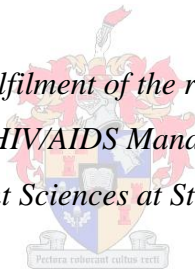


**INVESTIGATION INTO THE PARTICIPATION OF STUDENTS WITH  
DISABILITIES IN HIV AND AIDS PROGRAMMES AT THE UNIVERSITY OF  
JOHANNESBURG**

**by**

**PEARL BERLINDA RAMAFOLA**

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of Master of Philosophy (HIV/AIDS Management) in the Faculty of  
Economic and Management Sciences at Stellenbosch University*



Supervisor: Ms Anja Laas

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## **DECLARATION**

By submitting this assignment electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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## **ABSTRACT**

**PURPOSE:** The purpose of the study was to investigate the participation of students with disabilities on the HIV and AIDS programmes at the University of Johannesburg.

**METHOD:** The researcher used the quantitative method, by administering questionnaires with mainly closed-ended questions and a limited number of open-ended questions to collect data from 40 participants of the University of Johannesburg's four campuses. Students with disabilities have a support group called "DARE" (Demonstrating our Abilities and Recognizing Excellence) and the executive committee members of DARE distributed the questionnaires to some of the students, whilst other questionnaires were distributed at different campuses through the library and the primary health care facility. The study focused on knowledge about the existing policies and their applicability (HIV and AIDS policy, as well as the policy on people with disabilities), awareness and knowledge of existing HIV and AIDS programmes, participation on HIV programmes, barriers experienced by students in participation as well as ways to encourage students to participate in HIV initiatives.

**DATA ANALYSIS:** Data was analyzed by means of the Statistical Package for the Social Sciences (SPSS) programme, using descriptive statistics.

**RESULTS:** The study indicated that most participants were aware of the existing HIV and AIDS programmes on campus, and it was easy for them to access HIV and AIDS information. Despite this finding, the conclusion that can be drawn from the study is that the level of participation on HIV and AIDS programmes by students with disabilities at the University of Johannesburg is very low.

**CONCLUSION:** The University of Johannesburg's HIV and AIDS programmes have been well marketed on campus. However, involving students with disabilities in HIV committees, making HIV and AIDS policies fair and recruiting students with disabilities as peer educators, can help encourage participation of people with disabilities on HIV and AIDS programmes on campus.

## OPSOMMING

**DOEL:** Die doel van hierdie studie was om ondersoek in te stel oor die deelname van gestremde studente aan die MIV en VIGS-programme soos aangebied deur die Universiteit van Johannesburg.

**METODE:** Die navorser het gebruik gemaak van 'n kwantitatiewe metode van ondersoek. Daar is in totaal 40 deelnemers geïdentifiseer en navorsingsvrae was hoofsaaklik 'geslote-einde' met 'n beperkte aantal 'oop-einde' vrae. Die ondersoek het gestrek oor die vier kampusse van die Universiteit van Johannesburg. Gestremde studente het 'n ondersteuningsgroep, naamlik, 'DARE' (Demonstrating our Abilities and Recognizing Excellence). Die uitvoerende lede van die ondersteuningsgroep het gehelp met die verspreiding van die navorsingsdokumentasie aan studente. Ander metodes van kommunikasie het plaasgevind via die studente biblioteek en die universiteit se primêre gesondheidsfasiliteit. Die studie het gefokus op die kennis van studente met gestremdhede oor die universiteit se beleid en programme met betrekking tot MIV en VIGS. Daar is veral ondersoek ingestel oor hul kennis met betrekking tot die MIV-beleid asook die beleid oor mense met getremdhede. Verdere ondersoek het gehandel oor die vlak van bewustheid en kennis oor spesifieke programme van die universiteit, die deelname aan sulke programme, die weerstand of hindernisse wat ondervind word en studente se idees oor hoe om bewustheid en deelname te bevorder.

**DATA ANALISE:** Data is geanaliseer by wyse van 'n statistiese pakket spesifiek ontwerp vir die sosiale wetenskappe (SPSS). Die model maak gebruik van beskrywende statistiek wat relevant is vir die studie.

**RESULTATE:** Die studie het getoon dat die meeste deelnemers bewus was van die huidige MIV en VIGS-programme. Die studie het verder getoon dat dit vir die groep studente maklik was om toegang tot relevante inligting te verkry. Ongeag die bostaande bevinding, blyk dit egter dat deelname aan programme steeds onvoldoende is.

**GEVOLTREKING:** Die ondersoek toon dat die bemerking van MIV en VIGS-programme effektief is. Wat egter nodig is, is om studente met getremdhede veel meer aktief te betrek in relevante komitees en ander aktiwiteite soos om op te tree as opleiers vir mede studente. Dit sal bydra tot verhoogde deelname.

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**LIST OF ACRONYMS AND ABBREVIATIONS**

<b>ACRONYM</b>	<b>DESCRIPTION</b>
ADD	Action on Disability and Development
AIDS	Acquired Immune Deficiency Syndrome
APB	Auckland Park Bunting Road Campus
APK	Auckland Park King's way Campus
CBM	Christian Blind Mission
DARE	Demonstrating our Abilities and Recognizing Excellence
DFC	Doornfontein Campus
DFID	Department For International Development
HCT	HIV Counselling and Testing
HEARD	Health Economic and HIV/AIDS Research Division
HIV	Human Immunodeficiency Virus
KAP	Knowledge, Attitudes and Practices
LVCT	Liverpool VCT Care and Treatment
PMO	Programme Management Office
SPSS	Statistical Package for the Social Sciences
STIs	Sexually Transmitted Infections
SWC	Soweto Campus
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV and AIDS
VCT	Voluntary Counselling and Testing
VSO	Voluntary Service Overseas
WHO	World Health Organisation

## 1. INTRODUCTION

### 1.1. BACKGROUND AND RATIONALE

It is estimated that 600 million people in the world (1 person in 10) live with a disability and this figure is said to increase through population growth, advances in the medical field and the ageing process (UNAIDS and WHO, 2007). Of this total population, approximately 8% of people with disabilities are living in the developing world (Groce, 2004). Of greater concern is that there is limited or no HIV prevalence data on people with disabilities from Sub-Saharan Africa, Asia, Europe and the Caribbean (Ivom, 2009). Although prevalence rates are unknown within people with disabilities, they are presumed to be high. Few studies conducted on the hearing-impaired populations have suggested that the levels of infection are equal to or higher than the rest of the population (Taegtmeier, Henderson, Angala & Ngare, 2006).

According to Groce (2003) people with disabilities have similar risk factors as other HIV vulnerable groups, for example, they are more likely to be poor and they are marginalized. Added to that is that both HIV and AIDS and disability are still stigmatized in some communities (Swartz, Schneider & Rohleder, 2009; Nduta, Ajema, Opiyo & Mukoma, 2009). This can be attributed to the fact that policy makers and programme implementers have in the past targeted HIV interventions at people who were perceived to be at a higher risk of contracting HIV, namely, migrant labourers, commercial sex workers, men having sex with men, women and children, amongst other groupings, and thus excluding people with disabilities. It is only in recent years in the draft HIV and AIDS and STI strategic plan for South Africa 2007-2011 that people with disabilities have been included as a vulnerable population as well (Department of Health, 2007).

