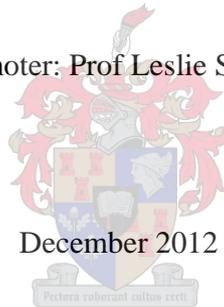


**HIV prevention issues for Deaf and hard of hearing adolescents: Views of parents, teachers, adolescents and organizations serving the Deaf community.**

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Dissertation presented for the degree of Doctor of Philosophy in the  
Faculty of Arts and Social Sciences at Stellenbosch University

Promoter: Prof Leslie Swartz



December 2012

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## **ABSTRACT**

Disabled adolescents are vulnerable to HIV infection particularly in countries like South Africa which has one of the largest HIV epidemics in the world. Like able-bodied adolescents, adolescents with disabilities are at a critical stage of their psychosocial and sexual development. They may be at risk of sexual abuse as perpetrators may believe that they are incapable of defending themselves or reporting the crime to the authorities. Deaf or hard of hearing adolescents are vulnerable to HIV/AIDS due to similar risk factors to other disabled adolescents. They also face difficulties in communicating with hearing people and receiving information in sign language, and they share characteristics with minority ethnic groups, which make them hard to reach for HIV prevention campaigns. There is a paucity of research in South Africa investigating the role of schools for Deaf and hard of hearing adolescents in delivering appropriate HIV and sexuality education to their learners. This thesis is an exploratory study and investigates HIV prevention issues for Deaf or hard of hearing adolescents in South Africa. More specifically, I aim to determine the ways in which participants believe schools, health systems and other organizations contribute or fail to contribute to the HIV/AIDS prevention needs of Deaf and hard of hearing adolescents. The study includes qualitative interviews with employees of Deaf organizations, educators of Deaf and hard of hearing adolescents, parents of Deaf and hard of hearing adolescents and Deaf and hard of hearing adolescents themselves in relation to sexuality and HIV related issues. Results indicate that Deaf organizations have an interest in the HIV prevention needs of the Deaf community and in Deaf schools. However they have experienced obstacles in delivering HIV education to learners. These obstacles include communication barriers as well as the fact that religious environments in some of the schools may not always be experienced as conducive to HIV education. Although all educators of Deaf

and hard of hearing adolescents interviewed in the previous phase of the study were aware that their learners are at risk of HIV/AIDS, some educators of Deaf and hard of hearing adolescents were constrained by the same issues of morality and religious conviction discussed in the first phase. Some participants had made efforts to produce appropriate HIV and sexuality materials for Deaf learners. Parents of Deaf and hard of hearing adolescents were affected by communication barriers with their children but seemed unaware of the religious ethos of many of the schools their children attended. The Deaf and hard of hearing adolescents knew they could be at risk of HIV/AIDS. Some displayed poor knowledge of HIV transmission. There are a number of issues to be addressed if schools for Deaf and hard of hearing learners are to provide adequate HIV/AIDS prevention information to their learners.

## OPSOMMING

Gestremde adolessente is kwesbaar vir MIV-infeksie veral in lande soos Suid-Afrika wat een van die grootste MIV-epidemies ter wêreld het. Soos nie-gestremde adolessente is gestremde adolessente in 'n kritieke stadium van hul psigososiale en seksuele ontwikkeling. Oortreders van seksuele misbruik mag gestremde adolessente beskou as sagte teikens aangesien daar die persepsie is dat hulle minder in staat is om hulself te verdedig of minder geneig is om 'n misdaad by die owerhede te rapporteer. Dowe of hardhorende adolessente is kwesbaar vir MIV / VIGS vir redes wat soortgelyk is aan die van ander gestremde adolessente. Dowe of hardhorende adolessente vind dit problematies om met horende (nie-gestremde) mense te kommunikeer, inligting in gebaretaal te ontvang, en deel te neem aan etniese minderheidsgroepe wat dit moeilik maak om hulle deur middel van MIV voorkomingsveldtogte te bereik. Daar is 'n gebrek aan navorsing in Suid-Afrika oor die rol wat skole vir dowe en hardhorende adolessente speel in die lewering van geskikte MIV en seksualiteitsopvoeding. Hierdie proefskrif verken en ondersoek kwessies met betrekking tot MIV-voorkoming onder dowe en hardhorende adolessente in Suid-Afrika. Meer spesifiek was die doel van hierdie studie om vas te stel wat deelnemers se persepsies is oor die bydrae of gebrek aan bydrae van skole, gesondheids- en ander organisasies tot die behoeftes van dowe en hardhorende adolessente wanneer dit kom by die voorkoming van MIV/ VIGS. Gedurende die studie is kwalitatiewe onderhoude met die volgende deelnemers gevoer: die werknemers van organisasies vir dowes; die onderwysers van dowes, ouers van dowe en hardhorende adolessente. Die onderhoude het hoofsaaklik gehandel oor seksualiteit en MIV-verwante kwessies onder gehoor gestremde adolessente. Die studie het bevind dat organisasies vir dowes 'n belangstelling toon in die behoeftes van dowe gemeenskappe en skole vir dowes wanneer dit kom by MIV-voorkoming. Hulle het dit egter

met tye problematies gevind om leerders op te voed oor MIV weens verskeie hindernisse. Hierdie hindernisse sluit in kommunikasie-hindernisse sowel as die godsdienstige etos wat wat in sommige skole teenwoordig is en wat nie altyd bevorderlik is tot MIV-onderrig nie. Alhoewel al die opvoeders van dowe en hardhorende adolessente gedurende die vorige fase van die studie aangedui het dat hul wel bewus is van leerders se risiko vir MIV/VIGS word sommige van hulle beperk deur bogenoemde kwessies van moraliteit en godsdienstige oortuiging. Sommige deelnemers het daarop geïndikeer dat hul pogings aangewend het om geskikte materiaal te produseer wat spreek tot MIV en seksualiteit onder dowe leerders. Ouers van dowe en hardhorende adolessente was bewus van en word beïnvloed deur kommunikasie-hindernisse, maar was nie bewus van die godsdienstige etos van die skole wat hul kinders bywoon nie. Dowe en hardhorende adolessente was bewus daarvan dat hulle die risiko loop om MIV / vigs op te doen, maar dit blyk dat sommige min kennis dra oor MIV-oordrag. Daar is 'n aantal kwessies wat aangespreek moet word voordat skole vir dowes en hardhorendes instaat sal wees om geskikte MIV/VIGS voorkomingsprogramme aan te bied wat voldoen aan die behoeftes van leerders.

## ACKNOWLEDGEMENTS

I wish to thank the following individuals who contributed to the study:

- The participants who willingly participated in the study.
- The staff at the schools for Deaf and hard of hearing learners particularly Ms Val Silva and Mrs Deshnie Naidoo for their hospitality, interest in the study and assistance with logistics.
- My supervisor Prof Leslie Swartz for his scientific rigour, knowledge of disability, patience, intellectual input and magnanimous nature. I hope to continue working with him in this field in the future.
- The late Professor Alan Flisher, who sadly passed away before the study was completed, for his original, early contributions.
- Dr John Joska and Dr Anna Strebel for their early contributions and discussions about protocol development.
- Dr Nicola Martin of the London School of Economics and Dr Linda Waldham of Sussex University for hosting me in October 2010 and for arranging for me to present results from my PhD to the Disability Equality Research Network (DERN) and the Institute of Development Studies (IDS) of their respective universities.
- Ms Clare Digby who facilitated the Oppenheimer Memorial Trust Grant awarded to me and Ms Chantal Swartz who facilitated a grant from the University of Stellenbosch to

enable me to spend time in 2011 at the University College London (UCL) while working on my PhD.

- Prof Nora Groce and her team at UCL who made me feel welcome during my stint as a visiting student in their unit from March- May 2011 and engaged my interest in a range of disability related topics.
- Dr Claudine Storbeck, Mr Lucas Magongwa and Mr Guy Mcillroy of the Centre for Deaf Studies, University of the Witwatersrand who assisted in providing resources for background reading.
- My colleagues at Stellenbosch University especially Dr Judy Mckenzie, Dr Brian Watermeyer, Dr Poul Rohleder, Dr Laila Asmal, Mr Richard Vergunst, Ms Margie Schneider, Ms Amelia van der Merwe and Ms Stine Hellum Braathen for their support and ongoing interest in my work as well as Mrs C Joubert who is always willing to provide administrative support.
- Dr Lucie Cluver of the University of Oxford for her continued interest in the project and for encouraging me to present my results at both the Orphans and Vulnerable Children Conference in 2010 and the Department of Social Development of South Africa in 2011.
- Ms Sanja Kilian for her assistance in translating the abstract of the thesis into Afrikaans.
- Mrs Dawn Kumm for the thorough proof- read of the thesis.
- My friends for their interest and the numerous informal exchanges and discussions about the topic.

- My family for their ongoing love and support throughout the project.
- In particular I wish to thank my two cousins, Adam Gibson of London, United Kingdom and Essa Adam of Cape Town, South Africa who both have hearing disabilities and who are largely my inspiration for working in this field. They have made different aspects of deafness worth trying to understand.

- This thesis is dedicated to my parents Anwar and Shahieda Mall who gave me life, unconditional love and a life-long quest for learning.

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The following papers have been published from this thesis:

Mall, S. & Swartz, L. (IN PRESS). Fear and anxiety of the risk of HIV/AIDS for deaf and hard of hearing adolescents in South Africa: Perceptions of parents. *Journal of Health Psychology*.

Mall, S. & Swartz, L. (IN PRESS). Intersections in HIV/AIDS and Mental Health. The role of deaf organizations in South Africa. *American Annals of the Deaf*.

## CHAPTER 1: INTRODUCTION

This PhD thesis explores HIV/AIDS prevention issues for Deaf<sup>1</sup> and hard of hearing adolescents in South Africa through four cross-cutting areas of analysis. These areas are: sexuality, disability, Deafness (or deafness) and HIV/AIDS prevention. The thesis consists of seven chapters:

Chapter 1 provides an introduction.

Chapter 2 reviews the literature pertaining to disability, sexuality, Deafness and HIV/AIDS risk.

Chapter 3 explores qualitative research paradigms available for studies like this one and then outlines the qualitative research methods employed in the study.

Chapter 4 presents the results of the study (Phases 1-4).

Chapter 5 presents the discussion and the conclusion and includes the recommendations arising from the study.

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<sup>1</sup> We use the term Deaf with a capital 'D' to denote affiliation to Deaf culture and communication in sign language as described by disability studies scholar, Lennard Davis in his memoir 'My Sense of Silence' (2000). We use the term 'hard of hearing' or 'deaf' to denote hearing loss but the individuals we are describing are not necessarily affiliated with Deaf culture. These definitions were discussed with the editor of the *American Annals of the Deaf* (see Appendix 1 for email correspondence with the editor). Not all deaf people communicate in sign language. This category is not necessarily related to degree of hearing loss but rather self identity. Grushkin as cited in Cambanis (2010) noted difficulty determining the boundaries between Deaf and hard of hearing as they vary along audiological, cultural and ideological lines.

In this introductory chapter of the thesis I will outline:

The definitions of disability and Deafness and key issues in the field (excluding HIV/AIDS and sexuality). This section outlines the various models of disability namely: the social, medical, capabilities and human rights models of disability. The social, capabilities and human rights models of disability are interrelated and this section considers the parallels between them.

The definitions of Deafness, the relationship of Deafness and disability, and the constructions of Deafness in relation to the social and medical models of disability.

The history of the identification of vulnerable groups in the context of the global HIV/AIDS epidemic and the exclusion of disabled people as vulnerable to HIV/AIDS.

Key debates in disability and sexuality that have influenced HIV/AIDS prevention issues for disabled people including the exclusion of disabled people from the HIV prevention sector as described above.

The historical emergence of the recognition of society of disabled people as a group vulnerable to HIV/AIDS.

The relationship between Deafness, disability, health care, and HIV/AIDS. including in definitions of disability and Deafness.

The South African context for the relationship between disability, Deafness and HIV/AIDS. This sub-section includes information about HIV/AIDS related challenges for Deaf and hard of hearing adults and adolescents as well as the efforts organizations that serve the Deaf community have made to deal with some of these challenges.

***The definitions of disability and Deafness and key issues in the field (excluding HIV/AIDS and sexuality):***

The definition of disability has been contested by scholars from medical and disability studies disciplines. Originally disability was considered a medical problem (Siebers, 2008) or simply the 'inability to do something' (Mitra, 2006, p. 237). This medical paradigm originated through the work of the American sociologist Parsons who argued that in Western society good health is a normal, desirable state of being and impairments are deviations from normality (as cited in Barnes, 1997). More recently, disabled people and researchers have acknowledged the role of social and environmental factors in influencing the definition of disability and as contributing to the experience of being a disabled person (World Report on Disability, 2011):

The transition from an individual, medical perspective to a structural, social perspective has been described as the shift from a 'medical model' to a 'social model' in which people are viewed as being disabled by society rather than by their bodies. (World Report on Disability, 2011, p. 4)

This consideration has led to further discussion regarding differing theoretical models of disability from sociological and political as well as medical perspectives (Mitra, 2006). These include the medical, social, capabilities and human rights models of disability mentioned briefly earlier in this chapter, all of which have 'far reaching social, economic and political implications' (Mitra, 2006, p. 236). I will now provide further details of the characteristics of these models of disability.

The medical model defines disability as an 'individual defect lodged in the person, a defect that must be cured or eliminated if the person is to achieve full capacity as a human being' (Siebers, 2008, p. 3). The medical model considers disability as solely biological impairment and does not

focus on social factors such as the attainment of human rights for disabled people, their experiences of discrimination, inclusion or exclusion from society. These factors are intrinsic to the experience of being disabled (Marks, 1999).

On the other hand, the social model of disability recognizes that disabled people face barriers constructed by social structures rather than physical limitations. Examples of societal barriers to inclusion of disabled people include the inaccessibility of many buildings to wheelchair users or the communication barriers Deaf people experience when attending health care services. Deaf people do not always have access to sign language interpreters and this results in further communication barriers (Shakespeare, 2006). Prominent disability scholar, Michael Oliver explains the characteristics of the social model of disability:

In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. To understand this it is necessary to grasp the distinction between the physical impairment and the social situation, called 'disability', of people with such impairment. Thus we define impairment as lacking all or part of a limb, or having a defective limb, organism or mechanism of the body and disability as the disadvantage or restriction of activity caused by a contemporary social organization which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. (Oliver, 1996, p. 22)

The social model of disability distinguishes between impairment and disability to understand the role of societal factors in the disability experience. Finkelstein and French as cited in Rohleder

(2008) define *impairment* and *disability* as concepts that are integral to the social model of disability:

*Impairment* is the lack of part of or all of a limb (e.g. arm or leg), 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 constructed by society.

As mentioned earlier, the social model of disability focuses on human rights approaches to development or an emancipatory and participatory perspective of disability (Albert & Hurst, 2004). Albert and Hurst (2004) discuss the characteristics of a human rights model of disability. They describe human rights as a concept developed during the 20<sup>th</sup> Century in response to the atrocities committed during World War 2. '(Human rights) set out an internationally accepted moral code by which the intrinsic humanity of every individual is recognized and protected. Human rights are the fundamental, universal and indivisible principles by which every human being can claim justice and equality' (Albert & Hurst, 2004, p.3). As disabled people face discrimination and this manifests in several ways, it is essential that the realisation of their human rights be recognized. Disabled people are frequently denied access to full and equal participation and due to conditions of poverty they can be at risk of further impairment. Although disabled people have themselves adopted a human rights approach and this is certainly reflected in the ethos of disabled people's organizations, their focus appears to be on understanding the oppression they have experienced. In this way, they are attempting to understand their struggles and achieve some form of social and political transformation. The human rights approach also

considers that disabled people should be agents for change on their own behalf and not allow others to act for them (Albert & Hurst, 2004).

'Nothing about us without us' was the slogan promoted by Disabled People's International at its founding in 1981 and has been used by disability rights activists ever since. It has been particularly effective in capturing a key idea of disabled people's struggle for human rights as self-determination is essential for achieving equality. This in turn has helped unite groups from countries throughout the world in a common cause. It has, for example, informed their message to governments taking part in the UN process of elaborating a convention on protecting the rights of disabled people: that in doing this they must listen to the voice of disabled people.' (Albert & Hurst, p. 7).

On the African continent, the organization Southern African Federation of the Disabled (SAFOD) has described the human rights approach to disability as one that removes physical and social barriers for disabled people, exemplifies shifts in attitudes for policy influential, employers, educators and caregivers and enforces penalties for those who violate rights of disabled people (Albert & Hurst, 2004).

However despite its preoccupation with social factors and human rights issues relating to disability, the social model of disability has also been criticized. Tom Shakespeare, an eminent disability activist and academic explains that the social model of disability came to exclude medical factors of disability completely and this was not optimal. Shakespeare (2006) explains that this model:

evolved into a rigid ideology claiming that disability was everything to do with social barriers, and nothing to do with individual impairment. Examining the history carefully shows how in Britain, one particular form of the social-contextual approach to disability-

the social model-triumphed over other, less extreme, versions of disability politics. The legend is of a polar switch: the social model replaced the medical model, thanks to the pioneering activists of the Union of Physically Impaired Against Segregation (UPIAS). (Shakespeare, 2006, p. 10)

Mitra (2006) considers Amartya Sen's capability approach which helps us to understand and develop a framework for understanding disability along with its political and social consequences. Initially this framework was developed to analyse concepts central to welfare economics. These include 'standard of living, personal well-being, quality of life, and poverty' (Mitra, 2006, p.239). The framework was initially used in the discipline of international development to analyse the relationship between disability, gender discrimination and poverty (Welch, as cited in Mitra, 2006). In his book, *Commodities and capabilities* (1985) Sen describes several central concepts to this framework including the individual capability to function versus opulence (which relates to individual's income). Sen regards capability as a practical opportunity and disregards the presence of a physical or a mental ability (Sen as cited in Mitra, 2006). Therefore Mitra (2006) places disability aptly within this framework:

Here, disability can be understood as a deprivation in terms of capabilities or functionings that result from the interaction of an individual's (a) personal characteristics (e.g. age, impairment) and (b) basket of available goods (assets, income) and (c) environment (social, economic, political and cultural). (Mitra, 2006, p. 237)

The 2011 World Report on Disability builds on from Mitra's analysis of Sen's capabilities approach and tries to propose solutions to the differences between the medical and social models, neither of which is considered complete. The report confirmed that, although the social and medical models are often presented as dichotomous, definitions of disability should incorporate

characteristics from both models. Disabilities could indeed arise from a pre-existing medical or health condition and as a consequence disabled people could experience barriers to health care, employment or education and could be stigmatized or excluded. Therefore the World Report on Disability proposed that the International Classification of Functioning, Disability and Health (ICF) (2001) be used as a conceptual framework when attempting to define disability. The ICF acknowledges that there are both environmental barriers and physical limitations that hinder the full potential of disabled people to participate in society (Officer & Groce, 2009). The ICF considers disability along a continuum of functioning and considers human functioning as operating across three dimensions:

- Impairments are problems in body function or alterations in body structure (e.g. paralysis).
- Activity limitations are difficulties in day to day activities (e.g. walking or eating).
- Participation restrictions are problems with involvement in any areas of life (e.g. discrimination in the work place or in transportation).

Countries all over the world have begun to collect prevalence data on disability through the ICF framework (i.e. focusing more on functioning than impairment). Different countries vary in prevalence rates and there are differences within individual countries themselves depending on the measures used. Two sources of data were used to report prevalence of disability in different countries for the World Report on Disability in 2011. These were the World Health Survey and the Global Burden of Disease study neither of which focused primarily on disability. Therefore the prevalence estimates presented in the World Report on Disability (2011) are not completely reflective of the true prevalence of disability. The World Health Survey, a face to face household survey conducted between 2002- 2004, is the largest multi country disability survey using

consistent questions and survey methods. The survey's conceptual framework and functioning domains are based on the ICF previously described. The survey covered different domains of health and functioning and was conducted in a total of 70 countries. These countries were recruited to the survey through a large set of criteria including income status (it was important to include a range of high income, middle income and low income countries), the paucity of disability prevalence data in some countries and the size of the adult population. The majority of these countries had data sets that could be used in estimating the prevalence of disability in the adult population (age 18 and above) (World Health survey as cited in World Report on Disability, 2011, p. 27). The second source of data for the World Disability Report was the Global Burden of Disease Study (2004). In analysing the data derived for this survey for the World Report on Disability, prevalence figures are estimated as following: 15.3% of the world population had moderate to severe disability while 2.9% had severe disability.

Table 1 on the next page show disability prevalence in 59 countries (source: World Report on Disability, 2011):

Table 1  
*Estimated Prevalence of Moderate and Severe Disability, by Region, Sex, and Age, Global Burden of Disease Estimates for 2004*

Moderate and severe disability	Sex/Age group	Global Prevalence	Africa	America	South East Asia	Europe	Eastern Mediterranean	Western Pacific
	Males	0.7	1.2	0.7	0.7	0.9	0.9	0.5
	0-14 years							
	15-59 years	2.6	3.3	2.6	2.7	2.8	2.9	2.4
	>60 years	9.8	15.7	9.2	11.9	7.3	11.8	9.8
	Females 0-14 years	0.7	1.2	0.6	0.7	0.8	0.8	0.5
	15-59 years	2.8	3.3	2.6	3.1	2.7	3.0	2.4
	>60 years	10.5	17.9	9.2	13.2	7.2	13.0	10.3
Moderate and severe disability	Males	5.2	6.4	6.5	4.6	5.3	4.4	5.3
	0-14 years							
	15-59 years	14.2	16.4	21.6	14.3	14.8	14.9	13.7
	>60 years	45.9	52.1	54.3	45.1	57.5	41.9	53.1
	Females 0-14 years	5.0	2.8	6.5	4.3	5.2	4.0	5.2
	15-59 years	15.7	12.6	21.6	14.9	18.0	13.7	13.3
	>60 years	46.3	37.4	54.3	43.6	60.1	41.1	47.0

Source: World Report on Disability (2011) p. 28.

Some of these difficulties in defining and obtaining prevalence of disability are also reflected in South Africa. In 1996, the South African Department of Health undertook to conduct a survey of disability in the country. The Community Agency for Social Enquiry (CASE) was awarded the tender to conduct the survey. This was the first national survey conducted to estimate a sense of the national prevalence of disability in South Africa. For the purposes of this survey disability was defined as a limitation in one or more daily living activities i.e. seeing, hearing, communication, moving, getting around, daily life activities, learning and intellectual or emotional processes. For each activity a series of probe questions were used to assist the interviewee in identifying possible activity limitations or disabilities experienced by themselves and/or members of their household. The results are a count of the number of people who reported disabilities or activity limitations. The results are not reflective of the full range of disability in South Africa as defined according to the ICF. Instead this survey focused on people with (permanent) moderate to severe disabilities. The fieldworkers visited 9260 households. The fieldworkers recruited households in each province in proportion to the population in each of South Africa's nine provinces). They also recruited households in rural areas across the different age and racial groups. The survey reported that 2435 of the total sample of 42974 people reported living with a disability (i.e. experiencing one or more activity limitations). When this figure is extrapolated to the general population, the survey could deduce that at the time there were between 2.3 and 2.5 million people living with disabilities in South Africa. This can be translated as approximately 5.7% - 6.1% of the total population (Schneider & Claassens, 1999).

In South Africa the 1996 and 2001 Census also incorporated questions about disability prevalence. The Census was conducted and phrased questions about disability differently to try

to obtain more representative statistics. In 1996, the survey constructed the question on disability as:

‘Does the person have a serious sight, hearing, physical or mental disability? If yes, circle all applicable disabilities for the person: Sight 1; Hearing/Speech 2; Physical Disability 3; Mental Disability 4.’

In contrast the disability question in the 2001 Census was constructed as:

‘Does the person have any serious disability that prevents his or her full participation in life activities? None 0; Sight 1; Hearing 2; Communication 3; Physical 4; Intellectual 5; Emotional 6.’

As the wording of the two questions is different, it is difficult to compare the data from the two surveys. The 2001 Census found that 2 255 982 persons (5 % of the total population) in South Africa reported having a disability. The African population reported the highest prevalence rate per population group (5.2%), and more women than men reported having a disability. Tables 2 and 3 on the next page present the number of disabled people categorized by racial group and gender:

Table 2

*Number of Disabled Persons in South Africa by Population Group and Sex*

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

Adapted from Census 2001: Prevalence of disability in South Africa, Statistics South Africa, 2005, p.12)

*Table 3**Prevalence of Disability in South Africa by Type*

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 Census 2001: Prevalence of disability in South Africa Statistics South Africa, p.12)

It is possible that in the 2001 Census the question about disability was not well formulated to elicit true prevalence data. The interviewers or the respondents may not have understood the questions entirely and disabled people who report that they function optimally in relation to questions about functioning may be excluded.

Therefore this is not necessarily a true reflection of prevalence of disability in South Africa. There are similar challenges experienced in obtaining prevalence of hearing loss in South Africa. These challenges are probably partly attributable to differing definitions of Deafness and the relationship to disability which are explained later. According to Swanepoel and Storbeck (2008) 180, 000 infants with permanent hearing loss are born annually in the Sub-Saharan African

region (based on an estimated incidence of 6 per 1, 000 live births). It is estimated that approximately 1.6. million Deaf people live in South Africa (Storbeck, 2005).

***Definitions of Deafness, the relationship of Deafness and disability and the constructions of Deafness in relation to the social and medical models of disability***

Deafness can be viewed from the point of view of either the medical model or the social model of disability. The two paradigms influence the ways in which society views Deaf and hard of hearing people and influences the education they will receive. Deaf education in South Africa is described in Chapter 3, the methods chapter.

Through the lens of the medical model, deafness (with a lower case 'd') is defined in terms of decibel levels (the volume of a sound). Schwartz, and Marschark point out that decibel levels indicate that people with severe hearing loss hear sounds from 60Db to 90Db (as cited in Morgans, 2009). Causes of permanent, congenital and early onset hearing loss (PCEHL) can be either genetic deficits or environmental causes. The genetic aetiologies include connexin 26 (a complex genetic disorder that causes interruption of potassium flow to the ear and subsequent hearing loss), Pendred and Usher syndromes. Pendred syndrome is a genetic disorder that causes sensorineural, bilateral hearing loss. Usher syndrome causes both hearing loss and a condition known as retinitis pigmentosa that results in loss of vision. There are environmental causes of deafness too including birth trauma, infection and neonatal jaundice (Olusanya, Wirz, & Luxon, 2008). According to Goldenberg, Culhane, and Johnson, maternal infections such as rubella, syphilis and cytomegalovirus can be implicated in an array of congenital defects including sensorineural hearing loss (as cited in Olusanyo, Abayami, & Oniya, 2009).

Deaf people often tend to view themselves through the lens of the social model of disability and this view is reflected in their campaigns for the right to communicate and be educated in sign language. Many Deaf people in fact see themselves as a cultural and linguistic minority rather than as a disabled group thereby rejecting the label of disability altogether. Schlesing and Meadow (1972) argued that they have rights to their own language (the sign language of their particular country), a common history, a sense of cohesion (as cited in Peel, 2004) and may partner or socialize with each other (Akbulut, 2008). Sign languages are visual-gestural means of communication used by Deaf people. Sign languages are found where there is a community of Deaf people and 'each one is a distinct, full language, using the same kinds of grammatical machinery found worldwide in spoken languages' (Pinker, 1994, p. 26). American Sign Language (ASL) is used by the Deaf community in the USA but does not resemble British Sign Language (BSL) or South African Sign Language (SASL) (Pinker, 1994).

Hearing people may choose to learn sign language to communicate with Deaf family members or friends. Sign languages can be considered in three categories: natural sign languages, pidgin sign languages, and manual sign codes. Natural sign languages e.g. British Sign Language, American Sign Language and South African Sign Language are a means of communication amongst members of a Deaf community. Erting notes that, like other languages of particular groups they denote group cohesion, a sense of community and membership (as cited in Penn & Reagen, 1990). Pidgin sign languages are used as a means of communication between Deaf and hearing people. Pidgin sign languages are 'the utilization of lexical items drawn primarily from a natural sign language in the word order and with some syntactic characteristics of a spoken language (Penn & Reagen, 1990, p. 92). Manual sign codes are direct translations of spoken language to signed language. Baker and Cokely point out that generally Deaf people find manual signed

language confusing (as cited in Penn & Reagen, 1990). Manual sign codes adhere to the structure of spoken language thereby losing qualities of natural sign languages. They fail to distinguish between concepts and result in great confusion for the Deaf child (Penn & Reagen, 1990).

Clearly, communicating in sign language is an integral component of Deaf culture. The importance of sign language to Deaf communities and Deaf culture is reflected when Deaf people are offered cochlear implants. A cochlear implant is a small, electronic device that assists in providing a sense of sound to people who are profoundly Deaf or severely hard of hearing. The implant consists of an external portion that sits behind the ear and a second portion that is surgically placed under the skin (National Institute of Deafness and Communication Disorders, 2011). Sometimes, when Deaf people are offered cochlear implants, they refuse. They report that they perceive the cochlear implant as a means of excluding them from Deaf Culture. Emily Howlett is a UK based Deaf actress who had been offered a cochlear implant before visiting her audiologist for a hearing test. The audiologist tried to persuade her to undergo a cochlear implant explaining that Howlett should not 'fall into Deaf society'. Howlett responded, explaining that although she was not born Deaf, she had since established a Deaf identity. She had acted in Deaf films, learned British Sign Language and made many Deaf friends (Swinbourne, 2011). She explained in an interview:

"My identity is as a Deaf person now. I didn't go to a Deaf school, and I didn't grow up with Deaf peers, but I'm Deaf now and I'm not sure I want to change that" as cited in Swinbourne, 2011.'

In addition to language, like other distinguishable groups, Charrow and Wilbur argued that Deaf people have their own norms and rules for social interaction including what is considered polite or humorous (as cited in Brown et al., 2010). McLellan (2002) describes an example of the

immersion in Deaf culture in a commentary in the Lancet. A lesbian, Deaf couple in the USA chose to have a Deaf baby through artificial insemination. The sperm donor they chose was also Deaf and a member of a family with a genetic history of Deafness. The couple justified their desire for a Deaf baby, saying that they saw themselves as members of a 'beautiful culture with its own history and language' (McLellan, 2002, p. 1315). They explained that these are characteristics that should be transmitted to the next generation. They reported that their decision was ethical as Deafness is not a disability like 'being blind or mentally retarded' but instead 'parallels being Jewish or black or a member of a minority group' (McLellan, 2002, p. 1315).

***The history of the identification of vulnerable groups in the context of the global HIV/AIDS epidemic and the exclusion of disabled people.***

Now that definitions of disability and Deafness have been established as well as the notions of Deaf culture and parallels between Deaf communities and other minority groups, I will describe the history of the HIV/AIDS epidemic and the exclusion of disabled and Deaf people as groups that could be at risk of HIV/AIDS infection. HIV/AIDS was first discovered in 1981 in the United States of America (USA) and its modes of transmission (i.e. mainly through unprotected sexual intercourse or exchange of blood products) were revealed through a large, epidemiological study conducted by the Center for Disease Control (CDC), USA (Jaffe, 2008). Shortly after its discovery, epidemiologists working in the USA identified the groups whose behavioural patterns made them vulnerable to infection. These included men who have sex with men (MSM) and intravenous drug users. Later, women were identified as a vulnerable group in the context of the epidemic due to exclusion from education about protection from HIV/AIDS or inability to negotiate safe sexual relationships (Mann, Gruskin, Grodin, & Annas, 1999). Therefore public HIV/AIDS prevention programmes in the USA were designed to address the

vulnerability of women. For example, effective prevention of mother to child transmission (PMTCT) programmes were implemented, antiretroviral (ARV) therapy was administered to HIV positive pregnant women and routine HIV testing was offered to all pregnant women (Center for Disease Control, 2006).

Recently, between 2005 and 2011, policy briefs and reports have been written regarding the risk factors for HIV infection for minority ethnic groups. For example, during the earlier phases of the epidemic, African Americans were led to believe that HIV/AIDS was a disease affecting white, homosexual men and therefore did not perceive themselves at risk of infection. Yet, they are disproportionately affected by HIV/AIDS.

In the Greater Mekong Sub-region of Asia (the region comprising Cambodia, the People's Republic of China, Lao, Myanmar and Thailand) the Asia Development bank has provided technical assistance to reduce the risk of HIV in minority ethnic groups. In a report produced by the Asia Development Bank in 2005, minority groups comprise about 75 million of the 255 million people inhabiting the region. They are described as having special cultural and linguistic needs with regard to information about HIV prevention. They also live in remote areas and are difficult to reach. Women are considered particularly vulnerable to HIV/AIDS due to inherent gender disparities (Asia Development Bank, 2005). In South Africa, epidemiologists identified migrant labourers, women and children (contracting HIV through mother to child transmission) as vulnerable to HIV infection. Heterosexual adults in particular were thought to be at risk of HIV (Cameron, 2005).

### ***Key debates in disability and sexuality.***

It is clear from the above discussion that disabled people have not been easily recognized as vulnerable to HIV/AIDS all over the world (Groce, 2003). I will now explain the reasons for

excluding disabled people from HIV/AIDS prevention programmes. These explanations will be supported by an outline of key issues in the intersecting debates of disability and sexuality. These include societal measures to control the sexuality of disabled people as well as a societal view that disabled people are not sexually active. Some of these issues offer an explanation why disabled people have been marginalized in HIV prevention efforts (Philander, 2007).

It is helpful to think of contemporary issues regarding HIV/AIDS and disability through the perspective of the 19<sup>th</sup> Century philosophy of eugenics, which influenced societal perceptions of the sexuality of disabled people. Eugenics is ‘the doctrine that claims it is possible and desirable through selective breeding and the elimination of undesirable individuals to alter the hereditary qualities of a race or population. Eugenics is based on the struggle for resources between fit and unfit.’ (Hume, 1996, p. 1). Therefore people who are ‘feeble-minded, insane, epileptic, diseased, blind, deaf and deformed’ (Hume, 1996, p. 1) were perceived as not having the right to exist. Advances in scientific and medical technology supported a belief that human perfection could be attained through a combination of technological and social manipulation, an improved understanding of genetics and the availability of surgical human sterilization techniques (Hume, 1996).

Sterilization of disabled people was seen as a means of preventing genetic disabilities from being transmitted to future generations. By January 1935, approximately 20 000 disabled people had been sterilized (Hume, 1996; Kempton & Kahn, 1991). During the same time period 41 states in the USA prohibited marriage of the ‘insane and feeble-minded’ (Hume, 1996, p. 1) and 17 states prohibited marriages for people who had epilepsy, yet another manifestation of an attempt to prevent disabled people from sexual relationships and to control the sexuality of disabled people.

The issue of sterilization of disabled people, though sometimes viewed as a figment of the past, has not left us. There have been recent cases (i.e. between 2007 and 2011) of sterilization of disabled women in several countries. One of the most controversial is that of 'Ashley the Pillow Angel' who lives in Seattle, Washington, USA. This was a case of great interest to bioethicists, medical professionals, disability scholars and the lay public, many of whom were appalled by it. Ashley was just over six years old when she was diagnosed with static encephalopathy, a disability that causes severe cognitive impairment. Her disabilities mean that she will be infantile or childlike for her entire lifespan, requiring assistance with basic functions such as eating or going to the bathroom (Clark & Vasta, 2007).

