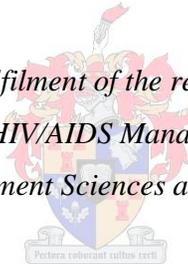


**THE VULNERABILITY OF THE VISUALLY IMPAIRED TO HIV AND AIDS: A  
STUDY OF THE HIV AND AIDS OUTREACH EFFORTS FOR VISUALLY IMPAIRED  
PEOPLE**

by

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Master of Philosophy (HIV/AIDS Management) in the Faculty of  
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## **DECLARATION**

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## **ABSTRACT**

This study argues that visually impaired people are vulnerable to HIV due to insufficient HIV and AIDS intervention programmes that are not modified for their diverse needs, also to lack of support from health care workers, sexual assault and risky sexual behaviour. The study is aimed at establishing the factors that expose the visually impaired to be vulnerable to HIV and suggest strategies for HIV prevention programmes for the visually impaired.

The researcher chose only totally blind people from the Johannesburg Society for the Blind, Ubuntu Workshop for the Blind and Blind SA which are all in Johannesburg, South Africa, to participate in the study. The researcher chose those organisations because they promote the abilities and potential of people with visual impairment by publicizing their achievements and their special needs. They also educate the community about visual impairment, including its treatment and prevention and they have a vast number of the visually impaired unlike searching for them in their scattered locations.

The researcher used a qualitative research approach where she interviewed the participants as a method of data collection where the visually impaired perceived themselves to be at higher risk of HIV infection due to the nature of their disability regardless of their awareness levels. Basically people with visual impairment are vulnerable to HIV because of lack of HIV programmes which are modified for their needs and social exclusion due to stigma attached to disability. The study concluded that the government has failed to recognize the visually impaired as a high risk group and therefore the visually impaired are not fully included in the existing HIV and AIDS intervention programmes.

## OPSOMMING

Die studie beweer dat gesiggestremde persone kwesbaar is vir MIV as gevolg van onvoldoende MIV en Vigs-voorkomingsprogramme wat nie vir hul spesifieke behoeftes aangepas is nie, ook as gevolg van 'n gebrek aan ondersteuning van gesondheidswerkers, seksuele misdrywe en onveilige seksuele gedrag. Die doel van die studie is om faktore te bepaal wat gesiggestremdes kwesbaar maak vir MIV en stel ook riglyne voor vir aanpasbare voorkomingsprogramme spesifiek vir hierdie persone.

Die navorser gebruik slegs mense wat totaal blind is van Johannesburg Society for the Blind, Ubuntu Workshop for the Blind and Blind SA wat in Johannesburg, Suid-Afrika, geleë is. Die navorser het 'n kwalitatiewe navorsingsbenadering gebruik deur onderhoude met die deelnemers te voer om data in te samel. Die deelnemers voel dat hul 'n hoë risiko vir MIV infeksie is as gevolg van die aard van hul gestremdheid, ongeag hul bewustheid rakende MIV en Vigs. Die studie sluit af deur te verwys na die regering se voorkomingsprogramme wat nie gesiggestremde persone in ag geneem het nie en dat hierdie persone dus nie nut kry uit bestaande MIV voorkomingsprogramme nie.

## **ACKNOWLEDGEMENTS**

I would like to sincerely thank my sister, Mandisa, for all the support and encouragement throughout the study. I must also take this opportunity and thank the participants at the Johannesburg Society for the Blind, Ubuntu Workshop for the Blind and Blind SA for providing important information which is the basis for my study. Their inputs gave me the insight in understanding the challenges the visually impaired face regarding HIV and AIDS intervention.

Special gratitude goes to my study leader, Ms Anja Laas, for all the guidance and support.

Finally I hope that this study will have an impact to all the individuals, organisations, government departments and other advocates for HIV and disability. It would be critical to respond to people with visual impairment as any risk groups, thus we need to work together and reduce HIV transmission among the visually impaired.

I dedicate this research project to my parents.

## **ABBREVIATIONS AND ACRONYMS**

AIDS	Acquired Immune-Deficiency Syndrome
AFUB	African Union for the Blind
ART	Antiretroviral Treatment
ARV	Antiretrovirals
CBO	Community-based organisation
DPSA	Disabled People in South Africa
DPO	Disabled Peoples' Organisation
HIV	Human Immuno-Deficiency Virus
ICF	International classification of Functioning and Disability
MDGs	Millennium Development Goals
NGO	Non-Governmental Organisation
OHCHR	Office of the High Commissioner for Human Rights
PWD	People with disabilities
STI	Sexually Transmitted Infection
TB	Totally Blind
UN	United Nations
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation

## **TERMINOLOGY**

### *People living with disabilities*

For the purpose of this study the researcher prefers to use the term people living with disabilities rather than disabled people. The researcher maintains the integrity of the participants and described the participants as human beings who have a sensory impairment, which is the loss of sight.

### *Visually impaired*

It is the preferred term but for the purpose of this study the researcher will use it interchangeably with blind/totally blind.

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# 1. INTRODUCTION

## 1.1 Background and introduction

Visually impaired people are often overlooked in HIV prevention and AIDS outreach efforts. The government, Non-Governmental Organisations (NGOs), Faith-Based Organisations (FBOs) and Community-Based Organisations (CBOs); have set up many programmes and campaigns to create awareness on how to prevent, manage and live positively with HIV and AIDS. Unfortunately, these programmes and campaigns are not accessible to visually impaired people. Visually impaired people are vulnerable to HIV due to various factors, as information is not provided in accessible formats like Braille or large print while demonstrations are visual using pamphlets, posters and other visual-oriented methods to distribute information to the general public. A lack of such information means that visually impaired people do not receive knowledge of how to prevent themselves from getting HIV, how to live with it or how to care for others with it (Nduta, 2007).

It has been demonstrated by UNAIDS (2008) that an estimated 650 million people, or 10% of the world's population, have a disability. Although people with disabilities are found within the populations at higher risk of exposure to HIV, not much attention has been paid to the relationship between HIV and disability. The Department of Health has not trained health practitioners in hospitals and clinics on skills necessary in dealing with visually impaired people. Therefore, there are no modified counselling and support services to suit the needs of visually impaired people. There is a major challenge of discrimination against the visually impaired which hinders them to seek acceptance and treatment from fellow peers and therefore one infected person may infect so many other visually impaired people as they are isolated in low cost houses, special institutions and informal settlements. In some circumstances, the vulnerability of visually impaired people to HIV is exacerbated by traditional beliefs and myths that visually impaired people are not sexually active thus they are excluded from voluntary counselling, testing and treatment facilities. Sometimes there are myths and perceptions that visually impaired people are free of diseases which subject them to be more vulnerable to HIV as some people rape the visually impaired with a belief that they will be cleansed from HIV.

The disability sector represent a fabric of communities with different kinds of human races, religions, cultural backgrounds who are living together, where you find the vulnerable, the poor, the exploited, the destitute, the abused, the neglected and most illiterate people who put their trust in the government and community leaders. Visual impairment is also in this category since its nature causes the visually impaired to be vulnerable to HIV. It is understood that the majority of people with visual impairment never had either the good nor mere opportunity of going to school, thus today they are termed illiterate in this country. The Department of Education aggravates the illiteracy by having an age limit in special schools which makes visually impaired learners to drop out of school without finishing Grade 12. We also understand that there are those who were fortunate enough to empower themselves with the most powerful tool called EDUCATION and those who also happen to acquire the impairment after having empowered themselves with such a tool which partially protects them from sexual exploitation that accelerates HIV infection. Therefore, the consequences end up on the grounds that now the focus on their ability gets shifted to their appearance.