Despite government policies and efforts in South Africa to include people with disabilities in mainstreaming HIV and AIDS programmes, there is still reluctance by people with disabilities themselves to participate in HIV and AIDS programmes. Parallel to that, people with disabilities are also often overlooked by programme implementers, even though research has suggested that they are also as vulnerable as any other person. According to PMO-DFID (2007) exclusion of people with disabilities is not a conscious decision, “but simply the attitudinal, institutional and environmental barriers that deny people with disabilities their rights of equality of access to all aspects of mainstream development. They argue that denying people with disabilities HIV services simply means that people with disabilities will remain unaware of such services, and therefore they won’t ask for information or access to services. Despite this view, Wangula and

Nduta (2009) argue that much as people with disabilities require equal opportunities to access HIV programmes and services, the reality is that there are limitations to that. They argue that disability is still seen as a welfare issue and therefore there is no mainstreaming of disability issues into HIV programmes, and even though policies are in place, there are no structures to ensure policy implementation.

South Africa's policy legislation on HIV and AIDS is therefore highly inclusive of people with disabilities, but the major challenge is still the practical implementation of the policy and accessibility of services by people with disabilities. Similarly, the University of Johannesburg also endeavours to embed inclusivity and creates equal opportunities for employees and students with disabilities. The University of Johannesburg has adopted a comprehensive disability policy and HIV and AIDS policy that promotes equitable access to all programmes and services (University of Johannesburg, 2011).

According to HEARD (2010) studies have proved that people with disabilities in South Africa have lower educational levels, in comparison with the general population, hence they miss out on AIDS education offered through health care systems and schools. On the contrary, the fact that students with disabilities at the University of Johannesburg have entered a higher learning institution, suggests that they are educated to a certain extent. It is yet to be determined whether students with disabilities participate in HIV and AIDS programmes at the University of Johannesburg.

## **1.2. RESEARCH PROBLEM**

It is not known whether students with disabilities participate in HIV and AIDS programmes at the University of Johannesburg. In addition to that, it is not known whether the University of Johannesburg HIV and AIDS programmes are aligned to meet the needs of students with disabilities. Lack of participation in HIV and AIDS programmes by any student undermines the existing HIV and AIDS programme initiative at the University of Johannesburg. The current practice is that for any HIV initiatives at the University of Johannesburg, there is an open invitation for all students to participate.

The study will focus on all types of disabilities experienced at the University of Johannesburg, so that the outcome of the study can address the needs of all people with different disabilities, and should be applied to all of them equally.

### **1.3. RESEARCH QUESTION**

The key research question is “do students with disabilities at the University of Johannesburg participate in HIV and AIDS programmes on campus”?

### **1.4. AIM OF THE STUDY**

The aim of the study is to ascertain whether students with disabilities from the University of Johannesburg do participate in HIV and AIDS programmes on campus.

### **1.5. OBJECTIVES OF THE STUDY**

The objectives of the study are:

- To establish the level of awareness of disabled students of HIV and AIDS programmes at the University of Johannesburg.
- To establish the nature and scope of the current participation of disabled students in HIV and AIDS initiatives at the University of Johannesburg.
- To identify the barriers experienced by students with disabilities, to participating in HIV and AIDS initiatives at the University of Johannesburg.
- To identify how students with disabilities can be encouraged to participate in HIV and AIDS initiatives at the University of Johannesburg.
- To offer recommendations for including students with disabilities in HIV and AIDS initiatives at the University of Johannesburg.

## **2. LITERATURE REVIEW**

In reviewing the literature, the researcher will start by defining disability.

### **2.1 DEFINITION OF A PERSON WITH DISABILITY**

The World Health Organization (WHO, 2011) defines a person with disability as “a person with physical, sensory, intellectual or mental health impairments that have a significant and long-lasting effect on the person’s daily life and activities”.

According to the United Nations Convention on the rights of people with disabilities, people with disabilities are “Those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (United Nations Enable, 2006).

For the purpose of this study, people with disabilities will be defined according to the University of Johannesburg’s definition as outlined in their policy “Policy on people with disabilities”. The University of Johannesburg defines a student with a disability as “A student with an impairment who experiences disability based on specific contextual barriers. Disability, as a consequence of an impairment as well as environmental and attitudinal barriers, substantially limits a student from equal participation in the learning environment” (University of Johannesburg, 2012).

Even though there is a relationship between HIV and AIDS and disability, there is some resistance from both disability and AIDS advocacy groups to define HIV and AIDS as a disability due to the fact that it will be seen as an additional stigma (Health Canada, 2009). However, in South Africa people who have AIDS-related conditions access a grant from the government, whilst conveniently forgetting that it is a “disability” grant, because it is financially beneficial to them at the time of receipt.

Groce (2004), Ivom (2009) and Swartz, Watermeyer, Lorenzo, Schneider and Priestley (2006) argue that the AIDS epidemic may increase the rate of disability on people not born with disability and may also lead to various health conditions and impairments, including sensory and cognitive impairments. For example, delays in the development of in-utero exposure, resulting from the AIDS epidemic.

Whilst literature suggests that people with disabilities face challenges in accessing HIV services, it is also argued that some people with disabilities may also be reluctant to access such services for reasons known to them. The University of Johannesburg policies on HIV and AIDS and people with disabilities are highly inclusive of people with disabilities, the challenge is that policy implementation to promote HIV and AIDS initiatives participation by people with disabilities, has often fallen short.

Article 4 of the UN Convention on the rights of persons with disabilities on HIV and AIDS states that “States should undertake to promote research and development of universally designed good,

services, equipment and facilities...in order to meet the specific needs of a person with disabilities, to promote their availability and use..." . An example is HIV testing facilities which should be accommodative of all different disabilities (Hanass-Hancock, Grant and Strode, 2012).

Countries like Tanzania, South Africa and Lesotho are few examples of countries that recognize the rights of people with disabilities regarding HIV and AIDS, and as such they have endorsed the recognition of people with disabilities in their national HIV and AIDS strategic plans (Gerntholtz, Grant & Hanass-Hancock, 2010).

## **2.2 APPROPRIATE ACCESS TO HIV AND AIDS SERVICES**

A study was done in Rwanda and Uganda in 2003 to explore knowledge about HIV and AIDS in disabled adolescents' vs non-disabled adolescents. The study also sought to determine factors which may increase vulnerability of disabled adolescents to HIV infection and/or appropriate access to HIV services (Yousafzai, Edwards, D'Allesandro & Lindstrom, 2005). The results from the survey would assist both countries in developing an HIV and AIDS inclusive strategy for people with disabilities whilst also acknowledging the uniqueness of each country. This was a qualitative study, using focus groups and interviews where data was collected from disabled adolescents and teachers (through the education system), non-disabled adolescents, parents, and disability and AIDS advocacy groups. The focus of questioning was on HIV and AIDS knowledge, access to HIV and AIDS services and perception of personal risk.