Her parents were concerned about her imminent sexual development including her menarche, breast development and fertility. Therefore in 2007 when she was nine years old and her transition to puberty imminent, they requested of doctors at Children's Hospital and Regional Medical Center, Seattle that she have a hysterectomy prior to her menarche. They justified the request for a hysterectomy on the grounds she should never be a mother and should she be a victim of sexual abuse, there should be no risk of an unwanted pregnancy. Secondly they requested the removal of her breast buds to prevent development of her breasts, arguing that fully grown breasts would cause discomfort (Ashley requires straps to hold her in her chair). Fully grown breasts may also encourage her caregivers to sexually abuse her. Thirdly, Ashley's parents requested that she undergo hormone therapy to limit her final adult height and weight. Although the ethics committee presented with this case was concerned that Ashley was unable to give consent to these procedures, they conceded that the operations were all in her best interests. Eventually, a hysterectomy was performed, her breast buds were removed and height attenuation treatment administered. The height attenuation treatment was considered appropriate as Ashley's

state of mind will always be childlike. Her parents thought that an adult body would be inappropriate for her. Her ovaries were not removed to ensure normal hormonal production throughout her life (Kittay, 2011).

Another similar case was debated this year in the United Kingdom. In February 2011, a British judge ruled that evidence was required before fulfilling a mother's wish to have her 21 year old intellectually disabled daughter sterilized. The mother was concerned that as her daughter already had one child, it would be difficult for her (the daughter) to support any more children. The mother was also concerned about the burden of supporting another grandchild as the rearing of the first child had been largely left to her. The court was asked to decide if the intellectually disabled woman concerned is able to make her own decisions about contraception use. If the court agrees that she lacks capacity to make her own sexual and reproductive decisions, her mother will certainly be able to have her sterilized. Ethicists questioned whether such an extreme measure was necessary. George Annas, bioethicist at Boston University, USA argued that such a decision 'needs to be based on the person's best interests, not the best interests of society or her caregivers'. He argued further that, in order to justify a sterilization of a disabled woman, doctors would need to demonstrate why a less invasive method such as contraception was inappropriate (Annas, 2011). The Mental Capacity Act (2005) (United Kingdom) also stipulates that decisions made on behalf of a person who is unable to give consent should be in their best interests and involve the least restrictive measure. In India it is encouraging to note that there are plans for a new law that will respect the rights of disabled women by outlawing the practice of sterilizations without consent. Previously, the country's public health sector had carried out sterilizations of women with intellectual disability as they were seen as vulnerable to sexual abuse. The proposed

law stipulates that sterilizations without consent will be a punishable by law. The offence could well result in an imprisonment of up to ten years or a fine (Balla, 2011).

The decision to request sterilization may be prompted by parents' or caregivers' fear of the vulnerability of their developmentally disabled child to potential exploitation, and some fear that talking about sex will encourage sexual activity. Another example of ignoring the sexuality of disabled children is the negation of privacy for adolescents with disabilities in hospitals. Adolescent girls and boys with disabilities have been placed in common wards in many hospitals. The sexual pre-occupation and self-consciousness experienced by all adolescents is often ignored because they are disabled. Both parents and professionals tend to focus on the disability and not the emerging identity and sexuality. Even for the most sophisticated parent or professional, discussing sexuality with a developmentally delayed child is challenging (Fritz, 2003). Hollomotz, as cited in Rogers (2010), and Mirfin-Veitch, as cited in Gilmore and Chambers (2010), contend that discourses that relate to disability, sexuality, intimacy and parenting are usually dominated by the need to protect disabled people from indulging in dangerous sexual behaviour.

Despite the contributions of the social model of disability to recognizing the rights of disabled people, there has been relatively little focus on sexuality issues. Finger (1992) quoted disabled feminist writer, Anne Finger, who summed up the issue of the neglect of the social model of sexual rights of disabled people most aptly:

Sexuality is often the source of our deepest oppression; it is often the source of our deepest pain. It's easier for us to talk about-and formulate strategies for changing-discrimination in employment, education, and housing than to talk about our exclusion from sexuality and reproduction. (as cited in Shakespeare, 1996, p. 5)

***The historical emergence of the recognition of disabled people as vulnerable to HIV/AIDS.***

This thesis, focusing as it does on the HIV prevention needs of Deaf and hard of hearing adolescents, exemplifies a shift in thinking about the sexuality of disabled people and the social model must have evolved to incorporate a focus on sexuality. Exploring the intersections of sexuality and disability is parallel to exploring the emergence of sexual rights for gay and lesbian people. The philosophy is human rights based and alludes to trying to win access for disabled people to the mainstream societal sexuality agenda and to challenging the ways in which sex and sexuality is perceived in modern day society (Shakespeare, 2000). It is now fairly well established, partly through the contributions of disability activists, that disabled people have the same range of experiences of sexuality as able-bodied people. Some sexual acts could cause disabled people discomfort. Therefore they need to experiment with sexual acts just like able-bodied people to find out what is pleasurable for them. They have the right to information about sexuality to empower them to make decisions about sexual lives, to achieve pleasurable experiences and to avoid painful experiences. Denying disabled people information about their sexuality could actually make them more vulnerable to sexual abuse (Maxwell, Belser, & David, 2007).

The above description of the focus on disability rights and sexuality provides a context for the emergence of the recognition of disabled people as vulnerable to HIV/AIDS infection. The magnitude of the HIV/AIDS epidemic has forced us to think critically about the sexuality of disabled people and how they are affected by HIV/AIDS (Fritz, 2003). Groce (2003) is probably one of the first eminent researchers to explicitly state the risk factors for HIV/AIDS infection for

disabled people. She identifies the risk of sexual abuse, high risk sexual behaviour, conditions of extreme poverty, and the potential for engaging in transactional sexual relationships and substance abuse as potential risk factors for HIV/AIDS for disabled people in a piece published in the *Lancet* in 2003. Groce (2005a) once again identifies the risk of sexual abuse for disabled children in several countries all over the world in a summary report prepared for UNICEF. Groce (2005b) explains that there are a number of factors that influence the extent of sexual or physical violence against disabled children. One of these factors is the stigmatization of disabled children. Sometimes the origins of this stigma are in cultural beliefs that disabled children are the result of a curse, an incestuous relationship or a sin that the parents must have committed previously.

Since these early studies conducted by Nora Groce there have been a number of studies that have investigated HIV/AIDS prevention issues for disabled people. For example, Philander and Swartz (2006) conducted qualitative research that explored the needs of visually impaired adolescents in South Africa in relation to HIV/AIDS prevention. These include modifying existing materials to Braille and audio format. Similarly Bisol, Sperb, Brewer, Kato, and Shor-Posner (2008); Groce, Yousafzai, and Van der Maas (2006), and Maart and Jelsma (2010) explored HIV/AIDS risk factors of disabled people including Deaf, visually impaired and physically disabled in a number of countries such as Brazil, Swaziland, Nigeria and South Africa.

In addition to the research on the relationship between disability and HIV/AIDS described above, further positive developments in the field include dedicated sessions to both the disabling effects of HIV/AIDS, and the risk of HIV/AIDS infection in those with pre-existing disabilities, at two major international HIV/AIDS conferences held in 2008 and 2010 in Mexico City, Mexico and Vienna, Austria respectively (Heidari & Kippax, 2009).

***The relationship between Deafness, disability, health care and HIV/AIDS.***

General health care services for Deaf and hard of hearing adolescents and adults need to accommodate their specialized communication needs. For example, there is a growing body of research on mental health and Deafness (particularly in the developed world) as well as attention to developing specialized mental health services for Deaf children, adolescents and adults. In London, United Kingdom, there is a Deaf Child and Family Service which is a part of the National Deaf Services and is located in a large public sector hospital in South West London. I visited the service in May 2011 as an Oppenheimer fellow based at the University College London (UCL). I observed the services offered through meeting with the psychiatrist and the clinical psychologist in charge as well as attending a clinical meeting where cases are discussed. The service consists of comprehensive mental health care for Deaf adults, adolescents and young children. Care is provided for mental disorders, emotional and behavioural problems by a multi-disciplinary team. Many of the health professionals on the team are proficient in British Sign Language (BSL) but they are assisted by BSL interpreters. The service works in partnership with families and carers of patients who attend the service (Deaf Child and Family Service, South West London and St George's Mental Health NHS Trust, 2011). Lessons can be drawn from the service offered for general health care services for Deaf people in general.

The risk factors for HIV/AIDS that affect other disabled people also affect Deaf and hard of hearing people including the risk of sexual abuse (Kvam, 2000). There are also important characteristics that Deaf individuals share with other minority groups that could result in increased vulnerability to HIV/AIDS. Firstly Deaf people experience communication barriers as most hearing people are not proficient in sign language. Therefore, it is difficult for researchers to address and include this population in studies investigating HIV prevention issues and for

practitioners to include Deaf people in prevention programmes. These communication barriers and access issues could result in poor knowledge of HIV/AIDS transmission making Deaf people vulnerable to HIV/AIDS (Bisol, Sperb, Brewer, Kato & Shor-Posner, 2008). A few studies (e.g. Bisol et al., 2008; Doyle, 1995; Groce, Yousafzai, Dlamini, Zalud & Wirz, 2006) have explored the knowledge of HIV/AIDS transmission of Deaf adults and adolescents. When compared to hearing peers, the knowledge of HIV transmission of Deaf people was shown to be inferior. There is little research conducted in South Africa investigating the vulnerability of Deaf people to HIV/AIDS. One study conducted by De Andrade and Baloyi in 2010 showed poor knowledge of HIV transmission of Deaf and hard of hearing adolescents in a school in Johannesburg, South Africa. Three of the seven participants recruited for the study correctly mentioned that unprotected sexual intercourse was a risk factor for HIV transmission while only one participant mentioned the risk of contracting HIV/AIDS when engaging in multiple concurrent partnerships (De Andrade & Baloyi, 2010).

### ***The South African context for the relationship between disability, Deafness and HIV/AIDS.***

I will now outline some of the HIV/AIDS issues affecting both disabled and Deaf people in South Africa. South Africa has one of the largest HIV/AIDS epidemics in the world. In 2009 5.6 million people were estimated to be living with HIV/AIDS with 310 000 deaths occurring from HIV/AIDS related causes. In the adult and adolescent population (aged 15-49 years) the HIV/AIDS prevalence is 17.8% with women aged between 25 and 29 disproportionately affected. HIV prevalence in South Africa varies by province with the Western Cape and Northern Cape regions least affected and the Mpumalanga and Kwa-Zulu Natal regions worst

affected. In 2009 the HIV prevalence for the Mpumalanga and Kwa-Zulu Natal regions was 15.4% and 15.8 % respectively (Health Systems Trust, South Africa, 2011).

Historically, the South African government has not dealt optimally with the HIV/AIDS epidemic. The post-apartheid era was characterized by President Thabo Mbeki's period of 'AIDS denialism' during which antiretroviral (ARV) treatment was not made available in the public sector. Mbeki and his government's minister of health Dr Manto Tshabalala-Msimang implemented a confusing HIV/AIDS policy. Msimang described ARV treatment as toxic and instead supported untested, traditional remedies as adequate treatment for HIV/AIDS. Their stance on HIV/AIDS resulted in large numbers of preventable AIDS related deaths and a range of dire social consequences including an increase in child headed households (Natrass, 2007).

The post-Mbeki era has seen some positive changes with regard to HIV/AIDS policy in South Africa including a widespread testing and counselling campaign. The National Strategic Plan for South Africa 2007-2011 now acknowledges that people with disabilities are vulnerable to HIV/AIDS (Simbayi & Davids, 2009).

A recent survey conducted by the Human Sciences Research Council (HSRC) in South Africa indicated that disabled people are at risk of HIV/AIDS. This study found that HIV prevalence in disabled people was relatively high (14.1% (Confidence Interval 9.9-19.6%)), higher, but not significantly higher than the national average and that disabled people had engaged in risky sexual practices. The prevalence of HIV in the general population is 10.9% (Confidence Interval 10.0% - 11.9%). This survey also found that disabled people did test for HIV/AIDS as much as able bodied people (Simbayi & Davids, 2009). Although the confidence intervals overlap and there is a wide confidence interval for the disabled population, this is the first HIV prevalence

data for disabled people in South Africa (Rohleder, 2010a) and could precede future HIV prevalence studies for disabled populations in the country.

In South Africa it is encouraging to note that there has been an acknowledgement that Deaf and hard of hearing individuals face the same challenges as other disabled people with regard to HIV/AIDS particularly from Non-Governmental Organizations serving the Deaf Community. Non-governmental organizations (NGO's) serving the Deaf community have responded to the threat of an emerging HIV/AIDS epidemic in South Africa and the vulnerability Deaf and hard of hearing people may face in this regard. These organizations, particularly Sign Language Education and Development (SLED) and the Gay and Lesbian Archives (GALA) have acknowledged the sexual development needs of Deaf and hard of hearing adolescents. The period of adolescence is a critical stage of psychological and sexual development. Adolescents with a disability could negotiate friendships easily but, as Shakespeare (1996) points out, may have difficulty 'experiencing the intimacies that non-disabled people take for granted' (as cited in Rogers, 2010, p. 64). For able bodied youth, the period of adolescence may be a period of awakening their sexuality. However for disabled adolescents, there may well be increased anxiety about their disability, resulting in diminished self-esteem (Rogers, 2010).

The SLED group whose history is described later in the thesis produced HIV education materials for Deaf school learners. These materials appear in the form of a booklet entitled 'Lifeskills, HIV and Education for the Deaf learner'. Figure 1 on the next page is an image from the SLED booklet:

- Alcohol and other drugs can increase the risk of HIV infection by making you less careful about the way you behave: you might have sex, when you don't really want to, you may find it more difficult to use a condom. You might even forget altogether about protecting yourself.
- Sharing equipment used to inject drugs can also pass on HIV. The best way to avoid infection is not to inject drugs.
- Don't have lots of different sexual partners. Stick to one partner.
- Never have sex without using a condom properly.
- Never have sex when you have other STIs.

**How can I become infected through sexual intercourse?**

- HIV is found in the sexual fluids of an infected person. For a male this means in the fluids which come out of the penis before and during sex. For a female, it means HIV is in the fluids produced in the vagina before and during sex to help make intercourse easier.
- If a male with HIV has vaginal intercourse without a condom, infected fluid can pass into the female's blood stream through a tiny cut or sore inside her body that she may be unaware of.
- If a female with HIV has sexual intercourse without a condom, HIV could get into the male's blood through a sore patch on his penis.
- If a couple have anal intercourse the risk of infection is greater than with vaginal intercourse. The lining of the anus is very delicate and is easily damaged during sex.
- If there is any contact with blood during sex, this increases the risk of infection. For example, there may be blood in the vagina if intercourse happens during a female's period. There can also be bleeding during anal intercourse.
- People with sexually transmitted infections (STIs) have a greater risk of getting and transmitting HIV.



Figure 1. Sign language education and development booklet (p. 24)

GALA, an organization which is also described in more detail later in the thesis, produced a comic book entitled 'Are your Rights Respected' focusing on reproductive rights and sexual diversity issues for Deaf youth. The comic book uses South African Sign Language (SASL) instead of speech bubbles and depicts the story of Deaf friends attending school and discovering their sexuality. Former director of GALA, Dr Ruth Morgan describes the comic book as 'a ground-breaking attempt to depict real life stories of an often unheard community' (Morgan, 2006, p. 2). The comic book was launched in Johannesburg, South Africa in 2006 (See Figure 2 below for an extract from the Gay and Lesbian Archives comic book).

# GALA comic book

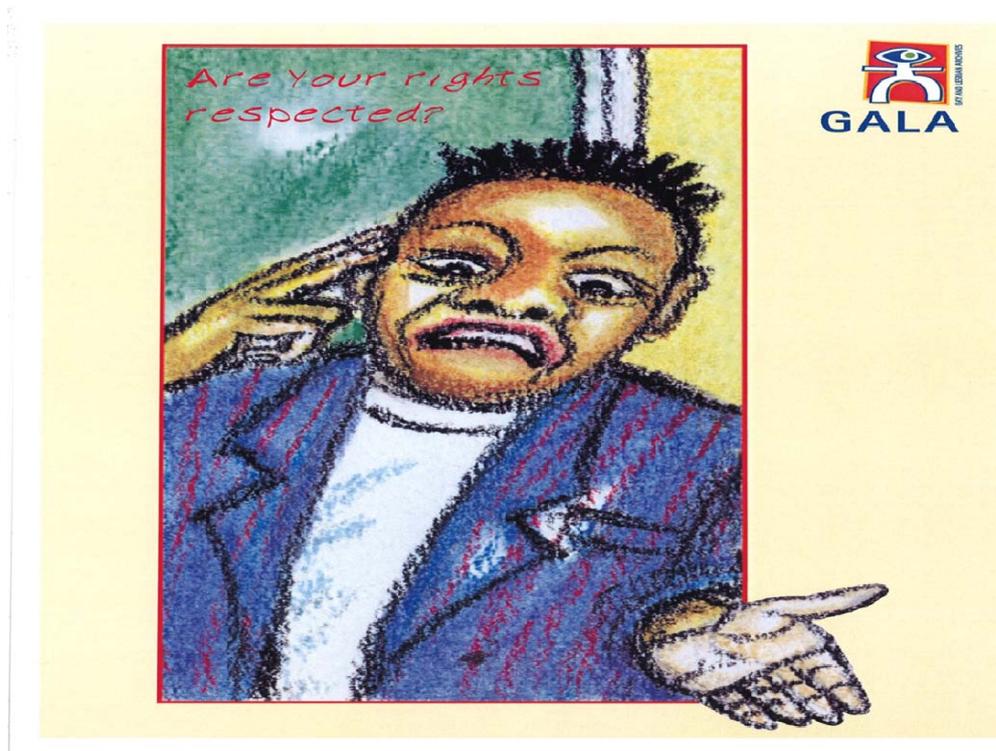


Figure 2. Extract from the gay and lesbian archives comic book (p. 1)

Prominent HIV positive South Africa activist, Judge Edwin Cameron spoke at the launch:

‘Deaf people are dying without HIV testing or treatment, family or community support.’

(Cameron, 2006)

Deaf adults and adolescents may struggle with processing information about HIV/AIDS due to special communication needs and a paucity of information about HIV/AIDS available in South African Sign language (SASL) (personal communication with Prof Clare Penn, 2008).

Despite the efforts of these NGO’s, the attitudes of the staff at the schools for Deaf and hard of hearing learners to emerging sexuality and HIV/AIDS risk is unknown. There is also the issue of

the education system in South Africa and the ways in which it may contribute to enhancing or reducing the vulnerability of disabled children to HIV infection. The publication of Education White Paper 6 on special needs education outlined a policy with regard to disability. The document highlighted the lack of basic service provision to disabled people. For example, 17.39% of disabled people in South Africa live in the country's Eastern Cape region but the province has only 41 schools for disabled learners. The report also identified the impact of racial disparities from the apartheid era on education of disabled children (Soudien & Baxen, 2006). Chapter 3 of the thesis, the methods section, provides a more detailed background of Deaf education in South Africa as a context for the research sites I chose for the study and methods employed in the PhD thesis.

## **AIMS AND OBJECTIVES**

In this thesis I aim to explore aspects of the education system for Deaf and hard of hearing adolescents in South Africa. More specifically I aim to determine the ways in which the system is contributing to the HIV/AIDS prevention needs of Deaf and hard of hearing adolescents given that Deaf and hard of hearing adolescents have special communication needs and belong to a cultural minority group. This includes an analysis of the attitudes of organizations, educators, parents and Deaf and hard of hearing adolescents to sexuality and HIV/AIDS related issues. This study is exploratory and achieves its aim through four phases:

- 1) Qualitative research with organizations serving Deaf and hard of hearing adults and adolescents

This phase, entitled 'Employees of Deaf Organizations' views on HIV issues for Deaf and hard of hearing adolescents' aims to explore the perceptions of both Deaf and hearing

staff who work at Non-governmental organizations (NGO's) serving the Deaf community, of HIV/AIDS prevention needs of the Deaf community. This phase of the research also included an exploration of the participants' perceptions of working in schools for Deaf and hard of hearing learners and their experiences of providing HIV/AIDS prevention education to these learners. This precedes the next three phases of the study all of which were conducted in schools for Deaf and hard of hearing learners.

2) Qualitative research with educators of Deaf and hard of hearing adolescents.

This phase, entitled 'Educators of Deaf and hard of hearing adolescents' views on HIV issues for Deaf and hard of hearing adolescents', aims to explore the perceptions of Deaf and hard of hearing educators regarding HIV/AIDS prevention needs of their learners. These include risk factors for HIV/AIDS of Deaf and hard of hearing learners as well as the ways in which the education programmes in these schools address these needs. This phase includes an exploration of the ways in which HIV/AIDS education material has been adapted for Deaf and hard of hearing adolescents.

3) Qualitative research with parents of Deaf and hard of hearing adolescents.

This phase, entitled 'Parents of Deaf and hard of hearing adolescents views on HIV issues for their children', aims to explore the perceptions of parents of Deaf and hard of hearing adolescents of the HIV/AIDS prevention needs of their children as well as their perceptions of the HIV/AIDS education their children are receiving at school. This phase includes an exploration of communication barriers that parents of Deaf and hard of hearing adolescents experience in relation to effective communication about sexuality with their learners.

4) Qualitative research with Deaf and hard of hearing adolescents.

This phase, entitled 'Deaf and hard of hearing adolescents' views on HIV issues that affect them', aims to explore the perceptions of Deaf and hard of hearing adolescents of their risk of HIV/AIDS and the ways in which their schools serve their HIV prevention needs.

## Chapter 2: Literature Review

### *Introduction*

As described in Chapter 1, despite the influence of the eugenics movement on the societal perception of the sexuality of disabled people, there has been a wide array of research on sexuality, disability and HIV/AIDS prevention over the past three decades. In this literature review, I describe both evidence-based research and ‘grey’ literature from as far back as 1981 when the HIV/AIDS epidemic was first discovered in the United States of America (USA). Literature surveyed for this review has been retrieved through the lenses of both the medical and social models of disability described in detail in the previous chapter. I argue that, despite the opportunities that the emergence of the HIV/AIDS epidemic has afforded to discuss intersecting issues of disability and sexuality (Fritz, 2003), the Deaf community and hard of hearing people have been sorely neglected in this regard. In most parts of the world, there are no prevalence studies of HIV/AIDS in the Deaf community, few specialized HIV/AIDS prevention initiatives for this group and few data on risk factors (Winningham, Gore-Felton, Galletly, Seal & Thornton, 2008). Deaf adolescents in particular not only have special communication needs they are also undergoing a critical stage of psychological and sexual development. I shall show that they are a marginalized group in both the research and intervention spheres. There has been limited effort to reduce their vulnerability to HIV/AIDS (Bisol et al., 2008; Mallinson, 2004a). As their communication needs are of paramount importance, I have included literature exploring communication issues in health care in general. This literature relates to some of the issues regarding language and communication that are identified in the studies exploring HIV/AIDS in the Deaf community. Lastly the literature review includes a section that describes theoretical

models of behaviour change which are important in underpinning HIV/AIDS prevention programmes.

### ***Methods or Search Strategies***

I searched the following databases for articles: Academic search premier, Academic Onefile on EBSCO host, the Cochrane library, Web of Science, Social Science Citation Index, Science Direct, Google Scholar, PUB MED, PSYCH INFO and the online catalogues of the Universities of Stellenbosch, Cape Town and Witwatersrand, South Africa. I employed the search terms: *disability, disabled people, HIV/AIDS risk and sexuality* as well as different permutations of these terms on all the different databases. As Groce (2003) identified the vulnerability of disabled people to sexual abuse as a risk factor for HIV infection, I conducted secondary searches using the terms *disability and sexual abuse*. I also searched for HIV/AIDS and sexuality literature in relation to specific disabilities. Therefore I searched for literature in relation to *autism and sexuality, Down Syndrome and sexuality, Deafness and sexuality*. As mentioned earlier communication issues are central to this project. Therefore I also included literature on communication disabilities, communication in health care and sexuality or HIV/AIDS issues. Mental disorders can catalyze high risk sexual behaviour and ultimately increase risk of HIV infection (Brown et al., 2010). Children with early onset, severe to profound d/Deafness are at higher risk of mental disorders than their hearing peers. Risk factors include developmental delays associated with early communication deprivation, central nervous system disorders associated with specific causes of deafness, and risk of sexual abuse (Hindley, 2005). I therefore included studies on mental health and deafness in the literature review to lay the groundwork for the data collection phase of the role of mental health in precipitating HIV risk behaviour. I retrieved these studies through use of the search terms *mental health and deafness*. I concede

there is a paucity of research in the area in South Africa. To my knowledge there is virtually no research investigating the role of mental disorders in precipitating high risk sexual behaviour (and ultimately potentially leading to HIV risk) in young Deaf people in South Africa or elsewhere.

In addition to the strategies described above, I searched the contents of three journals focused on disability namely *Journal of Disability and Rehabilitation*, *Disability and Society* and *Sexuality and Disability*. I searched the reference lists of all articles I retrieved from my searches for further sources to include.

With the help of my PhD supervisor, who is familiar with the disability sector in South Africa, I also contacted international and South African disability (non-governmental) organizations (NGOs) as well as the National and Provincial Departments of Health, South Africa and enquired if they had produced any educational material relating to disability and health or more specifically in relation to HIV/AIDS. I also contacted various HIV/AIDS and sexual and reproductive health NGOs to ask if they had produced any material related to disability. I acknowledge that three literature reviews (Hanass-Hancock, 2009; Hanass-Hancock & Satande, 2010; Rohleder, Braathen, Swartz & Eide, 2009) on disability, Deafness and HIV/AIDS risk were recently published and thus seek to build on the work of these authors. Two of these literature reviews focus on disability (Hanass-Hancock, 2009; Rohleder et al., 2009) more generally while Hanass-Hancock and Satande (2010) focus on HIV/AIDS related issues for the Deaf community. The latter has reviewed articles that have information about HIV prevalence in Deaf communities, knowledge of HIV/AIDS of Deaf or hard of hearing individuals and sexual risk behaviour in Deaf communities. This review has not retrieved literature from studies conducted in schools for Deaf and hard of hearing learners and has reviewed little literature from

studies conducted in South Africa. Hannass-Hancock (2009) reported on studies acknowledging the risk of HIV infection for disabled people (including lack of knowledge) and barriers to HIV prevention and care services for disabled people. Hannass-Hancock (2009) reported that there are limited studies on people with albinism in relation to HIV issues and there is also a paucity of evidence-based research on disability, homosexuality and HIV/AIDS. Rohleder et al. (2009) reported on studies on HIV/AIDS risk for disabled people including risk of sexual abuse and living conditions of extreme poverty. While Rohleder et al. (2009) and Hannass-Hancock (2009) focused on disability and HIV/AIDS and reported on available literature most extensively, they did not focus on human rights and sexuality issues pertinently. This is an area I have tried to focus on in this literature review, given that it is related to issues emerging in the results section of the thesis.

I excluded material focusing on disabilities caused by the HIV virus e.g. Ferguson and Jelsma, (2009) who provided prevalence data of motor delay in HIV positive children in South Africa or Mathew and Bhat (2008) who explored the relationship between HIV 1 and disorders of voice, swallowing and oral motor functioning.

### *Literature Sourced*

My searches retrieved 320 sources of which I included all 320 in this review. I excluded sources that were not available in English. Table 4 presents categories of the sources retrieved: reviews, studies employing qualitative methods, studies employing quantitative methods, commentaries (i.e. published articles that report on data from previous studies) or training manuals developed by disability organizations that focus on HIV/AIDS or sexuality issues for disabled people.

Table 4

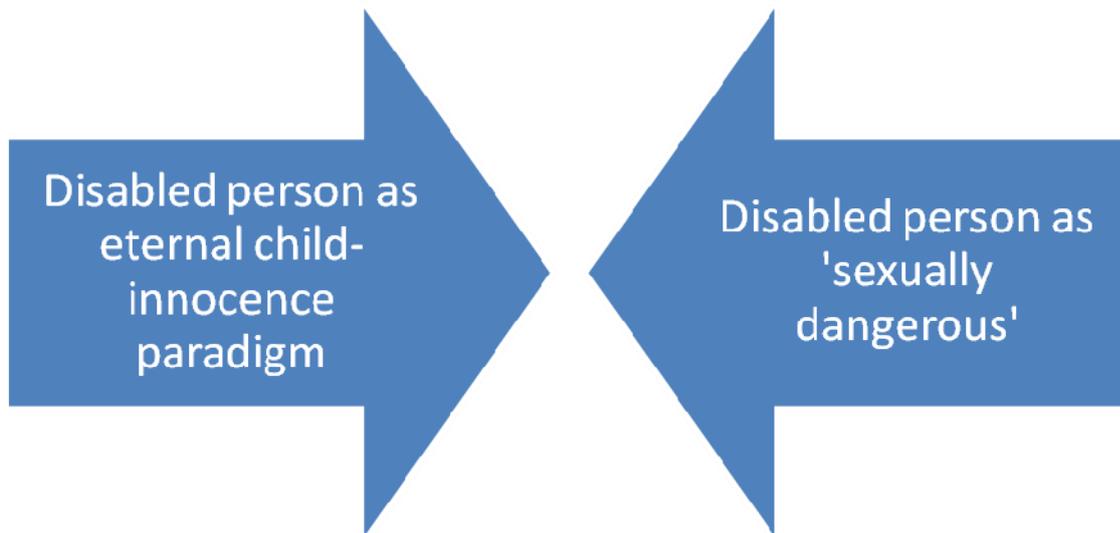
*Sources Retrieved for the Literature Review*

Category	Number of items included in literature review
Books	1
Cross-sectional survey	120
Retrospective cohort study	55
Qualitative study	70
Review	5
Reports	45
Commentary	11
Training Manual	5
Intervention	4
Post graduate theses	4
Total	320

I present and discuss the sources retrieved across the four themes identified earlier in the review, all of which are empirically derived from the sources retrieved and presented. (1) *Sexuality, disability and human rights*. (2) *HIV/AIDS risk factors for disabled people*. (3) *Public health responses to HIV/AIDS risk for disabled people*. (4) *Communication and health care* (5) *HIV/AIDS in the Deaf community: gaps in the literature*. The first three themes in which sources are categorized are relevant to the Deaf community as well.

### *Sexuality, disability and human rights*

I retrieved 74 sources that explore the intersection between sexuality, human rights and disability. While some studies or commentaries were clearly influenced by the medical model of disability others were influenced by the social model. Studies influenced by the medical model of disability, like that of Brown, tend to view the disabled child within the innocence paradigm (as cited in Gilmore & Chambers, 2010) or as a potential danger to society should they express their sexuality (see Figure 3 on which presents the components of the innocence paradigm i.e. the construction of disabled people as perennially innocent or as potentially dangerous should they express their own sexuality). Able-bodied people are also known to perceive disabled people as asexual or without the capacity to engage in intimate relationships. Milligan and Neufeldt (2001) pointed out that disabled people have been viewed as without sexual needs (as cited in Rohleder et al., 2009).



*Figure 3. Innocence paradigm*

Studies influenced by the medical model included those by Realmuto and Ruble (1999); Coskun and Mukaddes (2008) and Coskun, Karakoc, Kircelli, and Mukaddes (2009). Realmuto and Ruble (1999) presented a case study of a 21 year old autistic male attending community care. He was found to display inappropriate sexual behaviour, including excessive masturbation and a sexual interest in younger children, while taking 50 mg of loxapine succinate, a neuroleptic (drug to manage psychotic symptoms as he had also been diagnosed with schizophrenic symptoms). His caregivers and his parents were concerned about public displays of masturbation. After several incidents he was prescribed flutamine, an anti-androgen (drug that inhibits male sex hormones) and thereafter leuprolide to decrease his libido. A significant decrease in libido resulted with no further episodes of public masturbation. The medication that the patient was prescribed was effective in reducing inappropriate sexual behaviours. Coskun and Mukaddes

(2008) and Coskun et al. (2009) explored the effectiveness of mirtazapine (an antidepressant) for the treatment of inappropriate sexual behaviour in people with autism. Coskun et al. (2009) investigated the efficacy and safety of mirtazapine in the treatment of excessive masturbation and inappropriate sexual behaviour in these individuals. They recruited ten participants (two females and eight males) and prescribed mirtazapine for eight weeks. Five of their participants showed great improvement in their behaviour while three showed less improvement. The remaining participant showed moderate improvement in excessive masturbation. One participant was lost to follow up. The authors recommended the use of mirtazapine to alleviate inappropriate sexual behaviour, e.g. masturbation, in young people with autism. They also recommended further, rigorous placebo controlled studies on this topic. Lockhart, Guerin, Shanahan and Coyle (2010) identified adults with intellectual disability with sexually challenging behaviour and then matched them for gender, age and ability level with participants recruited to a control group who did not exhibit or display the same kind of sexually, challenging behaviour. Using validated measuring instruments, the study found that the sexually challenging group showed significantly higher levels of sexual knowledge in several areas.

The sources that are more influenced by the social model of disability include the book 'The Sexual Politics of Disability' by Shakespeare, Gillespie-Sells and Davies (1996). This book examines sexual politics of disability from the perspective of the disability rights movement and includes accounts of disabled people themselves. One such narrative included in the book is that of a young, disabled man who described one of his first sexual experiences at his college for disabled students. He described the 'vulnerability of the disabled male. We so often find ourselves in situations where we are exposed and naked and vulnerable. This leaves us open to domination, and even abuse' (p. 45). Dune and Shuttleworth (2009) argued that the media has

contributed to poor self-esteem in relation to the sexuality of disabled people. As popular magazines for girls between the ages of 12 and 15 portray sexuality and attractiveness to the opposite sex in a stereotypical way, those with illness and impairment could feel sexually marginalized. Similarly, Rogers (2010) discussed the portrayals of adolescence in Western culture as full of 'good looks and energy'. She pointed out that disability on the other hand is 'a signifier of ugliness, tragedy, asexuality, invalidity and frailty' (p. 64). Cambridge (1997) reported that men with learning disabilities, who have sex with other men, are excluded from the homosexual community and experience isolation. He argued that care or support arrangements actually marginalize emerging homosexual identity and people with learning disabilities are subsequently unable to have a lifestyle attributive to that of lesbian, bisexual or homosexual men.

Studies also clearly influenced by the social model of disability have explored the marginalization of disabled women and have shown that women with intellectual disability in particular have experienced obstacles in accessing contraception (Servais et al., 2002), antenatal care and general sexual health services. All too often, they have been denied the opportunity to become mothers (Jones, Binger, Mckenzie, Ramcharan & Nankervis, 2010). Chou and Lu (2011) conducted a qualitative study of decision making with regard to sterilization for women with intellectual disability living with their families. The study found that decisions to perform tubal ligation were mostly made by these women's husbands or parents in law. Their reasons for promoting sterilization were that these women were unable to care for their children, the family could not afford to support children, fear that the women's disability could be genetic and therefore passed on to their children, or fear of pregnancy from rape. Bernert (2010) explored similar research topics and conducted an ethnographic study of women with intellectual disability. The researcher collected data to learn how these women perceived their sexuality and

found that often guardians or caregivers were controlling of sexuality and relationship issues. In particular, they controlled dating patterns and marriage decisions. Similarly, Gilmore and Chambers (2010) explored attitudes of disability support workers (specifically working with people with intellectual disability) to the sexuality of intellectually disabled people. More specifically, they compared attitudes of their participants to the sexuality of intellectually disabled people, to their attitudes to patients without an intellectual disability. They found that staff were cautious about supporting pregnancy for intellectually disabled women.