Protecting the rights of people with all disabilities is a human rights issue which is legislated in the Constitution of the Republic of South Africa, 108 of 1996. However, people with visual impairment are still sexually exploited. One do not get advertisements in printed form which has a picture of a visually impaired person (with a guide dog or a white cane, which are symbols of blindness) to show the readers that people with visual impairment are not asexual. UNAIDS, WHO and OHCHR (2009) Policy Brief was written in line with UN Convention on the Rights of Persons with Disabilities. The Employment Equity Act, 66 of 1998 defines a disability as a condition caused by an accident, trauma, genetics or a disease which may limit a person's mobility, hearing, vision, speech, intellectual or emotional functioning. The UNAIDS, WHO and OHCHR (2009) Policy Brief emphasises the need for accessibility of services in two directions:

- (i) rehabilitation services for people living with HIV, and
- (ii) HIV services for people with disabilities.

## **1.2 Objectives**

Fundamentally this study was aimed at investigating the factors that make the visually impaired vulnerable to HIV and AIDS and suggest strategies for HIV prevention programmes for the visually impaired. Specifically, it attempted to determine the following:

- The knowledge of the visually impaired to HIV;
- If the visually impaired feel that they are more vulnerable to HIV;
- If the health care workers are trained to assist the visually impaired in health care facilities;
- If the HIV and AIDS outreach programmes are modified or adapted to suit visually impaired people;
- The type of outreach programmes that the visually impaired receive (verbal or Braille);
- The effectiveness of such outreach programmes to visually impaired people.

## **1.3 Theoretical framework**

The visually impaired exercise social integration when they access modified HIV information. In order to reduce their vulnerability to HIV, strategies must be structured on the following items:

- Customised and adapted HIV and AIDS intervention resources; audio recorded programmes, embossed diagrams/pictures, Braille text.
- Accessible environment
- Individual attention on condom demonstration
- Modified condoms
- Modified ARVs
- Women empowerment
- Health care workers who are sensitive on disability.

## **1.4 Research question**

The researcher was principally interested to determine how the lack of modified HIV intervention programmes contribute to the spread of HIV and AIDS to the visually impaired, by investigating how the correct format of the resources contributed to their vulnerability to HIV

and AIDS infection, the researcher laid down the groundwork for the investigation of how the lack of customized information may lead to the spread of HIV amongst the visually impaired and their communities. The researcher took into account the unreliable social factors such as poverty, illiteracy, traditional and religious beliefs. It seems credible that the visually impaired may or may not risk HIV infection. The lack of modified HIV programmes, engaging in sexual relations in order to fit into society for the visually impaired may contribute to high HIV prevalence but also religious beliefs control them into abstinence or having only one partner. This study attempts to determine if the lack of modified HIV and AIDS intervention strategies exacerbate the vulnerability of the visually impaired to HIV and AIDS. It also wants to determine if adapted HIV and AIDS intervention programmes will reduce the vulnerability of the visually impaired to HIV and AIDS.

The following research question guided the research: Will the lack of modified HIV and AIDS intervention strategies accelerate the vulnerability of the visually impaired to HIV and AIDS? The researcher also took into account the perplexing variables such as: sexual violence, poverty, behaviour of the health care workers, religious beliefs and different reasons for engaging in sexual activities as they may or may not influence the vulnerability of the visually impaired to HIV.

## **2. LITERATURE REVIEW**

The Free Merriam-Webster dictionary defines vulnerability as being open to damage or attack. The researcher has also used the notion of ‘modification’ as a key strategy to address issues of discrimination and exclusion. The International Day of Persons with Disabilities is commemorated annually on the 3rd of December. As a country, South Africa has put in place a legislative framework that supports the needs of persons with disabilities and has a progressive constitution that protects the rights of persons with disabilities. South Africa has adopted the United Nations Disability Convention, Article 24 of the UN Convention on the Rights of Persons with Disabilities which promotes equality of opportunity and the right to education without discrimination. The Employment Equity Act, no 55 of 1998 and the Promotion of Equality and Prevention of Unfair Discrimination Act, no 4 of 2000 are examples of the legal instruments aimed at improving the lives of people with disabilities in the country. The new international classification of functioning and disability (ICF) developed and adopted by the World Health

Organisation (WHO) in 2001. According to ICF's objective, focus must shift from disability as an innate deficit to disability as constructed through the interaction between the individual and the environment. The ICF encourages focus on kinds and levels of intervention appropriate to the disablement needs of individuals within specific contexts, and is consistent with the social model of disability that is upheld by disability rights organisations and many disabled people.

Rieser (2000) defines impairment as the loss or limitation of physical, mental or sensory function on a long term or permanent basis. Although disability is now firmly well-established in the South African legislation, no or few measures are in place to monitor the implementation within the different sectors. Groce (2008) mentions that 335 million people are estimated to live a pre-existing physical sensory impairment worldwide, out of which 80 million live in Africa.

The preceding on adapted programmes has been used to display how the government sector, legislators and civil society organisations can use the knowledge so that they can be able to accommodate the visually impaired and the reasons why they must include them.

## **2.1 Lack of knowledge about HIV**

A study by Taylor (2008) demonstrates that the visually impaired, cannot read communication materials unless it is produced in Braille. Therefore they are not exposed to information about HIV/AIDS distributed in printed text or pictures. Due to this there is a need to gather information on people with disabilities and then gauge their levels of knowledge, attitude and practices towards HIV and AIDS. A study by the National Union of Disabled Persons of Uganda (NUDIPU, 2003) found that the nature/mode of information dissemination about HIV/AIDS is not user-friendly to people with disabilities, especially the blind. The blind cannot read/see the posters generally used for disseminating such information on TV or printed media and therefore cannot easily benefit from what is currently available.

Lack of adapted HIV and AIDS material is due to the fact that society parallels disability with worthlessness. It is commonly accepted that disability and HIV/AIDS are rendered invisible because many of those who are affected by disabilities are poor (DFID, 2000). As demonstrated by DFID (2000) that the practicality of using a condom by the visually and physically handicapped was raised by the respondents as a challenge, for example, proper use of a condom

also necessitates reading of the expiry date. The respondents indicated that the visually impaired couldn't read, the respondents said they depend on their sexual partners if they even planned to use condoms. The dependency on the partner for safer sex compromises one's protection, thus increasing the vulnerability to HIV. The respondents also indicated that AIDS is one factor that may cause or aggravate the disability condition of an individual.

Another study conducted by Phillander and Swartz (2009) in South Africa, revealed that 93% of the 15 blind participants indicated that they could be at risk of contracting HIV. The World Health Organisation (2008) suggested a need to sensitise HIV information providers on how to interact with visually impaired persons by making provision for shared confidentiality in relation to HIV testing. Those participants emphasize that Braille and audiotapes are necessary to make AIDS services accessible to people with visual impairments. Taylor (2008) revealed that for the visually impaired and physically challenged, radio proved to be the most effective source of information.

Nduta (2007) demonstrates that information is not provided in accessible formats like Braille or large print while demonstrations are visual using posters and other visual-oriented methods to convey information to the public. Basson, Schneider and Swartz (2009) indicate that lack of information in Braille, and much of HIV and sexuality information is in English. People with disabilities, especially women have less decision-making power with regards to own sexuality. As demonstrated by Wazakili (2011) that consequently they do not benefit from HIV prevention and care efforts.

As demonstrated by Ranchod, Macdonald, Schneider, Swartz & Braathen (2009) that the lack of access to services, including HIV/AIDS and Voluntary Counselling and Testing (VCT), and accessible information are all factors that increase the risk of people with disabilities. Braathen, Basson, Schneider and Swartz (2009) agree that many of the informants feel that although their sexuality is no different from non-disabled people, they are faced with a number of barriers in accessing HIV prevention and treatment.