The results of the survey indicated that the barriers to access HIV and AIDS services depended on the nature of disability experienced and the severity thereof (Yousafzai et al, 2005). For example, deaf adolescents would experience a barrier if there was no sign language interpreter during the delivery of any HIV and AIDS programme or service, and this would normally require the interpreter to understand the local deaf culture. Other issues of accessibility that emerged were physical inaccessibility to health facilities, lack of privacy and confidentiality in cases when an interpreter was sought, as well as negative attitudes towards people with disabilities with regards to HIV testing, which prevented people with disabilities from visiting testing facilities. This study relates to the study under review in that the researcher also wants to assess the accessibility of HIV and AIDS services by people with disabilities, but focusing mainly on people with disabilities as the subject of the study.

### **2.3 GAPS IN THE SYSTEM OVERLOOKING PEOPLE WITH DISABILITIES FROM HIV AND AIDS EFFORTS**

A study on HIV and AIDS and disability: Capturing the hidden voices (Groce, 2004) is based on the global survey conducted as part of the World Bank global HIV and AIDS programme. It was a study to understand the impact of HIV and AIDS on people with disabilities, with the following objectives:

- To understand how people with disabilities are impacted by HIV and AIDS;
- To assess the state of knowledge on the impact of HIV and AIDS on people with disabilities and on disabled populations;
- To document activities related to HIV and AIDS and disability worldwide;
- To identify models of good interventions that were in place then or in the planning stage and
- To identify gaps in the system then where people with disabilities were overlooked or systematically excluded from HIV and AIDS outreach efforts, service delivery, etc.

The survey was also designed to ascertain if people with disabilities were included in mainstreaming HIV and AIDS programmes and if yes, what type of programmes were available to them (Groce, 2004). The subjects of the study were disability and AIDS advocacy groups, service organisations, government ministries, individuals or populations with disability.

The methodology used was through searching of all relevant scientific literature articles on HIV and AIDS in relation to people with disabilities and to disabled populations. The researcher also searched internet sources and training manuals to gain more information. The other method used to collect data was through the administration of questionnaires which were distributed electronically as well as by ground mail. Data was collected from groups and organizations working with people with disabilities and disabled populations, including organizations working on HIV and AIDS in general populations, ministries of health, education and other governmental programmes.

The outcome of the study indicated that people with disabilities are disproportionately more vulnerable to HIV infection than people without disabilities, and that people with disabilities are not included in most AIDS outreach efforts. The findings of this study are supported by various other studies. According to Naughton (2009) people with disabilities face up to three times greater risk of HIV infection than people who do not have a disability. Nduta et al (2009) also add that people with disabilities are also exposed to the same risk factors for HIV as any other person. They say these people are more vulnerable and at an even higher risk of contracting HIV,

because they are often marginalized and stigmatized. They are regarded as different and not fully functional, which often places them at high risk of HIV infection.

One of the objectives of this study was to identify the gaps in the system that lead to the exclusion of people with disabilities in mainstreaming of HIV and AIDS programmes. This relates directly to the study under review, as it will also ultimately identify the gaps, if any, for the participation of people with disabilities.

The results of a study done by Gaskins (1999) and Monaghan (2003) on deaf people in Maryland-USA also supported the World Bank and Yale University study, and showed that deaf people are 2-10 times more likely to be HIV positive. This was attributed mainly to challenges experienced by deaf people in particular, like poor access to information about HIV and AIDS and safe sex, insufficient treatment programmes, confidentiality issues and lack of prevention aimed specifically at them (also known as physical barriers).

## **2.4 HOW BEST TO SERVICE DEAF PEOPLE**

Another study on deaf people was done in Kenya by VSO & LVCT in 2003 within the deaf population to determine how best they could service such a population (Nduta et al, 2009). The lack of knowledge by health care workers on how to deal with the deaf population, and the use of interpreters to reach out to the deaf population without ratifying the authenticity of such interpreters, had resulted in poor uptake of HIV services by the deaf population. In turning things around, a deaf VCT programme was introduced for the deaf population, with the establishment of three stand-alone clinics for the deaf people.

They went further to get involved in policy development, HIV awareness workshops for the deaf population, training of deaf AIDS counselors and the introduction of other VCT sites for the deaf. With the introduction of the intervention by deaf personnel, serving fellow deaf peers, it is reported that by 2004, the uptake for VCT increased to more than 12 000. In 2009, the same programme was rolled out to include other groups of people with disabilities and it was renamed the disability programme. The success of the programme was attributed to the greater involvement of deaf people in shaping their own programme. In addition, according to CBM (2012) and PMO-DFID (2007) to get people with disabilities involved, disability organizations need to be capacitated on HIV work, advocacy, programme management, as well as other skills that are relevant to the disability needs.

Although there are no deaf students at the University of Johannesburg, the findings of this study are still relevant for the study under review, in that the findings have simply shown that it takes



the participation of people with disabilities to attract other people with disabilities to the HIV and AIDS programme.

## **2.5 ASSESSING CHALLENGES FACED BY PEOPLE WITH DISABILITIES**

A study was commissioned by An Action on Disability and Development (ADD) in 2004, to assess challenges faced by people with disabilities in utilizing HIV and AIDS communication and related health services in Uganda (ADD, 2005). The overall aim of the study was to analyze the experiences of people with disabilities in accessing HIV and AIDS information and health services in general.

The tools used for data collection was a combination of a qualitative case study, review of secondary sources, semi-structured questionnaire, key informants checklist, focus group discussions and observation. Samples were regionally and geographically represented. Five districts were sampled with 25-30 participants and 50 additional focus group discussions, totaling the sample of 300 (ADD, 2005).

The findings indicated that Uganda's health system and HIV and AIDS communication strategy were still not well equipped to meet the needs of people with disabilities. It also indicated that the stakeholders were reluctant to transform and adapt the health system and AIDS communication approaches that would eventually improve access to HIV and AIDS information by people with disabilities. Health is a fundamental right for all people therefore WHO (2008) say that this right should be fulfilled through a vigorous and accessible health system. On that note, the Human Rights Watch (2012) suggest that governments, UN agencies and HIV organizations should work together to ensure that HIV services are fully accessible. This study is relevant to the study under review as the current study also wants to establish the experiences of people with disabilities in their participation and accessing of HIV and AIDS programmes and services.

## **2.6 PARTICIPATION OF PEOPLE WITH DISABILITIES**

People with disabilities have the right to participate in decisions that affect them. According to the 2006 Convention on the rights of people with disabilities article 4(3), they should be involved from the design phase, to the implementation, as well as the evaluation of HIV and AIDS policies and programmes (WHO, 2009).