Some of the studies retrieved for this review reflect on the marginalization of disabled people in sexual and reproductive health care services including the medicalization of their sexuality. Appel (2010), Eastgate (2005), Eastgate (2008), Murphy and Elias (2006), and Tissot (2009) discussed different aspects of the rights of disabled people to experience a healthy sexuality. Tissot (2009) raised difficulties of emerging sexual identity in adolescents with autism who already experience deficits, in theory, of mind and social awareness. She described the efforts of a residential school in the United Kingdom that developed education programmes to help autistic learners engage positively with their sexuality. Appel (2010), in particular, raised ethical issues in recognizing the right of disabled people to a positive sexuality though he does not address personal skills or competencies in relation to the rights he describes. According to Oriel, sexual liberty in relation to the right to sexuality is a fundamental human right (as cited in Appel, 2010). The organization Health, Empowerment, Rights and Accountability gives a definition of sexual rights and Appel based part of his argument on this definition:

sexual rights are a fundamental element of human rights. They encompass the right to experience pleasurable sexuality, which is essential in and of itself and, at the same time, is a fundamental vehicle of communication and love between people. Sexual rights

include the liberty and autonomy in the responsible exercise of sexuality. (Appel, 2010, pp. 152-3)

Appel (2010) then defined sexual liberty as:

the autonomy to make one's own sexual decisions independent of state or societal interference. Crucial to this approach to sexual liberty is the recognition that it is not merely sexual stimulation that is an essential human right, but also the sexual pleasure that stems from relations between consenting individuals. Denying an individual the right to pursue sexual contact or even intercourse with his fellow human beings would not be excusable on the grounds that this individual might achieve comparable pleasure through self-stimulation, because social scientists and sexologists have long recognized that the pleasure achieved through two party sexual contact is both greater than and distinct from that achieved through masturbation. (Appel, 2010, p. 152).

Appel (2010) states that sexual relationships within psychiatric institutions should be encouraged, that sexual liberty should only be 'curtailed to the point that it is necessary to protect the health and safety of the individuals themselves' (Appel, 2010, p. 152), and that society has a moral obligation to fund sexual pleasure for the disabled through legalized prostitution. Although the services might be costly and a strain to already limited health care resources (such as in the USA), 'the solution is to redirect resources from other endeavours to sexual health and health care more generally, not to ignore a pressing need of a vulnerable population because other vulnerable populations have equally or more pressing needs' (Appel, 2010, p. 154). Di Nucci, (2011) challenged Appel's arguments in a subsequent piece entitled 'Sexual Rights and Disability'. Although di Nucci believed that the sexual needs of the severely disabled ought to be met, he had three concerns about Appel's argument. Firstly, he questioned whether we should

introduce the right to sexual pleasure in order to meet sexual needs of the disabled. Secondly, he questioned whether we should address the sexual needs of disabled people through public funding. Lastly, he asked whether we should be encouraging legalized prostitution as a means of fulfilling the sexual needs of people who have severe disabilities. Di Nucci (2011) argued that if the public is to fund sexual services for severely disabled people, then there is an obligation to also fund services for able-bodied people. Furthermore, there would be difficulty in deciding who has access to these services and who does not.

Murphy and Elias (2006), who are members of the American Academy of Paediatrics and experienced paediatricians, and who regularly treat children with developmental disabilities, advise that paediatricians ‘introduce issues of physical, cognitive and psychosexual development to parents and their children at an early age and continue discussions at most visits throughout adolescence and adulthood’ (Murphy & Elias 2006, p. 400). They also advise that parents of young people with developmental disabilities ‘optimize independence, self-care, social skills and developmentally appropriate sexuality education in home, community and school settings’ (p. 401). Eastgate (2008), an Australian based General Practitioner, uses her experience with patients with intellectual disability to promote a human rights agenda. She argued that people with intellectual disability require education to help them resist abuse, and assistance to develop advocacy skills. This would ensure that their immediate environment is protective to them’. Eastgate (2008) promoted the role of disability organizations in providing education to young, disabled women, particularly in menstrual management, hygiene and sexuality. Similarly, Murphy and O’Callaghan, (2004) stressed the importance of empowering disabled people to be aware of their sexual rights and protecting them from abuse.

Eastgate (2008) argued that it is rarely necessary to resort to surgical intervention such as hysterectomy. There are a variety of non-invasive methods for intellectually disabled women to manage their sexuality themselves, such as oral contraception and depot medroxyprogesterone acetate. Kittay (2011) considered the issue of sterilization of disabled women without their consent. She alluded to the case of Ashley, described in the first chapter, which she perceived as a human rights violation. She proposed an ethic of care framework where unequal and dependent parties are recognized. Intellectually disabled people are sometimes unable to make the decisions themselves are 'themselves not fully equal and autonomous agents in medical situations.' (Kittay, 2011, p. 615). The parents are dependent on the doctors and medical professionals who advise them. However the ethic of care framework suggests that the carer and the medical professional make themselves transparent to the needs of the disabled person whose needs they are serving. 'As carers our moral labour demands that we imagine the world from the perspective of the one cared for; that we respond to the one cared for in accordance with her own needs, desires and interests' (Kittay, 2011, p. 615).

The studies that focus on HIV/AIDS and disability raise the human rights issues just as pertinently. Banim, Guy and Tasker 1999; Satriano, Rothschild, Steiner and Oldham (1999); Collins (2006) and Rohleder and Swartz (2009) conducted studies in relation to sexuality, disability and HIV/AIDS prevention issues. While Satriano et al. (1999) and Collins (2006) focused on mental health care providers in the USA and South Africa respectively, Rohleder and Swartz (2009) focused on educators who provide sexuality education to people with learning disabilities.

Rohleder and Swartz (2009) recruited participants who had experience in providing sexual health education to adolescents with disabilities. Their participants were not opposed to delivering

sexual health education to youth with disabilities nor did they wish to deny them capacity for a meaningful sexual relationship. However they were concerned about their perceptions of morality and moral sexual behaviour. They were reluctant to distribute condoms to disabled youth as they believed this could precipitate high risk sexual behaviour. Similarly, Satriano et al. (1999) and Collins (2006) also found a reluctance on the behalf of mental health providers in the USA and South Africa respectively to conduct sexual risk assessment on mental health patients. Collins (2006) detected moral dilemmas with regard to sexual health education among the participants that she recruited. She found that nurses working in mental health services would provide condoms to patients they suspected of being sexually active, who had a sexually transmitted infection or had been sexually abused. They did not distribute condoms to patients whom they perceived to be too ill to use them. Collins (2006) also revealed that out patients in psychiatric hospitals were found to receive limited HIV/AIDS education. Satriano et al. (1999) found that only 30.5% of staff at sites recruited conducted HIV risk assessment on their patients at admission. Furthermore a small percentage of participants (38%) stated that the assessment was only conducted if they suspected HIV risk behavioural patterns. These findings are corroborated by Wazakili, Mpofu and Devlieger (2009) and Rohleder and Swartz (2009) who conducted research in South Africa. The former found that rehabilitation and procedures for adolescents with disabilities did not incorporate sexuality and HIV/AIDS prevention. The latter found that educators of disabled people are anxious about providing sex education to their learners. They foresaw harmful consequences such as inappropriate or high risk sexual behaviour. Levin (2006) conducted research in organizations providing residential care to people with intellectual disability in the Gauteng province of South Africa. She found that most participants believed that people with intellectual disability are at risk of HIV/AIDS and that

HIV prevention programmes for the general population may be inappropriate for intellectually disabled people. Some of these participants reported that intellectually disabled people in their care could access HIV testing or ask for condoms if they required them.

It is promising that the Guardian, the United Kingdom based newspaper, has featured a few articles by disabled people and given them an opportunity to speak for themselves. The topics of these articles have been discussions about sexuality. A UK based disability consultant and feminist writer, Naomi Jacobs, shared some of her views on the subject:

Disabled people may need support, advice and even training in sex – but what we need most of all is equality in society. That not only means better physical access to all sorts of venues but also a change in social attitudes, including in the media. When we are seen as equal people, *equally sexual people*, we will be empowered to move on from the idea that we can only have sex by exploiting others. (Jacobs, 2010)

It is equally promising that the Western Cape Forum for Intellectual Disability (WCFID), 2007 a non- governmental organization located in South Africa, have responded to arguments raised above and produced three facilitators' manuals for discussing sexuality with young adults with an intellectual disability entitled 'Step by Step: a sexuality and HIV/AIDS education programme for young adults with intellectual disability'; *All About Me: a Lifeskills, Sexuality and HIV/AIDS Education Programme for Learners with Intellectual Disability* and *Sexuality Education Picture Pack: Resources for All About Me: a Lifeskills, Sexuality and HIV/AIDS Education Programme for Adolescents* . Autism South Africa has helped produce one manual for teaching adults and adolescents with autism about sexuality. The manual, specifically related to autism and sexuality, is called 'I'm Growing Up'. The WCFID and Autism South Africa were assisted by Rebecca Johns, an experienced facilitator, who has delivered sexuality education to intellectually disabled

adolescents and learners. The manuals are targeted at carers, a term used to describe people who work with or care for people with intellectual disability. This could be paid or voluntary work and could be within a home or a work environment. The term can also refer to parents or guardians. The manuals acknowledge that discussing sexuality and HIV/AIDS education is important for the prevention of HIV/AIDS and other sexually transmitted infections. The manuals also acknowledge that sexuality is a core concept of the experience of being human and people with intellectual disability have the right to a positive sexuality. Figure 4 on the next page is an extract from one of the manuals (*All About Me: A Lifeskills, Sexuality and HIV/AIDS Education Programme for Learners with Intellectual Disability*):

### ***HIV/AIDS risk factors for disabled people.***

Epidemiological studies focusing on the risk of HIV/AIDS for people with a sensory, physical, intellectual or psychiatric disability are scarce but I managed to retrieve 100 sources that explore HIV risk for disabled people through differing methodologies. Groce (2003) highlighted 'significant risk factors for disabled people around the globe' (p. 1401) in the form of commentary in *the Lancet*. These risk factors include: the societal view that disabled people are not sexually active, living conditions of extreme poverty, engagement in high risk sexual behaviour, sexually transmitted infections, poor knowledge of HIV prevention, and increased risk of sexual abuse, compared to able-bodied peers. Disabled people may live in institutions or be dependent on carers placing them at risk of sexual abuse. Perpetrators may believe that disabled people lack the skills to identify and report an attacker (Groce, 2003). Groce (2005b) highlighted the practice of 'virgin rape' that has also targeted disabled people. Perpetrators may believe that disabled people are sexually inactive and therefore they could be victims of this practice. Disabled adolescents are often socially isolated and this 'limits their opportunities to

learn to set boundaries and compromises their ability to refuse when pressured to have sex or drugs' (Groce, 2005b, p. 217). Groce (2004) conducted a global survey sponsored by Yale University, USA and the World Bank. The survey aimed to explore risk factors for HIV/AIDS for disabled people all over the world. The survey found that poverty, lack of education, lack of sex education, and substance abuse were significant risk factors for disabled people for HIV infection. Drug abuse has been reported to be higher among disabled people than in the general population (Gaskins, 1999). According to Lowry et al., substance abuse can be associated with sexual risk behaviour and could lead to the risk of sharing needles which also results in vulnerability to HIV infection (as cited in Hannass-Hancock & Nixon, 2009).

A number of studies have explored the knowledge of disabled people of transmission routes of HIV/AIDS (e.g. Chireshe, Rutondoki & Ojwang, 2010; Eide et al., in press); Otte, Van der Maas & De Boer, 2008 Yousafzai, Dlamini, Groce & Wirz, 2004). For example, Yousafzai et al. (2004) explored the knowledge of disabled youth in Swaziland of HIV/AIDS. Through community liaison efforts, the researchers designed eight focus group discussions with disabled and able-bodied youth to explore both knowledge of HIV/AIDS and perceptions of sexual risk. Although awareness of HIV/AIDS seemed consistent across both groups, the knowledge of HIV/AIDS of the disabled youth was inferior. Otte et al. (2007) compared the knowledge of HIV/AIDS of visually impaired and sighted adolescents in Nigeria. They used a standardized questionnaire that was previously employed in similar studies. The questionnaire focused on modes of HIV transmission, modes of HIV prevention and accessibility to sources of HIV/AIDS information. Their main findings were that the visually impaired participants believed that incorrect modes of transmission of HIV/AIDS (e.g. kissing) were true and many were misinformed about means of prevention.

A number of studies have reported sexual risk activity in disabled people (e.g. Choquet, Du Pasquier & Manfredi, 1997; Comulada et al., 2010; Maart & Jelsma, 2010; Mustanski, Donenberg & Emerson, 2006). Maart and Jelsma (2010) compared the sexual behaviour of physically disabled adolescents and abled-bodied adolescents in South Africa. They conducted a cross-sectional survey of risk behaviour patterns of adolescents with physical disabilities attending special schools in South Africa. This study found that adolescents with a physical disability are indeed sexually active with 27% of the sample reporting having had two or more sexual partners, and 12% of the sample believing that they were not at risk of contracting HIV/AIDS. Only 18% of the sample reported consistent condom usage. Perry and Wright (2006) explored sexual behaviour patterns in patients with mental illness and compared their findings to behaviour patterns in the general population. They found that, although patients with mental illness used condoms more consistently in their relationships than the general population, they were more likely to have sex sooner with a newer partner. This heightens the risk of HIV/AIDS. Interestingly, Almond and Giles (2008) explored differences in harmful sexual behaviour patterns in adolescents with learning disabilities and adolescents without learning disabilities, finding no significant difference in the two groups. In fact, adolescents they recruited without disabilities actually had engaged in a wider range of offensive behaviour including vaginal penetration.

Sexual abuse of disabled children is a concern when investigating risk factors for HIV/AIDS for disabled children (Rohleder et al., 2009). Kvam (2000) highlighted methodological difficulties in determining prevalence of sexual abuse in disabled people. This is due in part to general difficulties in determining the prevalence of disability in many countries (as described in Chapter 2). She suggested that it might be optimal to recruit a group of disabled adults and to investigate

whether they had been abused as children. Alternatively one could recruit a group of abused people as informants and then determine the number who are disabled. She employed the latter method in a study of 1293 children who were admitted to Norwegian hospitals between 1994 and 1996 for suspected sexual abuse. Of these, 83 were disabled. Kvam (2000) concluded that caregivers of disabled children are sometimes negligent and do not notice signs of sexual abuse. She also suggested that health care providers are also not experienced in identifying disabled children and therefore sexual abuse of disabled children is underestimated. Bernard (1999) explored further complexities in a paper about the intersections of race, disability and abuse. Her paper was about black disabled children and how they experienced the aftermath of sexual abuse. She presented case studies taken from a research project on the sexual abuse of black, disabled children. She argued that black, disabled children who had been sexually abused experience additional stressors e.g. racial discrimination.

A number of studies including those conducted by Kvam, (2004), Ryerson (1984), Sullivan and Knutson, (2000), and Chamberlain et al. (1984), found that disabled children were more at risk of sexual abuse than able-bodied children. Alriksson-Schmidt, Armour, and Thibadeau (2010) and Jenta, Fugl-Meyer and Oberg (2008) investigated the risk of sexual abuse in children with mobility impairment. Alriksson-Schmidt et al. (2010) found that female students with a physical disability were more likely to report being forced into sexual intercourse than were their able-bodied peers. Similarly, Jenta et al. (2008) found in their study of 141 children and adolescents that 7% of disabled participants reported a history of sexual abuse. Hanass-Hancock (2008) explored the vulnerability of disabled women in South Africa to HIV/AIDS in a qualitative study of both of disabled people and their care givers over a time span of 3 years. She found that the threat of sexual abuse for disabled women is a major issue. She also explored myths about HIV

and disability finding that cultural representations were also contributing to the risk of HIV/AIDS for disabled people. For example, there was great stigmatization of people with albinism. There was also anxiety that albinism had a genetic component and would be passed to the next generation. Therefore women and men with albinism did not engage easily in permanent relationships and instead were found to be at risk of unstable relationships, characterized by sexual risk behaviour. Kvam and Braathen (2008) explored the experiences of disabled girls and women in a qualitative study conducted in Malawi. They found that, as in the Hanass-Hancock study, disabled women may well engage in unstable relationships. If approached by a potential partner, they were unlikely to refuse a sexual relationship as they thought this would be their only opportunity for a relationship.

I will now describe some of the studies retrieved on exploring mental health and deafness and how they may be useful when studying risk factors for HIV infection in Deaf and hard of hearing adolescents. Kvam, Loeb and Tambs (2007) compared the prevalence of common mental disorders in Deaf and hearing populations in Norway, finding that the prevalence of depression and anxiety disorders were considerably higher in the Deaf population than in the hearing population. Similar results were yielded in a study conducted by Mejstad, Heiling and Svedin (2009) in schools in Sweden. This study was conducted in schools for the Deaf and hard of hearing as well as mainstream schools that hard of hearing learners attended. Students in special schools for the hard of hearing seemed to report better mental health outcomes than students in schools for the Deaf. Fellingner, Holzinger, Sattel, Laucht and Goldberg (2009) found a relationship between the Deaf child's inability to communicate with their family members and the frustration of being misunderstood, and psychiatric disorder. I failed to find studies that investigate the role of mental disorders in Deaf and hard of hearing adolescents and adults in

precipitating high risk sexual behaviour. Denman (2007) explored the unique cultural and linguistic needs of Deaf adults in Australia who accessed public mental health care and reported that issues that needed to be addressed included communication concerns and accessibility if the same quality of services were to be provided to Deaf and hearing adults. Feldman, Kluwin and McCrone (2005) investigated the perceptions of Deaf clients attending counselling services in Florida, USA. They failed to establish a relationship between counsellors' sign language skills and the quality of the counselling as their sample size was small ( $n = 22$ ). Some of these communication issues are further developed in the section of the review on communication and health care.

***Organizational and public health responses to the impact of HIV/AIDS on disabled people.***

There have been a range of public health and organizational responses to HIV/AIDS among disabled people. I retrieved 100 articles on this topic. The majority of these focus on HIV prevention issues for people with psychiatric disabilities. These include exploratory studies to determine the best means of preventing HIV in this disabled people, HIV/AIDS testing, interventions for disabled people and HIV prevalence studies.

Philander and Swartz (2006) conducted qualitative research to explore the needs of visually impaired adolescents in South Africa in relation to HIV/AIDS prevention. These included modifying existing materials to Braille and audio format. Neri, Bradley and Groce (2007) compared HIV/AIDS testing rates in the USA for disabled and non-disabled people. They found that adults with a disability were more likely than adults without a disability to report having been tested for HIV. It is important to note that individuals with mental health or physical disabilities were more likely to report having been tested. Individuals with intellectual disability

were least likely to report having been tested. Philander (2007) designed and implemented an intervention for visually impaired adolescents in South Africa for his PhD. He employed a quasi-experimental approach to analyse measured data and to explore the relationship between variables over time. The intervention was a tailored HIV prevention programme designed to deal with knowledge, attitudes and risk behaviours (mainly substance abuse) related to HIV/AIDS. Participants were recruited to four different groups (one was an experimental group and the others comparison groups). The experimental group received a full intensive intervention programme (HIV prevention programme) and the control groups received a pre and post intervention questionnaire before and after the HIV prevention programme. The intervention's long term impact was assessed after three months with significant differences revealed between the post test and follow up periods particularly in the area of knowledge of HIV/AIDS.

Rohleder, Swartz, Schneider Groce and Eide (2010) conducted a survey of disability organizations in South Africa. They aimed to explore the attitudes of these organizations to the ways in which HIV/AIDS affects disabled populations and the efforts of these organizations to conduct HIV/AIDS education initiatives. They found that disabled people are largely excluded from HIV/AIDS campaigns. Similarly in 2007, Morrow, Arunkumar, Pearce and Dawson (2007) conducted a survey of HIV/AIDS organizations in India to explore their level of attention to disability issues. They found that although their participants that disabled people are at risk of HIV/AIDS their organizations had limited interest in integrating disabled people in their HIV/AIDS prevention programmes.

Empfield et al. (1993), Carey, Carey, Maisto, Gordon and Venable (2001), Lohiya (1993), Merrick and Morag (2000), and Sacks et al. (1991) all conducted HIV/AIDS prevalence studies in patients with severe mental illness. Carey et al. (2001) found that almost 69% of their

participants reported that they had been sexually active in the past year and that 23% of the screened patients (n = 354) could be classified as at increased risk for HIV/AIDS. The most common risk factor for HIV/AIDS was having multiple sexual partners, diagnosis with a sexually transmitted infection, transactional sex, intravenous drug use, and sharing needles. Of the 354 patients who were perceived as being at high risk for HIV/AIDS, 83% reported a single risk factor (e.g. transactional sex), 15% reported two risk factors and 2% reported three risk factors. Wainberg et al. (2007) sought to produce a culturally appropriate HIV/AIDS prevention model for psychiatric patients in Brazil. Their model was designed through a series of steps including intensive studying of previous interventions, eliciting advice from a team of stakeholders including clinicians, researchers and mental health activists, as well as collecting data on specific HIV related needs of the target population.

### ***Communication and health care.***

Numerous sources (e.g. Killian, Swartz & Joska, 2010; Penn, Watermeyer & Evans, 2011; Swartz & Drennan, 2000;) have explored communication issues in health care and many of these studies are comparable to issues arising when Deaf or hard of hearing people access health care. Some of these studies explore the communication issues in relation to health care for the Deaf community. For example, Steinberg, Wiggins, Barmada and Sullivan (2002) explored the experiences and perceptions of 45 Deaf women in the USA who accessed health care, using qualitative methods. They found that participants generally showed poor knowledge of mammography, papanicolau smears and hormone replacement therapy. Deaf women who had had access to American Sign Language interpreters described far more positive experiences of the health sector than Deaf women who had never benefitted from the assistance of an ASL interpreter. Similarly Orsi, Margellos-Anast, Perlman, Giloth and Whitman (2007) found that,

although culturally Deaf adults in the USA may have undergone cancer screening, they did not always understand the purpose of the particular screening.

Others studies, including Aylott (1999), explored the needs of people with varied communication disabilities in relation to health care. These included exploring the needs of people with autistic spectrum disorders who might find communication in health care settings difficult, people who suffered from aphasia after a stroke (e.g. Larrson & Thoren-Jonsson 2007; Le Dorze & Signori, 2010) or traumatic brain injury, as well as studies that explore the roles of interpreters in the health care setting (Penn & Watermeyer, 2007; Swartz & Drennan, 2000). Penn, Watermeyer and Evans (2011) explored the role of cross cultural communication strategies in the dispensing of ARV treatment in clinics in South Africa. They found that communication between pharmacists and patients is critical to both successful dispensing of ARV treatment and patient adherence to the treatment regimen.

Given that communication factors are so critical in health care, I will now focus on HIV/AIDS related issues for the Deaf community. The results of the searches for literature exploring these issues are presented in the next section.

### ***HIV/AIDS and the Deaf community.***

A few studies have been conducted exploring HIV/AIDS issues in the Deaf community (Winningham et al., 2008). Two articles, Stevens (1998) and Nyang'aya (1998), outlined the social and political obstacles that Deaf people encounter when accessing HIV/AIDS prevention information. Nyang'aya (1998) described a disregard for the right of the Kenyan Deaf community to access information about HIV/AIDS, including the use of the English language in literature on HIV/AIDS, the lack of Kenyan Sign Language interpretation on the television and

on many AIDS related programs, as well as in local public meetings. In addition, Deaf people cannot benefit from the services that are offered by some organizations such as telephone hotlines for counselling purposes, as well as for medical counselling services, unless there is an interpreter. However, the presence of an interpreter defeats the main purpose of these services, which is to offer anonymity and confidentiality. Mallinson (2004a) explored the barriers faced by Deaf men who have sex with men to HIV/AIDS prevention. He found that Deaf men who have sex with men had communication difficulties when accessing testing services. They also did not trust health care providers.

Studies have highlighted various risk factors for HIV infection in the Deaf community including poor knowledge of HIV/AIDS (Doyle, (1995); Heutel and Rothstein (2001); Groce et al., 2007; Enwereji and Enwereji, 2008; Goldstein et al., 2010; De Andrade and Baloyi, 2010) and risk of sexual abuse (Kvam, 2004).

Groce et al. (2007) conducted a study in 2007 in the Deaf community in Nigeria. They found that the Deaf community were more likely than their hearing peers to believe it was possible to contract HIV through hugging, airborne transmission and sharing utensils with a HIV positive person. Like the studies exploring sexual abuse of disabled people in general, a few studies have explored similar issues for Deaf and hard of hearing people. In 1986, Brookhouser, Sullivan, Scanlan and Garbarino (as cited in Cambanis, 2010) reported high rates of sexual abuse among Deaf and hard of hearing children. Their findings were corroborated by a study conducted by Sullivan, Vernon and Scanlon as cited in Cambanis (2010) who suggested that 54% of Deaf and hard of hearing boys and 50% of Deaf and hard of hearing girls had been sexually assaulted as children and the risk of sexual abuse was double for girls and five times as high for boys who are Deaf or hard of hearing. Kvam (2004) employed similar methods to those of the study she

conducted in 2000. In this study, conducted in 2004, she recruited Deaf adults residing in Norway through the Deaf registry services. A self-administered sexual abuse questionnaire was completed by the participants with the assistance of a Deaf social worker fluent in Norwegian sign language. A hearing control group was also recruited. Deaf respondents reported sexual abuse more frequently than hearing respondents. Bisol, Sperb and Moreno-Black (2008) conducted focus group discussions with Deaf and hard of hearing youth in Brazil preceding the development of a sexual behaviour questionnaire. Initially the researchers adapted questions from studies with adolescents in Sao Paulo by Figuerido and Peres (2002) and from the adolescent AIDS scale (Zimet, 1998). They included questions specific to the Deaf community. They found that both Deaf and hearing girls were open about their sexuality and spoke freely. Deaf and hearing boys adhered more to the questions posed to them in the focus group discussion. Their follow up study (Bisol et al., 2008) found that Deaf youth were more at risk of sexual abuse than hearing youth of their age. Touko, Mboua, Tohmuntain and Perrot (2010) found in their study of the Deaf community in Cameroon that the HIV prevalence rate was 4%, comparable to that of the general population. This study found relatively high prevalence of high risk sexual behaviour among the Deaf. Among those participants who reported that they were sexually active, 53% of men and 54.3% of women reported that during the past 12 months (prior to recruitment) they had engaged in multiple concurrent partnerships. There were reports of transactional sexual activity. Taegetmeyer et al. (2009) conducted operational research in Kenya and designed a Voluntary Counselling and Testing (VCT) service run by Deaf counsellors. The aim of the study was to determine if the service could recruit Deaf clients and encourage them to test for HIV. The study found that this was a positive initiative with a number of Deaf clients testing for HIV over a two year period.

Cambanis (2010) conducted research in schools for Deaf and hard of hearing learners in South Africa. She employed both qualitative and quantitative methods to investigate HIV/ AIDS and reproductive health education in schools for Deaf and hard of hearing learners in six provinces in South Africa, focusing on the factors influencing the educator's role in implementing HIV/AIDS education. This study found a number of obstacles to implementing optimal HIV/AIDS and reproductive health education in schools for Deaf and hard of hearing learners in South Africa. These included inadequate teacher proficiency in SASL as well as moral tension experienced by teachers when they are made to deliver reproductive health and HIV/AIDS education as I shall show. It is clear that there are methodological challenges in investigating HIV/AIDS issues for Deaf adults and adolescents. These mainly pertain to communication issues as well cultural and linguistic minority issues. Deaf people are hard to reach for prevention campaigns and there is usually a paucity of sign language interpreters available to assist. This study is necessary as it faces some of these challenges directly.

### ***Theoretical Models of Behaviour Change used in HIV prevention programmes:***

Fishbein as cited by Philander (2007) is of the opinion that it is important for scholars working in the behavioural sciences to engage with theory in order to plan and evaluate programmes that could help reduce risk behaviour. Theoretical models may have the ability to facilitate an understanding of health behaviour, direct research and facilitate 'the transferability of an intervention from one health issue, geographical area or health care setting to another' (Munro, Lewin, Swart & Volmink, 2007, p ).

As identified earlier in the literature review, there is limited research conducted in relation to disabled adolescents and their risk of HIV/AIDS. Little of this research has engaged with theoretical models of behaviour change. Munro et al. (2007) identify challenges in selecting

appropriate theoretical models for their research on adherence to treatment for HIV/AIDS and tuberculosis given that there are over thirty models of behavioural change. Therefore this section of the literature review describes four theoretical models that are useful underpinnings to HIV prevention programmes and can be applied to both able-bodied and disabled people. These models are: the health belief model (HBM), the AIDS risk reduction model (ARRM), stages of change and theory of reasoned action. The health belief model in particular is considered useful to this study as its key variables focus on perceptions of risk of disease including sexually transmitted infections and HIV/AIDS. I will revisit the HBM in the discussion section of the thesis and draw on its variables in relation to the data for the educators' and adolescents' phases:

*Health belief model:*

The HBM was developed in the USA during the 1950s by social psychologists who were concerned about the limited uptake of free screening programmes for TB available to the public sector. Subsequent to that, the HBM was adapted to HIV/AIDS related risk behaviour. According to this model, the perceived seriousness of a disease such as HIV/AIDS as well as one's perceived susceptibility or risk influence one's health behaviour. Demographic and social variables also influence perceived susceptibility and perceived seriousness of disease (Munro et al., 2007). Therefore the key variables of the model as defined by Rosenstock, Strecher and Becker (1994) are:

**Perceived threat**- this variable consists of two parts: perceived susceptibility and perceived severity of a health condition (e.g. HIV/AIDS).

**Perceived susceptibility** refers to the individual's subjective perception of the risk of contracting a health condition while **perceived severity** refers to the perceptions of the medical and social consequences of the disease.

**Perceived benefits:** this refers to how the individuals concerned view strategies to reduce the risk of contracting the illness (e.g. condoms to prevent HIV transmission).

**Perceived barriers:** this refers to how individuals perceive consequences of illness including social stigma or financial problems.

**Cues to action:** These are events that encourage people to take action on disease prevention e.g. media advertising.

**Self-efficacy:** the belief in being able to enact the behaviours.

### *The AIDS reduction model*

The ARRM is similar to the HBM and also provides a framework of behaviour change of individuals in relation to preventing sexual transmission of HIV/AIDS. This model is a three-stage model and incorporates several variables from other behaviour change theories, including the HBM. These include "efficacy" theory, emotional influences, and interpersonal processes. The stages, as well as the hypothesized factors that influence the successful completion of each stage are as presented below as outlined by Catania, Kegeles and Coates (1990):

#### **STAGE 1: Recognition and labeling of one's behaviour as high risk**

This stage consists of hypothesized influences including belief that one is at risk of HIV/AIDS, that HIV/AIDS is socially undesirable and of knowledge of HIV transmission.

**STAGE 2: Making a commitment to reduce high-risk sexual contacts and to increase low-risk activities**

This stage consists of cost and benefits and response efficacy (i.e. will the behavioural changes reduce risk of HIV infection), self efficacy as well as group norms or social support.

**STAGE 3: Taking action.**

This stage is broken down into three phases and includes :

- 1) information seeking;
- 2) obtaining remedies;
- 3) enacting solutions.

***Stages of Change:***

The stages of change theory was developed in 1982 in the USA. Psychologists were researching means of developing appropriate interventions for smokers. The stages of the model try to develop appropriate change for particular stages of the behaviour. As a result, the four original components or stages of the Stages of Change Theory (pre- contemplation, contemplation, action, and maintenance) were identified and presented as a linear process of change. Later, a fifth stage (preparation for action) has been incorporated into the theory, as well as ten processes that help predict and motivate individual movement across stages. In addition, the stages are no longer considered to be linear. Instead they are viewed as components of a cyclical process that is moderately different for each individual. The stages and processes, as described by Prochaska, DiClemente and Norcross (1992), are listed below:

**Pre-contemplation:** Individual has the problem (whether he/she recognizes it or not) (e.g. sexual risk behaviour) and makes no effort to change their behaviour.

**Processes:** Consciousness raising. In this phase the individual begins to absorb information and knowledge about the risk behaviour.

**Contemplation:** In this stage the individual recognizes the problem and begins to think seriously about changing.

**Processes:** Self-reevaluation (assessing one's feelings regarding behavior)

**Preparation for Action:** Individual recognizes the problem and intends to change the behavior within the next month. The individual reports behaviour change (e.g. condom usage) However, the defined behavior change criterion has not been reached fully (i.e., consistent condom usage).

**Processes:** Self-liberation (commitment or belief in ability to change)

**Action:** Individual has enacted consistent behavior change (i.e. consistent condom usage) for less than six months.

**Processes:** Reinforcement management (overt and covert rewards). This includes social support networks and access to self-help groups.

**Maintenance:** Individual sustains new behaviour for six months or more.

***Theory of reasoned action (TRA):***

The TRA is 'Based on the premise that humans are rational and that the behaviors being explored are under volitional control, the theory provides a construct that links individual beliefs, attitudes, intentions, and behaviour' (Fishbein, Middlestadt & Hitchcock, 1994). The TRA assumes that a person's intention to perform a specific behaviour is the only predictor of that behaviour. The intention to perform the behaviour is influenced by attitudes towards the action concerned e.g. beliefs as well as the evaluations of the behaviour. Furthermore it is influenced by

subjective norms including the perceived expectations of others. Behavioural intention then leads to action (Munro et al., 2007).

Components of the theory in more detail are presented below:

**Behaviour:** A specific behaviour defined by a combination of four components: action, target, context, and time (e.g., implementing a sexual HIV risk reduction strategy (action) by using condoms with partners (target) every time).

**Intention:** The intention to adhere to behaviour (e.g. condom usage) is the best predictor that the desired behavior will actually occur. In order to measure it accurately and effectively, intent should be defined using the same components used to define behavior: action, target, context, and time. Both attitude (person's feelings towards performing the defined behaviour) and norms (a person's perceptions of other people's perceptions of the behaviour).

In the discussion section, I will revisit how the HBM is most applicable to this study. Perceived benefits, the component of the HBM which refers to how the individuals concerned view strategies to reduce the risk of contracting the illness (e.g. condoms to prevent HIV transmission) is relevant to the ways in which educators and adolescents interviewed for this study respond to the threat of the HIV epidemic.