## 2.2 Lack of support

A study done by Nduta (2007) disclosed that health practitioners lack skills necessary in dealing with blind and partially sighted persons. Therefore, counselling and support services are not modified to suit the needs of visually impaired persons. Access, however, often depends on the attitude of those able-bodied people who regard people with disabilities as somehow deficient. Yungungu, Songok, and Mulinge (undated) indicate that a lack of skills is also an impediment to the health practitioners in providing HIV and AIDS services to the visually impaired. As a result, support services are not modified to suit the needs of the visually impaired. Additionally, the infected persons receive little support from the community due to social stigmatization thus accelerating their immunity deficiency.

Nduta (2007) further adds that counseling and support services are not modified to suit the needs of visually impaired persons. When people have such attitudes the Millennium Development Goals (MDG 6) which target is to combat and begin to reverse the spread of HIV and AIDS by the year 2015 might never be achieved if HIV and AIDS intervention programmes exclude people with disabilities. Taylor's research (2008) did HIV testing between the blind and the sighted in order to know HIV prevalence of the visually impaired and found that the visually impaired recorded the highest proportion at 70% and 62% respectively. While another study by NUDIPU (2003) discovered that visually impaired persons have no knowledge of VCT the study indicates that in cases of rape, people with disability pointed out that they have sometimes had to face rape as a result of inability to fight rapists due to their severe physical disability. Major interventions around HIV and AIDS prevention, care, support and mitigation have been done, but little or none has targeted the disabled people as a special category. For example awareness based interventions that have a strong component of information, education and communication have not looked at the needs of the visually impaired, even when AIDS service organisations promote safer sex lifestyles like condom use.

According to the HIV and AIDS disability conference report, Namibia June 2003, Page 10, the disabled people said "Policy makers and development agencies continue to talk about us without us" As if talking about them is not enough, people have gone ahead to do things they think are right for the disabled people, e.g. In the same report page 4, " .....and then the woman was put in a room with a man, because a blind woman will need a child to take care of her". Nganzi &

Matonhodze's (2004) research discovered that the majority of the respondents were aware of the existence of HIV and AIDS programmes and services in their communities. However they mentioned inaccessibility as a major limitation. On treatment in hospitals, the majority of respondents said they are ignored or mistreated. The study of Phillander and Swartz (2009) reveals that 93% of the visually impaired participants believed that "the general public holds myths about people with visual impairments, including beliefs about asexuality or abstinence".

The immediate people close to those living with disabilities will for this reason not engage in sex discussion or HIV and AIDS. Groce (cited by Mcelligott, 2003) also indicates that health professionals often assume that disabled patients are not sexually active and are less likely to be targets of sexual violence. According to UNAIDS, WHO and OHCHR new policy brief on disability and HIV (2009) persons with disabilities may not benefit fully from HIV and related sexual and reproductive health services because services offered at clinics, hospitals and in other locations may be physically inaccessible, fail to provide information in alternative formats such as Braille, audio or plain language. Also, service providers may lack knowledge about disability issues, or have misinformed or stigmatizing attitudes towards persons with disabilities. Saulo and Walakira (2012) found that lack of special services for blind people to be able to test for HIV was expressed. The health service for blind people was considered inadequate, unequal and discriminatory, and harassment by health care staff was expressed, but not sexual abuse. Basson, Schneider and Swartz (2009) indicate that there are also attitudinal barriers that hinder HIV programmes such as their assumed asexuality.

### **2.3 Stigma**

In Phillander and Swartz's study (2009), it was revealed that 93% of the visually impaired participants believe that "the general public holds myths about people with visual impairments, including beliefs about asexuality or abstinence"; 20% of the participants gave an indication that there are some people who believe that sex with a virgin or a disabled person can cure AIDS. SANAC (2007) in its study states that a visually impaired woman revealed that being blind and HIV positive, you face a double discrimination in the community and her son is continuously made fun of because of her condition. Taylor's (2008) study established that society assumes persons with disability have no sexual feelings.

A study conducted by Nganzi and Matonhodze (2004) demonstrates that there were high levels of stigmatization and discrimination by the community, being stigmatized and discriminated against due to both HIV and AIDS status and disability. However, the disabled people too stigmatize each other over HIV and AIDS status and there are also elements of self-stigmatization and discrimination by the disabled people themselves. All the respondents acknowledged that the disabled people's sexual behaviors are influenced by a number of factors, most importantly the societal expectations around femininity and masculinity, degree of wealth, social status, poverty and alcohol. However, these factors have a double effect on the disabled people; they said if one is a female, poor and disabled, the risk of infection is relatively high.

Groce (2008) indicates that attitudinal (negative) barriers stem from their exclusion from participating in various community projects because of some dangerous gadgets and/or surrounding involved in the processes. This demonstrates to the able bodied that the totally blind people are less valuable in the community and they cannot perform certain tasks. Some able bodied go to an extent of perceiving the totally blind as sexually inactive thus no need of HIV prevention awareness for them. This societal attitude might be an insight as to why the visually impaired are discriminated against. Basson et.al. (2009) also support that visually impaired people suffer the stigma of being seen visiting VCT. Nduta (2007) indicates that in some circumstances, the vulnerability of blind and partially sighted persons to HIV is exacerbated by traditional beliefs and myths that presume visually impaired people to be at no risk of contracting HIV and as a result they are excluded from VCT and treatment facilities. On the other hand, there are myths and superstition which often lead to the perception that it is "safe" to engage sexually with blind persons, as they are free of diseases, and this perception put them at extra risk of actually getting infected. UNAIDS, WHO and OHCHR new policy brief on disability and HIV (2009) also demonstrate that service providers may lack knowledge about disability issues, or have misinformed or stigmatizing attitudes towards persons with disabilities.

## **2.4 Impact of sexual violence**

Nduta (2007) demonstrates that blind women are particularly vulnerable to sexual abuse, which is common in many communities and is aggravated by poverty, illiteracy and low self-esteem.

The situation that reinforces the invisibility of visual impairment and HIV/AIDS is where women with disabilities who are sexually abused are socially excluded, particularly by other women, and resented instead of being supported. Rapuro (1998) says that 'girls' embedded lack of self-esteem, most likely from being kept hidden from a young age and their desire to be sexually attractive in the same way as their sighted peers is combined with the attitude of the man who sexually exploits them that the visually impaired girls, and most likely poor, are worth little and can be used for sex. In Phillander and Swartz's (2009) study, most of the blind people that he interviewed believed that economic dependency, in particular, contributes to gender-based violence. Taylor (2008) states that seven per cent of the 410 persons with disability (visually impaired, persons who are deaf and the physically challenged) who are sexually active were sexually violated in their first sexual encounter. Research done by Nganzi and Matonhodze (2004) concluded that all the respondents indicated that the communities have a belief that disabled people are free of HIV hence a safe target. As a result many disabled people have become victims of rape, defilement and sexual harassment.

UNAIDS, WHO and OHCHR (2009) indicate that a large percentage of persons with disabilities experience sexual assault or abuse during their lifetime, with women and girls, those in specialized institutions, schools or hospitals being at particularly high risk. Basson et.al. (2009) agree that people with disabilities are more at risk for HIV infection. People with disabilities, especially women have less decision-making power with regards to own sexuality. Wazakili (2011) indicates that people with disability are not suitable for marriage, yet favoured for secretive sexual relationships. Groce (cited by Mcelligott, 2003) agrees that disabled people are up to three times more likely to be victims of physical abuse, sexual abuse or rape as they are often perceived as easy targets for violence by would-be perpetrators. Braathen et al (2009) reveal that services are often inaccessible to individuals with disabilities, who are more likely than others to be poor, poorly educated, uneducated about sex, and who are more vulnerable to sexual abuse and substance abuse - all common risk factors for HIV infection.