Another study was conducted in Zambia in 2007 & 2008, on the overview of disability and HIV and AIDS response in Zambia (Sinwaba, 2008), with the following objectives:

- i. To assess the participation of people with disabilities in HIV and AIDS interventions and policy formulation.
- ii. To identify barriers that limits the participation of people with disabilities in HIV and AIDS interventions.

The participants sampled were people with disabilities, Disabled People's Organizations, HIV and AIDS strategic partners, people without disabilities, as well as HIV policy makers in the government departments. Tools used to collect data were questionnaires (qualitative and quantitative, using structured questions), focus group discussions and a stakeholder relevance approach. Demographic data was collected in 2007 & 2008 from different sources, and it was later integrated and subsequently analyzed according to disability groups and gender. Sinwaba (2008) listed the following findings:

- People with disabilities are vulnerable to HIV and AIDS because of their activity limitations, for example, there were no disability specific HIV and AIDS interventions.
- No consideration was made to accommodate the needs of people with disabilities, especially the blind and hearing impaired. There was no formatted language in information and communication material, as well as in other essential interventions. Care and support services were not easily accessible and they did not accommodate the needs of the deaf and dumb persons, and there was no evidence-based information on disability and HIV and AIDS where they could strengthen the interventions. This finding is similar to the Uganda ADD (2005) finding on lack of consideration for accommodating people with disabilities in alternative communication strategies.
- There were not enough disability inclusive and specific services, despite endorsement of legislation of people with disability by the government. This was attributed mainly to lack of implementation and enforcement of policies by government. Organizations dealing with disability issues were often lacking in skills and knowledge on HIV and AIDS programming.

Although different countries have integrated disability in their strategic response to HIV and AIDS, some of these countries may have done that on paper, and may have gone ahead developing HIV programmes to the exclusion of people with disabilities (Bogopane-Zulu, 2007). Bogopane-Zulu (2007) further goes on to say that even though others recognize people with disabilities as a vulnerable group, they “don't know how to respond to the challenges facing disabled people in their diversity”.

Groce, Trasi & Yousafzai (2006) say that existing HIV and AIDS programmes for people with disabilities should be evaluated to assess whether such programmes do make a difference in the knowledge, attitude and practices of people with disabilities towards HIV and AIDS. It was only in 2009 that the Joint United Nations programme on HIV and AIDS in Canada called for UN Convention on the rights of persons with disabilities committee of experts to provide guidelines for monitoring and evaluation of HIV and AIDS programmes directed at people with disabilities (Health Canada, 2009). They also recommend that disability advocacy groups should be involved in the planning and implementation of HIV programmes for people with disabilities as subject matter experts, as they can provide the best insight into local attitudes and practices on disability. This also supports the Kenya study for the deaf population, where it was found that programmes planned and administered by people with disabilities themselves, yielded good results in terms of participation (CBM, 2012).

## **2.7 VIEWS ON PROGRAMME DESIGN BY THE VISUALLY IMPAIRED**

A study on needs, barriers and concerns regarding HIV prevention among South Africans with visual impairments was conducted by Philander and Swartz in 2006. The purpose of the study was to assess the participants' views on HIV and AIDS prevention programme design for people who are visually impaired (Philander & Swartz, 2006). 15 participants holding senior positions in the organisations associated with the South African National Council for the Blind were surveyed. 80% of the participants had visual impairments. A semi-structured questionnaire was administered to the participants and the responses were transcribed and analyzed using content analysis. 67% expressed their concern about the growth in HIV infection among people with visual impairments. They indicated that HIV workshops were designed for sighted people and that most of the HIV material was offered in inaccessible formats. It was also found that only 20% of the participants were aware of any HIV and AIDS prevention initiatives for people with visual impairments. All participants perceived HIV and AIDS to be a serious problem that require preventative measures. They believed that people with disabilities are socially excluded from participation in HIV and AIDS programmes and that HIV programmes lack information in accessible formats.

The observation is that if 20% of the participants are aware of HIV services for people with visual impairments, it means that even though those services are available, they are not marketed to the people they are meant to service. Therefore, a lot has to be done to show visibility of these

services. This study is relevant to the study under review since it also wants to determine if students with disabilities are aware of HIV services and if so, if they participate in such services.

## **2.8 ACCESS TO VCT SERVICES BY PEOPLE WITH DISABILITIES**

A research project was conducted by Swartz, Eide, Schneider, Braathen, Basson, Ranchod and Schur (2009) in South Africa to determine knowledge, attitudes & practices (KAP) on HIV and AIDS and sexuality amongst people with disabilities, as well as their access to voluntary counselling and testing (VCT) services. The study had three components to it, namely:

- i. The extent to which organisations for people with disabilities are dealing with HIV and AIDS.
- ii. KAP survey of people with disabilities in relation to HIV and AIDS and sexuality, as well as their access to VCT services.
- iii. A qualitative in-depth study on KAP of people with disabilities in relation to HIV and AIDS and sexuality, as well as their access to VCT services.

This qualitative study was conducted in Gauteng, Western Cape and Kwa-Zulu Natal, with interviewers being disabled persons themselves. The sample consisted of 285 participants from the rural, urban and peri-urban areas of each three provinces. Questionnaires were administered to approximately 100 people per province and data was collected over a period of four months in 2008. Since there is no data-base for people with disabilities, the Disabled People South Africa was helpful in assisting the researchers to identify people with disabilities. The researchers further used the snowballing technique to identify a sufficient sample. The findings were similar to those of Yousafzai et al (2005) which also indicated that people with disabilities had less access to HIV and AIDS services in comparison to the general population, for example, physical barriers-especially in rural settings, knowledge barriers - lack of information, as well as stigma and discrimination which prevents people with disabilities from accessing HIV and AIDS programmes and services. It was also found that factors such as gender, level of education as well as the geographical location were predictors for access to information about HIV and AIDS and level of knowledge about HIV and AIDS prevention in the three provinces under study.

Other findings suggested that knowledge, attitude and practices on people with disabilities differ from disability to disability. It was found that people with physical disabilities had the highest knowledge of HIV and AIDS in comparison with intellectually and communication disabled

respondents who had the lowest score on HIV knowledge (Swartz et al, 2009). Of particular interest was the finding that very few women respondents reported to have had a forced sexual encounter by a partner. This is a surprising finding, as few studies that have been conducted elsewhere suggest that women with disabilities are the most vulnerable within the disability population and are prone to experience violence and rape.