### ***Motivation for the Research and Conclusions***

This literature review shows that there is a substantial amount of research on disability, sexuality and HIV/AIDS covering issues that are relevant to Deaf and hard of hearing adults and adolescents. A number of studies exploring the intersections between HIV/AIDS, sexuality and disability raise the human rights issues pertinently. There is also a growing body of literature investigating the risk factors for disabled people with regard to HIV infection and there have

been a few interventions in this regard. The HIV risks described for disabled people are similar to those identified for able-bodied people and there is limited research conducted in South Africa to determine the nature of risk for disabled people with regard to HIV/AIDS. Deaf and hard of hearing adolescents and adults also face communication barriers to accessing adequate HIV prevention information. Yet, there is limited research focusing on Deaf and hard of hearing youth in South Africa and their HIV prevention needs, particularly in relation to communication. Cambanis (2010) conducted research in schools for Deaf and hard of hearing learners in South Africa and found a range of inhibitory factors. These included poor SASL instruction in the schools and moral and religious conflict on behalf of the educators.

The principal motivation for my research is to build on some of the work conducted by Cambanis (2010) in relation to HIV prevention needs for the Deaf and hard of hearing. Firstly, my study aims to explore the context of the schools for the Deaf and hard of hearing in relation to the environment for delivering HIV/AIDS and sexuality education. Secondly, I seek to explore the ways in which the schools are accommodating the HIV/AIDS prevention needs of Deaf and hard of hearing adolescents. I would also like to engage with the Health Belief Model described above and how its components relate to attitudes of participants recruited for the study.

### **Chapter 3: Methods**

This chapter describes the methods employed in the study. Firstly, the rationale for the qualitative approach is offered as well as different approaches to qualitative methods from which I extracted ideas. The history of Deaf education in South Africa and Deaf organizations in South Africa are also described so that the reader gains a sense of the context for the research sites. The tools employed for analysing the data - the framework approach - are also described.

The research question: Investigating HIV prevention needs of Deaf and hard of hearing adolescents in South Africa, determined the choice of qualitative methods. As I have demonstrated in previous chapters, we know relatively little about the issues at hand and an exploratory qualitative approach is suitable for mapping out a new field. Qualitative research consists of a number of different approaches. Usually the researcher chooses the most appropriate methodology according to the research problem (Silverman, 2010). I considered a number of different qualitative approaches for collecting and analyzing the data in consultation with my supervisor.

Silverman (2010) refers to 'a model of reality' (Silverman, 2010, p. 190) to guide the formulation of the research question. In this thesis I sought to explore how different groups of people who work with Deaf and hard of hearing adolescents as well as the adolescents themselves, in South Africa, perceive HIV/AIDS prevention needs for this group. I was interested in asking empirical questions about the topic. Collecting ethnographic data can be useful when researching a group of people such as a cultural or a linguistic minority. Although I did not employ an ethnographic approach to collecting data for this study, there are useful lessons to be gained from ethnographic studies, for example, with regard to research access.

Walsh (as cited in Silverman, 2010) distinguished between two different kinds of research settings where ethnographic methods can be employed:

- Closed or private settings where access is controlled by gatekeepers.
- Open (accessible) or public settings where access is possible but not always without difficulty. There may be practical or ethical difficulties in accessing the group concerned.

In the case of ethnographic research methods, depending on the research problem chosen, two means of research access can be employed:

- Covert access without subjects' knowledge.
- Overt access based on informing subjects and getting their agreement, often through gatekeepers.

Given the importance of ethical issues here, and the history of exclusion of Deaf and disabled people from decision-making in general, an overt approach to access was employed for this study.

The research for this thesis requires a qualitative approach for a number of reasons. Firstly, the research is exploratory as there is a paucity of research conducted on HIV/AIDS concerns for Deaf and hard of hearing adolescents in South Africa. Secondly, a number of sources (Storbeck, 2005; Storbeck, Magongwa & Parkin, 2009) indicated that, as the literacy levels of Deaf and hard of hearing adolescents and adults in South Africa tend to be poor, a self-administered questionnaire would not be an optimal method of data collection. I was advised that qualitative research, where I could interview participants one on one or through joint interviews (where participants are interviewed in pairs), or focus group discussions (consisting of four participants

or more) would be the best means of data collection for this project. I was advised by a number of people who have worked with the Deaf community in South Africa and other countries, that the assistance of a SASL interpreter would be imperative for the data collection process. Given that Storbeck et al. (2009) indicate that literacy levels of Deaf adolescents and adults in South Africa tend to be poor, written instructions would not have been appropriate for this study (personal communication with Leila Monaghan & Claudia Bisol, August 2008).

Qualitative research methodology consists of different procedures. These include individual interviews, joint interviews or focus group discussions. Individual interviews are considered a generic method of qualitative research methodology but can take a number of forms e.g. semi structured or structured interviews (Lambert & Loiselle, 2008). Focus group discussions (FGD) are a flexible form of qualitative research methodology and are employed to explore a range of issues. Their greatest advantage is their ability to provide interaction data (from the discussion between participants). Not only does this increase the depth of the responses, it also 'unveils aspects of the phenomenon assumed to be otherwise less accessible' (Lambert & Loiselle, 2008, p. 229), as FGD develop from the interaction of 'context dependent group interactions' (Lambert & Loiselle, 2008, p. 229). Hollander (2004) outlines four different social contexts that could develop within the group and influence the dynamic or interaction between members:

- (1) Associational context (common characteristic(s) that have brought the participants together).
- (2) Status context (social status of participants).
- (3) Conversational context (flow of the discussion and types of discussion within the group).
- (4) Relational context (how well the participants knew each other before).

According to these contexts created within a particular FGD, participants could feel comfortable disclosing information. In addition, there is the potential advantage that participants could view the FGD as a discursive space and a means through which they could construct their experiences. Therefore an additional realm of data could be obtained (Lehoux, Blake & Daudelin, 2006).

Some participants in my study requested joint interviews or to be interviewed at the same time as a colleague or spouse (i.e. in groups of two). They thought that the discussion would be enhanced if joint interviews were conducted as data produced through a joint interview is different to data obtained from an individual or one on one interview. Although this was entirely at request of the participants, I respected their wishes due to the potential benefits of joint interviews. Potential benefits of joint interviews include more comprehensive data and the elicitation of similar and different findings on particular issues. There is also the possibility that the joint interview would give a participant confidence to express their perceptions on a particular issue (Polit & Beck, 2004). Studies employing these methods have explored different generations' attitudes to health enhancing behaviour (Backett, 1990), experiences of non-sexist child rearing (Statham, 1986), and the experiences of living with a disabled child (Baruch, 1981; Voysey, 1975).

In order to fulfil the research question, similar innovative qualitative methods were required. This approach helped to explore the research question from different angles. As the Deaf community consider themselves a cultural and linguistic minority, aspects of the ethnographic approach to qualitative research were employed. I visited Deaf organizations before commencing the research to gain support for the project. Some of the participants also requested to be interviewed through focus group discussions (FGD) rather than as individuals. They felt that their responses would be well framed if they could be interviewed with colleagues. They also felt

that as the researcher I would gain more from FGD than from individual interviews, as I would see their arguments and perceptions more coherently. The decision to use this form of triangulation (i.e. individual interviews, joint interviews and focus group discussions) was prompted by a need to obtain a comprehensive understanding of the HIV/AIDS programmes developed by these organizations. Qualitative method triangulation is employed as a strategy to 'lead to enhanced data richness and depth of enquiry' (Lambert & Loiselle, 2008, p. 228). There are three rationales for integrating the two methods:

1. Pragmatic reasons
2. The need to compare and contrast participants' perspectives.
3. Striving towards data completeness.

Lambert and Loiselle (2008) used a case study of patterns of information seeking about cancer to illustrate the value of this approach. They conducted a combination of individual in-depth interviews and focus group discussions to explore information seeking about cancer (Lambert & Loiselle, 2005).

I searched for a qualitative study similar to the study I was envisaging for my PhD. Preferably the comparative study should have recruited disabled people as participants. Philander (2007) developed a methodological framework for exploring HIV/AIDS prevention needs in adolescents with visual impairment in South Africa, an under researched phenomenon at the time. His approach consisted of preliminary qualitative work with key informants who work with people with visual impairments, the development of an intervention focused on risk reduction strategies specifically for a adolescents with a visual impairment, as well as a qualitative process to gain information about the intervention. The subsequent qualitative process aimed to gain a deeper understanding of the concerns and experiences of participants who participated in the

intervention. The qualitative approach in particular was motivated by a range of theorists as it allowed for in depth investigations and a flexible and iterative approach. Tillotson and Maharaj, and Jacelon and O'Dell both cited in Philander (2007) believed that the advantage of qualitative research in a context such as this one is that it contributes to understanding risk behaviour and the contextual idiosyncrasies that affect attitudes, beliefs and behavioural practices. Researchers such as Hartley and Huhit, and Latkin and Knowlton (as cited in Philander, 2007) argued that qualitative investigation is essential to generate a deeper understanding of the attitudes, beliefs, and perceptions of adolescents, and how they affect risk behaviour and safe sex practices. The intervention developed by Philander (2007) showed significant changes in visually impaired adolescents' knowledge of HIV/AIDS across time.

A similar qualitative approach that Philander employed before his intervention is employed throughout my study, although I will not be producing an intervention just yet. Depending on the availability of funds in the near future I may use this formative qualitative research to design a HIV/AIDS related intervention for Deaf and hard of hearing adolescents. I raise this issue as one of the recommendations from the thesis in the discussion chapter. For now, my formative qualitative research aims to explore HIV/AIDS prevention needs of Deaf and hard of hearing adolescents in South Africa. Similar to the community studied for Philander's study, the Deaf community in South Africa are also under researched and their HIV prevention needs virtually unknown.

### **Study Context**

In order to provide a context for the study, I will now provide a brief history of disability, and disability and Deaf organizations in South Africa, as well as a history of the country's Deaf education system. As the research was conducted at Deaf organizations and Deaf schools it is

important to provide a context for the research sites. I have also included a background to the language policies of the schools in South Africa. This is of great importance to the study.

South Africa adopted a new Constitution in 1996 that acknowledged the role of civil society organizations and individuals in contributing to the new democracy. The Constitution also stipulated that all South Africans, including those with a disability, have basic human rights. Disabled people may not be discriminated against on the basis of their disability. During the apartheid era disabled people suffered discrimination regardless of racial background. However, the experiences of black and white disabled people were quite different. Black disabled people experienced added pressures and discrimination. Disabled People South Africa (DPSA) was founded by disabled activists as a response to both international events and the unfairness of the apartheid era. DPSA is modelled on an international organization called Disabled People's International (DPI). The organization is also inspired by the pioneering work of the Self-Help Association of Paraplegics in Soweto, South Africa and of disabled activist Joshua Malinga who started the Zimbabwean movement of disabled activists. In its philosophy DPSA also has traces of the Black Consciousness Movement in South Africa. DPSA does not differentiate amongst different disabilities. The organization believes that distinction between disabilities would redirect focus on impairment rather than disability (Howell, Chalklen & Alberts, 2006).

There are organizations that were founded to respond to the needs of the Deaf community in South Africa. They focus on literacy issues, campaigns for the right to information in SASL, HIV/AIDS issues, mental health issues and general inconsistencies in the education system.

The National Institute of the Deaf (NID) in Worcester, Western Cape, claims to be the oldest organization in South Africa serving the Deaf community. The NID was founded in 1881. The NID consists of a Deaf nursery, primary and senior school, a college, and an old age home. It

provides employment for deaf residents through its tea garden and Deaf market and also provides food services and support services. As the NID has a Christian ethos, there is a training programme for Deaf pastors. There is also a residential facility known as “Lewensruimte” (Space for living) that caters for the medical and social needs of deaf people with additional intellectual disabilities. “Lewensruimte” is modelled on a therapeutic community model where residents participate in the decision making. The model includes: positive appreciation and promotion of human decency, community interaction, and a biopsychosocial approach, as well as appropriate evaluation, care, rehabilitation, therapy and development programmes, with a view to maximum independent functioning. Residents of “Lewensruimte” have access to a monthly mental health service and are assisted in employment options. The NID has a strong interest in community service and enlists the assistance of a social worker to support Deaf people in disadvantaged communities in the Boland/Overberg district.

The Deaf Community Cape Town (DCCT) aims to serve the needs of historically disadvantaged Deaf communities. In 1996, the DCCT developed a literacy project for Deaf adults (Glaser & Lorenzo, 2006). DCCT started training Deaf VCT counsellors in 2008 (personal communication with Steven Lombaard and Ronel Davids, 2010).

Sign Language, Education and Development (SLED) described in the introduction of the thesis was founded in 2001. SLED responded to the paucity of appropriate materials in SASL for the Deaf community by creating manuals on HIV/AIDS prevention for Deaf youth. SLED participates in the health and social sectors

The Gay and Lesbian Archives (GALA) based at the University of the Witwatersrand, South Africa have had an interest in the Deaf community and HIV/AIDS issues since 2002 (personal communication with Dr Ruth Morgan, February 2010). The comic book produced by GALA that

was described earlier in the thesis was implemented in Deaf schools. The project was detailed and included a number of different phases including two HIV and AIDS information sessions for all teaching staff at the school, six HIV and AIDS training sessions with five Deaf facilitators comprising two Deaf teaching assistants and two Deaf teachers at Sizwile and twelve contact sessions with learners from Grades 7 to 12 co-facilitated by GALA staff members, teaching assistants and teachers, and monitored by an independent consultant (Morgan, 2006).

The South African Society of Mental Health and Deafness (SASMHD) was founded in 2003 by a mixed group of mental health professionals and people working closely with the Deaf community. SASMHD is concerned with the delivery of mental health services in SASL. Delivering mental health care to Deaf patients in SASL can result in prompt recognition of mental distress and appropriate access to care. SASMHD has facilitated mental health workshops in the Deaf community. SASMHD also has contact with the Africa Contact Group for Mental Health and Deafness (ACGMHD). ACGMHD has established networks between African countries. African countries' contributions to providing health, education and social services to the Deaf community with regard to health and education were presented at the ACGMHD workshop in Swaziland in 2011. I was invited to address this workshop in 2011 and presented data from this thesis. I also attended various presentations about Deafness at this meeting.

Although disability and Deaf organizations in South Africa have taken both models of disability into account, their ethos has not infiltrated into the country's schools for Deaf and hard of hearing learners.

There are 43 schools for Deaf and hard of hearing learners in South Africa (Storbeck, 2005) of which the majority have historically religious roots. The Roman Catholic Dominican Order is the founder of Deaf education in South Africa and the first schools for Deaf or hard of hearing

learners were started by the Order. The Dominican Grimley School was opened in Cape Town, South Africa, in 1863. The nuns implemented and adhered to the principles of oralism which can be regarded as hegemony from the hearing world and could potentially forfeit Deaf autonomy.

In 1877 the German Dominican sisters opened the Dominican School for Deaf and hard of hearing learners in King Williams Town in the Eastern Cape Province, South Africa. This school then migrated to Johannesburg, Gauteng Province, South Africa and today is known as St Vincent School for the Deaf or hard of hearing learners. In 1881, the Dutch reformed church opened the Institute for the Deaf and Blind in Worcester. The school expanded rapidly and in 1905 separated into schools for Deaf learners and blind learners. Today we know the school for Deaf learners as De la Bat School for Deaf Learners (Peel, 2004). Historically De la Bat School has used oralism as a medium of instruction and SASL for learners who had difficulty in learning how to speak. Today SASL is used as a medium of instruction and the school teaches English and Afrikaans as second or third languages for reading and writing depending on what the learners require (personal communication with Anna-Maria Loftus, September, 2011).

I will now describe the apartheid government's influence on Deaf education in South Africa. In 1934, state schools in South Africa were separated into the categories European and non-European. This separation was further enforced during the Nationalist Government's rule from 1948. In 1934 the Dominican Grimley School in Cape Town split into two schools of which one was located in Hout Bay and the other in Wynberg. The Hout Bay school accepted only white learners and the Wynberg school was allowed to accept 'coloured' learners. In 1941, the first school for black, Deaf learners was established in Katlehong (Peel, 2004). De la Bat School accepted white learners during this time (personal communication with Anna-Maria Loftus, August, 2011).

In 1953, the government endorsed an act known as the Bantu Education Act in the general education system. The Act stipulated that black Africans would be educated separately from other racial groups and that education would prepare them for future careers as labourers. In the Deaf education system, this segregation resulted in inconsistent language policies, with some schools educating their learners in South African Sign Language (SASL) and others enforcing oral methods. From as early as 1948, lessons were delivered in schools for black Deaf learners and hard of hearing children in basic sign language, while schools for the white Deaf learners generally delivered their lessons in spoken language. This distinction was also attributable to economic conditions. White parents were able to afford hearing aids and assistive technologies. The SASL environment in the black schools was not reflective of pure SASL. Instead the signs adopted in these schools were manual signs based on English words (Reagen et al., 2006).

The demise of apartheid education in South Africa in the early 1990s saw the adoption of a means of communication, known as total communication, where (hearing) educators of the Deaf in South Africa who were unable to communicate in SASL, communicated with their learners by signing and speaking simultaneously. According to Denton, this means of communication had been introduced in other parts of the world in 1970, (as cited in Glaser & Lorenzo, 2006), It is known as signed English or signed Afrikaans (depending on the medium of instruction of the particular school concerned), or total communication. The signs may be invented by the educator concerned. Facial expressions, critical to successful sign language, may also be omitted in this means of communication. The use of total communication has been shown to be unsuccessful in educating Deaf learners. The system uses lexemes (words) from SASL or another sign language simultaneously with the inflections and word order of another language (e.g. English or Afrikaans). When educated using this method, the messages that the Deaf learners are receiving

are therefore incomplete and difficult to understand thereby creating barriers to learning. These barriers to learning have resulted in poor literacy amongst deaf people in South Africa. In schools where oral based methods are entrenched there is still evidence of SASL communication during recess or after school (Morgan, 2008).

Although South African Sign Language (SASL) is recognized in the South African Constitution (Heap & Morgans, 2006, a number of issues have prevented its assimilation in the education system. Education for the Deaf and hard of hearing in South Africa is inequitable across racial groups, a legacy of the apartheid government. In 1990, Penn and Reagen wrote 'nowhere can the effects of this legislated system of racial discrimination be seen more clearly, perhaps than in the field of South African Sign Language studies' (Penn & Raegen, 1990, p. 91).

The overall data analysis strategy and ethical considerations for the study are described below:

### **Data Analysis**

I was interested in participants' perceptions of HIV/AIDS related issues in the Deaf community in South Africa. With my supervisor's assistance, I considered the different means of analysis available for analysing qualitative data:

- Sociolinguistic methods can be employed to analyse discourse and conversation. These explore the use and meaning of language.
- Grounded theory focuses on developing theory.
- Content and thematic analysis describes, interprets and compares participants' views.
- The framework approach is similar to thematic analysis as it also entails identifying recurring and significant themes (Smith & Firth, 2011).

The qualitative data analysis for all four phases of this study was conducted using the framework approach, an appropriate approach in health systems enquiry. This approach to analysis was developed during the 1980s by social policy researchers as a method to manage and analyse qualitative data in applied health or social policy research. In the framework approach, the aims and objectives are focused and the interviewers use interview guides to extract their data. This approach is a contrast to inductive approaches such as grounded theory where the research is an iterative process and the analysis develops in response to the data obtained. The framework approach emphasizes transparency in data analysis and the links between the different stages of the analysis (Smith & Firth, 2011).

Jill Smith conducted research that is useful to developing analysis tools for my study as her approach is similar to mine. Her research investigated parents' perceptions of living with a child with hydrocephalus (Smith & Firth, 2011). An interview guide was developed to enable the researcher to explore parents' experiences of raising a child with hydrocephalus as well as barriers to accessing appropriate care. Interviews were conducted face to face either one on one with parents or jointly. Thereafter they were transcribed.

This approach, as employed by Smith and Firth (2011), consists of four phases leading to data analysis. These are described by Ritchie and Lewis (2003). These interconnected phases allow the researcher to move back and forth across the data until a coherent analysis emerges. The phases are:

1. Familiarising one-self with the data, i.e. reading and re-reading the transcriptions, developing codes and assigning data and themes to the codes developed. Initially the codes develop through summaries of the participants' own words. This is a measure employed to present the data as honestly as possible.

2. Summarising and synthesising coded data.
3. Developing associations or patterns within concepts and themes and ensuring that participants' statements/views have been fairly presented.
4. Interpreting the meaning within the themes and applying them widely to broader contexts (Smith & Firth, 2011).

Like Smith's study, initially the data management for my study entailed written notes and memos with significant phrases highlighted. I wrote numerous comments in the margins of the transcriptions. Codes and categories were developed by analysing the transcriptions line by line. Initial comments developed into a coding matrix. Thereafter I used NVIVO 7, a qualitative software programme. The programme consists of coding retrieval and search facilities. My supervisor and I were able to review the coding matrices together. Smith and Firth (2011) recommended tabulating how initial thoughts develop into a coding matrix, how the coding matrix is used to identify codes and categories and the coding index. I have completed tables in relation to the analysis tools for my study below. There was no need for inter-rater reliability check given that I was the only person conducting the interviews:

### **Ethical Considerations**

I was granted ethical approval from both the University of Cape Town (where I was originally registered as a doctoral candidate) and the University of Stellenbosch (where I later transferred after the death of my original PhD supervisor, Prof Alan Flisher) to conduct the study.

I assured participants of confidentiality through an informed consent procedure. For Deaf participants, the procedure was assisted by a SASL interpreter who delivered the principles of informed consent in SASL. Although Morgan (2008) video recorded Deaf participants for a

collection of narratives published in a book called 'Deaf me Normal', I could not employ the same method. Many of my Deaf participants declined a video recording of their interview. They felt self-conscious discussing issues of sexuality and HIV/AIDS in a video recorded interview. I decided to be consistent and not video record any participant, even those who reported they were comfortable with this method.

Specific ethical procedures were followed for the phase of the study where I interviewed Deaf and hard of hearing adolescents. In accordance with the SA National Health Act No.61. (2003). Chapter 9. Section 71, I obtained informed consent from participants who were above the age of 18 and consent from parents or legal guardians if they were below the age of 18. I then obtained assent from those participants who were below the age of 18. The study team's contact details were made available to the parents and legal guardians of potential participants should they require more information about the study. I disseminated the results of the study at the schools for Deaf and hard of hearing learners where I collected data. I offered to disseminate the results at the Western Cape and national Departments of Education, South Africa. In February 2011 I was invited to deliver a report back of results to the National Department of Social Development. I have also delivered the results in the form of numerous conference presentations at both local and international events.

The data gathered for my PhD thesis comes from 81 in-depth interviews conducted at four levels of enquiry. The four inter-related phases (outlined below) aim to explore HIV/AIDS prevention challenges for Deaf and hard of hearing adolescents in South Africa:

1. A study of key informants (n = 21) including people influential in policy formulation, Nongovernmental organizations (NGO) employees and university academics. Some of these participants are leaders in the Deaf community.

2. A study of educators of Deaf and hard of hearing adolescents (n=27). The sample includes school nurses, school psychologists, teachers and Deaf teaching assistants.
3. A study of parents (n = 9) of Deaf and hard of hearing adolescents.
4. A study of adolescents who are Deaf or hard of hearing (n= 24).

## **Phase 1: Employees of Deaf Organizations' Views of HIV Prevention Needs of the Deaf Community**

### **Participants and study sites**

#### *Locating Deaf Organizations in South Africa.*

As there is no formal list available of Deaf organizations in South Africa I had to develop a means of locating potential participants. Initially I attended a meeting in late 2009 in Johannesburg, South Africa, organized by Disabled People South Africa (DPSA) and the South African National AIDS Council (SANAC). A few leaders of Deaf organizations were present at this meeting. I communicated informally with these leaders and arranged interview slots in early 2010. With the help of my supervisor, who is well known to the disability sector, I employed snowball sampling to identify additional organizations. Due to financial constraints, Prof Swartz and I developed a sampling frame of Deaf organizations in the Western Cape and Gauteng provinces of South Africa. The study team is based in the Western Cape region and the Gauteng region offers access to a number of well- established Deaf organizations.

#### **Participants**

After this, I contacted the NGOs which have an interest in the social, HIV/AIDS, mental health or education needs of the Deaf community in South Africa. This pool of participants had knowledge of issues that affect health or social conditions of Deaf people in general. I

telephoned or emailed directors of the organizations to inform them of the aims of our study. I then visited the organizations and met with the directors before commencing the research.

I employed convenience sampling and recruited directors of the organizations. If the directors declined to be interviewed I asked that they recommend employees for interviews. If they agreed to be interviewed I also suggested that they recommend employees to be interviewed. In total I interviewed 21 participants of whom five were hearing, three were hard of hearing (i.e. had substantial hearing loss but communicated orally and not in SASL) and 14 were Deaf. Seven participants were involved in Deaf education, including SASL lobbying, development and training. Six were focused on social and general health care needs (including HIV/AIDS). One was a psychiatrist who regularly treats Deaf patients and works in the field of mental health advocacy. One worked on HIV/AIDS information dissemination and mental health advocacy issues. Four participants were trained HIV/AIDS counsellors. The remaining two participants worked in the area of sexual diversity rights of which a major component is HIV/AIDS.

The interviews were conducted in English. If the participants were Deaf the interviewer was assisted by a SASL interpreter. Interviews were recorded and transcribed by an independent transcription service.

### **Measures.**

I first collected background demographic information including age, sex and number of years that participants had worked with the Deaf or hard of hearing. I conducted individual interviews, joint interviews (consisting of two participants each) and a focus group discussion that consisted of four participants. The decision to use this form of triangulation has been motivated earlier in this chapter. The individual interviews and the FGD were facilitated by the same open-ended interview guide (see Appendix 1). We developed the initial version of the interview guide by

studying key issues in the literature from both Deaf studies and HIV/AIDS studies. For example, published literature in Deaf studies and public health research (Doyle, 1995; Mallinson, 2004b) indicated that communication barriers were paramount when Deaf people tried to access health care. Therefore, we included questions in our interview guide on communication challenges for the Deaf community in accessing health care. Further key domains probed during the interviews were HIV/AIDS programmes offered by the organizations, mental health interventions offered by the organizations (including counselling), participants' perceptions of mental health issues in the Deaf community, general challenges facing the Deaf community with regard to HIV/AIDS and mental health components of various HIV/AIDS programmes. As some of the organizations are involved in education projects for Deaf learners we also explored their activities within these schools as well as their perceptions of the current state of Deaf education in South Africa.

## **Phase 2: Educators of Deaf and Hard of Hearing Adolescents: Views of HIV/AIDS prevention needs of their learners.**

### **Participants and Study Sites.**

I obtained a list of schools for Deaf and hard of hearing learners in South Africa from Dr Claudine Storbeck, the director of the Centre for Deaf Studies, University of the Witwatersrand, South Africa. As in the previous phase of the study, I decided to approach schools for the Deaf and hard of hearing in Cape Town and Johannesburg as potential research sites. The study team is based in Cape Town and the Johannesburg schools for the Deaf have a long history of Deaf education on opposite ends of the racial spectrum. I then telephoned the listed schools in Johannesburg and Cape Town and asked if they taught in an oral or sign language medium. I also found out if the schools taught secondary school learners. Permission was obtained from the Departments of Education in the Western Cape and Gauteng regions of South Africa to conduct

research. Eventually we selected all the schools for the Deaf and hard of hearing in the Western Cape (where the study team is based) and two schools in Johannesburg. We selected the schools in Johannesburg due to their long tradition of education for the Deaf and hard of hearing. These two schools had also recently been sites of HIV/AIDS interventions developed by the Gay and Lesbian Archives (GALA). This intervention entailed contributions from a Deaf, HIV positive activist to an education programme on sexual diversity and HIV/AIDS prevention complemented by the comic book tailored for Deaf youth described in Chapter 2.

Some of the schools which cater for Deaf and hard of hearing learners in Johannesburg accommodate learners with intellectual disability (e.g. intellectual disability and autistic spectrum disorder or intellectual disability and cerebral palsy or Down syndrome) as well. While some of these learners do have hearing loss as well, others merely show signs of the intellectual disability. These learners are schooled alongside Deaf and hard of hearing learners. For the purposes of the broader work of our research team these schools and their learners may be participants; for the more focused study reported in this thesis we decided to focus on participants who worked solely with Deaf and hard of hearing learners. One of the six schools selected for the study was oral medium and the other schools were SASL based schools.

I made contact with the schools in Cape Town and Johannesburg and explained the components of the project to the principals. I employed convenience sampling and recruited 21 educators (15 high school teachers, two school psychologists, two school nurses, and two teaching assistants) from six schools for the deaf and hard of hearing in South Africa for in depth interviews. Six of our participants were deaf and employed at the schools either as teachers or teaching assistants. As in the previous phase of the study, I conducted a combination of joint interviews (two consisting of two participants each) and individual, in depth, interviews. I conducted all of the

interviews as I had no previous relationship with the schools for the Deaf and hard of hearing and I was unknown to the participants. The interviews were conducted in English or Afrikaans if the participants were hearing. If the participants were Deaf, the interviewer was assisted by an independent SASL interpreter (i.e. not employed at the schools but instead recruited from an independent agency). Interviews were recorded and transcribed by an independent transcription service.

### **Interview guide.**

The interviews were facilitated by an open-ended interview guide (see Appendix 2). Together with my supervisor we developed the interview guide by studying key issues in the literature from both Deaf studies and behavioural adolescent literature. Key domains probed during the interviews were participants' perceptions of HIV/AIDS risk in their learners, participants' understanding of mental disorders as a risk factor for HIV/AIDS, participants' understanding of substance abuse, and participants' understanding of the risk of sexual abuse for deaf and hard of hearing learners. I also asked about the HIV/AIDS programmes within the schools including the attitudes towards condom education and the distribution of the GALA material.

## **Phase 3: Parents of Deaf and Hard of Hearing Adolescents' Views on HIV Prevention**

### **Participants and Study Sites.**

I contacted the same schools used in the previous qualitative phase of the study to ask if it was possible to interview parents of Deaf and hard of hearing adolescents. The majority of schools that I had initially contacted in Cape Town advised that it would be too difficult to recruit parents of adolescent learners. Adolescent learners tend to travel home by transport provided by the school or use public transport. Therefore their parents have little or no contact with the school.

Staff at the schools generally advised that many parents of Deaf or hard of hearing learners in South Africa are pre-occupied with unemployment or other socio-economic concerns and therefore unable to attend school meetings regularly. Only two of the four schools in the Western Cape were able to assist us in recruiting parent participants. The staff at the Johannesburg schools were sceptical about recruiting parents but agreed to offer their assistance in this regard.

Eventually I employed convenience sampling and decided on two of the schools for Deaf and hard of hearing learners in the Western Cape and two schools in Johannesburg to recruit participants. I then enlisted help from administrative and academic staff at the schools to contact parents of high school learners telephonically. Parents were informed of the study and the procedure both telephonically (by the schools' administrators) and through a letter that encapsulated the aims and objectives of the study. At one school, staff suggested that I attend a governing body meeting where parents were present to recruit for interviews. The other schools requested that parents meet the principal researcher for interviews at the school.

I once again employed convenience sampling and recruited nine participants, of whom three were fathers and six were mothers of Deaf and hard of hearing learners. The age range of the participants' children was between twelve and twenty years<sup>2</sup>. I conducted seven, individual in-depth interviews and one joint interview with two parents together (a couple who are parents of a hard of hearing child together. I conducted all the interviews. The interviews were conducted in English. Two of the participants were interviewed in Zulu with the assistance of a lay interpreter, a cleaner at the school. Interviews were recorded and transcribed by an independent transcription service.

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<sup>2</sup> In South Africa, it is not uncommon to find learners in schools who are above the average age of their grade. They could be age 20 or older and still at school. This is often the case in the predominantly black, African schools.

### **Interview Guide/Measuring Instrument.**

I collected socio demographic data from participants. The interviews were facilitated by an open-ended interview guide (see Appendix 3). I developed the interview guide by studying key issues in the literature from both Deaf studies and behavioural adolescent literature pertaining to sexual behaviour or HIV/AIDS. Key domains probed during the interviews were parents' perceptions of the risk of HIV/AIDS in their Deaf or hard of hearing children, key challenges facing Deaf and hard of hearing youth with regard to HIV/AIDS, and schools' initiatives to address HIV/AIDS risk and concerns.

### **Phase 4: Deaf And Hard Of Hearing Adolescents Views On HIV Prevention**

#### **Issues**

##### **Participants and Study Sites**

Once again, contact was made with the six schools for Deaf and hard of hearing learners identified for the previous phases of the study.

I designed the study as in depth qualitative study. As I was advised by the schools that literacy levels of Deaf and hard of hearing learners was generally low, a self-administered questionnaire would have been inappropriate. Therefore I opted to interview these learners individually, employing qualitative methods. I employed convenience sampling and recruited 24 Deaf and hard of hearing adolescents from five of the six schools originally identified for recruitment in this study, for in depth interviews. At the time of recruitment there was disarray in South Africa in the public service due to strikes. Therefore I was unable to conduct interviews at one of the schools originally identified due to their staff being on strike. I recruited 14 females and 10 males across Grade 8 to Grade 12. Their ages ranged from 16 to 19 . If the participants were

Deaf, I was assisted by an independent SASL interpreter (i.e. not employed at the schools but instead recruited from an independent agency). If the participants were hard of hearing and unable to communicate in SASL I interviewed them individually in English. I listened carefully to the interviews and took notes during the interviews. Two of the hard of hearing learners in the oral school struggled with communicating with the principal researcher. Although the interview was recognizable on tape, it was a challenge for an independent transcription service to transcribe. Therefore I transcribed these interviews myself assisted by the notes taken during the interview. The remaining interviews (three of them with hard of hearing participants and 19 with deaf, SASL participants) were recorded and transcribed by an independent transcription service.

### **Demographic Information and Interview guide.**

I collected basic socio-demographic information from participants, including age, languages and information about their families (e.g. if they live in a single parent household). The actual interviews were facilitated by an open-ended interview guide (see Appendix 4). We developed the interview guide by studying key issues in the literature from both Deaf studies and behavioural adolescent literature. Key domains probed during the interviews included participants' perceptions of HIV/AIDS risk, participants' perceptions of HIV/AIDS education in schools for the Deaf and hard of hearing, and participants' perceptions of condom usage. I chose not to ask participants if they had already experienced their sexual debut but instead allowed them to discuss this spontaneously should they feel comfortable doing so.

Table 5

*A Summary of the Methods Employed in Each Phase of the Study:*

Study	Participants	Procedure	Analysis
1 Deaf organization key informants	Key informants from Deaf organizations, university academics and leaders from the Deaf community.	Qualitative	Framework approach.
2 Educators of the Deaf and hard of hearing	School nurses, psychologists, teachers and Deaf teaching assistants.	Qualitative	Framework approach.
3. Parents of Deaf and hard of hearing adolescents.	Parents	Qualitative	Framework approach.
4. Adolescents who are Deaf and hard of hearing	Adolescents who are Deaf and hard of hearing	Qualitative	Framework approach.

In the following chapter, I present the results of the study.