As demonstrated by Groce and Trasi (2004) that the idea that sex with a virgin can cure AIDS has also fueled some violence because disabled women are often assumed to be asexual and therefore virgins, many are "systematically raped by people who are desperate to get rid of their infection". UNAIDS, WHO and OHCHR (2009) indicate that there is also evidence that in some

cultures, persons with disabilities are raped in the belief that this will “cure” an HIV-positive individual.

## **2.5 Risky sexual behaviour**

As demonstrated by UNAIDS, WHO and OHCHR (2009) evidence shows that people with disabilities are at the same or greater risk of HIV infection as non-disabled people. Due to insufficient access to appropriate HIV prevention and support services, persons with disabilities may engage in behaviours which place them at risk of HIV infection, such as unprotected heterosexual or male-to-male sex (including in the context of sex work) and injecting drug use. There is also evidence that in some cultures, persons with disabilities are raped in the belief that this will “cure” an HIV-positive individual (Nganzi & Matonhodze, 2004).

Taylor’s (2008) study demonstrates that early engagement in sex increases the vulnerability of persons with disability. Nearly a third of persons with disability (people who are deaf, visually impaired and physically disabled) engaged in sex before the age of 16 years. Overall, a quarter of the deaf, blind and physically challenged have engaged in sex for pay or to obtain special favours. Due to social rejection, persons with disability tend to keep multiple and or serial partners.

## **3. METHODOLOGY**

### **3.1 Overview**

The study has been guided by the social model concept of disability that focus on the health sector as the main factor in the acquisition of knowledge by the visually impaired, taking into consideration the aim of modifying and adapting the HIV and AIDS intervention strategies which are sensitive to the visually impaired. The participatory assessment took a qualitative approach that used participatory tools and methods to collect data. The researcher used this method in order to dig deeply into the lives of the visually impaired in order to study the world as they perceive it. The researcher responds that the health sector must collaborate with the CBOs and the DPOs and develop HIV initiatives that are sensitive to the visually impaired.

### **3.2 Study population**

The assessment was done at the Johannesburg Society for the Blind, Ubuntu Workshop for the Blind and Blind SA, targeted and reached 40 visually impaired people, comprising of 19 males and 21 females from ages 18-65. The participants originally came from all the provinces of South Africa and were based in Gauteng province for economic reasons. Some of the participants at the Johannesburg Society for the Blind were Computer Literacy students others are employees, while at the Ubuntu workshop for the Blind and Blind SA all are employees. Some of them are also members of various disabled people's organisations. The researcher used purposeful sampling. All of the participants were totally blind.

### **3.3 Interview methodology**

The researcher used the interview method to confirm the levels of understanding and awareness of HIV among the visually impaired people and their perceptions of vulnerability to HIV infection. The interview schedule had a total of 21 questions and was divided into 5 sections; background information, awareness of HIV and AIDS, sexual history, opinions and closing among the visually impaired people. The interviews contained 14 closed-ended questions (including demographic information) and 7 open-ended questions.

The researcher wrote the responses as she was conducting the interviews, she also used a recorder to ensure that there was not missing information or misunderstandings. The interview schedules are in Appendix 1 and the aggregated responses are in Appendix 2.

The researcher did not write the participants' names on the interview questions, they were anonymous and she identified the respondents as candidates 1-40. The anonymous approach encouraged the respondents to express themselves freely knowing that they would not be identified. The research took place over a period of two weeks.

### **3.4 Data analysis**

The researcher used descriptive validity using two strategies; Reflexivity: Involves self-awareness and critical self-reflection by the researcher on or her potential biases and

predispositions as these might affect the research process and conclusions. The other strategy was external audit from a Clinical Psychologist who assessed the quality of the study.

The researcher conducted the statistics question by question. The open-ended questions had pre-arranged answers which were projected and they were given appropriately.

## **4. RESEARCH FINDINGS AND ANALYSIS**

### **4.1 Research findings**

The researcher spoke with a Director of HIV and AIDS at the Department of Women Children and People with Disabilities in Gauteng who mentioned that they recently wrote a report on people with disabilities and HIV which was not available to the general public at that time. The researcher spoke with an employee who works at the HIV department at National Organisation of the Blind in South Africa (NOBSA) who conveyed that there were no statistics of the visually impaired who are living with HIV and AIDS in the country. The researcher also met a DPSA representative who works in their HIV department and he admitted that people are marginalized in the following areas:

- Visually impaired people are marginalized and viewed as being “abnormal” or “different” and thus not able to function like “normal” people.
- Visually impaired people are amongst the poorest people in South Africa. Poor people do not have access to basic services and HIV prevention, treatment and care programmes.
- Visually impaired people are perceived to be asexual. It is widely believed that disabled people do not have, nor enjoy, sexual relationships. As a result there is a misconception that disabled people cannot be infected by HIV.
- Visually impaired people are still not treated with respect, dignity and fairness by service providers, nurses, doctors, counsellors and social workers lack knowledge on how to engage with disabled people.

The DPSA representative elaborated further on the social exclusion of people with disabilities in a case study which found that the most abuse on disabled people begins within the family e.g. a disabled child who earns a disability grant is used for other family members' needs, he/she has little or none access to his/her own needs. Furthermore, people with disabilities become victims of violence within their families with little or none intervention from their parents. Complaints are being lodged with the department of housing as most houses built are not accessible. In one area they clustered accessible houses for the disabled people forming a disability hostel/township.

Some civil society groups that the researcher met admitted that they had HIV and AIDS campaigns which were not tailored for the visually impaired. The Johannesburg Society for the Blind has a programme called "HIV & AIDS Sees No Disability" which is a custom made intervention to meet the unique needs of people with visual impairment regarding prevention, support and care. They have made presentations at the 5th SA AIDS Conference in Durban, June 2011 and at the SAHARA Conference in December 2011 programme. When the researcher was at the Johannesburg Society for the Blind conducting the interviews, most of the participants were not aware of the programme. There is also a clinic at the Johannesburg Society for the Blind, surprisingly some HIV-positive participants admitted that they are scared to utilise the clinic for HIV treatment as they don't trust the staff because the visually impaired feel partially included at the Society for the Blind, they mentioned that there is no equal representation between them and the sighted people in their management.

The modes of transmission are the same for both visually impaired and sighted people thus the researcher points out that visually impaired people are like any risk groups such as truck drivers and sex workers and also involved in substance abuse which further subjects them to HIV infection. There must be acknowledged that a good number of people living with HIV have lost their sight completely after becoming HIV positive through opportunistic infections (i.e.cytomegalovirus). Most of these people were already sexually active and now have joined the world of the visually impaired further subjecting other HIV-negative visually impaired people at risk of HIV infection.

Some visually impaired young adults got the opportunity of learning about existing HIV programmes in a tailored manner at the schools for the visually impaired in the Life Orientation

classes, however the programmes were not fully inclusive. Some of the programmes were visual others verbal while there were no individualised condom demonstrations. These are the reasons why the modified HIV and AIDS intervention campaigners must adapt their programmes to suit the needs of the visually impaired people in order to reduce the vulnerability of the visually impaired to HIV infection.

The visually impaired are perceived to be physically unattractive, yet considered to be sexually attractive. They are believed to be asexual and free of diseases and so far they are over-sexed and at increased risk for HIV infection. Some visually impaired women are involved in commercial sex work while others have been abused or raped by HIV positive men and they are now infected with HIV. Some visually impaired people are alcohol or drug users whose sexual behaviour exposes them further to HIV infection. Some participants feel threatened by HIV and AIDS because of the nature of their disability and others do not.