## **2.9 RESPONSE TO HIV AND AIDS BY PEOPLE WITH DISABILITIES**

A multi-sectoral area development project in the area of HIV and AIDS was done in three communities in India. Three communities were targeted by this project in order to evaluate the response to HIV and AIDS by people with disabilities. The outcome of the evaluation was that the impact of the HIV and AIDS projects had not reached people with disabilities in one of the three targeted communities; hence the “inclusion for all” project was developed to address this gap (CBM, 2012). The project was implemented by the World Vision India, with the aim of creating awareness of HIV and AIDS among people with disabilities, and increasing inclusion of people with disabilities within other existing development projects and the wider community (CBM, 2012). The aim was to increase awareness and accessibility of HIV and AIDS programmes to people with disabilities, and to influence policy and programmes to accommodate people with disabilities. Multi-sectoral area development programmes were implemented within the three communities, and they included HIV and AIDS programmes. The outcome of this project indicated that there was increased awareness of HIV and AIDS as well as disability rights among people with disabilities and the broader community. Also on the findings was that there was positive change of attitude toward disability by both people with disabilities themselves and the broader community.

It was reported that raising awareness about the disability rights and including them in community-based organisations brought about a significant increase in representation of people with disabilities as members, office bearers and leaders in community-based organisations. The outcome of the project indicated that the confidence, respect and dignity of people with disabilities were enhanced considerably, through the implementation of this project, but it was also found that people with disabilities and the broader communities had limited insight when coming to linking disability with HIV and AIDS (Nduta et al, 2009). Of greater interest is the finding that the impact of the project amongst people with disabilities was influenced by gender and the nature of impairment. This is a similar finding to two different studies conducted in three different countries, namely, a study done in South Africa by Swartz et al (2009) to determine KAP on HIV and AIDS by people with disabilities and their accessibility to VCT services, as

well as studies done in Rwanda & Uganda for disabled adolescents and non-disabled adolescents by Yousafzai et al (2005). The study in South Africa indicated that gender, amongst other factors, was the predictor for access to HIV and AIDS information and knowledge (Swartz et al, 2009) and the Rwanda and Uganda studies which found that barriers to access HIV and AIDS services depended on the nature of impairment and the severity thereof (Yousafzai et al, 2005).

In their guidelines on inclusion of people with disabilities in HIV and AIDS outreach efforts, Groce et al (2006) argue that even though there have been a few HIV and AIDS interventions targeted at people with disabilities, almost none of them have been monitored or evaluated. They thus proposed a three-tier strategy for practical inclusion and access of HIV services by people with disabilities at limited or no expense.

- a. Including people with disabilities in general outreach efforts within existing programmes. For example, using venues that can be accessed by all.
- b. Minor moderations to existing programmes to ensure greater participation of people with disabilities. For example, translating the HIV material into braille to accommodate the blind community or getting an interpreter for the deaf community.
- c. Specific disability outreach programmes targeted mainly at people with disabilities. For example, targeting the deaf people only in their small group using sign language interpreter who would speak their local sign language.

Groce et al (2006) argue that the few existing disability HIV programmes do not reach across disability groups, most are disability specific e.g. programme for the deaf community, may unintentionally exclude accommodation of physical disabilities. They also add that including people with disabilities in HIV and AIDS programmes should not be a once off, isolated targeted intervention. This is exactly what is happening in many organizations that claim to be including people with disabilities in their programmes. They further maintain that when implementing HIV and AIDS programmes, efforts should be made to reach people with disabilities in numbers that reflect their presence in society.

## **2.10. CONCLUSION**

There seems to be a lack of immediate recent studies on participation and access to HIV and AIDS by people with disabilities, but despite that, there is ample evidence from research studies reviewed between 2003 and 2009 to suggest that people with disabilities of all forms, experience

barriers to access HIV and AIDS programmes and services merely because HIV services don't meet their disability specific needs. Despite policies in place to accommodate people with disabilities in HIV programming, the implementation and monitoring is still lacking.

### **3. RESEARCH METHODOLOGY**

#### **3.1 INTRODUCTION**

This section will outline the research process used to collect data in conducting the study. Details will be provided on the methodology and fieldwork done to collect data in order to analyse the research question. The research question to be answered is whether students with disabilities at the University of Johannesburg do participate in HIV and AIDS programmes on campus. Focus will be on the following issues: The research design, research participants, method of data collection, data collection process, analysis of data, as well as ethical considerations of the study.

#### **3.2 RESEARCH DESIGN**

Christensen, Johnson & Turner (2011) describe a research design as the structure or plan used to conduct the research process, in order to answer the research problem. The research problem is that it is not known whether students with disabilities do participate in HIV and AIDS programmes at the University of Johannesburg. It is also not known whether the University of Johannesburg HIV and AIDS programmes are aligned to meet the needs of students with disabilities.

The researcher used the quantitative method, by administering questionnaires with mainly closed-ended questions and a limited number of open-ended questions to collect data.

#### **3.3 RESEARCH PARTICIPANTS**

Participants were students with disabilities at the University of Johannesburg's four campuses (Kingsway, Bunting road, Doornfontein and Soweto). Their disabilities range from physical, intellectual, sight, emotional, hearing, disabled but unspecified, partial disability, multiple and communication disabilities. The students were located at the University of Johannesburg's four campuses, but the majority were located at the Auckland Park campus. From a population of 149

students registered with the Office of People with Disabilities, the researcher used a sample of 40 students. The researcher used random sampling.

### **3.4 METHOD OF DATA COLLECTION**

Participants were given questionnaires to complete, whilst two participants were assisted to complete the questionnaires. The researcher first consulted with the Office: People with Disabilities to get a clearer understanding of the nature of disabilities as classified, so that she could design the questionnaires in the appropriate format and be accommodative of all disabilities.

Students with disabilities have a support group called “DARE” (Demonstrating our Abilities and Recognizing Excellence) and this group meets on a monthly basis. The researcher requested a slot and attended one of the executive committee meetings of the DARE group to have a discussion about her intention to conduct the study. The executive committee members of DARE offered to distribute the questionnaires to the students. Some of the questionnaires were distributed at different campuses through the library and the primary health care facility. Completed questionnaires administered by the DARE group were dropped off at a central point at the Office: People with Disabilities, whilst those at the other three campuses were collected from the library and primary health care facility by the researcher.

The information covered on the questionnaire (Annexure A) was on the following:

- Knowledge about the existing policies and their applicability (HIV and AIDS policy, as well as the policy on people with disabilities)
- Awareness and knowledge of existing HIV and AIDS programmes at the University of Johannesburg
- Participation on HIV and AIDS programmes
- Barriers experienced by students in participation
- Ways to encourage students to participate in HIV and AIDS initiatives

### **3.5 DATA ANALYSIS**

The raw data collected from the questionnaires was coded and entered on the excel spread sheet. It was then transferred into the Statistical Package for the Social Sciences (SPSS) programme. Descriptive statistics was done to analyze the quantitative data.



### **3.6 ETHICAL CONSIDERATIONS**

Permission to undertake the study was granted by Stellenbosch University's ethics committee, as well as the University of Johannesburg's Institutional Research Unit, where the study was conducted (Attached, permission letter from Stellenbosch's ethics committee - Annexure B and permission letter from the University of Johannesburg - Annexure C). The Office of People with Disabilities was also consulted to seek permission for administrative assistance, such as helping with accessing students with disabilities, and using their office as a collection point for questionnaires.