## **Chapter 4: Results**

### **Phase 1: Qualitative Study of Representatives of Deaf Organizations**

I recruited 21 participants: a Deaf parliamentarian, 12 members of non-governmental organizations (NGO), a psychiatrist working in the public sector, four members of a university based Deaf education organization, two members of a sexual diversity organization with an interest in the Deaf community and two members of a SASL advocacy organization. The mean number of years of working with the Deaf community in this sample was 11.4 years. Table 6 on the next page presents the demographic characteristics of the sample including age, gender and number of years working with the Deaf community.

Table 6

*Socio-Demographic Characteristics of Participants who Work for Deaf Organizations*

Participant	Area of work	Sex	Number of years working with Deaf and hard of hearing people
1	National Government	Female	22
2	NonGovernmental (NGO) sector	Male	22
3	NGO Sector	Male	5
4	NGO Sector	Male	11
5	Public Health services and NGO Sector	Male	5
6	Deaf Education	Female	20
7	Deaf Education	Male	6
8	Deaf Education	Male	35
9	Deaf Education	Female	9
10	Deafness and Sexual Diversity	Female	20
11	Deafness and Sexual Diversity	Male	8
12	NGO	Male	3
13	NGO	Male	3
14	NGO	Female	3
15	NGO	Female	3
16	Deaf Education	Female	18
17	NGO	Male	4
18	NGO	Female	10
19	NGO	Female	0.5
20	SASL development	Female	9

21	SASL development	Female	9
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A number of themes emerged from the analysis. I present the most salient themes from the analysis:

(1) *HIV/AIDS programmes offered by Deaf organizations in South Africa*; (2) *Participants' perceptions of HIV/AIDS programmes in schools for the Deaf and hard of hearing in South Africa*; (3) *Participants' perceptions of mental health issues in the Deaf community*; (4) *Addressing HIV/AIDS : the role of Deaf Organizations in South Africa*

### **HIV/AIDS programmes offered by Deaf organizations in South Africa.**

Participants described the HIV/AIDS programmes their organizations had developed for both Deaf adults and adolescents. These varied from dissemination of information to the Deaf community to organizing HIV/AIDS testing services for Deaf people. One organization had, with the assistance of a well-known HIV/AIDS testing and counselling centre, trained nine Deaf people as HIV/AIDS counsellors. These counsellors provide pre and post HIV/AIDS testing counselling in SASL. One participant explained that pamphlets or brochures for the Deaf have to be of an appropriate linguistic level and also contain visual material, while a Deaf social worker explained the procedure for counselling Deaf clients who wish to access HIV testing services:

(We have developed a) ... primary information brochure on HIV/AIDS and deafness. Everything, as you will see there, has to be extremely graphic, but when linguistics, language issues in the written format may be a problem because of, again, communication barriers and the way that language is constructed. Producing DVD's, videos, of interaction between a group, like a dramatization of an issue or issues around HIV/AIDS, usually involving people that the Deaf community can relate to ...

(Researcher HIV/AIDS, Deaf Organization, Cape Town)

We have, we the first organization that you know, trained Deaf people to go for HIV counsellors and we started of last, two years ago, three counsellors, Deaf counsellors...to, became a counsellor and then, then last year, six pass and they became counsellors, so we got nine Deaf counsellors we are serious about HIV/AIDS. (they are accessible) for deaf people working with deaf to deaf in terms of communication).

(Director, Deaf Organization, Cape Town)

Some people do not know nothing about HIV/AIDS, ... so I give them information regarding HIV/AIDS before I go with them to the clinic to be tested because previously deaf people, when they go for, for a test and they go out of their own and they get the results and it's positive, so they don't know what to do in that, so, because previously they never had any counselling....

(Social auxiliary worker, Deaf organization, Cape Town)

### **Participants' perceptions of HIV/AIDS programmes in schools for the Deaf and hard of hearing in South Africa.**

As this sub-study preceded research in the schools for the Deaf and hard of hearing, I asked if participants had had more specific involvement in schools for the Deaf. Eight participants had co-ordinated projects in schools for the Deaf and hard of hearing. Although these projects were focused on HIV/AIDS they varied in content. For example, two participants had co-ordinated workshops in SASL for Deaf and hard of hearing learners, focusing on basic information about HIV/AIDS. This included access to testing, condom usage, etc. The two participants who worked for the sexual diversity organization had conducted workshops in schools for the Deaf and hard of hearing in the Gauteng region. Four participants alluded to the difficulty of working in the

religious environments of some of the schools for the Deaf and hard of hearing. One of them, a psychiatrist, referred to his experiences of working with both adult and adolescent Deaf patients who also have an intellectual disability (e.g. autism or cerebral palsy). He described the efforts of the organization he is affiliated with in creating a 'mini-village' for Deaf adults with additional intellectual disabilities. Within such a residential setting, staff face challenges in monitoring what they consider 'inappropriate sexual behaviour' of residents:

For example the institute has a, a kind of mini-village that they call for people with both deafness and other disabilities, so both physical and mental disabilities and a large number of those patients are actually intellectually disabled, so it's actually a relatively common problem that you see there is inappropriate or what the staff deems inappropriate sexual behaviour between, between people living there. It's difficult because it's always difficult to, to know how to deal with, how to approach, how to manage sexual relationships between adults who are intellectually disabled or, or mentally ill in other ways because what, I mean a large part of deciding what your approach should be is actually ethical and not, not just, not really pure science. So it's a complicated thing to deal with and a lot of what would be deemed inappropriate by staff would be deemed inappropriate by staff based on their own moral convictions and not necessarily on any kind of objective kind of approach or protocol based approach that the institute would have, and that would then land up with me because it would be seen as a mental health problem ...

(Psychiatrist and mental health activist)

The participant also described the difficulties of discussing sexuality with some of his Deaf patients who may have been schooled in a historically religious environment:

Often the patients come from a school which is a conservative organization, so sexuality wouldn't have been something that would be, be discussed often and it might be difficult even for only that reason to kind of broach the subject now in an adult and say "how are we going to deal with these urges you have?"

(Psychiatrist and mental health activist)

A participant working for a Deaf organization in Cape Town also described the religious ethos of the schools for the Deaf as a barrier to effective sex education. The two participants who work for the sexual diversity organization described their work as quite unsuccessful. One of them explained that enlisting help from Deaf teaching assistants at one of the schools was challenging. These Deaf teaching assistants had pre-conceived ideas about HIV/AIDS as well as appropriate sexual behaviour:

There were a lot of pregnancies in the Deaf community because sexual information was not being given to them and they did not have access to that. And now, even worse, in a Catholic school, they refuse to teach sexual terminology, I hope it have changed but I doubt it, but in the past it did not happen, but access to that information, can you imagine how hard is that going to be, to bring HIV/AIDS into that environment ...

(Member of Deaf Organization, Cape Town)

We're main-streaming the issues of sexual rights and sexual diversity in relation to gay and lesbian issues into, into a broader human rights, sexual rights, HIV, sexual abuse project into schools. We wanted to train Deaf teaching assistants them to work with the older learners to basically give them correct information about HIV. With the Deaf teaching assistants, there were a lot of problems because of their own preconceptions about HIV...

(Director, Gay and Lesbian Organization, Johannesburg)

Addressing HIV/AIDS: the role of Deaf Organizations in South Africa.

I engaged participants in a discussion on HIV/AIDS Deaf community. There were six participants who described their organizations' efforts regarding HIV/AIDS counselling for Deaf people.

The four participants who are trained as HIV/AIDS counsellors also described their work in addressing social and mental health issues experienced by Deaf people accessing Voluntary Counselling and Testing services (VCT):

Most psychiatric disorder would impact on a variety of aspects of your behaviour including sexual risk taking or not risk taking. So if people have a disorder that would incline them to be more disinhibited, incline them to be more risk taking – they would have more risk taking sexual behaviour. If they have a disorder that had an impact on their libido, they would have less risk taking behaviour, they would have less sexual disinterest in general. Most of what I've really seen are patients with, with some degree of intellectual disability in addition to, to the deafness. Where there are problems with sexual disinhibition, inappropriate sexuality, what we would call risk taking behaviour ...  
(Psychiatrist and mental health activist)

Naturally mental health issues will arise whenever HIV/AIDS is a factor and that is not a hearing specific phenomenon, it is as much a deaf phenomenon as it is a hearing phenomenon and the issues are the same. Access to antiretrovirals may not be as easily obtained for the deaf community, not because they are inherently different, but because they may not be aware that they have the right to access antiretroviral medication or the right to access counselling services, or that any such services even exist. Trained psychiatrists, trained health professionals who are familiar with the deaf community and

how to communicate with them culturally. Deaf person are few and far between, it's a whole new area for the mental health fraternity.

(Researcher HIV/AIDS, Deaf Organization, Cape Town)

I would give support in terms of information and then monitor their life progress to see whether the person is confident enough to have a positive living and, and to live a positive living. So it, then also to try and, just basically to see the person's well-being and to check the person's well-being after the counselling, once the counselling is done, so having post sessions after the test is done ...

(Deaf HIV/AIDS Counsellor, Cape Town)

## **Conclusions.**

A number of important issues emerged from this phase of the study. Participants had experienced barriers to providing HIV/AIDS information in schools for Deaf and hard of hearing learners. Participants were aware of risk factors for HIV/AIDS for Deaf and hard of hearing youth and adults. Although some participants believed that mental health problems were not an important issue for the Deaf community, others embraced the idea of integrating mental health and HIV/AIDS prevention programmes. Implications of the findings will be discussed in the Discussion chapter at the end of the thesis.

## **Phase 2: Educators of Deaf and Hard of Hearing Adolescents Views on HIV Prevention for their Learners**

The sample recruited for this phase of the study consisted of 27 participants of whom six were Deaf or hard of hearing. We interviewed 19 high school teachers, two school psychologists, one matron or 'hostel mother', three teaching assistants and two school nurses. The mean number of

years of working with the Deaf or hard of hearing for each category of participant in presented in Table 7 on the next page. The high school teachers had reached tertiary level education and the school psychologists held post graduate degrees. The teaching assistants had reached secondary education and the school nurses held diplomas. I present the socio demographic characteristics of participants in Table 7.

Table 7

*Socio Demographic Characteristics of Educator Participants*

<b>Category of participant</b>	<b>Mean number of years working with the Deaf and hard of hearing</b>
20 X Teachers	14.9 years
2 x school psychologists	16.0 years
2 x school nurses	20.5 years
1 x 'hostel mother'	15.0 years
3x teaching assistants	12.5 years

A number of themes on HIV/AIDS risk factors, schools' attitudes towards HIV/AIDS prevention, and communication barriers to receiving information about HIV/AIDS prevention emerged from the analysis. I present the most salient of these themes:

*(1) Participants' perceptions of sexual risk behaviour of Deaf and hard of hearing learners; (2) Participants' perceptions of substance abuse patterns; (3) Participants' perceptions of the risk of sexual abuse for Deaf and hard of hearing learners; (4) Participants' perceptions of the differences in HIV/AIDS risk for Deaf, hard of hearing and hearing adolescent;. (5) Schools*

*policy on condom education; (6) Perceptions of the GALA comic book; (7) Key communication challenges in extracting information about HIV/AIDS for the Deaf and hard of hearing; (8) Participants' efforts to provide accessible HIV/AIDS material to Deaf and hard of hearing learners; (9) Language policies in the schools for the Deaf and hard of hearing.*

I present the scope of HIV/AIDS prevention activities in each of the schools in Table 8 below.

Table 8  
*Schools' HIV/AIDS Prevention Policies*

School	Region	HIV/AIDS prevention activities including condom policy
1	Gauteng	Condom education including demonstrations
2	Gauteng	Condom education including demonstrations. Distribution of GALA comic book unsuccessful
3	Western Cape	Condom education minimal. Condom demonstrations discouraged on school premises.
4	Western Cape	Condom education minimal. Condom demonstrations discouraged on school premises.
5	Western Cape	Condom education including demonstrations
6	Western Cape	Condom education including demonstrations

### **Participants' perceptions of sexual risk behaviour of Deaf and hard of hearing learners.**

Participants described sexual risk behaviour patterns in the Deaf and hard of hearing learners with whom they worked. A number of factors were perceived as important in precipitating both

early sexual debut and subsequent high risk sexual behaviour patterns. Twenty participants believed that their learners were already sexually active but they differed in their views of the age they believed their learners had experienced sexual debut. One high school teacher believed that the majority of the hard of hearing learners in her school had experienced sexual debut once they had reached Grade 11 or 12. Another teacher, working in the same school, believed some learners to be sexually active already but was uncertain about others. He said learners did confide and discuss their relationships with him but he was not sure whether or not they were telling the truth. Five participants believed that their students did not use condoms. A high school teacher described her efforts to produce a play about HIV/AIDS prevention for her Deaf learners. She felt that students who participated in the play did not benefit from the content:

I've been told... and also because they will come and tell me a lot of stuff that they don't tell other people. ... but I wouldn't say it is actual sexual intercourse, I don't think is you know, prevalent among the majority of them, but yes it does happen...  
(High school teacher)

A lot of Deaf people don't know the HIV is there, but then, some don't understand, some don't want to use condoms... Some want to do flesh to flesh, that's how they feel, they want to feel, when they see ...

(Deaf teaching assistant)

I put on a play with that very group of what HIV, and I asked them to just do a mime on stage for the rest of the things, but of the six learners, the girl was pregnant from a boy in that class – ...they have the knowledge... because when I spoke to them we had, the one used to say to me, “no, no, he'll wear two, three condoms,” but do you understand,

although they knew about it, they knew how you contract and yet the, the girl was pregnant, from the boy in the class, and they were the two who took part in the play ...

(High school teacher)

Two participants explained that the hostel or boarding school environment was a significant factor for premature sexual activity. One of them, a school psychologist explained that the exposure to one another in the hostel environment precipitated early sexual activity in learners. The other, a matron working at a school in Johannesburg, described the approach she took when witnessing signs of sexual activity. The matron's views were corroborated by another high school teacher who explained that Deaf learners' curiosity might also lead to premature sexual debut. Another thought that Deaf or hard of hearing learners were pressurized by hearing friends to engage in sexual activity:

In the hostels ... the Deaf sort of have limited access to the opposite sex...they are together from the age of three years old, more or less, they grow up like brothers and sisters that, with, say eight children in, in the grade 7 class, I mean how many available girlfriends and boyfriends are there? They, they don't have the big group to, to pick from, so they're exposed to one another. I'm quite surprised at the young age that they do get sexually active.

(School psychologist)

When they start playing, like sexual and sex and do what, what, but we try to explain to them that this is not for you, this is wrong, why – and you don't do it because you are young. This is for only, for adult people who are married ...

(Hostel matron)

The ones that are, that have got less of a hearing loss, mix more with children who are hearing, so then the pressure will come from there. I mean the children who are profoundly deaf and whose speech is not that great, they don't mix as readily with hearing teenagers and so then they become isolated, but ... if they can get by without a hearing aid on or covering the hearing aid up with a beanie and nobody knows that, that they're deaf and they go into a group of people who they don't really know, they can pass as hearing children, so then you know, then that pressures that they have will be the same as the pressures I presume that most teenagers will face ...

(High school teacher)

Three high school teachers thought that their hard of hearing learners were naive when it came to relationships. They explained that, as these learners were lonely and felt isolated due to their hearing disability, they might accept offers for relationships without thinking too much about the consequences. One of these participants thought that her hard of hearing girls might be flattered if approached by a hearing boy for a relationship.

What saddens me is that they don't understand what friendship is really all about and I think because they're lonely, they, they are, I think, can be easy victims in that if any boy, I'm talking now I suppose from a girl point of view, but if any, if any male shows any interest whatsoever, they immediately think, you know the person loves me, without giving it time and, and because they're so desperate for that affirmation, for that love, for that care ...

(High school teacher)

I think, especially Deaf girls, they are more flattered when a hearing boy come along and then the deaf girl think "oh, that's too wonderful," so that's how it happens, and I've

heard a lot of stories that, sleeping together with hearing boys without using condoms.

But with the deaf boys, I don't know really, I haven't really heard...

(High school teacher)

Two of these participants also knew of a few cases of teenage pregnancy in their school over a period of a few years. They had recently counselled a female learner in their school who had had a termination of pregnancy (TOP). The school principal had come to hear of the learner's TOP from her (the learner's) peers:

She said "yes, that I had an abortion." I said "well," I said "it's got nothing to do with me but you know, do your parents know, are you okay," and so on and she assures me, I haven't phoned the parents, but she assures me that it happened in the December holidays and that her parents sat her down and that they made an informed decision to abort.

(High school teacher)

### **Participants' perceptions of substance abuse patterns.**

Participants discussed their experiences of dealing with learners and substance abuse. Most participants believed that Deaf and hard of hearing learners do not differ in substance abuse patterns compared to hearing adolescents. However, a school nurse working in the Johannesburg area thought that Deaf or hard of hearing learners could be influenced by hearing peers in their communities. She believed that the Deaf or hard of hearing youth might engage in substance abuse patterns to gain acceptance from the hearing community and maintain friendships:

They (the hearing) see a deaf child looking lonely, easily influenced. "Ah, you know what, he's got a bit of money – ah, he's got money on him, let's befriend him, and let's give him one of our joints and then maybe tomorrow he'll buy us and, and we'll tell

him,” and you know ... That’s the perception that I have, not that I’m living in the townships and I see it, but from what I’ve heard ...

(School nurse)

One participant, currently a school psychologist, explained that substance abuse was a problem among learners in the skills streams more than in the academic streams at his school. Another school psychologist suspected three of her male learners of smoking cannabis. Educators in the Johannesburg area had counselled learners who were using a drug known as ‘Nyaope’ in the Gauteng area. The drug is a mixture of marijuana and heroin:

There was huge alcohol abuse, the kids would often smoke dagga in the school property. Often, we’ve had one or two learners that come to the school drunk and we’ve had to send them home.

(School psychologist)

We’ve only got three male Grade 12 and we suspect that all of them are, at some stage are on dagga. I don’t think, I sincerely hope not, but I don’t think it’s anything, I don’t think it’s more than just that.

(School psychologist)

It’s a mixture of dagga and heroin, so we had a case of that. Just minor, I wouldn’t say it’s alcohol abuse, you know like when teenagers grow, they start drinking, so I wouldn’t say they are abusing alcohol, I will say it’s underage drinking ...

(High school teacher)

A high school teacher believed that alcohol advertising (e.g. posters or television) attracted Deaf or hard of hearing learners. She believed that the advertising for alcohol companies created an

attractive image for those who use their products. There is no advertising for drug use and therefore Deaf or hard of hearing youth might not feel drawn to recreational drugs as much:

I think alcohol has a better kind of image, alcohol makes you manly or womanly doesn't it, it's in those adverts that say. I think they are (influenced), by visual things ...

(High school teacher )

The school nurse also described the rehabilitation process for a high school learner who had had a drug abuse problem. He had entered a rehabilitation programme at an organization in Johannesburg. The counsellors at this organization had found him to be unresponsive for about six weeks. Thereafter, a SASL interpreter was employed to accompany him. He responded much better with the assistance of the interpreter:

(The counsellor explained) "We gained so much more in this hour with him than we had gained in the whole 6 weeks." She said she realises now how much this poor kid had missed out on, they thought that they were doing okay, they kept saying no, coz we kept offering our services, we kept saying we can send a teacher you know, for sessions and they kept saying "no, we're coping fine, he's writing, we're writing to him, he's interacting, he's doing fine," but she said to me after last week's session, she said she realises now how important it is for these deaf children to actually have an interpreter, that's, that they can communicate openly with and so much came out and – it was a positive ...

(School nurse)

### **Participants' perceptions of the risk of sexual abuse for Deaf and hard of hearing learners.**

Participants described their fears that their Deaf or hard of hearing learners were at risk of sexual abuse. Eleven participants were aware of cases of sexual abuse of Deaf or hard of hearing learners. Of these 11, six thought that Deaf or hard of hearing learners were more vulnerable to sexual abuse than hearing learners. They explained that perpetrators might believe that Deaf or hard of hearing youth were incapable of reporting the crime to the authorities as they lacked the communication skills required. One participant explained that Deaf and sometimes hard of hearing people were incapable of 'screaming' for help during an attack. A school principal had encouraged teachers at her school to attend 'persona doll training'. If the teachers suspected a child of being abused, they could encourage interaction with the doll. Visual cues could direct communication about sexual abuse:

The junior school teachers have just gone on a persona doll training thing, it's not those anatomically correct dolls, it's another thing, where's you've got a, it's a course that they've done where there's a doll, and the doll gets a personality and we're hoping to use that to see if anything comes out. It's a less threatening, you know, tell your news to the doll, I don't know, there, there different ways of using it...

(High school teacher)

It's that kind of misconception that people have and I think in most of our poorer areas, they are really more at risk and I mean that is a huge problem, because they're not articulate enough to be able to say what they have experienced or what is happening to them and that is where they are being taken advantage of all the time ...

(High school teacher)

Hearing people, when they see deaf person they're thinking, they don't have HIV, or rather, I have HIV and this person who is deaf doesn't have HIV, or the person doesn't know HIV, they know, so now they can rape this person, some they can gun-point a person and rape a person because they know that most of deaf people don't have, don't have HIV and AIDS or they don't have sex, they don't know. Sometimes they can go to the house and knock to the house, if the person doesn't talk, they know the person doesn't talk, cannot scream, so they get in and rape the person and the person's going to be HIV+ at the end, ultimate and end ...

(Deaf teaching assistant)

### **Participants' perceptions of the differences in HIV/AIDS risk for Deaf, hard of hearing and hearing adolescents.**

Participants described their overall opinion of risk factors for HIV/AIDS for Deaf adolescents. They discussed the nature of risk factors and if Deaf or hard of hearing adolescents were more at risk of HIV/AIDS infection than hearing adolescents of their age. They also discussed differences in the nature of the risk for HIV/AIDS infection between Deaf and hard of hearing adolescents.

Participants' opinions on this issue were varied. Some (five) participants thought that Deaf adolescents might reach their sexual debut later than hearing or hard of hearing adolescents. Deaf adolescents were thought to be more sheltered by their care givers than hearing adolescents. Generally, hard of hearing adolescents were thought to be more advantaged than Deaf adolescents in terms of access to HIV/AIDS information. However, one participant, currently a teacher at an oral based school, thought her hard of hearing learners were more 'worldly' than Deaf learners and likely to become sexually active more early than their Deaf peers:

I think the, the really deaf ones are not as pressurized and not as aware, they're more curious but it's almost a, almost like a little 5 year old boy's type of curiosity. ... my perception is that the deaf ones are still exploring and not sure and so on, whereas the ones that are hard of hearing are far more worldly wise and they can, they often come in with stuff that I don't think that our deaf ones that have been here for a while are aware of.

(High school teacher)

### **Schools' policy on condom education.**

None of the schools seemed to have a written policy regarding condom usage. Thus, their views on the subject differed between schools (of different religious backgrounds). Individual respondents working in the same school also expressed different views on the subject:

Two of the schools were neutral regarding condoms and neither educated their learners about usage nor discouraged usage. Two participants working at the same school where condom education was part of sex education discussed their views on the subject. One respondent explained that it was important to have condom demonstrations so that Deaf learners could understand how to use them. Another participant, working in the same school found condom demonstrations to be problematic. He thought they could potentially encourage premature sexual activity in Deaf learners:

When I talk about condoms, I teach them the sign, I teach them the appropriate Afrikaans or English word. I let them have a look at the condom, feel it, it doesn't bite and it's okay to use .

(School psychologist)

So I almost want to say, the thing that's bad, the motivation from the adults (to) use a condom... actually encourages, to say...it's all right, ....the message that actually comes through is, you can have go ahead and have sex....it's actually a bad message...that is given out to the community...

(High school teacher).

Another school, although historically Catholic, seemed to have always educated learners about condoms. Two participants were former learners at the school and now teachers. They recalled that they had received adequate information about condom usage when they were learners at the school. However, there are limitations to condom education at this school. A school nurse who had worked at the school for many years did point out that the school's previous principal (a nun) had not allowed her to distribute condoms to learners:

We don't have any nuns here now, when I was young, they gave us sex education, but it did not start from the nuns, they took somebody from outside to present sexuality to us, 22 years ago, they gave us sex education and showed us on a banana how to use a condom.

(High school teacher)

Until the end of last year, we had a, a nun that was our principal... I was given a donation of condoms a couple of years ago and I wanted to hand them out and she wouldn't allow me to. ... we have a volunteer – she's been doing the sex education with the children. She would hand out condoms in her classroom, so I gave her the box, so the condoms did eventually get to the kids

(School nurse).

Although the remaining two Catholic schools appeared to adopt a different stance on condom demonstration policies, participants working in the same school varied in their attitudes. For example, although the headmistress of one school explained that they (the staff) were under pressure from the nuns and therefore could not have condom demonstrations at school, four participants working at the same school (15% of the full sample) had different approaches. The principal conceded the reality of early sexual risk behaviour amongst her adolescents and the necessity of condoms:

At the very least (I tell the learners) “use condoms,” which I know as a Catholic I shouldn’t promote, but I mean if a child is already sexually active ...

(High school teacher)

Another two participants working at another, originally Catholic, school explained that they had attended a condom demonstration for teachers offered by a local HIV/AIDS clinic. One explained that, although she had not thought about offering condom demonstration before her interview for this study, she was keen to incorporate condom demonstrations in her Life Orientation and Biology classes. Another teacher said although he did not mind condom demonstrations using bananas, he would like to do so privately with his class ‘with the door closed’:

That’s never been spoken about since I’ve been here, usually, usually Catholic institutions are against the, the use of contraception, but we talk about condoms and they see it in their text books but I’ve never demonstrated it in, in the classroom. Maybe that’s something worthwhile considering in the future.

(High school teacher)

... bring in a banana and then explain how to put on a condom, if I was going to do that I would close the classroom door and I would probably just do it anyway.

(High school teacher)

The headmistress of another historically Catholic school was adamant that condom demonstrations were not allowed at her school to 'protect Catholic ethos':

It's (condom usage) not encouraged and I respect, I am not a Catholic but I am the principal of this school and I had, I have decided to come and work in this school and that has been the stance of the Catholics ever since I have come into this school and therefore I feel it's right that I uphold their ethos. If I feel, if I can't do that then my services should, I should terminate my service because I have applied to be in this school.

(School principal)

However one of her staff, a teacher, discussed the complexity of the Catholic stance on condom usage but also explained that there may be room for adaptation of certain values:

The owners of the school are Catholic sisters ...I don't think it, we're going to get away with that (condom demonstrations) I would say so in the past (condoms were discouraged) because of the Catholic issue, but now I've put a poster up there with A, B, C (Abstain, be faithful, condomise) ... and nobody has taken down you know, taken them down ....the only thing they would not allow is the condom dispensers.

(High school teacher)

### **Perceptions of the GALA Comic Book.**

I explored participants' perceptions of the GALA comic book. One participant, a high school teacher, suggested that the comic book was distributed during a pressurised time at school (e.g.

examinations) and thus was not as successful as it could have been had it been distributed during a less pressurised time:

We started off with the grade 9 learners and then they had to do exams and they had to be taken off the project ... , that was still year, year before last and last year.

(High school teacher).

She also suggested that learners in the senior primary grades may lack the required literacy to understand the content of the comic book:

...with the grade 7s, ... he first had to do a lot of vocab ... And then it took a while to establish a good rapport with the learners, so he would come every week and then they would start and they would discuss different aspects of the comic. But then he gets bogged down by language...learners not having the sign for specific concepts....

(High school teacher)

Two Deaf teaching assistants who were integral in assisting in this project gave their views as to why distribution had not been successful:

I didn't understand the book, it was not right, because I didn't know which line to follow, gay or HIV, woman and a man, they have sex, yes, but then you have to use condom so that you don't have HIV .....when you page to the other page, it's gay people having sex, they're doing things, boys, ... And they want to follow this thing that is happening, and the gay life, so it was wrong for me, it was not good, the book it was bad

(Deaf teaching assistant 1)

I looked at the comic book and then in the comic book there, it was good about prevention of HIV and AIDS, but then when I went to the other page I was shocked to see things about gay people ... I saw gay people is funny, and mad, how they have sex, so I didn't feel comfortable, I

wondered how did they marry, so I didn't like it that way. I did not accept. The Deaf didn't feel okay about the book ...so they threw them away and then ... god knows that... god made Eve and Adam, so we know that there has to be a man and a woman.

(Deaf teaching assistant 2)

### **Key communication challenges in relation to HIV/AIDS for Deaf and hard of hearing learners.**

Participants discussed the key challenges that Deaf and hard of hearing learners faced with regard to HIV/AIDS. They discussed communication barriers in accessing information about HIV/AIDS. One participant, a high school teacher working in an oral based school, explained that her hard of hearing learners do lack knowledge of HIV/AIDS. A school psychologist explained the difficulties for Deaf patients who may struggle to communicate with their doctor. He also mentioned the HIV/AIDS stigma which presents challenges to accessing prompt HIV/AIDS prevention and care services in both the hearing and the Deaf communities:

They, they're lacking information, because some things are learnt just in passing, by people that are hearing, but people that are hard of hearing or completely deaf, they don't do any incidental learning as other, other kids would do and sometimes they can't hear the TV properly or they, they haven't got that access to information that they, that would be better for them to have ...

(High school teacher )

It's almost like the information passes them, they can tell you that they understand and they know, but their actions and behaviour is contrary, contrary to what they are telling you, so it's obvious that they don't really fully understand the whole thing on HIV and

AIDS and even on how it's contracted, not all the kids, some of them do, especially the ones who are in the more academic classes, they have a better understanding.

(High school teacher ).

Another high school teacher, working in a SASL medium school, worried that Deaf learners might misinterpret visual material about HIV/AIDS. He thought there was a danger of these learners becoming sexually active too early if exposed to too much visual material about HIV/AIDS:

I also think, because they're very visual, they also see things, on television, newspapers, books, magazines ... interpret that also, it can be positive, but it can also be negative if we talk about the subject generally, sexuality, it also be negative meaning that they become aware about those things and unfortunately, children are very aware, so they see many thing where a hearing person ... they see them and those things that they see, they take them on board. So unless they are also exposed and ... or know material and so on, it can have negative consequences ...

(High school teacher )

Overall six participants believed that the hard of hearing were more advantaged than the Deaf in terms of accessing information about HIV/AIDS:

I'm presuming that those hard of hearing learners will be in a mainstream school so they would have the same sort of access as a hearing learner and they can have access to television and probably their parents can communicate.

(School psychologist).

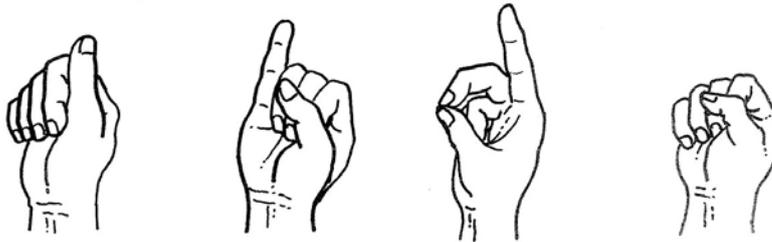
A hard of hearing child with a hearing aid they can still maybe understand or hear or lip read, but I found that the profoundly deaf child got a lot of problems if you can't sign and the, to me I call it a myth, that they say – every deaf child can lean to lip read – it's a myth.

(High school teacher )

**Participants' efforts to provide accessible HIV/AIDS material to Deaf and hard of hearing learners.**

Participants discussed their efforts to produce appropriate HIV/AIDS prevention materials for their Deaf and hard of hearing learners. These ranged from visual material (e.g. smart board or overhead projectors) to introducing a Deaf man living with HIV/AIDS to teach Life Orientation in SASL. Figures 5 and 6 are examples of HIV material for Deaf learners that was adapted from material used in the USA. One of the schools for Deaf learners in Cape Town circulated this material in teaching about HIV/AIDS.

# AIDS



LEARN ABOUT AIDS  
BE RESPONSIBLE. BE SAFE.

PROTECT YOURSELF FROM AIDS.

(WARNING! SEXUAL GRAPHIC MATERIAL)

*Figure 4.* HIV/AIDS material for Deaf and hard of hearing learners (adapted from book produced by Gary Crawford, USA, p. 1).

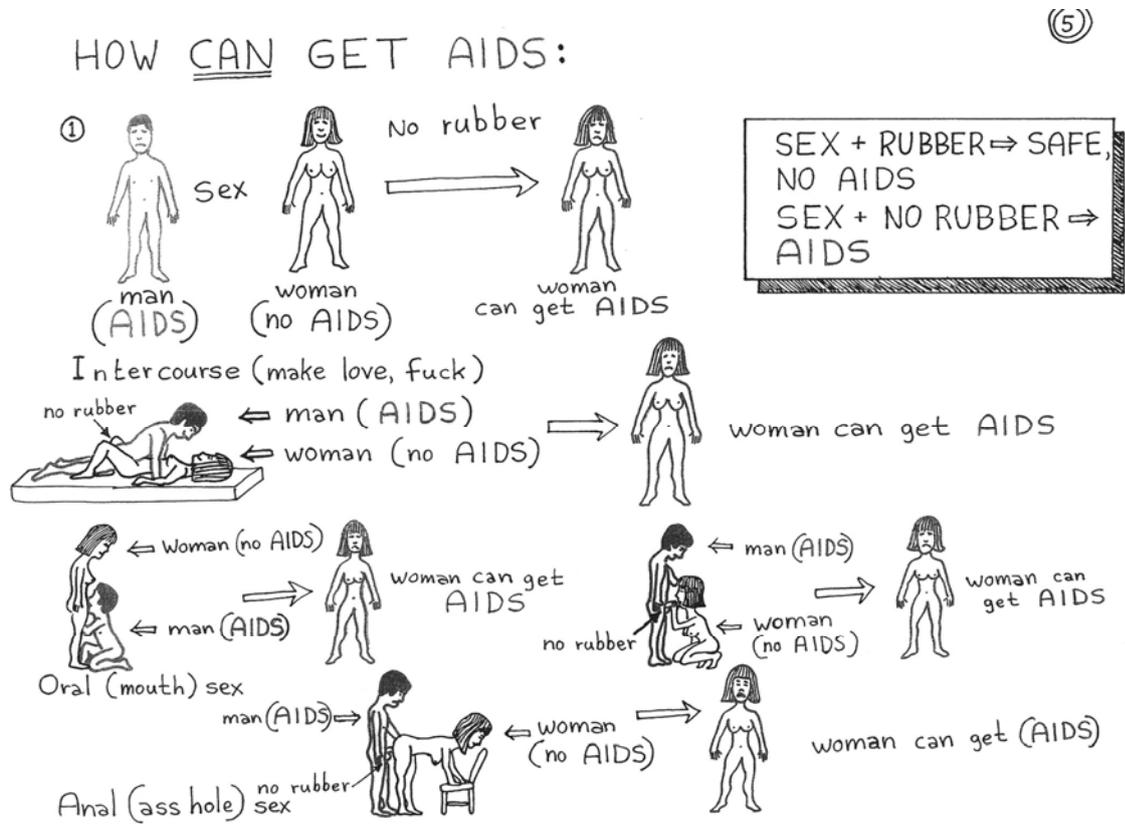


Figure 5. HIV/AIDS material for Deaf and hard of hearing learners (adapted from book produced by Gary Crawford, USA, p. 1).