The respondents acknowledged the role of literacy in access to information on HIV and AIDS, however, the majority of the visually impaired people are illiterate and the access to information is further disadvantaged by the nature of their disability. The visually impaired have difficulties in reading STI, HIV and AIDS information which puts them at risk of infection, and they also recognized the fact that there is not much HIV material which is tailored for their special needs. Some of them are concerned that the information in Braille is written in contracted (abbreviated) Braille which is complicated for those who acquired the visual impairment later in life. They are also concerned about a lack of Braille literacy facilitators.

Most of the visually impaired mentioned how the health care workers are not trained to deal with the visually impaired. The health care workers assume that visually impaired people are asexual thus some of them were discriminated when they sought HIV and AIDS information. Although there were door-to-door campaigns that were also done in the institutions of the visually impaired, the intervention programmes were not modified. The visually impaired were concerned about how the government takes them for granted which opens a door for the community to also exclude them.

Most visually impaired women mentioned the traditional beliefs that having sex with a visually impaired or any person with a disability will cure people from HIV and AIDS thus the women

are vulnerable to rape. Some of the respondents revealed that they are rape survivors and the rape was aggravated by their disability, some were too traumatized to even seek help after being raped. In some instances some spoke about such experiences for the first time while the researcher was conducting the interviews. Most respondents mentioned that visually impaired women are honest lovers in relationships; they choose sighted partners to avoid social and sexual exclusion and get involved in risky sexual behaviour where they are sexually exploited by sighted men. Both men and women recognized the role of poverty which puts most women at risk of HIV infection as they will try to eradicate poverty by engaging in transactional sex.

Some families of the visually impaired engage in HIV topics with their visually impaired family members and inform them about prevention measures while some family members do not discuss HIV with their visually impaired family members fearing to expose them to sexual activities, other family members think their visually impaired family members are asexual thus no need to equip them on HIV prevention. Most of the visually impaired admitted that their religion promotes abstinence but most of them do have sexual partners that they are not married to. It raises a concern if ever they are using the condoms correctly hence all the respondents admitted that they have never touched or used female condoms, nor had any condom demonstration sessions. The visually impaired cannot easily monitor the movements of their partners especially those partners who are not visually impaired, which makes faithfulness inconsistent which indicates that the visually impaired are not in control of their sexual life hence the risk of infection.

As South Africa also commemorate the International Disability Day annually, the visually impaired are not satisfied on how the government disregards people with disabilities especially with visual impairment. The visually impaired people have similar opinions they raised regarding the lack of adapted HIV intervention programmes that aggravate their vulnerability to HIV and AIDS infection. They wish that the government could have a fund, targeting all sectors where they can find the visually impaired e.g. pay points and supply adapted HIV and AIDS information. The visually impaired feel that there is no support from the government, there is no proper infrastructure even at their employment sector i.e. the Ubuntu Workshop for the Blind.

Printed information is a challenge as the visually impaired can't read it; there are some books in Braille but very limited. Information in Braille for the visually impaired people would help them to know how

to protect themselves from HIV. Those who are not Braille literate struggle, they should have an assistant to read for them especially people who acquired the impairment later in life. It is a problem because there are privacy issues; they can't go with other people when they go for an HIV test. Knowledge is important as it promotes people to another level of doing things right. There are people who haven't heard about HIV because some parents deny them to be part of the communities they lock them at home. A sighted person must read for blind people in order for them to understand. The lack of information is a problem, people make wrong decisions and some of them do not have access to the internet. It is a problem especially in rural areas, there are no awareness programmes and visually impaired people lack knowledge. Lack of information can kill the nation and if the HIV information such as brochures could be in Braille it could make a difference. Sometimes the visually impaired become scared of going to the clinic to seek for HIV information fearing bad attitudes from the health workers. There is no information such as posters and therefore people lack knowledge.

The visually impaired emphasized certain matters relating to their vulnerability to HIV (their interest in knowing when and how to use hand gloves in order to protect themselves from HIV when performing certain tasks. They also wish that sighted people could inform them when they have blood or open cuts so that they also protect themselves from the risk of being infected. They need publicity around disability and HIV. Social exclusion of the blind makes them to be vulnerable to HIV, resulting in them sleeping around. Blind women are honest lovers, when they are in relationships they are looking for love while sighted men have other intentions of sexually exploiting them. Visually impaired women feel normal when they are involved with sighted men. When blind people are staying in an excluded environment, there is a need to have somebody facilitating sexual education and HIV and AIDS awareness programmes. Blind people only depend on the media which is sometimes audiovisual. The visual part of the media plays a big role in depriving blind people proper information.

The government should ensure that the information concerning ARVs is written in Braille. The health workers must be educated on HIV and disability. The blind feel that the government doesn't respect them which accelerate the disrespect from the community. There is a problem of social exclusion and poverty which subjects the visually impaired women to be sexually exploited. Poverty is another issue of concern especially for women; they get involved in transactional sex in order to support themselves and their families. The disability grant is not a living wage, it doesn't meet their financial needs which also accelerates the commercial sex. Not

many visually impaired people are educated which makes them to be unemployed and remain in the cycle of poverty. They wish that the government could give the visually impaired equal opportunities to education so that they can be educated, get good jobs and thus protect themselves from being vulnerable to HIV.

There is stigma around disability and sexuality which creates a problem. Blind women get easily raped because of their disability. Visually impaired people should take care of themselves because people target them. It will be vital if blind women can be financially empowered or the government can increase the disability grant. Some visually impaired people are concerned that they may be infected with Tuberculosis (TB) as they sometimes may be guided by a person who is infected with TB, they would also like to be tested for TB maybe twice a year. People must stop believing that when they have sex with blind people they will be cured of HIV because that increases HIV prevalence among the visually impaired. The government should make institutions for the visually impaired safe, because the women can be easily raped. Health workers should be sensitized on disability. Visually impaired people should be taught on one on one basis on condom usage. The visually impaired want equal access to all the resources, in campaigns they should have Braille material. They could print the material in one page in both Braille and print in order to sensitise the sighted people. They can't see a consent form before the HIV test is done, a sighted person reads in print for them, the rapid test should have speech software. There is no privacy as people should look at their CD4 count and read for them. Some parents are not discussing HIV talks with their blind children in order to be aware of HIV. Some visually impaired wish that they could be integrated into society and not stay in special facilities because they become hypersexual and they exchange sexual partners thus increase their chances of being infected with HIV.

The visually impaired women would like to be accepted by the society and not seen as sex objects. Visually impaired women get raped a lot and they are scared to report the attacks. The visually impaired are concerned about people who blame blind women when they are raped and say they attract men. Communities must also believe the visually impaired when they report their rape cases.

It is evident that the government should firstly consult, then have a joint partnership with the DPOs, FBOs and CBOs as it will be naive of us to expect the visually impaired to be experts in

health matters, nor the government to be experts on how to meet the needs of the visually impaired without collaborating with them.

## **4.2 Findings from interviews with visually impaired people**

### **Demographic information**

The participants were all totally blind, some were born blind others acquired it later in life. The researcher interviewed 19 males and 21 females. Their ages range from 18-65 years. Some of them are married, divorced, widowed single or have life partners. 37.5% of the participants were employees at the Ubuntu Workshop for the blind which is located in Katlehong in East Rand, where they make security gates and burglar proofs. All of them were Africans and they reside with their families. 12.5 % of the participants were employees at Blind SA which is in Mayfair, South of Johannesburg. All of them are proofreaders who translate printed information into Braille. All of them reside with their families. The remaining 50% of the participants were from the Johannesburg Society for the blind, which is in central Johannesburg. Some of them were computer literacy students, others employees who make cane furniture. The Johannesburg Society for the blind has a residence facility where 20% of the participants stay there permanently while others go home on certain occasions and others commute daily. The participants were from different racial groups.