A letter of introduction was distributed to all participants (Annexure D), explaining the reasons for the study and the selection criteria. Participants were requested to sign an informed consent form, which explained what was expected of them. Only a few participants returned the completed consent form. The introduction letter also explained that they had an option to withdraw their participation at any time during the study.

It was explained to the participants that their participation would be kept confidential. It was also explained that data would be used for research purposes only, and that the results would be shared with the University of Johannesburg's HIV and AIDS committee.

Completed questionnaires were stored in a lockable cabinet which could only be opened by the researcher. Once all questionnaires were collected, they were stored in a lockable cabinet in the researcher's office which was also lockable. After all the analysis was done, the researcher disposed all the questionnaires by shredding them.

### **3.7 CONCLUSION**

In this section, the methods used to conduct the study amongst students with disabilities at the University of Johannesburg were outlined. A quantitative research design was used to collect data from a sample of 40 students. All 40 questionnaires were fully completed. Of all the students that participated, only two requested to be assisted with the completion of the questionnaire.

## 4. FINDINGS

### 4.1 INTRODUCTION

This section will focus on the outcomes of the data analysed. Forty participants (University of Johannesburg's students with disabilities) were randomly selected to participate in the study, wherein they completed questionnaires to establish whether they do participate in the HIV and AIDS programmes at the University of Johannesburg. The questionnaire had six themes that were analysed, namely:

- General information of participants.
- Knowledge about existing policies.
- Awareness of existing HIV and AIDS programmes.
- Level of participation.
- Barriers to participation, and
- Encouraging participation.

### 4.2 GENERAL INFORMATION OF PARTICIPANTS

The profile sample  $n=40$

**Figure 1: Distribution by age group ( $n=40$ )**

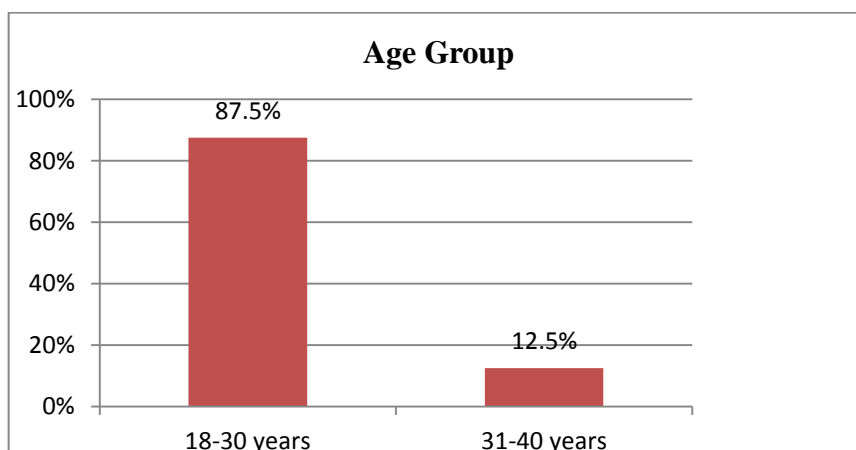
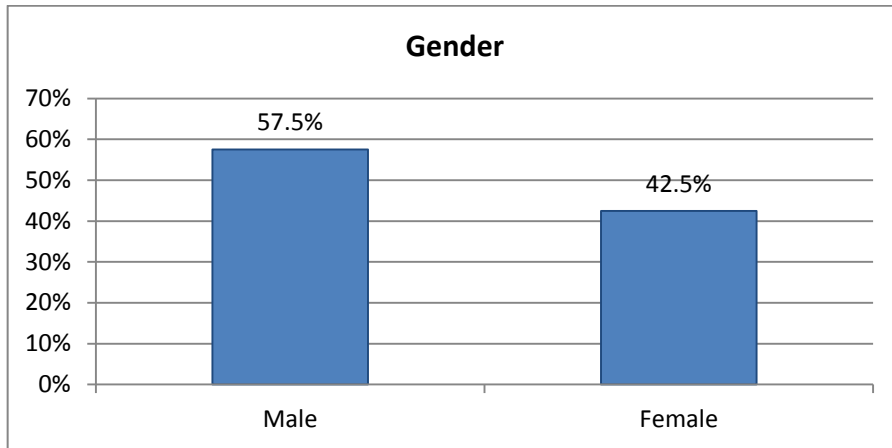


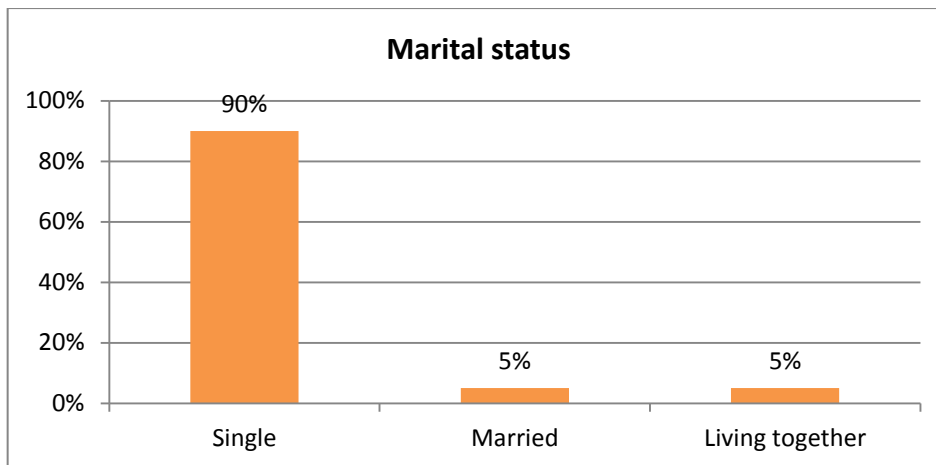
Figure 1 indicates that most of the participants were in the age group of 18 to 30 years (87.5%), whilst only 12.5% were in the age group of 31 to 40. This is an indication that the general age group of university students is between 18 and 30 years.

**Figure 2: Distribution by gender ( $n=40$ )**

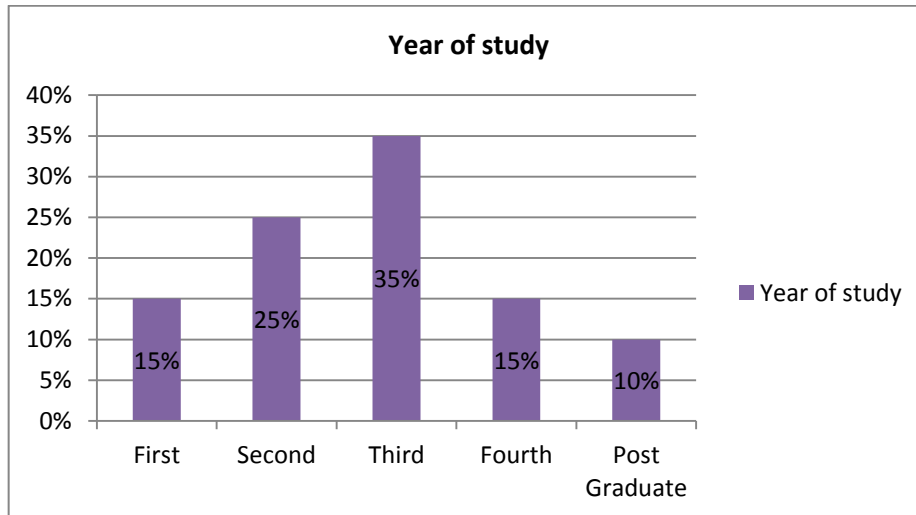


With regards to gender, there were more male participants (57.7%), compared to female participants (42.5%).