One participant described the recent contributions of a European non-governmental organization that had organized workshops about the importance of HIV/AIDS prevention. This organization had produced a video showing well known members of the adult Deaf community accessing voluntary testing and counselling. A SASL interpreter had assisted in facilitating the workshop. A school nurse said she had decorated the walls and ceiling of her consultation room with posters

about HIV/AIDS. Deaf and hard of hearing learners could view the posters in her office when consulting her about illness. She encouraged discussion about these posters.

A high school teacher described the work of the Deaf activist who assists in the Life orientation classes:

I would face the students at all times and I would do some modifications in how communicate with them. I would face them, I would make eye contact, I would try and write lots of things on the chalk board, have lots of visual aids, use the smart board – those kind of things to, you know to, to enhance their learning since they, they do have difficulty lip reading.

(High school teacher)

We didn't have appropriate materials on sex education, especially for the deaf, so I had to start out and prepare my own materials and so on. Stuff that's more visually orientated, that the children can have access to that information. And to sort of re-write available stuff into what is accessible in terms of, of the language of the Deaf.

(School psychologist)

... so that they can understand more, because J is deaf, they will understand and, J is HIV+, so they will understand more when he's teaching, he is the person who is giving it and who is having sign language. he came with a power flash that shows kinds of STD's, how a person can get infected in HIV, how to be protected against HIV, all those things, he came with the power flash and the samples and all of this, he's, condoms, all of this, his charts, different kinds of people, relationships, all these things...

(High school teacher)

### **Language policies in the schools for Deaf and hard of hearing learners.**

Participants discussed the language policies in their schools. One school is oral based. The others use a combination of SASL or oral based methods (depending on what the learners require). There are teachers who use total communication methods to communicate with their Deaf learners. Two high school teachers and a school psychologist explained the complexities of the different backgrounds of their learners and how this impacted on the learning environment. A high school teacher, currently a principal of a school for the Deaf, said she hoped that her school would equip learners to communicate with the Deaf and hearing communities. Another teacher explained that teaching in ‘signed English’ could result in omission of words or concepts:

Signing, it’s very limited, when it comes to further education, the signings not going to take them anywhere, you can’t teach through signing, there aren’t signs for the words, it’s a long winded way to explain simple words because there’s not one sign for the word, so therefore I have a, take a very strong view on that, that children must be able to do both, they must function in the deaf world and the hearing world...

(High school teacher)

When you’re giving signed English, you’re still missing out the words, there’s sort of lots of words that there isn’t a sign for – there is a sign for “a” but it’s, you kind if leave it out, but here, then they can see how it goes...

(High school teacher)

Another high school teacher explained that he generally instructed in SASL. He experienced difficulty as textbooks are generally produced for hearing students who have better literacy levels than Deaf or hard of hearing students. One of his colleagues explained that it was challenging to deliver education to learners who used different modes of communication:

What I believe you should do ethically, is really for, well you should match the communication of the people. people use a mixture, some of our children coming in here don't know a single sign when they come in. They're from hearing schools and they have virtually no language because they don't have English, Zulu or anything else really.

(High school teacher)

Up to now we catered mostly for Deaf learners using sign language with Afrikaans as the language for reading and writing ... especially from grade 7 upwards and especially after grade 9, for children who need sign language and English and wants to follow an academic course. We have some hard of hearing children whose first language is Afrikaans, but they're mostly deaf with a capital D and use sign language. We're increasingly getting some children who, who are, or who were in the mainstream up to now and they, sign language is not their first language and they, in these classes, ...you often have to sort of use the two mediums together which makes it quite difficult and demanding, because there are some children who do not understand sign language.

(School psychologist)

First of all the reason for using sign, sign language is to make sure that they understand the story fully, to make sure that the story is well explained to them in their own language. Because social sciences is in English, the books are written in English, I use signed English for them to understand the texts that are written in English.

(High school teacher)

Two participants, who are Deaf teachers, explained the importance of their role in minimizing some of the language barriers Deaf learners faced at school:

The hearing teachers never had the experience of having the, being taught within that concept, they don't understand the limits they have. We know what the level is or what the language is and it's easier to communicate in various levels of SA Sign Language with them whereby the hearing teacher cannot do that, they must still try to understand what the child is telling them, missing out on a lot of information and so it's more time consuming and it's taking longer for them to teach the children because they still need to understand what the question was, is that true ...

(Deaf high school teacher)

### **Conclusions.**

In this phase, several cross cutting themes emerged, including the participants' perceptions of HIV/AIDS risk for Deaf and hard of hearing youth, attitudes to HIV prevention education in schools for Deaf and hard of hearing learners, as well as information about accessibility of HIV/AIDS prevention materials for these learners. Although participants perceived their Deaf and hard of hearing learners to be at risk of HIV/AIDS, there was some reservation about forfeiting religious belief for condom education or education about sexual diversity. Some participants had adapted existing HIV materials, that were originally developed for hearing youth, for Deaf learners. They had done so by enhancing the visual quality of the material. I will further expand on some of these issues in the Discussion chapter at the end of the thesis.

### **Phase 3: Parents' of Deaf and Hard Of Hearing Adolescents' Views Of HIV Prevention Issues:**

I interviewed nine parents in total of whom three were fathers and six mothers. All the participants were living with their children at the time of their interview.

Four of participants had tertiary level education while one had completed her secondary schooling. The remainder of the sample reported limited schooling. Table 9 below presents socio-demographic characteristics of the sample.

Table 9

*Socio Demographic Characteristics of Parent Participants*

Participant	Mother/Father	Level of Education	Deaf or hard of hearing child	Age of child	Sex of child
1	Father	Secondary schooling	Hard of hearing	20	Male
2	Father	Tertiary Education	Hard of hearing	18	Female
3	Father	Tertiary Education	Hard of hearing	17	Female
4	Mother	Primary Schooling	Deaf	12	Female
5	Mother	Primary Schooling	Deaf	18	Male
6	Mother	Primary Schooling	Deaf	18	Male
7	Mother	Secondary Schooling	Deaf	18	Female
8	Mother	Tertiary Education	Hard of hearing	15	Female
9	Mother	Tertiary Education	Hard of hearing	17	Male

A number of themes emerged from the analysis. I report on the most salient inter-related themes:

(1) *Participants' fears of the risks of HIV/AIDS in their children;* (2) *Participants' perceptions of their children's sexuality during adolescence;* (3) *Experiences of being a parent of a child who is*

*Deaf or hard of hearing. (4) Participants' perceptions of schools measures to address HIV/AIDS risks in Deaf and hard of hearing learners; (5) Experiences of being a parent of a child who is Deaf or hard of hearing.*

The first two themes are strongly related to one another and the communication challenges are clearly a hindrance to discussing HIV/AIDS risk and broader issues of sexuality.

### **Participants' fears of the risks of HIV/AIDS in their children.**

All nine participants feared that their children were at risk of HIV/AIDS. Participants from more impoverished communities (three out of the total of nine) perceived the risk of HIV/AIDS or contracting another sexually transmitted infection (STI) for their children as imminent:

To be a parent of a Deaf child at this present moment, (I worry about) the various diseases, most especially the HIV/AIDS ...

(Father)

You will contract cervical cancer, that's why you see young people die so young, it's because they were so active at an early stage you know and then they die young, because of cancer ...

(Mother)

A father of a teenage Deaf boy, living in a low income area in Gauteng, thought that Deaf and hard of hearing youth were at risk of sexual abuse due to a common perception in some communities that having sex with a virgin could cure HIV/AIDS. Perpetrators might believe that Deaf or hard of hearing youth were not sexually active because of their disability or that they lacked sufficient language to report the crime to the authorities. A mother living in an urban area

in Johannesburg echoed his view. She also thought that Deaf and hard of hearing youth were more vulnerable to sexual abuse than hearing youth:

Maybe if they meet them sexually, they'll get cured from HIV and AIDS. I think that maybe the (perpetrators) take advantage because they think that they (the Deaf) don't know how to explain that such and such a person did this to....

(Father)

Well we've heard rumours, I mean you know, they are more vulnerable than normal kids because they can't communicate normally, and we know a few things have happened to some of the kids at school if something had to happen to him (my Deaf son), I'm not entirely sure that he would be able to tell us what happened...

(Mother)

### **Experiences of being a parent of a child who is Deaf or hard of hearing.**

All nine participants discussed the challenges of communicating with their children either orally or by means of South African Sign Language (SASL). One mother who lives in a low income area a considerable distance from her child's school discussed financial and transport barriers to attending SASL classes held at the school. Another mother also felt constrained by career pressures and could not attend SASL classes held at her child's school. She also mentioned that her son's father was resistant to learning SASL and thus their son had learnt to speak. Another mother reported that her son did not enjoy attending youth camps or groups with his hearing siblings. He felt out of place as the only Deaf person there:

I live very far, I can't come and attend on a weekly base, the sign language classes because of finances ...

(Mother)

His dad's not going to ever sign, he just, from day one, he was not going to sign, so he'd had to go oral ...

(Mother)

When we ask him to attend youth with the other children he tells me he's the only one that's deaf there, I think he prefers to be around people like himself ...

(Mother)

Despite communication difficulties experienced by the participants, the majority (eight out of nine participants) seemed to communicate about sexuality and HIV/AIDS issues with their children. One mother explained that their views about teenage sexuality were influenced by their Christian beliefs. A father described the tension between holding religious values and discussing sexuality with his daughter:

We actually try and dissuade them from that for various reasons but obviously also because of our religious beliefs and, and our moral beliefs and things like that.

(Mother)

We talk about it openly and things like, but it's, it's very difficult from, especially when you come from a conservative family to actually talk about sex the way you are expected to speak to your children, you know what I'm saying, but I mean from the safety precaution side, I mean it's probably easier to say that you know, you must be careful in terms of what you get involved in and where you get involved in and these things you know, specially to boys, I always told, I always tell her ...

(Father )

He will come and explain to (me) – you know at, at school they taught us about this illness, HIV and they told us that it's so dangerous that we must just wait for the right time ...

(Mother)

Another mother explained that, although other people seem to pity parents of Deaf and hard of hearing children, with a little assistance they (the Deaf) can function really well in society:

They're very normal except when it comes to the hearing and their lives can be made much easier when other people accept that there, there's nothing else wrong with them and they can function as proper people ...

(Mother)

### **Participants' perceptions of their children's sexuality during adolescence.**

Despite their awareness and fear of the risk of HIV/AIDS for their children, the majority of participants (seven out of the nine participants) believed that their children had not become sexually active yet. They described their adolescent children as 'innocent' or currently interested in other activities such as sport. There was also the issue that Deaf and hard of hearing adolescents were considerably lonely and found socialising difficult due to communication barriers with the hearing world, and this could impact on delay of relationships:

Yes, now I know deaf kids are more physical, you know they, they touch each other but, I just get the, the impression that they are active, but I'm, I'm pretty sure mine's not yet...

(Mother)

One mother described her fears of peer pressure potentially catalysing premature sexual activity. She highlighted an incident where her son was exposed to pornographic videos distributed by

Deaf peers at his school, and described the measures taken by his parents to destroy the material. She also described the role of social networks such as *facebook* as providing a space where Deaf and hard of hearing adolescents can express their anxieties about their sexuality:

They (the Deaf learners) were distributing it (DVD) amongst each other, so I think if they're not able to talk to us about it...I was very worried about where he got it so I went to school and his father broke it.

(Mother)

I think, communicating, is a huge problem, it's not easy, especially the older they get, the more difficult it is, because for her to just walk up to someone or for someone to talk to her is a problem so she will shy away from, from making friends quickly and she obviously depends on, on others around her to interpret for her...

(Mother)

He's not really physically aware, he hasn't been up to now, he's been more interested, he's very active, he plays volley ball, plays cricket, plays soccer, he mountain bikes, he's very athletic, but he's never really pursued the girl side of things, but that's changing now, coz his friends are 17, 18, the one's just turned 18 and they're very interested in girls and it's now rubbing off ...

(Mother)

One mother thought her twin Deaf sons had already experienced their sexual debut and said she advised them to use condoms. Another mother had had an unfaithful sexual partner and had contracted a STI. Therefore she understood the necessity of using condoms during sexual intercourse and said she would encourage her daughter to do the same:

I want to emphasise why I use condoms. I discovered that my husband is not faithful (vaginal) discharges coming out and I went to the clinic more than 4 times. The nurses advised me to use condom because the man was not faithful ...

(Mother)

A mother described her son's process of choosing a partner, a Deaf girl attending a different school from the one he currently attends. She also described cultural issues such as choosing a partner from a different racial group:

I asked him "why a coloured girlfriend," and he said he doesn't have anyone around his age that is Indian and that is interested in him and I think he was always, I think he felt that he couldn't have a hearing girlfriend ...

(Mother)

### **Participants' perceptions of schools' measures to address HIV/AIDS risks in Deaf and hard of hearing learners.**

All nine participants believed that the schools for the Deaf and hard of hearing where their children were educated were receiving adequate information about the risks of HIV/AIDS. They were aware of condom education (and in some cases availability) and education about abstinence at school. They favoured these measures.

As far as I know they (condoms) are available to them, if they want them from the school nurse...

(Mother)

The teacher advise them not have sex with boys because they're going to contract HIV/AIDS.

(Mother)

She's very up to date with what's happening in the newspapers and what's happening on the news and I think in school they will discuss it as well. So it will become, it will become a general discussion and then we will discuss whatever issues that she has, if she wants to know something we will discuss it and I think that's one thing that I can say is that even being Deaf, even at the previous school and at this school they, they do get the information that is, that is necessary.

(Mother)

However, one mother was concerned that her son and his peers did not process or understand the information given at school properly:

They've got school classes...they're apparently taught about sex and protection and the diseases that you can pick up, I just don't think they really understand. he knows that he, you need to use a condom when you have sex, to protect you against AIDS but I don't think they understand what happens (the mechanism) ...

(Mother)

### **Conclusions.**

In this phase, parents expressed their worry that their Deaf or hard of hearing adolescent children were at risk of HIV/AIDS. In more impoverished areas, participants perceived their children to be at risk of sexually transmitted infections including HIV/AIDS. Participants described communication challenges as a barrier to discussing HIV/AIDS and sexuality issues with their children. Some of these issues will be expanded on in the discussion section at the end of the thesis.

### ***Phase 4: Deaf or Hard Of Hearing Adolescents' Views on HIV/AIDS***

I interviewed 10 males and 14 females in Grades 8- 12. The mean age of participants was 17.7 years. Eight participants self-identified as hard of hearing while 16 reported they were culturally Deaf and communicated in SASL. Table 10 below presents the age and sex of the participants.

Table 10

#### *Socio- Demographic Details of Adolescent Participants*

Number of Participants	Sex	Mean Age
10	Male	17.7 years
14	Female	17.6 years

I identified key themes from the analysis:

*(1) Participants' perceptions of their schools' efforts of protecting them from HIV/AIDS; (2) Participants' perceptions of their own risk of HIV/AIDS infection; (3) Participants' perceptions of condoms; (4) Participants' perceptions of the differences in HIV/AIDS risk for Deaf, hard of hearing and hearing adolescents.*

#### **Participants' perceptions of their schools' efforts of protecting them from HIV/AIDS.**

Five participants said that they did not learn about HIV/AIDS at school. Two participants explained that they learned very little about HIV/AIDS at school. One reported that the skills class did not receive adequate information about HIV/AIDS compared to the academic stream:

No (I did not learn about HIV), I was in N1(the skills stream) and the, that's all...

(Deaf, male participant, age 19)

They've (the teachers) been teaching us just basic things, they don't go in detail with It ...

(Deaf female participant, age 16)

### **Participants' perceptions of condoms.**

Strongly linked to the previous theme is that of participants' perceptions of condoms. Seven participants reported that they had learned about condoms at school. While some participants were aware of the purpose of condoms (as both a barrier method and a contraceptive), five participants thought that condoms were solely contraceptives and not barrier methods against HIV/AIDS or sexually transmitted infections. One female learner said she had learnt that condoms were a barrier method from her parents and not from her school. Another female learner at a different school said she had learnt about condoms at school and initially did not understand what she was taught. She asked her teachers questions and then said she understood more fully. However she then reported that condoms were a contraceptive:

It helps if you have sex, the girl can't get pregnant...

(Deaf male learner, age 18)

Yes, if you don't have a condom, say for example a man doesn't have a condom then the girl should say no, she doesn't want to have sex, because that could be a risk ...

(Deaf female learner, age 18)

Before in LO we learnt about condoms and we didn't understand everything so we asked, we asked for it to be explained to us to help us understand about condoms... It's very important for a lady or a girl to keep her body safe, it's very, very important. Sometimes it could happen that you could fall pregnant if you're not careful...

(Deaf female learner, age 18)

A Deaf male learner reported that generally Deaf adolescents do not use condoms while a Deaf female learner thought that there is no need to use condoms while menstruating:

If I'm a girl and if I'm going out with a boy and if the boys ask me to have sex and he forgot about a condom and, then it's impossible to allow the boy to have sex with me, it's important to have a condom...

(Deaf, female participant, age 18)

It helps if you have sex, the girl can't get pregnant...

(Deaf, male participant, age 18)

Condoms, they are the protection for you not go get pregnant, when I'm in my periods, I don't have to use condom, I have to wait until I'm done with my cycle ...

(Deaf, female participant, age 17)

### **Participants' perceptions of their own risk of HIV/AIDS infection.**

Participants discussed that they could be at risk of HIV/AIDS and spoke of a number of related issues including lack of knowledge of barrier methods, sexual debut, abstinence until marriage and impaired communication with their parents about sexuality and HIV/AIDS issues. Two male Deaf participants described barriers in accessing information about HIV/AIDS. One explained that Deaf youth tend to receive information about HIV/AIDS from hearing peers and due to communication barriers they may receive fragments of information rather than the whole picture:

There isn't much information so we just gets bits and pieces from, mostly the guys that are hearing ...some of the friends that we have, we just get the info from them...

(Deaf male participant, age 16)

Similarly, participants reported communication barriers in their home environment as obstructive to discussing sexuality or HIV/AIDS. The majority of caregivers or parents are not proficient in SASL. This was reported to impact on potential communication space for discussing HIV/AIDS and sexuality issues. A Deaf female learner who is in the care of an aunt spoke of communication difficulties with her aunt as well as her parents (who she reported seeing regularly). She also described the added complexities of a father who is a migrant labourer. Due to his work patterns and the little time available when he is present there is limited opportunity for establishing a communicative relationship. A Deaf female learner reported that her parents rarely discussed HIV/AIDS and sexuality issues and when they did it they advised abstinence from sexual activity until marriage. Another Deaf male learner, who is in the care of relatives, said he was shy to discuss HIV/AIDS risk with them: He reported that, as his biological father had died of HIV/AIDS, he feared his caregivers may be scared or angry if he broached the subject:

She (my aunt) doesn't understand sign language, so that's an issue. We (my parents and I) never talk when he (my father) gets home, he doesn't stay that much, he gets home and then he leaves.

(Deaf female learner, age 16)

Mom signs a bit but my Dad doesn't sign at all I'm a bit shy and they might get angry quickly. my father died of AIDS and I might get the same.

(Deaf, male learner, age 17)

Four participants reported they had experienced their sexual debut already. One female hard of hearing participant said she had not experienced her sexual debut yet. The remaining 19 participants did not discuss whether or not they had reached their sexual debut yet.

A female hard of hearing learner reported she had had sexual intercourse with her boyfriend once. Another three hard of hearing male learners reported they had experienced their sexual debut. One of these participants reported that although his religion (Islam) preached against pre-marital sexual activity, he had already experienced his sexual debut:

In my religion, I'm Muslim, I'm not supposed to have sex before I am married, but I'm naughty (laughter) ...

(Hard of hearing male learner, age 18)

The other two participants reported that they consistently used condoms. One reported he had had an HIV test the previous year. Another said that, although he had always used condoms, his girlfriend had fallen pregnant the year before:

I have always used a condom, I have never done it without sex and look, in the last term we had a HIV test from the, from this, I don't know what organisation it was, they came to our school, and then we had ourselves tested and I was always, I was like, how can I say, I was, I was, I was scared that I did have it maybe, even though I did use a condom all the time, so but then I was safe, so I was like okay...

(Hard of hearing male learner, age 18)

Five participants discussed abstinence from sexual activity until the end of high school as a means of protecting themselves from HIV/AIDS. A Deaf male participant and a Deaf female participant discussed the importance of accessing voluntary counselling and testing (VCT) with a prospective marriage partner. Another Deaf male participant was influenced by his sister's death from HIV/AIDS. A female participant who did not disclose if she had already experienced her sexual debut said it was important to trust a potential partner before sexual intercourse takes place:

I know if, if, if I think about having sex, the first thing, the two of us must go to the clinic and get tested for HIV. I want to know and then we'll wait before we get the results from the clinic before because I don't want AIDS. But first we need to get married. If (my prospective marriage partner is HIV positive) I will leave it, I, I won't get married. To another one, yes, but not to the one who's got AIDS...

(Deaf male learner, age 17)

My sister died of HIV/AIDS. I was very sad, I felt very sad about it, I just focus on my school work and I read, it's very important. My brother gave me the phone number of where my sister was and when I saw her, I saw that she had died that was in 2002 and my brother told me and I understand about HIV/AIDS, like for example with the girlfriend and if a girl is shy and doesn't want to, doesn't want to, so my brothers taught me. My sister's married, ja my eldest sister, my sister's married now, she has her own house, she's got a very nice house and she's got her own work.

(Deaf, male learner, age 19)

Not to fall pregnant, no sex and not to have a boyfriend and not to sleep with men and not to go out with a, with a man and sleep with him...

(Deaf, female learner, age 18)

Six participants reported the risk of sexual abuse as a risk factor for HIV/AIDS. A Deaf female participant explained that Deaf and hard of hearing youth might feel isolated and lonely in their communities. This loneliness increased their vulnerability to HIV/AIDS infection. Another Deaf female participant described her caregiver's reaction to this vulnerability. She was in the care of an aunt who did not allow her to socialise or leave the home easily for fear that she would be at

risk of sexual abuse. A third Deaf female learner spoke of the fears of sexual abuse in the community:

Most of the time we were told that we shouldn't walk alone and all of these things. Somebody might be following you they'll probably rape me ...

(Deaf female learner, age 16)

I think maybe it's because in their homes they are lonely and they go maybe and look for something that they don't have and then they get raped ... my aunt, let's say she doesn't want me to go anywhere or yet to go out, she just wants me to stay at home not even to socialise with my friends. Sometimes they are raped, so at night it's, it's hard for them to, to hear what's happening behind them or what's happening around them so they get raped ...

(Deaf female learner, age 17)

I do know (a Deaf girl who was sexually abused), there was one at the age of 15 and I think there was a 40 year old that actually abused her and she became pregnant and she had to have an abortion and she was actually kicked out from her home, her family kicked her out and sent her to, to live with that man ...

(Deaf female learner, age 18)

### **Participants' perceptions of the differences in HIV/AIDS risk for Deaf, hard of hearing and hearing adolescents.**

Participants discussed the differences in risk factors for HIV/AIDS infection for Deaf, hard of hearing and hearing adolescents. Two Deaf female learners reported that hard of hearing adolescents experienced their sexual debut earlier than Deaf adolescents. One reported that hearing and hard of hearing adolescents were more likely to socialize and attend parties. The

other reported that hearing youth were more prone to substance abuse patterns than Deaf or hard of hearing youth. Two Deaf female learners reported that Deaf youth abused alcohol more than their hearing or hard of hearing peers. A Deaf female learner reported that there was pressure from hearing peers to abuse alcohol. Deaf and hard of hearing youth might feel they should drink alcohol to feel accepted. A hard of hearing female learner reported that Deaf adolescents felt pressurized to start sexual activity especially if there was a possibility of a hearing partner: A Deaf female learner reported that there were Deaf girls who were vulnerable to abuse by hearing boyfriends.

Because they're (hearing adolescents) always going out, Monday to Friday so I think that's why it is, because most of their friends, they go out on the weekends...

(Deaf female learner)

Another Deaf female learner explained that Deaf or hard of hearing girls were seen as an easy target by hearing men and therefore were at risk of sexual abuse:

They (the men) think that the deaf girls are stupid and they can be easily bought...

(Deaf female learner, age 18)

She also mentioned that, in her opinion, Deaf youth engaged in risky drinking patterns to gain acceptance in social circles:

It's more for socialising and they go out, if a man and a girl goes out to some place then the girl also drink and when, the girl then has to lie to her family and when she goes out visiting with the boyfriend she has to pay for the drinks and she pays for, again and again and again and then the next day when she comes back home, the family realises, they can see that her eyes are red and that she's been drinking...

(Deaf female learner, age 18).

### **Conclusions.**

Adolescents perceived themselves at risk of HIV/AIDS infection and believed that their schools did not prepare them adequately for protecting themselves. Many participants believed that they did not learn about condoms at school and a few thought that condoms were merely contraceptives and not barrier methods as well. Limited differences between Deaf, hearing and hard of hearing adolescents were perceived with regard to sexual behaviour and general HIV/AIDS risk. Communication challenges were raised as a barrier to obtaining correct, effective information about HIV/AIDS. I will further expand on some of these issues in the discussion section at the end of the thesis.

### **Summary**

Overall the key issues that emerged from the results section of the thesis included participants' descriptions of: sexuality education for Deaf and hard of hearing adolescents, HIV risk issues for Deaf and hard of hearing adolescents, and mental health issues for the Deaf community. Table 11 on the next page presents a synopsis of some of these emergent issues that will be further expanded on in the discussion section of the thesis.

Table 11

*Synopsis of Key Issues Emerging from the Groups of Participants*

Key issue	Group	Main perceptions
Sexuality education for the Deaf community	Deaf organizations' key informants	Religious ethos in schools for Deaf and hard of hearing learners potentially obstructive to sexuality education. In particular education about sexual diversity in one school for Deaf and hard of hearing learners was seen as challenging.
	Educators of Deaf and hard of hearing adolescents	Catholic position on condom usage influenced condom education in two historically Catholic schools but not the third Catholic school which had managed to adapt accordingly. Sexual diversity education seen as immoral.
	Parents of Deaf and hard of hearing adolescents	Aware of condom education and the schools encouraging abstinence until after the final year of high school.
	Deaf and hard of hearing adolescents	Some felt that they do not receive adequate HIV/AIDS education at school. Limited knowledge of condom usage.
HIV risk for Deaf and hard of hearing adolescents		Well acknowledged in all the groups. Communication challenges of paramount importance, risk of sexual abuse viewed as imminent. Educators discussed substance abuse and alcohol abuse.
Mental health issues		Poor understanding of mental health across all groups.

## **Chapter 5: Discussion**

This chapter of the thesis presents the interpretation of my findings as well as recommendations for future research.

It is important first to describe the limitations faced in the research process and show how these limitations affect interpretation of the data. I will then describe the issues that have emerged from the data and lastly provide recommendations based on my findings.

### **Limitations of the Research**

Limitations were encountered in all four phases of the research. I will first discuss common limitations encountered across all the different phases and then discuss limitations specific to each phase.

My study (i.e. all four of the interlinked phases) was limited in scope as it was restricted to two provinces in South Africa. Where participants were Deaf, I was assisted by SASL interpreters. Some of the interpreters were not completely fluent in English and thus struggled to articulate the participants' responses in English. If the participants were hard of hearing, I interviewed them myself, taking copious notes throughout the process. There were sometimes challenges in transcribing material from interviews with hard of hearing participants. In the phase where I interviewed adolescents, one of the main limitations was communication barriers. I had to interview the participants who were hard of hearing myself without the assistance of a SASL interpreter. They were unable to sign and some struggled to speak. Many of these interviews were difficult to transcribe. I had to transcribe them myself with the assistance of the notes I had taken during the interviews. In the schools where lessons were delivered in SASL or total communication, the adolescent participants sometimes had difficulty in communicating in SASL

(with the assistance of the SASL interpreter). This meant their responses were not detailed and the data analysis was challenging.

In all four of the phases of the research, I held substantial discussions about HIV/AIDS risk factors with participants. Although I elicited valuable information about the HIV/AIDS risk, the data cannot be read to provide objective information as to whether Deaf and hard of hearing adolescents are more at risk of HIV/AIDS than hearing adolescents of their age. The study was not designed as an epidemiological study to assess risk but rather an exploratory, qualitative study to determine a broad picture of the main issues, and is thus dependent on the views of participants, which may be incorrect.

It was challenging to recruit parents into the study. The staff at the schools for the Deaf and hard of hearing advised us that most parents were not involved in decision making around their Deaf and hard of hearing children's education and therefore tended not to visit the schools regularly. In poorer areas, most learners lived a considerable distance from their schools and travelled home by themselves on public transport. In a way my sample is biased as I recruited parents who were contactable and who communicated with their children's schools regularly. A further problem was experienced with interpretation of the interviews. I had to enlist the services of a lay interpreter (a cleaner at the school) in these interviews as I was unaware that two of the participants who had been recruited were Zulu speaking and unable to articulate themselves in English. It is certainly not ideal to conduct interviews using informal interpreters, though the use of such interpreters is common practice in South Africa in the health and mental health fields due to a paucity of formally trained interpreters in the public sector (Kilian, Swartz & Joska, 2010; Swartz & Drennan, 2000).

There were particular challenges associated with interviewing the adolescents. Although throughout the study all I elicited was opinion (see earlier discussion), the adolescents may have had particular reasons to censor what they said to me or even to be untruthful, as it is not easy for any adolescent to speak openly about private sexual matters. It was difficult to determine if the adolescents were completely truthful about their sexual debut and other related issues. Although participants alluded to friends or acquaintances who had HIV/AIDS, had accessed a termination of pregnancy service, or who had been sexually abused, none of them admitted to this themselves. This is a well acknowledged limitation of research on sexual behaviour. Participants may provide inaccurate reports of their sexual behaviour due to social desirability issues. This may be influenced by a range of factors including messages about condom usage, inability to recall information truthfully or poorly worded questions (Minnis et al., 2009). I also sensed anxiety on behalf of some of the participants that I would ask them if they were actually HIV positive. The fear of others knowing one's HIV status or suspecting a HIV positive diagnosis is not uncommon in South Africa.

The concerns expressed about HIV status are also not surprising in the South African context. There is tremendous stigma attached to HIV positive diagnosis in the country and this may well affect the decision to disclose one's status (Iwelunmor et al., 2010; Sorsdahl, Mall, Stein & Joska, 2011).

### **Interpretation of Results**

It is helpful to discuss the differences and similarities in the responses of the four groups recruited for interviews. Data were collected using qualitative methods to try to fulfil the aims and objectives of the study, i.e. the role of the education system for Deaf and hard of hearing adolescents in meeting the HIV prevention needs of the learners.

### **Acknowledgement of HIV/AIDS risk of Deaf and hard of hearing adolescents.**

All participants perceived Deaf people who live in South Africa as at risk of HIV/AIDS. Therefore they saw HIV/AIDS prevention programmes as a priority. Risk factors not exclusive to Deaf and hard of hearing adolescents were discussed by participants interviewed for the educators study. In fact the risk factors for HIV infection described by participants are similar to those that affect able bodied adolescents (Speizer, Gomez, Stewart & Voss (2011). These educators had had experience of Deaf and hard of hearing adolescents indulging in high risk sexual behaviour, (i.e. not using condoms or having multiple concurrent partnerships), exhibiting substance abuse behaviour patterns or falling victim to sexual violence. There was no sense that participants believed that disabled people were not sexually active or that they should not be sexually active and therefore not at risk of HIV/AIDS. Most participants believed that Deaf and hard of hearing learners were not substantially different from their hearing peers with regard to sexual debut. However, the hostel environment and exposure to the opposite sex was cited as a potential factor in an earlier sexual debut than hearing adolescents. Deaf and hard of hearing adolescents were also perceived as particularly lonely or desperate to feel socially adequate. Therefore they might be at risk of a premature sexual relationship or a sexual predator who could potentially exploit them. This finding is in contrast to that of Milligan and Neufeldt (2001) who reported that disabled people have been constructed as asexual or sexually disinhibited and that sexual acts between disabled people were not viewed favourably.

Participants from the educators' phase described their fears that their Deaf or hard of hearing learners were at risk of sexual abuse. Eleven participants were aware of cases of sexual abuse of Deaf or hard of hearing learners. Of these 11, six thought that Deaf or hard of hearing learners were more vulnerable to sexual abuse than hearing learners. They explained that perpetrators

might believe that Deaf or hard of hearing youth were incapable of reporting the crime to the authorities as they lacked spoken language to do so. One participant explained that Deaf people were incapable of screaming for help during an attack.

Parents from more impoverished communities (three out of the total of nine) perceived the risk of HIV/AIDS or contracting another sexually transmitted infection (STI) for their children as imminent. A father was anxious about the common perception in some communities that having sex with a virgin could cure HIV/AIDS. He thought that his teenage Deaf son was at risk of sexual abuse (and ultimately HIV/AIDS) due to this practice. Risks for HIV/AIDS infection for adolescents with a disability as expressed by participants is well documented in the literature.

Like our participants who described the danger of sexual abuse faced by their children (due to difficulties in reporting a crime), Philander (2007) described the fear of sexual abuse expressed by blind adolescents in South Africa. His participants believed that perpetrators thought that the blind were incapable of identifying a perpetrator after an attack. Groce (2003) affirmed that there were reports that Deaf and hard of hearing, intellectually disabled, physically disabled and people with psychiatric disability have been victims of virgin rape, although Epstein and Jewkes (2009) reported that there was no proof that the practice was widespread. Our findings also indicated that participants who resided in low income areas perceived the threat of HIV/AIDS as imminent.

This finding is reminiscent of that of Harries, Moodley, Barone, Mall and Sinanovic (2009) who explored the feasibility of the vaccine for the Human Papilloma Virus (a sexually transmitted infection (STI)) in South African communities. They also found that in low income areas participants feared the reality of the risk of sexual abuse for their children and therefore supported any form of protection against STI.

Many of the issues that the educators and the parents discussed as barriers to risk proofing their children's or learners' experiences are not confined to Deaf and hard of hearing adolescents. Challenges related to poverty, abuse, and violence (including sexual violence) are endemic in the areas where these adolescents live. Wilbraham (2009) drew attention to 'risk protective effects of certain child-rearing practices in families. She mentioned 'the risk-proofing efficacy of child-centred management of sexual socialization - taking low incidence of unwanted teenage pregnancy as a measurable outcome' which is common in European countries and described this model as 'at odds with some classed or raced niches of childrearing and communication practices in South African family practices'(p. 59). Regarding perceptions of risk, parents of Deaf and hard of hearing children might be even more aware than others of the ubiquitous risks regarding sexual violence and HIV, and it would certainly be helpful to do more comparative studies with parents from similar backgrounds whose children are not Deaf or hard of hearing.