### **HIV Awareness**

The study discovered that the visually impaired people had relatively high awareness levels of HIV and AIDS prevention programmes. The aggregated responses are indicated in Appendix 2. All of the respondents indicated that they have previously received HIV information. 87.5% mentioned that they heard about HIV from the media, at school, from the internet, HIV campaigns, from the community members, at work and in local clinics. A total of 12.5% are proofreaders; they get printed information and translate it using their computers that have speech software into Braille. They receive the information from the government, some CBOs, FBOs and DPOs.

All of the respondents could recognize a male condom and none of them have ever “seen” a female condom. The majority of the respondents (77.5%) indicated that they can insert a condom

without help. The remaining 22.5% rely on their partners for that. Being visually impaired affects the efforts of the disability community on how to protect themselves against sexual violence leading to HIV infection.

The majority of the respondents (85%) indicated that the information they received from available HIV intervention programmes are not suitable for their needs, the information is not translated into Braille, demonstrations are visual and the pictures are not thoroughly explained. They also mentioned the following reasons:

- The awareness campaigns are graphic so they end up not understanding what is happening. They could not imagine the exact thing which is described and end up confused.
- There are not enough ways to propagate information. There is no information such as leaflets, brochures in Braille - it deprives them from proper information.
- They have to depend on a sighted partner to read and demonstrate the printed information (i.e. condom usage).
- The information is not in Braille even the one in Braille e.g. the pamphlets are written in constructed Braille. Some visually impaired people aren't adequately trained in Braille literacy because some acquired the impairment later in life and there is a lack of Braille facilitators.
- They are not comfortable about accepting the HIV test results, they can't trust what the health workers report. Resulting to the invasion of their privacy because there must be a third person in the consultation room.
- They can't fully comprehend the description on the media; on TV they can't see how a STI looks like.

This literally means that the visually impaired lack HIV and AIDS intervention programmes. This evidence has been confirmed by the literature review. However, 10% mentioned that the programmes are suitable for their needs as some of them lost their sight later in life and they were already aware of the existing HIV and AIDS programmes and saw the visual demonstrations and 5% said the programmes do not matter because they are HIV-positive already.

## **Sexual history**

The majority of the respondents (85%) feel that they are vulnerable to HIV due to various reasons: they can be easily raped; they can't see the signs that may suggest a person(s) is HIV-positive and have a sexual relationship with such person/people.

Most visually impaired behave like sighted people as some stated that "being in a relationship feels normal" thus 77.5% of the visually impaired disclosed that they have sexual partners. Those who are single have serial partners while 20% do not have sexual partners and 2.5% engage in casual sex with whoever is available at that moment. A total of 87.5% have tested for HIV and know their HIV status. The 12.5% who have not tested and do not know their HIV status can't be excluded from those who are sexually active, because their lack of knowledge of their HIV status might be accredited to either the lack of HIV awareness, the distance to the testing centre or stigma.

The visually impaired had different experiences regarding the health workers' attitudes when they accessed HIV information. In private clinics the health care professionals were respectful and professional, in local clinics some health care workers felt sorry for the visually impaired while others were rude but most surprisingly the health care professionals thought the visually impaired were asexual to an extent that they asked some visually impaired "why do they bother themselves with HIV?" It is confirmed by the aggregated responses (47%) where the visually impaired mentioned that the health care workers thought they were asexual and the majority of the respondents were under 40 years. While 35% said the health workers treated them with respect and 18% reported that the health care workers were rude, they asked questions like "how does a blind person have sex with another blind person?"

Sexual violence is also evident to the visually impaired, therefore the researcher wanted to know if being visually impaired can accelerate sexual violence. Visually impaired girls attend special schools and some stay in special institutions where they are not so safe as 12.5% of women disclosed they were raped - mostly in those institutions. It is a relief that 85% indicated they have never been raped and 2.5% were nearly raped. It is disturbing when we read and hear stories of how people with disabilities are sexually violated due to the nature of their disabilities as the respondents narrated that all of them were raped by sighted people. Surprisingly, 65% of the respondents said that their religious beliefs urge them to uphold abstinence. It is contradictory

because although their religion teaches abstinence the visually impaired indulge in pre-marital sex because some single respondents said they do have sexual partners.

## **5. LIMITATIONS AND RECOMMENDATIONS**

The limitation of the study was that the researcher did not get equal racial representation, only 8% of participants were non-Africans. At Blind SA only Africans participated, other racial groups refused. The researcher hopes that they don't perceive HIV and AIDS to occur in certain racial groups. The researcher would have loved to know how HIV infection is perceived in different racial groups. The study has pointed out to the government, NGOs and CBOs that the visually impaired seriously need to be attended to in terms of fully adapting HIV and AIDS intervention programmes. Furthermore, the research has highlighted the gaps that are in the existing HIV and AIDS intervention programmes.

It would be critical to have a consultative and a participatory process involving the visually impaired, where the Department of Health and DPOs can invent HIV & AIDS policies that will enable the implementation of HIV and AIDS programmes for their members. When there are situations where committees run HIV and AIDS programmes, they should have people living with HIV & AIDS and with visual impairment.

Intense individual attention is needed by some visually impaired people who may not be reached due to Braille illiteracy especially those illiterate people who have acquired the impairment later in their lives and those who have never been to school.

Visually impaired people themselves should participate in HIV and AIDS training workshops within their institutions.

DPOs should initiate training of visually impaired people in home-based care (HBC), counselling peer education and orphan care etc. The visually impaired should be optimistic and partake in the existing HBC programmes within their communities. Sighted people should be trained on sighted guide skills and how to care for the visually impaired within a HBC programme. It would be crucial to strengthen the fight against stigma and discrimination of visually impaired people. Health care professional should be trained on disability and HIV, in the

existing campaigns sighted people need to be sensitised by having a picture of a person with a guide dog or a white cane. The media should eradicate the myths around the practices that prompt the visually impaired to HIV infection; these practices are pre-disposed by societal expectations, poverty and gender imbalance.

Inaccessible services and facilities, discrimination, stigma as well as self-stigma disadvantage the visually impaired in partaking in other development programmes. Such situations impose a challenge as the impact of HIV and AIDS on them is quite high. In such instances there should be programmes collaborating the visually impaired with the CBOs and FBOs. Visually impaired people also have experienced family resource reduction due to HIV and AIDS. Though the visually impaired are not empowered enough to deal with those issues there is a need to address such challenges. The Johannesburg Society for the Blind has an HIV and AIDS programme targeted for the visually impaired which was launched in August 2011 but the intended recipients are not aware of the programme and are not utilizing it, the HIV office should publicise the programme to the intended recipients.

There is a need to acknowledge and celebrate diversity so as to accept visual impairment and sexuality as cross-cutting.

There must be execution of public education programmes in the media and by other means to raise awareness of HIV and AIDS as a problem facing visually impaired people, and to encourage the visually impaired and their families to utilise the programmes available to them.

Reference is made to Appendix 3 which comprises of three types of strategies to include the visually impaired people in HIV and AIDS outreach efforts (adapted from Groce, 2008).

Type 1 is about the inclusion of the visually impaired as part of the general HIV and AIDS outreach with no modifications (Brailled text or audio-visual material). The visually impaired here are included in HIV and AIDS outreach efforts and services as members of the general population which need little or no additional modifications. Theatre is used to sensitise the sighted on visual impairment and HIV.