**Figure 3: Distribution by marital status ( $n=40$ )**



Most of the students were single (90%) and there was an equal distribution of those who were married and those who were living together (5%). This is a clear indication that these were young people that had just entered the higher learning institution.

**Figure 4: Distribution by year of study ( $n=40$ )**

Most of the students were registered for undergraduate studies, with only 10% that were registered postgraduate students. The majority of students were in their third year of study (35%), followed by second year of study (25%). There was an equal distribution of first and fourth year students (15%).

According to HEARD (2010) studies have proved that people with disabilities in South Africa have lower educational levels, in comparison with the general population. Despite this assertion, this study has shown that students with disabilities are educated and are able to advance beyond the first year of university study, and up to postgraduate studies.

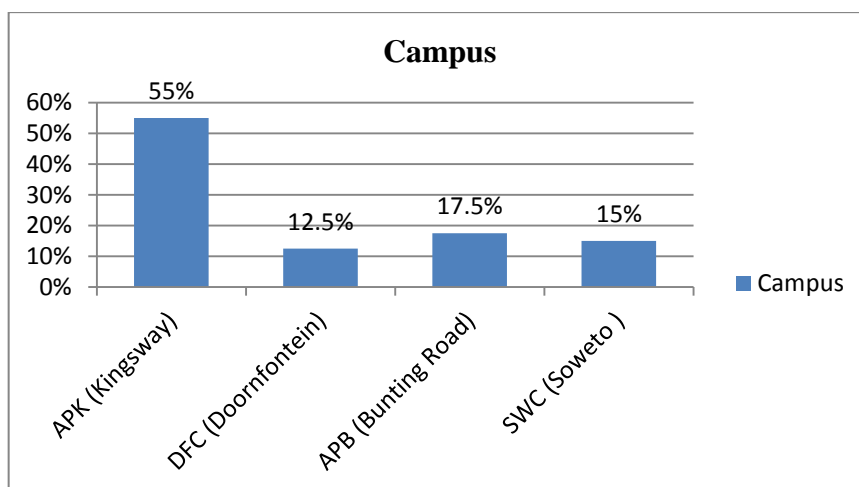
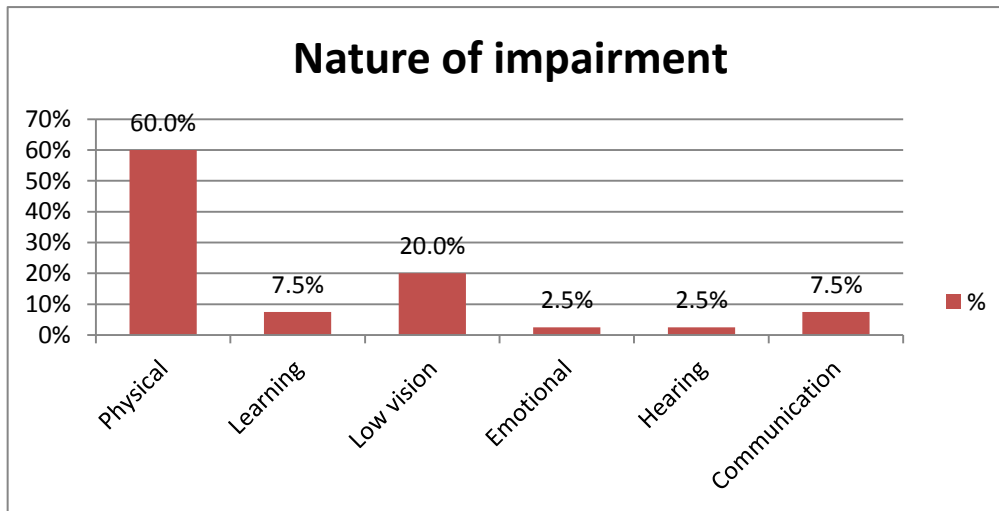
**Figure 5: Distribution by campus ( $n=40$ )**

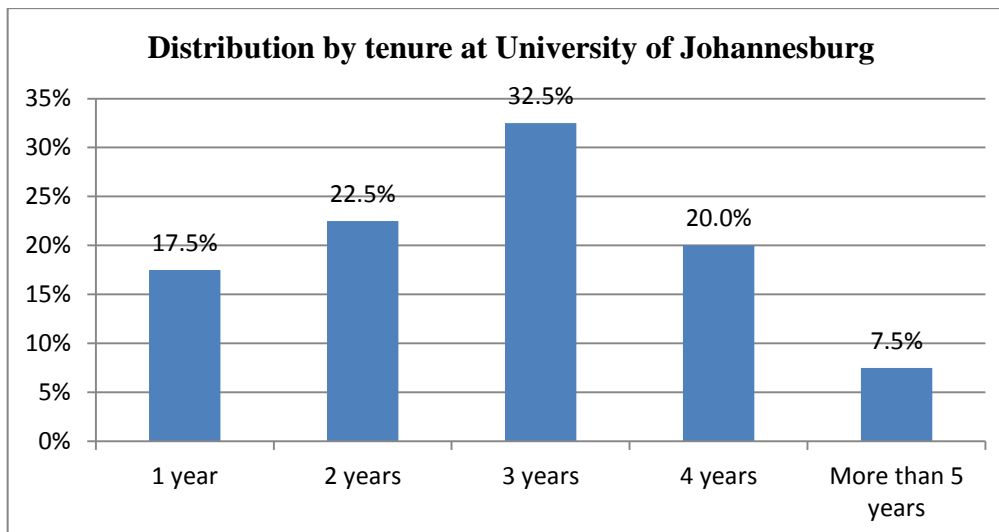
Figure 5 shows that the majority of participants (55%) were located at Kingsway campus, followed by Bunting Road campus (17.5%) and Soweto and Doornfontein campus respectively (15% and 12.5%).

**Figure 6: Distribution by nature of impairment ( $n=40$ )**



Although there were eight classifications of disabilities at the University of Johannesburg, only six types of disabilities were represented in this study. Figure 6 indicates that most of the participants (60%) had a physical disability, followed by low vision (20%). There was an equal distribution of learning and communication disabilities (7.5%), followed by emotional and hearing disabilities (2.5%).