### **Communication challenges.**

Communication challenges were seen as a barrier to accessing HIV/AIDS information across all groups of participants. A school nurse interviewed in the educators' phase referred to the positive impact of a SASL interpreter on the drug rehabilitation process of a young Deaf boy. The SASL interpreter was introduced to the process after about six weeks and the staff were able to see the substantial difference in their client. In the parents' interviews communication barriers were also identified as a barrier to discussing sexuality and HIV/AIDS issues with Deaf children. Other educators interviewed alluded to their efforts to create material about HIV/AIDS that was accessible to Deaf youth. This finding is also well documented in the literature. Crowe (2003) and Mallinson (2004a) both alluded to creating accessible HIV prevention materials for Deaf adolescents and adults. However, it is worrying that many of the adolescent participants claimed

that they did not learn about HIV/AIDS at school, despite the statements from educators about teaching them about HIV/AIDS. This could well be due to communication barriers and, particularly, the total communication methods employed in most of the schools, which could result in great confusion for Deaf learners (Penn & Reagan, 1990).

This finding about communication is not exclusive to the Deaf community. Phetla et al. (2006) assessed an intervention conducted in a rural area in South Africa. The intervention, a community based, randomized, controlled trial entailed integrating microfinance, participatory education, and HIV and gender awareness, as well as promoting communication about sexuality between adults and youth. The study found that women who participated in the intervention reported significantly higher levels of communication about sexuality with their children than women did not participate in the intervention arm.

The issue of communication has been highlighted in previous studies of the Deaf community in relation to HIV/AIDS as well as other illnesses. Mallinson (2004b) found that Deaf men in the USA who accessed HIV/AIDS prevention services, were sometimes expected to read information which is usually disseminated orally or discussed with the health care provider. This was considered ill-advised because many Deaf people in the USA who communicate through American Sign Language (ASL) find reading English difficult and, consequently, there is a risk of inaccurate information being transmitted. Steinberg et al. (2002) found that Deaf women in the USA delayed access to mammography or papanicolau smears due to lack of knowledge of the importance of screening. They were more positive about health care access when an ASL interpreter was available.

The most important effort made by Deaf organizations regarding HIV/AIDS was training Deaf counsellors in HIV/AIDS testing programmes. These counsellors were well trained to deal with

social issues such as financial or domestic violence. They were also fluent in SASL and understood the importance of delivering counselling sessions in this medium of instruction.

### **HIV programmes in the schools.**

It is worrying, but not unsurprising, that participants from the Deaf organizations interviewed for Phase 1 had experienced difficulties in providing HIV/AIDS education in schools for the Deaf and hard of hearing. They perceived the religious ethos in schools as potentially obstructive to HIV education, including condom education and promotion. Two participants had also experienced difficulties in delivering education about sexual diversity in schools for the Deaf. These participants had received limited help from Deaf teaching assistants who were generally misinformed about HIV/AIDS transmission. Similarly, Rohleder (2008) found that staff at disability organizations and schools for disabled children were opposed to condom promotion, views which were grounded in religious beliefs. This was not the case for the participants from Phase 3 and 4. Parent participants seemed unaware of the influence of the religious ethos in two of the schools and believed that the schools for Deaf and hard of hearing learners where their children were educated were providing adequate information about the risks of HIV/AIDS. They were aware of condom education (and in some cases availability) and education about abstinence at school. They favoured these measures.

Similarly the adolescents themselves did not discuss religious ethos in the schools as a potential barrier to learning about HIV/AIDS or sexuality issues. Some learners claimed that the skills streams at their school received inadequate information about HIV/AIDS. This was reflected in the poor knowledge of condoms expressed by a few participants. They thought that condoms were solely contraceptives and not barrier methods. There was also confusion about the necessity of condom usage during menstruation. Similar findings were yielded in previous studies of Deaf

youth in South Africa, USA and Swaziland. For example, Groce et al. (2006), who conducted a pilot survey of a Deaf population in Swaziland, found poor knowledge of HIV transmission. The authors attributed this finding to poor education for Deaf youth in Swaziland where there are only two schools for Deaf learners,

This theme of moral and religious conflict was further explored in Phase 2 which comprised interviews with educators, some of whom were employees of historically Catholic schools. The ambivalence expressed by educators of Deaf and hard of hearing learners interviewed for Phase 2 of the study, regarding condom education in these schools, is undesirable, considering that condoms are amongst the most efficient means of preventing HIV/AIDS and other sexually transmitted infections. One school had successfully managed to reconcile religious belief with HIV/AIDS prevention needs. While some educators in the other traditionally Catholic schools were making efforts to do the same, they were not always supported by their supervisors who were adamant that the Catholic stance on condom usage be upheld.

When conducting research in mental health services in South Africa, Collins (2006) also detected moral dilemmas amongst mental health service providers in South Africa regarding condom distribution. In many cases, she found that nurses working in mental health services would provide condoms to patients they suspected of being sexually active, who had a sexually transmitted infection or had been sexually abused. They did not distribute condoms to patients whom they perceived to be too ill to use them. This study also revealed that out-patients in psychiatric hospitals were found to receive limited HIV/AIDS education. While this finding can be attributed to a perception of providers that sexual desire or activity (in the psychiatric setting) is an expression of illness rather than sexuality, our findings related to moral or religious obligation. What I have found is a clash between religious value and the threat of an emerging

HIV/AIDS epidemic. Casale, Nixon, Flicker, Rubincam and Jenney (2010) explored the dynamics of a HIV/AIDS prevention programme organized by a Faith based organization for adolescents in South Africa. They found that the programme delivered ambiguous messages regarding condom promotion and participants expressed doubt about their usefulness in HIV prevention.

Similar sentiments were expressed with regard to the distribution of the GALA comic book in one of the schools. The project was reported to be unsuccessful. Not only had the book been distributed at a pressurized time for the school (i.e. during examinations), but it was reported that learners lacked the levels of literacy required to understand its key concepts. Furthermore, Deaf teaching assistants viewed the book as immoral due to its mention of sexual diversity. Comparisons can be drawn with the findings of Rohleder (2008) and Rohleder and Swartz (2009), who detected reservation on behalf of participants (educators in disabled schools) to deal with issues of homosexuality. They were reluctant to teach disabled people in their care about homosexuality due to religious and ethical conflicts.

These findings reveal some key dilemmas for those concerned about HIV issues for marginalised groups. Parents of Deaf or hard of hearing learners have little choice in terms of the moral and religious ethos of the schools to which they send their children. As employees of religious schools, on the other hand, teachers are arguably entitled to their own views on issues of HIV and sexuality. But it appears that these views may be an impediment to pupils' receiving appropriate HIV and sexuality education. Some might argue that, in order to make sure that as many Deaf learners as possible receive HIV and sexuality education, materials should defocus on sexualities which may make teachers uncomfortable – such as homosexuality. To collude with such a view, however, would be to be complicit in the broader stigmatization of homosexuality.

Stigmatization of homosexuality is problematic and hampers public health HIV/AIDS interventions, and, according to Makgoba, the role of homosexual transmission in HIV/AIDS is understated (as cited in Cameron, 2005). There is no easy solution to the tension between pragmatism and the issue of human rights and sexual rights for all citizens.

I would now like to revisit the theoretical models of disability discussed in the introduction of the thesis and then the health belief model presented as part of the literature review in relation to the results for this study. It is clear that the application of the medical model of disability alone is not sufficient when examining the results of this study. Instead the social, capabilities and human rights approaches in conjunction with the medical model are for more applicable to this context. Certainly, the lack of resources in some schools to address communication issues for Deaf and hard of hearing adolescents is resulting in further disablement and difficulty in their access to adequate information about HIV/AIDS. The attitudes of some educators to condom education can also be viewed through the lens of the social model of disability. Some educators believed that the Catholic stance on condom usage should be upheld. One educator thought that in educating Deaf and hard of hearing youth about condom usage, there is a risk of encouraging premature sexual relationships. These attitudes may prevent access to information for Deaf and hard of hearing youth and could result in increased risk of HIV infection. Sen's capability approach which helps us to understand and develop a framework for understanding disability is useful in this regard. Deaf adolescents are being prevented from reaching their full potential and their environment is resulting in further disablement.

I will now discuss the components of the health belief model in relation to the results from my study:

**Perceived threat-** this variable consists of two parts: perceived susceptibility and perceived severity of a health condition (e.g. HIV/AIDS). Most educators and parents believed that their Deaf and hard of hearing learners or children were at risk of HIV/AIDS due to risk of premature sexual behaviour or risk of abuse. Some educators also discussed that Deaf youth are often socially isolated or lonely and therefore could misinterpret inappropriate gestures by a perpetrator.

**Perceived susceptibility** refers to the individual's subjective perception of the risk of contracting a health condition while **perceived severity** refers to the perceptions of the medical and social consequences of the disease. Adolescents interviewed for the study saw themselves at risk of HIV/AIDS. One Deaf boy had seen his sister die of HIV/AIDS and thus was cautious about protecting himself. Adolescent participants described the experiences of Deaf friends who were at risk of HIV/AIDS due to danger of sexual abuse.

**Perceived benefits:** this refers to how the individuals concerned view strategies to reduce the risk of contracting the illness (e.g. condoms to prevent HIV transmission). As mentioned before there were moralistic attitudes of teachers towards condoms and to the GALA comic book which was in some respects seen as immoral. Many of the adolescents showed limited understanding of condoms and viewed them as contraception alone rather than as a barrier method as well. A Deaf girl thought it was not necessary to use condoms during menstruation.

**Perceived barriers:** this refers to how individuals perceive (negative) consequences of illness including social stigma or financial problems. *Adolescent participants perceived HIV/AIDS infection as an illness with dire consequences.*

**Cues to action:** These are events that encourage people to take action on disease prevention e.g. media advertising. There are educators who are taking the initiative to provide adequate

education about HIV to their Deaf and hard of hearing learners. They address the specialized communication needs of these learners and have employed appropriate risk reduction strategies e.g. counseling couples about contraception, supporting the efforts of the Deaf HIV positive activist to teach Deaf youth about HIV prevention and adapting existing materials.

**Self-efficacy:** the belief in being able to enact the behaviours. Some adolescents who reported they had experienced their sexual debut reported that they used condoms consistently. Others reported they were currently abstaining from sexual activity.

In a study conducted in mainstream schools in Cape Town, South Africa, Mathews et al. (2009) investigated predictors of early sexual activity in able-bodied adolescents. In using the constructs of the theory of planned behaviour they found that adolescents with sound knowledge of HIV transmission were less likely to have reached their sexual debut. Adolescents who associated positive social status (e.g. more friends) with the start of sexual activity were more likely to have had their sexual debut. More studies that employ the constructs of theoretical models should be conducted to investigate choices about sexual relationships for disabled adolescents.

### **Recommendations for Further Research**

More Deaf people should be trained as VCT counsellors and operational research similar to that of Taegetmeyer et al. (2009) should be conducted to determine the best ways of producing an intervention. .

Educators of Deaf and hard of hearing learners must undergo compulsory SASL training to ensure ability to teach Deaf learners in their first language. A number of models from first world countries (e.g. Sweden) are available. In Sweden research has been conducted on bilingual development in Deaf children. This research showed that development of Swedish sign language

is essential for Deaf children to develop literacy skills. Therefore parents of Deaf children in Sweden are encouraged to attend Swedish sign language classes. Deaf children are also encouraged to socialize with other Deaf children to develop sign language skills. Extra lessons in literacy are offered to Deaf children and the content of written texts is presented in Swedish sign language (Svartholm, 2011). SASL classes should be made available and accessible to parents of Deaf and hard of hearing adolescents based in South Africa so that they can communicate easily with their children.

Educators should undergo HIV/AIDS and condom education from both health professionals and disability organizations. The Department of Education should conduct audits of schools to ensure that there is consistency with regard to condom policies. There is no easy solution to the negative attitudes to homosexuality expressed by educators in schools for Deaf and hard of hearing learners. Previous studies (e.g. Rohleder & Swartz, 2009) have shown that educators are often reluctant to deliver HIV education for disabled people. It is interesting that Nair et al. (2011), who conducted research in Kerala, India, found that educators of able-bodied adolescents were also reluctant to discuss sexual and reproductive health issues with their learners. However, research conducted by Ebersohn and Ferrerira (2011) in South Africa, in mainstream schools, found more promising results. They found that educators could promote resilience and psychosocial support in schools in the context of a high burden of HIV/AIDS. Educators working in schools for the Deaf and hard of hearing should also be encouraged to become better agents.

Interventions relating to HIV/AIDS and sexuality with appropriate cultural and linguistic components should be targeted at Deaf and hard of hearing adolescents in South Africa. These interventions can draw on existing resources from SLED and GALA. The schools should be encouraged to develop and circulate these materials.

## References

- Akbulut, V. (2008). *Cochlear implants. A threat to deaf culture: A thematic analysis of current medical discourse on cochlear implants*. Paper presented at the annual meeting of the NCA 94th Annual Convention, TBA, San Diego, California
- Albert, B., & Hurst, R. (2004). *Disability and human rights approach to development*. Retrieved from [www.disabilitykar.net](http://www.disabilitykar.net)
- Almond, L., & Giles, S. (2008). Young people with harmful sexual behaviour: Do those with learning disabilities form a distinct subgroup? *Journal of Sexual Aggression, 14*(3), 227-239. DOI:10.1080/13552600802304909
- Alriksson-Schmidt, A. I., Armour, B. S., & Thibadeau, J. K. (2010). Are adolescent girls with a physical disability at increased risk for sexual violence? *The Journal of School Health, 80*(7), 361-367. DOI:10.1111/j.1746-1561.2010.00514
- Annas, G. (2011). Can forced sterilization ever be ethical? *Practical Ethics*. University of Oxford. Retrieved from <http://blog.practicaethics.ox.ac.uk/2011/02/can-forced-sterilization-ever-be-ethical>.
- Appel, J. M. (2010). Sex rights for the disabled? *Journal of Medical Ethics, 36*(3), 152-154. DOI:10.1136/jme.2009.033183
- Asian Development Bank Report. (2005). *HIV and the greater Mekong sub region: Strategic directions and opportunities*. Philippines:

Aylott, J. (1999). Is the sexuality of people with learning disability being denied? *British Journal of Nursing*, 8(7), 438-442.

Backett, K. (1990). Image and reality: Health enhancing behaviours in middle class families. *Health Education Journal*, 49(2), 61-63. DOI: 10.1177/001789699004900205.

Balla, N. (2011, July 12). India plans to ban forced sterilization of disabled women. *Trust law*. Retrieved from <http://www.trust.org/trustlaw/news/india-plans-to-ban-forced-sterilisation-of-disabled-women-report>.

Banim, M., Guy, A., & Tasker, P. (1999) Trapped in risky behaviour: empowerment, disabled people and sexual health, *Health, Risk & Society*, 1, 209-221.  
DOI:10.1080/13698579908407019.

Baruch, G. (1981). Moral tales: Parents' stories of encounters with the health professions. *Sociology of Health & Illness*, 3(3), 275-296. DOI: 10.1111/1467-9566.ep10486851.

Bernard, C. (1999). Child sexual abuse and the black disabled child. *Disability and Society*, 14(3), 325-339. DOI:10.1080/09687599926172.

Bernert, D. J. (2010). Sexuality and disability in the lives of women with intellectual disabilities. *Sexuality and Disability*, 29(2), 129-141. DOI:10.1007/s11195-010-9190-4

- Bisol, C. A., Sperb, T. M., Brewer, T. H., Kato, S. K., & Shor-Posner, G. (2008). HIV/AIDS knowledge and health-related attitudes and behaviors among deaf and hearing adolescents in Southern Brazil. *American Annals of the Deaf*, 153(4), 349-356.
- Bisol, C.A., Sperb, T.M., & Moreno-Black, G. (2008). Focus groups with deaf and hearing youths in Brazil: Improving a questionnaire on sexual behavior and HIV/AIDS. *Qualitative Health Research*, 18(4), 565-578. DOI:10.1177/1048732307888.
- Brown, L. K., Hadley, W., Stewart, A., Lescano, C., Whiteley, L., Donenberg, G., DiClemente, R. (2010). Psychiatric disorders and sexual risk among adolescents in mental health treatment. *Journal of Consulting and Clinical Psychology*, 78(4), 590-597. DOI:10.1037/a0019632.
- Cambanis, E. (2010). *An investigation of the form of HIV/AIDS and reproductive health education (RHE) in South African secondary schools for the deaf and the factors influencing teacher implementation thereof*. (Unpublished master's thesis) University of Kwa-ZuluNatal. South Africa.
- Cambridge, P. (1997). How far to gay? The politics of HIV in learning disability. *Disability and Society*, 12(3), 427-453. DOI:10.1080/09687599727272.
- Cameron, E (2005). *Witness to AIDS* . London, UK: Tauris & Co. Ltd.

- Carey, M. P., Carey, K. B., Maisto, S. S. A., Gordon, C. M., Venable, P. A. (2001). Prevalence and correlates of sexual activity and HIV-related risk behavior among psychiatric outpatients. *Journal Consult Clinical Psychology*, 69(5), 846-850. DOI:10.1037//0022-006X.69.5.846.
- Casale, C., Nixon, S., Flicker, S., Rubincam, C., & Jenney, A. (2010). Dilemmas and tensions facing a faith-based organization promoting HIV prevention among young people in South Africa. *African Journal of AIDS Research*, 9(2), 135-145.
- Catania, J.A., Kegeles, S.M., & Coates T.J. (1990). Towards an understanding of risk behavior: An AIDS risk reduction model (ARRM). *Health Education Quarterly*, 17(1), 53-72.
- Center for disease control (2006). Retrieved from <http://www.avert.org/hiv-testing-pregnancy.htm>
- Chireshe, R., Rutondoki, E. N., & Ojwang, P. (2010). Perceptions of the availability and effectiveness of HIV/AIDS awareness and intervention programmes by people with disabilities in Uganda. *SAHARA Journal*, 7(4), 17-23.  
DOI:10.1080/17290376.2010.9724973.
- Choquet, M., Du Pasquier Fediaevsky, L., & Manfredi, R. (1997). Sexual behavior among adolescents reporting chronic conditions: A French national survey. *The Journal of Adolescent Health*, 20(1), 62-67. DOI:10.1016/51054-139X(96)00091-2.

Chou, Y. C., & Lu, Z. Y. (2011). Deciding about sterilisation: Perspectives from women with an intellectual disability and their families in Taiwan. *Journal of Intellectual Disability Research*, 55(1), 63-74. DOI:10.1111/j.1365-2788.2010.01347.x.

Clark, P. A., & Vasta, L. (2007). The Ashley treatment: An ethical analysis. *Journal of Law, Healthcare and Ethics*, 5(1), 1-20.

Collins, P. Y. (2006). Challenges to HIV prevention in psychiatric settings: Perceptions of South African mental health care providers. *Social Science & Medicine*, 63, 979-990. DOI: 10.1016/j.socscimed.2006.03.003

Coskun, M., Karakoc, S., Kircelli, F., & Mukaddes, N. M. (2009). Effectiveness of mirtazapine in the treatment of inappropriate sexual behaviors in individuals with autistic disorder. *Journal of Child and Adolescent Psychopharmacology*, 19(2), 203-206. DOI:10.1089/cap.2008.020.

Coskun, M., & Mukaddes, N. M. (2008). Mirtazapine treatment in a subject with autistic disorder and fetishism. *Journal of Child and Adolescent Psychopharmacology*, 18(2), 206-209. DOI:10.1089/cap.2007.0014.

- Crowe, T. V. (2003). Using focus groups to create culturally appropriate HIV prevention material for the deaf community. *Qualitative Social Work.*, 2(3), 289-308.  
DOI:10.1177/14733250030023005.
- Davis, L. (2000). *My sense of silence. Memoirs of a childhood with deafness*. Chicago, USA, University of Chicago Press.
- De Andrade, V., & Baloyi, B. (2010). HIV/AIDS knowledge among adolescent sign language users in South Africa. *African Journal of AIDS Research*, 9(3), 307-313.  
DOI:10.1080/17450128.2011.597795.
- Denman, L. (2007). Enhancing the accessibility of public mental health services in Queensland to meet the needs of deaf people from an indigenous Australian or culturally and linguistically diverse background. *Australasian Psychiatry: Bulletin of Royal Australian and New Zealand College of Psychiatrists*, 15(Suppl 1), S85-89. DOI:10.1080/10398560701262.
- Di Nucci, E. (2011). Sexual rights and disability. *Journal of Medical Ethics*, 37(3), 158-161.  
DOI:10.1136/jme.2010.036723.
- Doyle, A. G. (1995). AIDS knowledge, attitudes and behaviors among deaf college students: A preliminary study. *Sexuality and Disability*, 13(2), 107-134. DOI:10.1007/BF02590060.

Dune, T. M., & Shuttleworth, R. P. (2009). It's just supposed to happen: the myth of sexual spontaneity and the sexually marginalized. *Sexuality and Disability*, 27(2), 97-108. DOI: 10.1007/s11195-009-y.

Eastgate, G. (2005). Sex, consent and intellectual disability. *Australian Family Physician*, 34(3), 163-166. DOI: 10.1108/13595471111158657.

Eastgate, G. (2008). Sexual health for people with intellectual disability. *Salud Publica De Mexico*, 50(Suppl 2), s255-259. [DOI:10.1590/S0036-36342008000800019](https://doi.org/10.1590/S0036-36342008000800019).

Ebersohn, L., & Ferreira, R. (2011). Coping in an HIV/AIDS dominated context: Teachers promoting resilience in schools. *Health Education Research*, 28(4), 596-613. DOI:10.1093/her/cyr016.

Eide, A. H., Schur, C., Ranchod, C., Rohleder, P., Swartz, L., & Schneider, M. (in press). Disabled persons' knowledge of HIV prevention and access to health care prevention services in South Africa. *AIDS Care*, 23. DOI:10.1080/09540121.2011.575119.

Empfield, M., Cournos, F., Meyer, I., McKinnon, K., Horwath, E., Silver, M., . . . Herman, R. (1993). HIV seroprevalence among homeless patients admitted to a psychiatric inpatient unit. *American Journal of Psychiatry*, 150(1), 47-52.

- Enwereji, E. E., & Enwereji, K. O. (2008). Disabled persons and HIV/AIDS prevention: A case study of deaf and leprosy persons in Nigeria. *East African Journal of Public Health*, 5(2), 55–61.
- Epstein, H., & Jewkes, R. (2009). The myth of the virgin rape myth. *The Lancet*, 373, 1419. DOI:10.1016/S0140-6736(09)61859-6.
- Feldman, D., Kluwin, T. N., & McCrone, W. P. (2005). Deaf clients' perceptions of counselling expertise as a function of counsellors' signing skill, gender and therapy type. *American Annals of the Deaf*, 150(5), 408-414. DOI:10.1353/aad.2006.0003.
- Fellinger, J., Holzinger, D., Sattel, H., Laucht, M., & Goldberg, D. (2009). Correlates of mental health disorders among children with hearing impairments. *Developmental Medicine and Child Neurology*, 51(8), 635-641. DOI:10.1111/j.1469-8749.2008.03218x
- Ferguson, G., & Jelsma, J. (2009). The prevalence of motor delay among HIV infected children living in Cape Town, South Africa. *International Journal of Rehabilitation Research*, 32(2), 108-114. DOI:10.1097/MRR.0b013e3283013b34
- Fishbein, M., Middlestadt, S.E., & Hitchcock, P.J. (1994). Using information to change sexually transmitted disease behaviors. In R. J. Diclemente & J. L. Petersen (Eds.), *Preventing AIDS: Theories and methods of behavioural interventions* (pp. 61-68), New York, NY: Plenum Press.

Fritz, G. (2003). Sexuality education for the developmentally disabled. *Brown University Child and Adolescent Behavior Letter*, 9(7), 8.

Gaskins, S. (1999). Special population: HIV/AIDS among the deaf and hard of hearing. *Journal of Association Nurses AIDS Care*, 10(2), 75-77. DOI:10.1016/51055-3290(06)60301-4.

Gilmore, L., & Chambers, B. (2010). Intellectual disability and sexuality: Attitudes of disability support staff and leisure industry employees. *Journal of Intellectual & Developmental Disability*, 35(1), 22-28. DOI: 10.3109/13668250903496344

Glaser, M., & Lorenzo, T. (2006). Developing literacy with deaf adults. In B. Watermeyer, L. Swartz, T. Lorenzo, M. Schneider, & M. Priestly. (Eds.), *Disability and social change: A South African agenda* (pp. 192-205). Cape Town: HSRC Press.

Goldstein, M. F., Eckhardt, E. A., Joyner-Creamer, P., Berry, R., Paradise, H., & Cleland, C. M. (2010). What do deaf high school students know about HIV? *AIDS Education and Prevention*, 22(6), 523-537. DOI: 10.1521/aeap.2010.22.6.523.

Groce, N. E. (2003). HIV/AIDS and people with disability. *Lancet*, 361, 1401-1402. DOI:10.1016/S0140-6736 (03)13015-2.

Groce, N.E (2004). *HIV/AIDS and disability global survey*. Yale Survey/World Bank. Retrieved from <http://globalsurvey.med.yale.edu/surveys.html>.

Groce, N. E. (2005a). *Summary report. Violence against children with disabilities*, UNICEF. New York, NY, USA.

Groce, N. E. (2005b). HIV/AIDS and individuals with disability. *Health and Human Rights*, 8(2), 215-224. DOI:10.2307/4065341.

Groce, N., Yousafzai, A., Dlamini, P., Zalud, S., & Wirz, S. (2006). HIV/AIDS and disability: A pilot survey of HIV/AIDS knowledge among a deaf population in Swaziland. *International Journal of Rehabilitation*, 29(4), 319-324. DOI:10.1097/MRR.0b013e328010c68f.

Groce, N. E., Yousafzai, A. K., & Van der Maas, F. (2007). HIV/AIDS and disability: Differences in HIV/AIDS knowledge between deaf and hearing people in Nigeria. *Disability and Rehabilitation*, 29(5), 367-71. DOI:10.1080/09638280600834567.

Hanass-Hancock, J. (2008). *Invisible- The notion of disability in the context of HIV/AIDS in KwaZulu-Natal, South Africa*. (Unpublished doctoral dissertation) Faculty IV, Rehabilitationswissenschaften. Berlin, Humboldt University Berlin, PHD: 240.

Hanass-Hancock, J. (2009). Disability and HIV/AIDS - a systematic review of literature on Africa. *Journal of the International AIDS Society*, 2(1), 9-20. DOI: 10.1186/1758-2652-12-34.

Hanass-Hancock, J., & Satande, L. (2010). Deafness and HIV/AIDS: A systematic review of the literature. *African Journal of AIDS Research*. 9(2), 187-192.  
DOI:10.2989/16085906.2010.517488.

Harries, J., Moodley, J., Barone, M. A., Mall, S., & Sinanovic, E. (2009). Preparing for HPV vaccination in South Africa: Key challenges and opinions. *Vaccine*, 27(1), 38-44.  
DOI:10.1016/j.vaccine.2008.10.033.

Health Systems Trust (3<sup>rd</sup> April, 2011), South Africa Retrieved from [www.hst.org.za](http://www.hst.org.za)

Heap, M., & Morgans, H. (2006). Language policy and SASL: Interpreters in the public service. In B. Watermeyer, L. Swartz, T. Lorenzo, M. Schneider, & M. Priestly. (Eds.), *Disability and social change: A South African agenda* (pp. 134-147). Cape Town, South Africa: HSRC Press.

Heidari, S., & Kippax, S. (2009). Special theme on HIV and disability - time for closer bonds. *Journal of the International AIDS Society*, 12(1), 1. DOI:10.1186/1758-2652-12.

- Heuttel, K. L., & Rothstein, W. G. (2001). HIV/AIDS knowledge and information sources among deaf and hearing college students. *American Annals of the Deaf*, 146(3), 280–286.
- Hindley, P. A. (2005). Mental health problems in deaf children. *Current Paediatrics*, 15(2), 114–119. DOI: 10.1016/j.cupe.2004.12.008.
- Hollander, J. A. (2004). The social contexts of focus groups. *Journal of Contemporary Ethnography*, 33(5), 602–637. DOI:10.1177/1089124160428988.
- Howell, C., Chalklen, S., & Alberts, T. (2006). A history of the disability rights movement in South Africa. In B. Watermeyer, L. Swartz, T. Lorenzo, M. Schneider, & M. Priestly (Eds.), *Disability and social change: A South African agenda* (pp. 46–84). Cape Town, South Africa: HSRC Press.
- Hume, J. (1996). *Disability, feminism and eugenics: Who has the right to decide who should or should not inhabit the world?* Women's Electoral Lobby National Conference, University of Technology, Sydney. 26<sup>th</sup> January 1996.
- Iwelunmor, J., Zungu, N., & Airhihenbuwa, C. O. (2010). Rethinking HIV/AIDS disclosure among women within the context of motherhood in South Africa. *American Journal of Public Health*, 100, 1393–1399. DOI: 10.1177/17579759114047475.

Jacobs, N. (2010, August 23). Disabled people do have sex lives. Get over it. *The Guardian*.

Retrieved from <http://www.guardian.co.uk/commentisfree/2010/aug/23/disabled-people-sex-lives-equality>.

Jaffe, H. W. (2008). The early days of the HIV-AIDS epidemic in the USA. *Nature Immunology*, 9(11), 1201-1203. DOI: 10.1038/ni1108-1201.

Jones, L. K., Binger, T. E., McKenzie, C. R., Ramcharan, P., & Nankervis, K. (2010). Sexuality, pregnancy and midwifery care for women with intellectual disabilities: A pilot study on attitudes of university students. *Contemporary Nurse: A Journal for the Australian Nursing Profession*, 35(1), 47-57. DOI:10.5172/conu.2010.35.1.047.

Kempton, W., & Kahn, E. (1991). Sexuality and people with intellectual disabilities: A historical perspective. *Sexuality and Disability*, 9(2), 93-111. DOI:10.1007/BF01101735.

Killian, S., Swartz, L., & Joska, J (2010). Competence of interpreters in a South African psychiatric hospital in translating key psychiatric terms. *Psychiatric Services*, 61(3), 309-312. DOI:10.1176/appi.ps.61.3.309.

Kittay, E. (2011): Forever small: The strange case of Ashley X. *Hypatia*, 13(4), 610-631.

[DOI:10.1111/j.1527-2001.2011.01205.x](https://doi.org/10.1111/j.1527-2001.2011.01205.x)

- Kvam, M. H (2000). Is sexual abuse of children with disabilities disclosed? A retrospective analysis of child disability and the likelihood of sexual abuse among those attending Norwegian hospitals. *Child Abuse and Neglect*, 24(8), 1073-1084. DOI:10.1016/S0145.
- Kvam, M. H., & Braathen, S. H. (2008). 'I thought this is my chance'. Sexual abuse against girls and women with disabilities in Malawi. *Sexual Abuse*, 20(5), 5-27. DOI:10.1177/1079063208314817.
- Kvam, M. H., Loeb, M., & Tambs, K. (2007). Mental health in deaf adults: Symptoms of anxiety and depression among hearing and deaf individuals. *Journal of Deaf Studies and Deaf Education*, 12(1), 1-7. DOI:10.1093/deafed/en1015.
- Lambert, S. D., & Loiselle, C. G. (2005). Refinement of a questionnaire to assess individuals' patterns of health information-seeking behaviour. *Canadian Oncology Nursing Journal*, 15(4), 262-263. DOI:10.11971089124160428988.
- Lambert, S. D., & Loiselle, C. G. (2008). Combining individual interviews and focus groups to enhance data richness. *Journal of Advanced Nursing*, 62(2), 228-237. DOI:10.1002/pon.1317.
- Le Dorze, G., & Signori, F. H. (2010). Needs, barriers and facilitators experienced by spouses of people with aphasia. *Disability and Rehabilitation*, 32(13), 1073-1087. DOI:10.3109/096382809003374121

Lehoux, P., Blake P., & Daudelin, G. (2006). Focus group research and "the patient's view".

*Social Science and Medicine.*, 63, 2091-2104. DOI:10.1111/j.1356-2648.2007.04559.x.

Levin, T. (2006). *Beliefs and practices regarding HIV/AIDS awareness and prevention among service providers for adults with intellectual disability in Gauteng.* (Unpublished master's thesis) University of the Witwatersrand. Johannesburg, South Africa.

Lockhart, K., Guerin, S., Shanahan, S., & Coyle, K. (2010). Expanding the test of counterfeit deviance: Are sexual knowledge, experience and needs a factor in the sexualised challenging behaviour of adults with intellectual disability? *Research in Developmental Disabilities*, 31(1), 117-130. DOI:10.1111/j.1741-1130.2009.00235.x

Lohiya, G. S. (1993). Human immunodeficiency virus type-1 antibody in 6703 institutionalized mentally retarded clients: An unlinked sero-survey at seven California developmental centers. *AIDS Research Human Retroviruses*, 9(3), 247-249. DOI:10.1089/aid.1993.9.247.

Maart, S., & Jelsma, J. (2010). The sexual behaviour of physically disabled adolescents.

*Disability and Rehabilitation*, 32(6), 438-443. DOI:10.1007/s11136-010-9648-y2010.

Mallinson, R. K. (2004a). Deaf culture: When "positive" is a good thing. *The Journal of the*

*Association of Nurses in AIDS Care*, 15(4), 21-22. DOI:10.1177/1055329004267339.

Mallinson, R. K. (2004b). Perceptions of HIV/AIDS by deaf gay men. *The Journal of the Association of Nurses in AIDS Care*, 15(4), 27-36. DOI: 10.1177/1055329004267338

Mann, J., Gruskin, S., Grodin, M.A., & Annas, G.J. (1999). *Health and human rights: A reader*. New York, NY : Routledge

Marks, D. (1999). *Disability: Controversial debates and psychosocial perspectives*. London, UK: Routledge.

Maxwell, J. Belser, J.W., & David, D. (2007). *A health handbook for women with disabilities*. Berkeley, CA.: Hesperian Foundation.

McLellan, F. (2002). Controversy over deliberate conception of deaf child. *Lancet*, 359(9314), 1315. DOI: 10.1016/S0140-6736(02)08322-8

Mejstad, L., Heiling, K., & Svedin, C. G. (2009). Mental health and self-image among deaf and hard of hearing children. *American Annals of the Deaf*, 153(5), 504-515.  
DOI:10.1353/aad.0.0069.

Mental Capacity Act, 17.(2002). Retrieved from <http://legislation.gov.uk/urpga/2005/9/> 2005.

- Merrick, J., & Morag, A. (2000). Human immunodeficiency virus (HIV) in institutions for the mentally retarded in Israel. *International Journal of Rehabilitation Research*, 23(3), 173–175. DOI:10.1097/00004356-200023030-00006.
- Milligan, N. S., & Neufeldt, A. H. (2001). The myth of asexuality: A survey of social and empirical medicine. *Sexuality and Disability*, 19(2), 91-109.  
DOI:10.1023/A:1010621705591.
- Minnis, A. M., Steiner, A. J., Gallo, M. F., Warner, L., Hobbs, M. M., Van der Straten, A., . . . Padian, N. S. (2009). Biomarker validation of reports of recent sexual activity: Results of a randomized controlled study in Zimbabwe. *American Journal of Epidemiology*, 170, 918-924. DOI: 10.1093/aje/kwp219.
- Mitra, S. (2006). The capability approach and disability. *Journal of Disability Policy Studies*, 16, 237-247. DOI:10.1177/10442073060160040501.
- Morgan, R. (2006). *Deaf sexual diversity and HIV awareness project*. Final project report. South African History Archives/Gay and Lesbian Archives (SAHA/GALA). University of the Witwatersrand, South Africa.
- Morgan, R. (2008). *Deaf me normal: Deaf South Africans tell their life stories* (1<sup>st</sup> ed.). Pretoria: University of South Africa.