Type 2 has moderate adaptations to the general programmes that foster inclusion. Here the accessible HIV and AIDS materials meant for the sighted people are modified to suit the visually impaired who are part of the community. Here they may have embossed diagrams, pictures described, printed information translated into Braille text and some individualised attention so that the visually impaired can also be involved in the HIV and AIDS intervention programmes, the visually impaired will be assigned individuals who will give them individual attention while being part of the general public.

Type 3 is a specific HIV and AIDS intervention programme for the visually impaired people alone. There are some visually impaired people who may not be accessed due to Braille illiteracy especially those people who have acquired the impairment later in life and those who have never been to school. The individuals are met separately away from the general population.

## **6. CONCLUSION**

The government has failed to recognize the visually impaired as a high risk group, therefore the visually impaired are not fully included in the existing HIV intervention and AIDS programmes. There must be HIV and AIDS intervention programmes which are customized for the visually impaired. The government must evaluate their MDG six whose focus is to combat HIV and AIDS which does not have specific provisions for the blind.

It has been clearly indicated that the health care workers are not adequately trained to deal with the diverse needs of the visually impaired as some are discriminated against when they seek assistance. There is a lot of stigma around sexuality especially to people with disabilities, it would be critical for all the stakeholders to redress that as HIV accelerates to those with disabilities. Poverty is a major concern to the visually impaired which is aggravated by the infringement of the rights of the visually impaired to education which can open employment opportunities. Poverty becomes a driving force of sexual exploitation for blind girls and women as they try to supplement the disability grant which is not a living wage.

The traditional healers and leaders have a major role to play by eradicating the myth that having sex with the visually impaired or any disability cleanses people from HIV because it exacerbate their sexual abuse. It must be everybody's responsibility to protect the vulnerable groups of our

society. Social exclusion is another driving force of risky sexual behaviour amongst the visually impaired and it could be reversed by social integration.

The CBOs and FBOs should collaborate with the government and integrate the visually impaired into the communities. The lives of the visually impaired are no less valuable than the lives of all other citizens and there can be no significant argument that justifies placing the visually impaired at the bottom of an HIV and AIDS priority list.

## 7. BIBLIOGRAPHY

Basson, S.H., Schneider, M. & Swartz, L. (2009). Technology and society: Hearing the voices of disabled people in South Africa. Presentation in Stellenbosch, South Africa.

Braathen, S.H., Basson, S.H., Schneider, M. & Swartz, L. (2009). Hearing the voices of disabled people in South Africa: Barriers to HIV prevention and care: Oral presentation at the AfriNEAD 2009 Symposium, Cape Town

Constitution of the Republic of South Africa, 108 of 1996.

DFID. (2000). Disability, Poverty and Development Department for International Development, London.

Employment Equity Act, 55 of 1998. <http://www.labour.gov.za>

Free Merriam-Webster dictionary: Merriam-Webster Online. [www.merriam-webster.com](http://www.merriam-webster.com)

Groce, N. & Trasi, R. (2004). Rape of individuals with disability: AIDS and the folk belief of virgin cleansing. *The Lancet* 363: 1663-1664.

Groce, N. (2008). HIV/AIDS and Disability: guidelines for inclusion of individuals with disabilities in HIV/AIDS outreach efforts. Washington: The World Bank.

Mcelligott, M. (2003). Africa: Disabled People at Significantly Increased Risk' of HIV Infection: Africa, AIDS, Health, Human Rights. [www.allAfrica.com](http://www.allAfrica.com)

Nduta, S. (2007). African Union of the Blind (AFUB). HIV and AIDS awareness and training project for blind and partially sighted persons in Africa. Project report.

Nganzi, P. & Matonhodze, G. (2004). Disability and HIV & AIDS: A participatory rapid assessment of the vulnerability, impact and coping mechanisms of disabled people on HIV/AIDS. Zimbabwe Parents of handicapped Children, Bulawayo.

- NUDIPU. (2003). Assessment of the Level of Knowledge of HIV/AIDS, HIV/AIDS Service Access and Vulnerabilities for Young People with Disabilities.
- Phillander, J.H. & Swartz. L. (2009). Journal of the International AIDS Society and Disability in South Africa. Volume 12 <http://www.jiasociety.org>
- Ranchod, C., Macdonald, C., Schneider, M., Swartz, L. & Braathen, S.H. (2009). HIV/AIDS and Sexuality of People with Disabilities in South Africa.
- Rapuro, O. (1998). On the subject of disability. Baobab 27. Arid Lands Information Network (ALIN) Dakar.
- Rieser, R. (2000). History of our oppression. Why the social model in education is inclusive education. Paper presented at the international special education congress, Manchester, England, July 13 2000.
- Saulo, B. & Walakira, D.E. (2012). Sexual & Reproductive Healthcare - Access to healthcare for disabled persons. Volume 3, Issue 1, pages 49–53.
- South African National AIDS Council (SANAC). (2007). HIV, AIDS and Disability in South Africa.
- Taylor, D. (2008). Research findings on the knowledge, attitude, practice and access to HIV and AIDS information and services amongst persons with disability. Handicap International. <http://www.handicap-international.org.uk>
- UNAIDS. (2008). Global Survey on HIV/AIDS and Disability. Yale University, World Bank.
- UNAIDS, WHO and OHCHR. (2009). New policy brief on disability and HIV. [http://www.who.int/disabilities/jc1632\\_policy\\_brief\\_disability\\_en.pdf](http://www.who.int/disabilities/jc1632_policy_brief_disability_en.pdf)
- Wazakili, M., (2011). Contradictory scripts: a negative catalyst to disabled young peoples experience of sexuality and HIV and AIDS: Stellenbosch.

World Health Organisation (WHO). (2008). Guidelines on “Priority interventions, HIV and AIDS Prevention, treatment and care in the health sector. [www.who.int](http://www.who.int)

Yungungu, A., Songok, A. & Mulinge, P. (Undated). Accessibility & utilisation of HIV and AIDS services among the visually impaired in Kenya. [www.who.int/icf](http://www.who.int/icf)

## **APPENDIX 1: Interview schedule for employees who are visually impaired**

### **Opening**

After observing that HIV programmes are not tailored for people who are visually impaired, I shall arrange to interview people who are visually impaired. During the interview I would like to ask some questions about the participant's demographic information, their knowledge of HIV, their sexual history and their observations of the visually impaired in service centres especially those that are for HIV related services.

The interview should take 30 to 40 minutes.

The interview will be semi-structured, guided by the following different sections: Demographic information, Background knowledge and awareness of HIV and their Sexual history.

### **A. Demographic Information**

1. What is your gender?
2. How old are you?
3. What is your marital status?
4. Where do you reside?
5. What is the nature of your visual impairment and were you born with it?
6. If not born with it, how old were you when you lost your sight?

### **B. Knowledge of HIV**

1. Have you ever received any HIV information?
2. If yes please explain where and how?
3. If given a condom, male/female can you recognise it?
4. Can you insert a condom without help?
5. Do you feel that the existing HIV awareness, prevention, care and support programmes are suitable for your needs?

If no, please explain.

**C. Sexual history**

1. As a visually impaired person, do you feel that you are vulnerable to HIV? If yes please explain how.
2. Do you have a sexual partner(s)?
3. Have you ever done an HIV test in your life?
4. If yes to the above question, how was the experience/the health worker's attitude to you?
5. Did you receive any pre test counselling?
6. Does your family discuss HIV topics with you?
7. Have you ever been involved in sexual violence?
8. How does your religion help in managing your sexual behaviour?

**D. Opinion**

1. Do you think the lack of HIV programmes for the visually impaired makes people more vulnerable to HIV? Please explain your answer.

**E. Closing**

1. Are there any other matters regarding the vulnerability of visually impaired people to HIV you would like to emphasise?

## APPENDIX 2: Aggregated Responses

### SECTION A – Demographic information

TOTAL PARTICIPANTS =40

<b>Gender</b>	Males : 47.5%	Females : 52.5 %
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<b>Marital status</b>	Married: 20%	Single: 60%	Divorced: 17.5%	Widowed: 2.5%
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<b>Age</b>	18-30 : 32.5%,	31 – 40: 27.5%	41-50:10%	51 – 65:30%.
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<b>Residence</b>	At special institutions: 20%	With their families: 80%
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### Age when sight was lost

Birth to 11 years	57.5%
13-16 years	15%
21 – 25 years	7.5%
26 – 34 years	10%
40 - 65 years	10%

Born blind: 30% and 70% acquired it later.

### SECTION B - HIV Awareness

1. Have you ever received any HIV information?

Yes: 100%

No: 0%

2. If yes please explain where and how?  
12.5% Proofreaders  
87.5% Media, school, clinics, community members
  
3. If given a condom, male/female can you recognise it?  
Yes: 100% only male condom  
No: 0%
  
4. Can you insert a condom without help?  
Yes:77.5%  
No:22.5%
  
5. Do you feel that the existing HIV awareness, prevention, care and support programmes are suitable for your needs?If no, please explain.  
Yes: 10%  
No: 85%  
Doesn't matter: 5%

### **SECTION C: Sexual history**

1. As a visually impaired person, do you feel that you are vulnerable to HIV? If yes please explain how.  
Yes:85%  
No: 15 %
  
1. Do you have a sexual partner(s)?  
Yes: 77.5%  
No: 20%  
Casual sex 2.5%

3. Have you ever done an HIV test in your life?  
Yes: 87.5%  
No: 12.5%
  
4. If yes to the above question, how was the experience/ the health worker's attitude to you?  
Asexual:47%  
Rude:18%  
Fine:35 %
  
5. Did you receive any pre-test counselling?  
Yes: 82.5%  
No:17.5%
  
6. Does your family discuss HIV topics with you?  
Yes:65%  
No: 35%
  
7. Have you ever been involved in sexual violence?  
Yes:12.5 %  
No:85%  
Nearly raped: 2.5%
  
8. How does your religion help in managing your sexual behaviour?  
Helps:65%  
No HIV talks:7.5 %  
No religious affiliation: 27.5%

**SECTION D: Opinion**

Do you think the lack of HIV programmes for the visually impaired makes people more vulnerable to HIV? Please explain your answer.

Yes:95%

No: 2.5 %

Blame the devil: 2.5%

**SECTION E: Closing**

Are there any other matters regarding the vulnerability of visually impaired people to HIV you would like to emphasise?

**APPENDIX 3: Sample of modified guide for outreach efforts**

Suggested guide for the inclusion of the totally blind people in HIV/AIDS outreach programmes (adapted from Groce, 2008).

Table 1: Low modifications to existing programme

Strategy	Purpose of strategy	Suggested activities	Examples of suggested activities	Check points

**Type 1**

To enable the blind people who are in the community access HIV/AIDS outreach programmes.

1. Use the materials already available to general public, incorporating simple adaptations to ensure accessibility by the blind people (totally blind & partially sighted).

1.1 Depicting individuals with visual impairment (partially sighted & a totally blind person who uses a white cane) in aids posters and bill boards that are produced. Also include examples of blind people in published materials.

1.1.1. Are blind people depicted in posters, billboards, theatre etc especially those that are intended to show that even blind people are at risk?

1.1.2 Are there blind people in the stories and vignettes used to illustrate HIV/AIDS issues?

2. Ensure that AIDS educational outreach and services available to the general population include blind people.

2.1 Moving HIV/AIDS education, testing and service delivery programmes as well as drug, alcohol and domestic violence programmes to accessible meeting places.

2.1.1 Is the place where you are holding your programme accessible for blind people; does the venue require people to walk long distances?

2.2 Making sure that blind people in the community are aware of the AIDS activities being offered and know that they are invited to attend.

2.2.1 Have the field staff invited the blind people from the area or encouraged them to participate in the programme's activities.

3. Inform AIDS educators, outreach workers, clinical and social service staff about challenges faced by the blind people.

3.1 Making simple adaptations in AIDS prevention interventions to ensure that messages are understood by the Braille users, the totally blind.

3.1.1 Do you pass a condom so the blind people in the community could and where they can source for the condoms and HIV testing?

4. Establish a partnership with local DPOs to educate AIDS outreach workers about visual impairment issues.

4.1 Partner with local NGOs to make sure presentations and language used are as inclusive as possible.

4.1.1 Have you called upon local DPOs for support in reaching blind people who cannot otherwise be reached?

Table 2: Moderate modification and/ or additions to existing programmes

Strategy	Purpose of strategy	Suggested activities	Examples of suggested activities	Check points

## Type 2

Adaptations are made to outreach campaigns to ensure that blind people are included as members of the general public.

1. Adapt existing HIV materials to ensure that messages are accessible and available to the blind people.

1.1 Making AIDS materials available for the blind in inexpensive cassette formats.

Is the AIDS announcements clear and well formatted in Braille?

2. Ensure access to and dissemination of HIV/AIDS information in either large print or Braille.

2.1.1 Are AIDS messages available on inexpensive tape or CD versions to distribute to individuals who are blind or partially sighted?

2.1.2 Is there a local radio station that will be willing to talk about HIV/AIDS using simple messages that could reach blind individuals?

2.1.3 is there a local programme specifically targeting the blind?

3. Establish a partnership with local DPOs and identify training needs.

3.1 Developing a training of trainers curriculum with relevant topics to train AIDS outreach workers about visual impairment.

3.1.1 Are members of the HIV outreach team in contact with DPOs for guidance and oversight to ensure they understand visual impairment issues and concerns?

3.2 Train individuals who are blind to be AIDS educators for the whole community.

3.2.1 Have you identified individuals with blindness willing to help disseminate HIV/AIDS messages?

3.2.2 Have you worked with local DPOs to ensure outreach to all blind people?

Table 3: Specific programmes targeting the harder-to-reach blind people

Strategy	Purpose of strategy	Suggested activities	Examples of suggested activities	Check points

### Type 3

Adaptations for the blind are made, existing materials and new materials are developed to reach blind individuals outside the bounds of the general public, targeting harder to reach individuals.

1. Develop outreach efforts specifically for the blind.

1.1 Train/hire AIDS educators and staff to specialise in issues related to serving specific blind population.

1.1.1 Is sex education available in integrated schools with blind learners?

1.1.2 When blind learners are integrated into the regular classroom, are they allowed to be part of the sex education lessons or are they sent out because teachers do not think they need this information?

1.1.3 When there are special programmes for street children, are blind children, adolescents included?

1.1.4 Do you have sessions that would attract blind individuals with similar life experiences ?

1.2 Working in collaboration with local DPOs and others, identify all the hard-to-reach and identify a local strategy to reach these individuals concerns to meet, discuss and become empowered? For example, blind adolescents, adults, women, men etc.

1.2.1 Do you know how many blind people live in your area?

1.2.2 Do you know how many of these are being reached by AIDS outreach efforts?

1.2.3 Have ever assessed what their knowledge, attitude and practices about HIV/AIDS are in comparison with the surrounding able-bodied population?

2. Train disability advocates to be AIDS educators specifically for the blind community.

2.1 Develop and test training curriculum with people who are blind .

2.1.1 Is there a TB individual who is a Braille user who could provide information to peers?