- Morgans, H. G. (2009). *The attitudes of deaf adults in the area of Johannesburg to writing English as a second or third language*. (Unpublished master's thesis) University of the Witwatersrand, Johannesburg, South Africa.
- Morrow, M., Arunkumar, M. C., Pearce, P., & Dawson, H. E. (2007). Fostering disability-inclusive HIV/AIDS programs in north East India: A participatory study. *Biomed Central Public Health*, 26(7), 125-133. DOI: 10.1186/1471-2458-7-125.
- Munro, S., Lewin, S. Swart, T., & Volmink, J (2007). A review of health behaviour theories: How useful are these for developing interventions to promote long-term medication adherence for TB and HIV/AIDS? *BMC Public Health*, 11(7), 104. DOI:10.1186/1471-2458-7-104.
- Murphy, G. H., & O'Callaghan, A. (2004). Capacity of adults with intellectual disabilities to consent to sexual relationships. *Psychological Medicine*, 34, 1347-1357.  
DOI:10.1017/S0033291704001941.
- Murphy, N. A., & Elias, E. R. (2006). Sexuality of children and adolescents with developmental disabilities. *Pediatrics*, 118(1), 398-403. DOI: 10.1542/peds.2006
- Mustanski, B., Donenberg, G., & Emerson, E. (2006). I can use a condom, I just don't: The importance of motivation to prevent HIV in adolescent seeking psychiatric care. DOI: 10.1007/s10461-006-9098-2

Nair, M. K., Leena, M. L., Paul, M. K., Pillai, H. V., Babu, G., Russell, P. S., & Thankachi, Y.

(in press). Attitudes of parents and teachers towards adolescent reproductive and sexual health education. *Indian Journal of Pediatrics*. 26. DOI:10.4103/0253-7184.62765.

National Health Act, 61 S.A. chap9 s71 (2003). Retrieved from

<http://www.info.gov.za/view/DownloadFileAction?id=68039>

Nattrass, N. (2007). *Mortal combat: AIDS denialism and the struggle for antiretrovirals in South Africa*. Scottsville: University of KwaZulu-Natal, South Africa.

Neri, S. V., Bradley, E. H., & Groce, N. E. (2007). Frequency of HIV testing among persons

with disabilities: Results from the national health interview survey, 2002. *AIDS Education and Prevention*, 19, 545-554. DOI:10.1521/aeap.2007.19.6.545.

Nyang'aya, D. (1998). Addressing special populations. Forgotten: A view of the social and

political obstacles to the prevention and treatment of AIDS in Kenyan deaf people. *Afr Link*, 5, 20-22.

Officer, A., & Groce, N. E. (2009). Key concepts in disability. *Lancet*, 374, 1795-1796.

DOI:10.1016/50140-6736(09)61527-0.

Oliver, M. (1996). *Understanding disability: From theory to practice*. Basingstoke: Macmillan.

- Olusanya, B. O., Wirz, S. L., & Luxon, L. M. (2008). Community-based infant hearing screening for early detection of permanent hearing loss in Lagos, Nigeria: A cross-sectional study. *Bulletin of the World Health Organization*, 86, 956-963. DOI:10.2471/BLT.07.050005
- Orsi, J. M., Margellos-Anast, H., Perlman, T. S., Giloth, B. E., & Whitman, S. (2007). Cancer screening knowledge, attitudes and behaviors among culturally deaf adults: implications for informed decision making. *Cancer Detection Prevention*, 31(6), 474-9. DOI:10.1016/j.cdp.2007.10.008.
- Otte, W. M., Van der Maas, F., & De Boer, A. (2008). Comparison of knowledge and accessibility to information sources of HIV/AIDS between blind and sighted populations in Nigeria. *AIDS Care*, 20(9), 1093-1097. DOI:10.1080/09540120701842787
- Peel, E. L. (2004). *"Inclusive practice in South Africa: A deaf education perspective"*. (Unpublished master's thesis), University of the Witwatersrand, Johannesburg, South Africa.
- Penn, C., & Raegan, T. (1990). How do you sign "Apartheid"? The politics of South African sign language. *Language Planning and Language Behaviour*, 14, 91-103. DOI:10.1075/lplp.14.2.02pen

Penn, C., Watermeyer, J., & Evans, M. (2011). Why don't patients take their drugs? The role of communication, context and culture in patient adherence and the work of the pharmacist in HIV/AIDS. *Patient Education and Counselling*, 83(3), 310-318.

DOI:10.1106/j.pec.2011.02.018.

Perry, B. L., & Wright, E. R. (2006). The sexual partnerships of people with serious mental illness. *Journal of Sex research*, 43(2), 174-81. DOI:10.1080/00224490609552312.

Phetla, G., Busza, J., Hargreaves, J. R., Pronyk, P. M., Kim, J. C., Morison, L. A., . . . Porter, J. D. (2008). 'They have opened our mouths' increasing women's skills and motivation for sexual communication with young people in rural South Africa. *AIDS Education Prevention*, 20, 504-518. DOI:10.1521/aeap.2008.20.6.504

Philander, J. H. (2007). *The development and evaluation of a pilot school-based programme for prevention of HIV/AIDS among visually impaired and blind South African adolescents*. (Unpublished doctoral dissertation), Stellenbosch University, South Africa.

Philander, J. H., & Swartz, L. (2006). Needs, barriers, and concerns regarding HIV prevention among South Africans with visual impairments: A key informant study. *Journal of Visual Impairment and Blindness*, 100 (4), 111-114.

Pinker, S. (1994). *The language instinct* (1<sup>st</sup> ed.). New York, NY: W. Morrow and Co.

Polit, D. F., & Beck, C. T. (2004). *Nursing research. Principles and methods*. Philadelphia, PA : Lippincott, Williams & Wilkins.

Prochaska, J.O, Velicer, W. F., Rossi, J.S., Goldstein, M.G., Marcus, B.H., Rakowski, W., . . .

Rossi, S.R. (1992). Stages of change and decisional balance for 12 problem behaviors.

*Health Psychology, 13(1)*, 39-46. DOI: 10.1037/0278-6133.13.1.39.

Realmuto, G. M., & Ruble, L. A. (1999). Sexual behaviors in autism: Problems of definition and management. *Journal of Autism and Developmental Disorders, 29(2)*, 121-127.

DOI:10.1023/A:1023088526314.

Ritchie, J., & Lewis, J. (2003). *Qualitative research practice. A guide for social science students*.

London, UK: SAGE Publications.

Rogers, C. (2010). 'But it's not all about the sex: Mothering, normalisation and young learning

disabled people. *Disability and Society, 25(1)*, 63-74. DOI:10.1080/09687590903363365

Rohleder, P. (2008). *HIVAIDS and disability: An exploration of organizations' responses to*

*HIVAIDS as it affects people with disabilities*. (Unpublished doctoral dissertation).

Stellenbosch University, South Africa.

- Rohleder, P. (2010a). Educators ambivalence and managing anxiety in providing sex education for people with learning disabilities. *Psychodynamic Practice*, 16(2), 165-182.  
DOI:10.1080/14753631003688100
- Rohleder, P. (2010b). 'They don't know how to defend themselves': Talk about disability and HIV risk in South Africa. *Disability and Rehabilitation*, 32(10), 855-863. DOI: 10.3109/09638280903314077
- Rohleder, P., Braathen, S. H., Swartz, L., & Eide, A. H. (2009). HIV/AIDS and disability in Southern Africa: A review of relevant literature. *Disability and Rehabilitation*, 31(1), 51-59.  
DOI: 10.1080/09638280802280585.
- Rohleder, P., & Swartz, L. (2009). Providing sex education to persons with learning disabilities in the era of HIV/AIDS: Tensions between discourses of human rights and restriction. *Journal of Health Psychology*, 14(4), 601-610. DOI:101177/1359105309103579.
- Rohleder, P., Swartz, L., Schneider, M., Groce, N., & Eide, A. H. (2010). HIV/AIDS and disability organisations in South Africa. *AIDS Care*, 22(2), 221-227.  
DOI:10.1080/09540120903111494
- Rosenstock I., Strecher, V., & Becker, M. (1994). The Health Belief Model and HIV risk behavior change. In R. J. DiClemente, and J. L. Peterson (Eds.), *Preventing AIDS:*

*Theories and Methods of Behavioral Interventions* (pp. 5-24). New York, NY: Plenum Press.

Ryerson, E. (1984). *Sexual abuse and self-protection for developmentally disabled youth* (SIECUS Report XIII.) Seattle. Sexuality Information and Education Council of the USA.

Sacks, M., Dermatis, H., Looser-Ott, S., Burton, W., & Perry, S. (1992). Undetected HIV infection among acutely ill psychiatric inpatients. *American Journal of Psychiatry*, *149*(4), 544–545.

Sacks, M. H., Dermatis, H., Looser-Ott, S., & Perry, S. (1992). Seroprevalence of HIV and risk factors for AIDS in psychiatric inpatients. *Hospital Community Psychiatry*, *43*, 736–737.

Satriano, J., Rothschild, R. R., Steiner, J., & Oldham, J. M. (1999). HIV service provision and training needs in outpatient mental health settings. *The Psychiatric Quarterly*, *70*(1), 63-74.

Schneider, M. M., & Claasens, Z. (1999). *We also count: The extent of moderate and severe reported disability and the nature of disability experience in South Africa*. CASE Disability survey prepared for the Department of Health. Pretoria, South Africa: Department of Health.

Servais, L., Jacques, D., Leach, R., Conod, L., Hoyois, P., Dan, B., (2002). Contraception of women with intellectual disability: Prevalence and determinants. *Journal of Intellectual Disability Research*, *46*(2), 108-119. DOI:10.1046j.1365-2788-2002.00360.x

Shakespeare, T. (Ed.). (1998). *The disability reader social sciences perspectives*. London, UK:

Cassell.

Shakespeare, T. (2006). *Disability rights and wrongs*. London, UK: Routledge.

Shakespeare, T., Gillepsie-Sells, K., & Davies, D. (1996). *The sexual politics of disability*.

London, England: Cassell.

Shakespeare, T. (2000). Disabled sexuality: towards rights and recognition. *Sexuality and*

*Disability*, 18 (3), 159-166. DOI:0146-1044/0010900-0159.

Siebers, T. (2008). *Disability theory*. University of Michigan: Ann Arbor Press.

Silverman, D. (2010). *Qualitative research: Theory, method and practice*. London, UK: Sage

Publications.

Simbayi, L., & Davids, A. (2009). *South African National HIV Prevalence, incidence, behaviour*

*and communication survey 2008: Disability and HIV in South Africa*. AIDS Impact

Conference, Botswana. September 2009.

Smith, J., & Firth, J. (2011). Qualitative data analysis: The framework approach. *Nurse*

*Researcher*, 18(2), 52-62.

Soudien, C., & Baxen, J. (2006). Disability and schooling in South Africa. In B. Watermeyer, L. Swartz, T. Lorenzo, M. Schneider, & M. Priestly, (Eds.), *Disability and social change: A South African agenda* (pp. 149-163). Cape Town, South Africa: HSRC Press.

Speizer, I. S., Gomez, A. M., Stewart, J., & Voss, P. (2011). Community-level HIV risk behaviours and HIV prevalence among women and men in Zimbabwe. *AIDS Educ Prev* 23(5), 437-47. DOI:10.1521/aeap.2011.23.5.437.

Statham, J. (1986) *Daughters and sons: Experiences of non-sexist child raising*. Oxford: Basil Blackwell.

Statistics South Africa (2005). *Census 2001: Prevalence of disability in South Africa*. Pretoria. Statistics South Africa.

Steinberg, A., Wiggins, E., Barmada, C. H., & Sullivan, V. J. (2002). Deaf women: Experiences and perceptions of healthcare system access. *Journal of Women's Health*, 11, 729-741. DOI:10.1089/15409990260363689

Storbeck, C. (2005). *Deaf education in South Africa*. Galludet University Research Institute. Retrieved from <http://research.gallaudet.edu/Presentations/>

Storbeck, C., Magongwa, L., & Parkin, I. (2009). Education of the deaf in South Africa. In D. F. Moores, & M. S. Miller. (Eds.), *Deaf people around the world: Educational and social perspectives* (pp. 133-144). Washington, DC: Gallaudet University Press.

Sullivan, P. M., & Knutson, J. F. (2000). Maltreatment and disabilities: A population-based epidemiological study. *Child Abuse Neglect*, 24, 1257–1273. DOI:10.1016/S0145-2134(00)00190-3.

Svartholm, K. (2011). *Sign language bilingualism: A Swedish experience*. Unpublished presentation. University of Cape Town, South Africa.

Swanepoel, D., & Storbeck, C. (2008). EHDI Africa: Advocating for infants with hearing loss in Africa. *International Journal of Audiology*, 47(1), S1-2. DOI:10.1016/ijporl.2009.01.007.

Swartz, L., & Drennan, G. (2000). Beyond words: Notes on the ‘irrelevance’ of language to mental health services in South Africa. *Transcultural Psychiatry- Racism and Psychiatry*, 37(2), 183-200.

Swinbourne, C. (2011, August 5). Not all deaf people want to be fixed. *The Guardian*.

<http://www.guardian.co.uk/commentisfree/2011/aug/05/deaf-people-cochlear-implants>.

The National Institute of Deafness and Communication Disorders. Retrieved from

<http://www.nim.nih.gov/medlineplus/cochlearimplants.html>

Tissot, C. (2009). Establishing a sexual identity. Case studies of learners with autism and learning difficulties. *Autism: The International Journal of Research and Practice*, 13, 551-566. DOI: 10.1177/1362361309338183

Touko, A., Mboua, C. P., Tohmuntain, P., & Perrot, A. (2010). Sexual risk factors and HIV seroprevalence among the deaf and hearing-impaired in Yaounde. [Vulnerabilite sexuelle et seroprevalence du VIH chez les deficients auditifs de Yaounde] *Sante (Montrouge, France)*, 20(2), 109-115. DOI:10.1186/1758-2652-13-5.

Voysey, M. (1975) *A constant burden: The reconstitution of family life*. London, England: Routledge & Kegan Paul.

Wazakili, M., Mpofu, R., & Devlieger, P. (2009). Should issues of sexuality and HIV and AIDS be a rehabilitation concern? The voices of young South Africans with physical disabilities. *Disability and Rehabilitation*, 31(1), 32-41.

DOI: <http://dx.doi.org/10.1080/09638280802280619>

Western Cape Forum for Intellectual Disability. (2007). *Sexuality education picture pack: Resources for all about me: A life skills, sexuality and HIV/AIDS education programme for adolescents*. South Africa.

Wilbraham, L (2009). Manufacturing willingness: Parents and young people talking about sex in a HIV/AIDS epidemic. *South African Journal of Psychology*. 39(1), 59-74.

Winningham, A., Gore-Felton, C., Galletly, C., Seal, D., & Thornton, M. (2008). Lessons learned from more than two decades of HIV/AIDS prevention efforts: Implications for people who are deaf or hard of hearing. *American Annals of the Deaf*, 153(1), 48-54. DOI: 10.1353/aad.0.0002.

*World Report on Disability* (2011). World Health Organization, Geneva, Switzerland.

Yousafzai, A. K., Dlamini, P. J., Groce, N., & Wirz, S. (2004). Knowledge, personal risk and experiences of HIV/AIDS among people with disabilities in Swaziland. *International Journal of Rehabilitation*, 27(3), 247-251. DOI: 10.1097/01.mrr.0000139047.00365.8c

**Appendix 1:**

Sep 15 (11 days ago)

Hello Sumaya,

In the Annals, I prefer that the phrase be d/Deaf or hard of hearing (d/Dhh). The capital "D" covers people who are members of the Deaf Culture, have Deaf identity, etc. The little "d" and hh refers to individuals with hearing losses from slight to profound.

Hope this helps.

Nil desperandum,

pvp

On 9/11/11 5:52 AM, Sumaya Mall wrote:

Dear Dr Paul

Do the Annals of the Deaf have some guidelines for terminology when referring to Deaf people? For example, do they refer to 'the Deaf' or 'Deaf people'? I would like a reference for my PhD thesis

Many thanks

Sumaya

--

Sumaya Mall

D Phil Candidate

University of Stellenbosch

## **Appendix 2: Interview Guide for Deaf Organizations**

- 1) Can you describe the context of your work and how it relates to the Deaf community or the hard of hearing?
- 2) Can you describe your understanding of some of the behavioural characteristics of the Deaf community? How do these differ from the hard of hearing? (If sexual behaviour is not raised spontaneously, the interviewer should try to elicit more explicitly)
- 3) What is your perception of schools for the Deaf and hard of hearing in terms of HIV/AIDS education?
- 4) What is your perception of the HIV/AIDS component of the Life Orientation component? Can you describe this?
- 5) Do you receive feedback from Deaf or hard of hearing learners about the HIV/AIDS component of the Life Orientation curriculum?
- 6) What is your understanding of mental health? How do mental health conditions impact on the behaviour of Deaf and hard of hearing learners (If sexual risk behaviour is not raised spontaneously interviewer should discuss if respondent believes that mental health conditions influence sexual risk behaviour).
- 7) Are you aware of substance abuse in the Deaf or hard of hearing? Would you say that there is more substance abuse amongst Deaf or hard of hearing adolescents as compared to hearing adolescents? Can you explain?
- 8) What are the main issues that the Deaf community are facing with regard to HIV/AIDS? Can you describe efforts that have been made with regard to addressing these HIV/AIDS related issues in the Deaf community and the deaf or hard of hearing?

- 9) What is your perception of sexual risk taking behaviour amongst adolescents who are deaf or hard of hearing? Are sexual behaviour patterns of deaf adolescents different from hearing adolescents? How so?
  
- 10) Does the age of sexual debut differ in deaf, hard of hearing and hearing adolescents? How so?
  
- 11) Are there high rates of teenage pregnancy in the deaf community?
  
- 12) Would you say that Deaf or hard of hearing adolescents feel pressurised to begin sexual activity? Is this pressure more so than hard of hearing or hearing adolescents? What would you say is the median age for sexual activity in the Deaf or the hard of hearing adolescents? What informs your view? What factors influence sexual debut amongst Deaf or hard of hearing adolescents?
  
- 13) What do you know about the fertility intentions of Deaf or hard of hearing adolescents? Do they differ from hearing or hard of hearing adolescents?

**Appendix 3: Interview Guide for Educators of Deaf and Hard of hearing adolescents**

- 1) Can you describe your teaching career? How did you come to be an educator of the Deaf or hard of hearing?
- 2) Can you describe the school where you currently teach?
- 3) Can you describe your proficiency in sign language?
- 4) Can you describe your understanding of some of the behavioural characteristics of the Deaf community? How do these differ from the hard of hearing?
- 5) What is your perception of schools for the Deaf and hard of hearing in terms of HIV/AIDS education?
- 6) Do you mainly teach in sign language? How are your lessons conducted? Do you use techniques such as sign writing? Sign supported English? Interpreters?
- 7) Are you involved in sex education? Do you feel comfortable teaching the deaf and hard of hearing this subject?
- 8) What is your perception of the HIV/AIDS component of the Life Orientation component? Can you describe this?
- 9) Do you receive feedback from Deaf or hard of hearing learners about the HIV/AIDS component of the Life Orientation curriculum? Do they describe how their attitudes to HIV or sexual behaviour change after they have experienced learning material from the LO curriculum?
- 10) What is your understanding of mental health? How do mental health conditions impact on the behaviour of Deaf and hard of hearing learners (If sexual risk behaviour is not raised

spontaneously interviewer should discuss if respondent believes that mental health conditions influence sexual risk behaviour).

- 11) Are you aware of substance abuse in the Deaf or hard of hearing? Would you say that there is more substance abuse amongst Deaf or hard of hearing adolescents as compared to hearing adolescents?
- 12) Does the age of sexual debut differ in deaf, hard of hearing and hearing adolescents? How so?
- 13) Are there high rates of teenage pregnancy in the deaf community?
- 14) Do you know of learners who have been abused physically or sexually abused? What protocol was followed by the school or the Education Department. What would your suggestions be in this regard?
- 15) What are the main issues that the Deaf community are facing with regard to HIV/AIDS? Can you describe efforts that have been made with regard to addressing these HIV/AIDS related issues in the Deaf community and the deaf or hard of hearing?
- 16) What is your perception of sexual risk taking behaviour amongst adolescents who are deaf or hard of hearing? Are sexual behaviour patterns of deaf adolescents different from hearing adolescents? How so?
- 17) Would you say that Deaf or hard of hearing adolescents feel pressurised to begin sexual activity? Is this pressure more so than hard of hearing or hearing adolescents?
- 18) What do you know about the fertility intentions of Deaf or hard of hearing adolescents? Do they differ from hearing or hard of hearing adolescents?

**Appendix 4: Interview Guide for Parents of Deaf and deaf adolescents**

Category (Deaf or hard of hearing) -----

Name of Interviewer -----

- 1) Can you describe the experience of being a parent of a child who is Deaf or hard of hearing?
- 2) Can you describe what the period of adolescence has been like for your child?
- 3) Do you have other children?
- 4) Can you describe your understanding of some of the behavioural characteristics of the Deaf community? How do these differ from the hard of hearing
- 5) What is your understanding of mental health? How do mental health conditions impact on the behaviour of Deaf and hard of hearing learners (If sexual risk behaviour is not raised spontaneously interviewer should discuss if respondent believes that mental health conditions influence sexual risk behaviour).
- 6) What is your understanding of HIV/AIDS  
[Interviewer should probe for respondent's understanding of VCT, PMTCT, ARV Treatment, sexual risk behaviour]
- 7) Have you discussed HIV/AIDS in your home with your child?
- 8) Can you describe what you know about the HIV/AIDS education in your child's school? Does the school have a policy on condom demonstrations? Does your child give feedback on the sex education he or she receives at school? Did you know about the comic book for deaf learners that was circulated at Sizwile? What about John Meletse's workshops?

- 9) Have you heard of abuse of members of the Deaf Community or the hard of hearing?
  
- 10) Do you discuss sexual and physical abuse in your home with your child?
  
- 11) What is your perception of sexual risk taking behaviour amongst adolescents who are deaf or hard of hearing? Are sexual behaviour patterns of deaf adolescents different from hearing adolescents? How so?
  
- 12) Would you say that Deaf or hard of hearing adolescents feel pressurised to begin sexual activity? Is this pressure more so than hard of hearing or hearing adolescents? What about your child?
  
- 13) What do you know about the fertility intentions of Deaf or hard of hearing adolescents? Do they differ from hearing or hard of hearing adolescents?

**Appendix 5: Interview Guide to facilitate In depth interviews with Deaf and hard of hearing Adolescents to facilitate the development of a HIV/AIDS and Sexual Risk Taking Questionnaire**

- 1) Are you a member of a Deaf community? If yes, can you describe what it is like to be a member of a deaf community? How is this different from being hard of hearing?
- 2) Can you describe your school? What do you like about school? What don't you like about school? Do you learn about HIV/AIDS at school? Do you learn about mental health at school?
- 3) What is your understanding of HIV/AIDS  
[Interviewer should probe for respondent's understanding of VCT, PMTCT, ARV Treatment, sexual risk behaviour]
- 4) What is your understanding of mental health? How do mental health conditions impact on the behaviour of Deaf and hard of hearing learners (If sexual risk behaviour is not raised spontaneously interviewer should discuss if respondent believes that mental health conditions influence sexual risk behaviour).
- 5) Have you discussed HIV/AIDS in your home with your parents?
- 6) Have you heard of abuse of members of the Deaf Community or the hard of hearing?
- 7) What is your perception of sexual risk taking behaviour amongst adolescents who are deaf or hard of hearing? Are sexual behaviour patterns of deaf adolescents different from hearing adolescents? How so?
- 8) Would you say that Deaf or hard of hearing adolescents feel pressurised to begin sexual activity? Is this pressure more so than hard of hearing or hearing adolescents?
- 9) Does the age of sexual debut differ in deaf, hard of hearing and hearing adolescents? How so?

- 10) What factors do you think influence age of sexual debut in deaf, hard of hearing and hearing adolescents?
- 11) Have you discussed violence in relationships with anyone at all? What do you think girls who are victims of violence should do?
- 12) Are there high rates of teenage pregnancy in the deaf community?
- 13) What do you know about the fertility intentions of Deaf or hard of hearing adolescents? Do they differ from hearing or hard of hearing adolescents?

**Appendix 6: Consent Form for Deaf Organizations****RESEARCH STUDY: “*The Design and Process of a Sexual Behaviour Questionnaire for Deaf and Hard of Hearing Adolescents in South Africa*” INFORMED CONSENT AND INFORMATION FOR PARTICIPANTS**

Hello, my name is..... I work at Stellenbosch University. We are talking to policy makers who work in deaf organizations, education and health policy, NGO and research. We plan to interview various policy makers to see what different professionals think about this important area. We plan to ask questions about your perception of knowledge of HIV in the deaf community, risk behaviour in the deaf community and the access of the deaf to care. This study is part of a PhD study at the university.

1.

2. *Participant Rights*

If you agree to participate, we would take up about one hour of your time to talk about these issues. Your participation in this interview is completely voluntary. You are not required to answer any questions that you are not comfortable with. You can also decide to stop participating at any time. Not participating in the study or withdrawing from the study will not be shared with anyone. If you agree to participate we will ask you to tell us your thoughts on a series of issues. There are no right or wrong answers to any of the questions. We only want to know your opinions and ideas.

To help us in remembering what you say here today, I will be taking notes and would also like to record today's session on tape. Only our research team will review the tape. Your name will not be used as part of any of the results from this study. Your discussion with us will be kept confidential. We would also ask that you do not share anything that has been said during this discussion with anyone. Are you OK with this? Lets go on.

If you have questions about the study you may ask them now. If you don't have any questions and agree to participate in the interview then we will go ahead and begin. But first, I will ask you to sign this form stating that I, the interviewer, have informed you of your rights as a participant and that you have agreed to participate in today's discussion. This is the only place where your name will be entered.

We thank you for your time. The study has been approved by the Research Ethics Committee of the Faculty of Health Sciences, University of Cape Town. Tel: 021-

If you need to contact us to ask us any further questions after the discussion:

Sumaya Mall

Prof Alan Flisher

Prof Leslie Swartz

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Participant Signature

Date

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Interviewer Signature

Date

**Appendix 7: Consent for educators****RESEARCH STUDY: *The Design and Process of a Sexual Behaviour Questionnaire for Deaf and Hard of Hearing Adolescents in South Africa* INFORMED CONSENT AND INFORMATION FOR PARTICIPANTS**

Hello, my name is..... I work at Stellenbosch University. We are talking to parents of deaf adolescents. We plan to interview teachers who work in deaf schools or with hard of hearing learners to see what they think about this important area. We plan to ask questions about your perception of knowledge of HIV in the deaf adolescents, risk behaviour in the deaf community, discussions you have with your learners and the access of the deaf to healthcare. This study is part of a PhD study at the university.

***Participant Rights***

If you agree to participate, we would take up about one hour of your time to talk about these issues. Your participation in this interview is completely voluntary. You are not required to answer any questions that you are not comfortable with. You can also decide to stop participating at any time. Not participating in the study or withdrawing from the study will not be shared with anyone. If you agree to participate we will ask you to tell us your thoughts on a series of issues. There are no right or wrong answers to any of the questions. We only want to know your opinions and ideas.

To help us in remembering what you say here today, I will be taking notes and would also like to record today's session on tape. Only our research team will review the tape. Your name will not be used as part of any of the results from this study. Your discussion with us will be kept confidential. We would also ask that you do not share anything that has been said during this discussion with anyone. Are you OK with this? Lets go on.

If you have questions about the study you may ask them now. If you don't have any questions and agree to participate in the interview then we will go ahead and begin. But first, I will ask you to sign this form stating that I, the interviewer, have informed you of your rights as a participant and that you have agreed to participate in today's discussion. This is the only place where your name will be entered.

We thank you for your time. The study has been approved by the Research Ethics Committee of the Faculty of Health Sciences, University of Cape Town. Tel: 021-

If you need to contact us to ask us any further questions after the discussion:

Sumaya Mall

Prof Alan Flisher

Prof Leslie Swartz

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Participant Signature

Date

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Interviewer Signature

Date

**Appendix 8: Consent form for parents****RESEARCH STUDY: “*The Design and Process of a Sexual Behaviour Questionnaire for Deaf and Hard of Hearing Adolescents in South Africa*: INFORMED CONSENT AND INFORMATION FOR PARTICIPANTS”**

Hello, my name is..... I work at the University of Stellenbosch. We are talking to parents of deaf adolescents. We plan to interview parents to see what they think about a number of issues that affect their deaf adolescent children. We plan to ask questions about your perception of knowledge of HIV of the your children, risk behaviour in the deaf community, discussions you have with your children and the access of the deaf to healthcare. This study is part of a PhD study at the University of Stellenbosch.

*Participant Rights*

If you agree to participate, we would take up about one hour of your time to talk about these issues. Your participation in this interview is completely voluntary. You are not required to answer any questions that you are not comfortable with. You can also decide to stop participating at any time. Not participating in the study or withdrawing from the study will not be shared with anyone. If you agree to participate we will ask you to tell us your thoughts on a series of issues. There are no right or wrong answers to any of the questions. We only want to know your opinions and ideas.

To help us in remembering what you say here today, I will be taking notes and would also like to record today's session on tape. Only our research team will review the tape. Your name will not be used as part of any of the results from this study. Your discussion with us will be kept confidential. We would also ask that you do not share anything that has been said during this discussion with anyone. Are you OK with this? Lets go on.

If you have questions about the study you may ask them now. If you don't have any questions and agree to participate in the interview then we will go ahead and begin. But first, I will ask you to sign this form stating that I, the interviewer, have informed you of your rights as a participant and that you have agreed to participate in today's discussion. This is the only place where your name will be entered.

We thank you for your time. The study has been approved by the Research Ethics Committee of the Faculty of Health Sciences, University of Cape Town. Tel: 021-

If you need to contact us to ask us any further questions after the discussion:

Sumaya Mall (084 657 0490)

Prof Leslie Swartz

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Participant Signature

Date

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Interviewer Signature

Date

**Appendix 9: Consent form for parents/guardians (to provide consent for their children to participate in the in-depth interviews)**

**RESEARCH STUDY: *The Design and Process of a Sexual Behaviour Questionnaire for Deaf and Hard of Hearing Adolescents in South Africa* INFORMED CONSENT AND INFORMATION FOR PARTICIPANTS**

I give my consent for my child \_\_\_\_\_) to participate in the research titled, "The Design and Process of a Sexual Behaviour Questionnaire for Deaf and Hard of Hearing Adolescents in South Africa" which is being conducted by Ms Sumaya Mall, a PhD student at the University of Stellenbosch.

I understand that this participation is entirely voluntary; I or my child can withdraw consent at any time without penalty and have the results of the participation, to the extent that it can be identified as my child's, returned to me, removed from the research records, or destroyed.

1. The reason for the research is to investigate the experiences and perceptions of Deaf and hard of hearing adolescents of sexual behaviour amongst themselves and their peers. The research aims to produce an appropriate sexual behaviour questionnaire for deaf and hard of hearing adolescents.
  2. The researcher will be conducting in-depth interviews with Deaf and hard of hearing adolescents. I understand that the researcher might be asking my child a number of potentially sensitive questions.
  3. No discomforts or stresses are foreseen.
  4. No risks are foreseen. My child's participation is voluntary.
  5. The results of this participation will be confidential, and will not be released in any individually identifiable form without the prior consent of myself and my child, unless otherwise required by law.
  6. The interviews and observations will be assisted by a sign language interpreter and recorded. Access to the tapes will be restricted to the researcher. The tape will be stored in a secure area (e.g., locked filing cabinet). The tapes will be transcribed, and the words of my child may be quoted. If so, a pseudonym will be used to ensure that my child cannot be identified in any way.
  7. The researchers will answer any further questions about the research, now or during the course of the project, and can be reached by phone at 084 657 0490
- Please sign both copies of this form. Keep one and return the other to the investigators.

Signature of Researcher

Signature of Parent/Guardian

**Appendix 10: Assent/Consent form for the adolescents**

**RESEARCH STUDY: *The Design and Process of a Sexual Behaviour Questionnaire for Deaf and Hard of Hearing Adolescents in South Africa*: INFORMED CONSENT AND INFORMATION FOR PARTICIPANTS**

Your parents or care-giver has given permission for you to help with a questionnaire for deaf and hard of hearing adolescents.

We would like to tell you all about the questionnaire so you can decide if you would like to help us. If you don't understand, please ask questions. You can choose to be in the study, not be in the study or take more time to decide.

**What is the name of the study?**

The Design and Process of a Sexual Behaviour Questionnaire for Deaf and Hard of Hearing Adolescents in South Africa

**Who is in charge of the study?**

Ms Sumaya Mall. You can contact her at 084 657 0490 or [sumaya.mall@gmail.com](mailto:sumaya.mall@gmail.com)

**What is the study about?**

We are trying to research sexual behaviour of deaf and hard of hearing adolescents. We would like to know your opinions and your ideas on this subject. There are no right or wrong answers. We would just like you to help us by telling us what issues are important to deaf and hard of hearing adolescents.

**What will happen to me in the study?**

You will be asked some questions, none of which you have to answer. You can choose to stop the interview at any time. Nobody will be upset with you if you don't want to be in the study or if you want to stop being in the study.

You have had the study explained to you. You have been given a chance to ask questions. By writing your name below, you are saying that you want to be in the study.

**Appendix 11: Assent form for adolescents to participate in the questionnaire**

**RESEARCH STUDY: “*The Design and Process of a Sexual Behaviour Questionnaire for Deaf and Hard of Hearing Adolescents in South Africa*: INFORMED CONSENT AND INFORMATION FOR PARTICIPANTS”**

Your parents or care-giver has given permission for you to help with a questionnaire for deaf and hard of hearing adolescents.

We would like to tell you all about the questionnaire so you can decide if you would like to help us. If you don't understand, please ask questions. You can choose to be in the study, not be in the study or take more time to decide.

**What is the name of the study?**

The Design and Process of a Sexual Behaviour Questionnaire for Deaf and Hard of Hearing Adolescents in South Africa

**Who is in charge of the study?**

Sumaya Mall. You can contact her at 084 657 0490 or [sumaya.mall@gmail.com](mailto:sumaya.mall@gmail.com)

**What is the study about?**

We are trying to research sexual behaviour of deaf and hard of hearing adolescents. We would like to know your opinions and your ideas on this subject. There are no right or wrong answers. We would just like you to help us by telling us what issues are important to deaf and hard of hearing adolescents. You could also help us by telling us which parts of the questionnaire you like or do not like.

**What will happen to me in the study?**

You will be asked some questions, none of which you have to answer. You can choose to stop the interview at any time. Nobody will be upset with you if you don't want to be in the study or if you want to stop being in the study. Everything you say to us will remain confidential. We will also ask that you do not share any part of this discussion with anyone.

You have had the study explained to you. You have been given a chance to ask questions. By writing your name below, you are saying that you want to be in the study.

**Signature of Researcher**

**Signature of Participant**