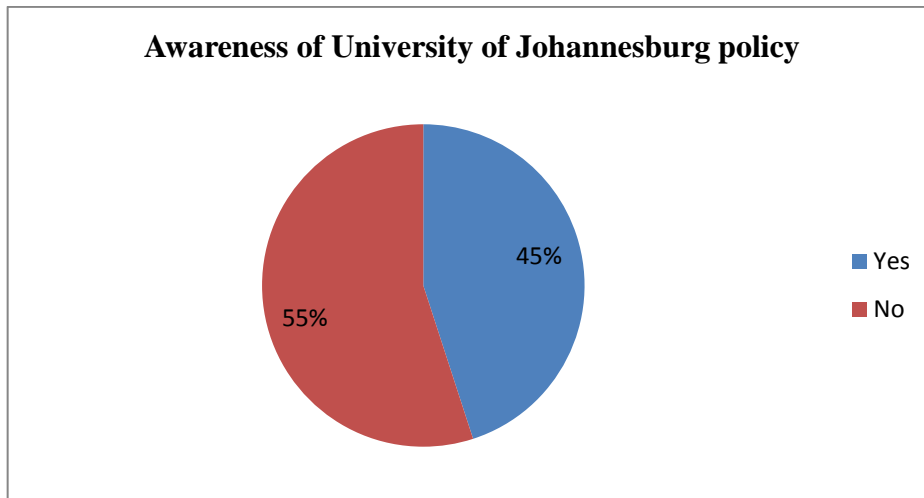
**Figure 7: Distribution by tenure ( $n=40$ )**



Most of the participants have been studying at the University of Johannesburg for 3 years (32.5%), 2 years (22.5%) and 4 years (20%). Only 17.5% were at the University of Johannesburg for one year and 7.5% had been at the University of Johannesburg for more than 5 years. With the collective amount of tenure at the University of Johannesburg, there is an indication that most of the participants have been around for a long time.

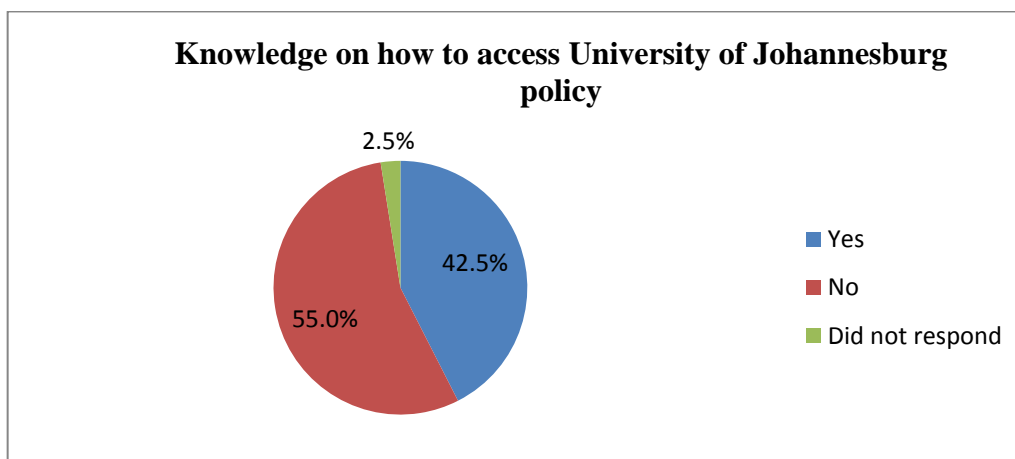
### 4.3 KNOWLEDGE ABOUT EXISTING POLICIES

**Figure 8: Awareness of the University of Johannesburg disability policy?**



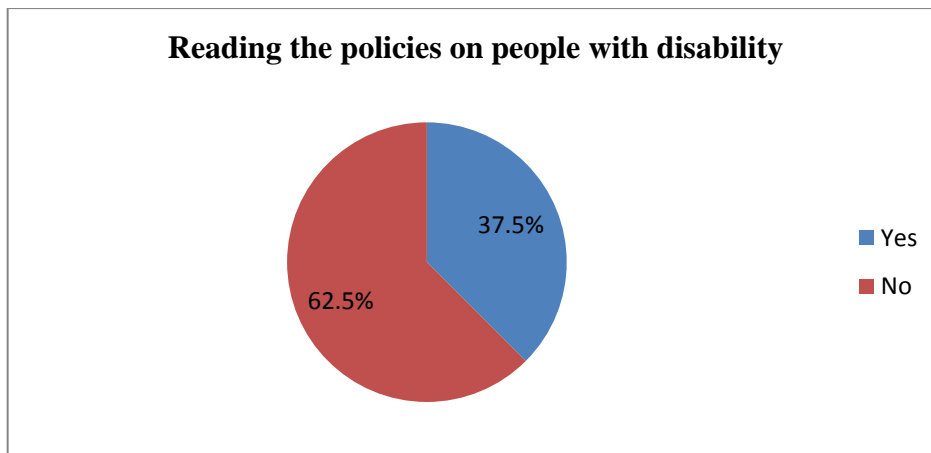
More than half of the participants (55%) were not aware of the University of Johannesburg disability policy, whereas 45% were aware of the disability policy. Although the margin was very low between those who were aware of the policy and those who were not, it was concerning that they were not aware of the University of Johannesburg disability policy, as most had been at the University of Johannesburg for at least two years and more.

**Figure 9: Knowledge on how to access the University of Johannesburg disability policy**



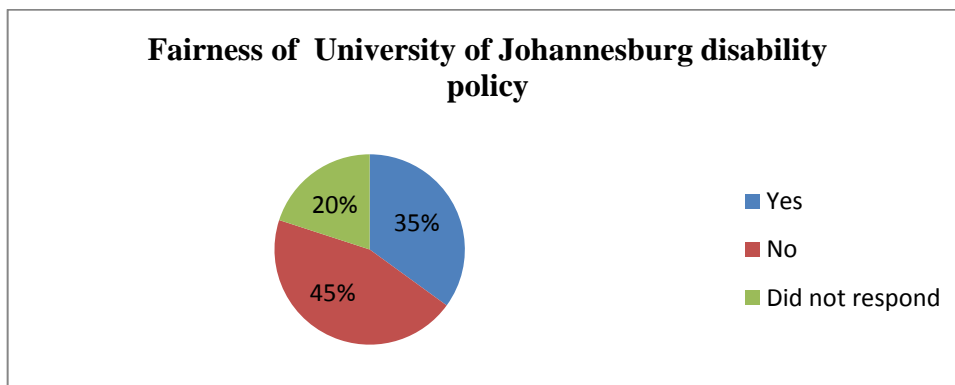
Of the 45% who were aware of the University of Johannesburg disability policy, only 42.5% knew how to access the University of Johannesburg disability policy. 55% of the participants did not know how to access the UJ disability policy, and 1 participant (2.5%) did not respond to this question.

**Figure 10: Reading the policy on people with disabilities**



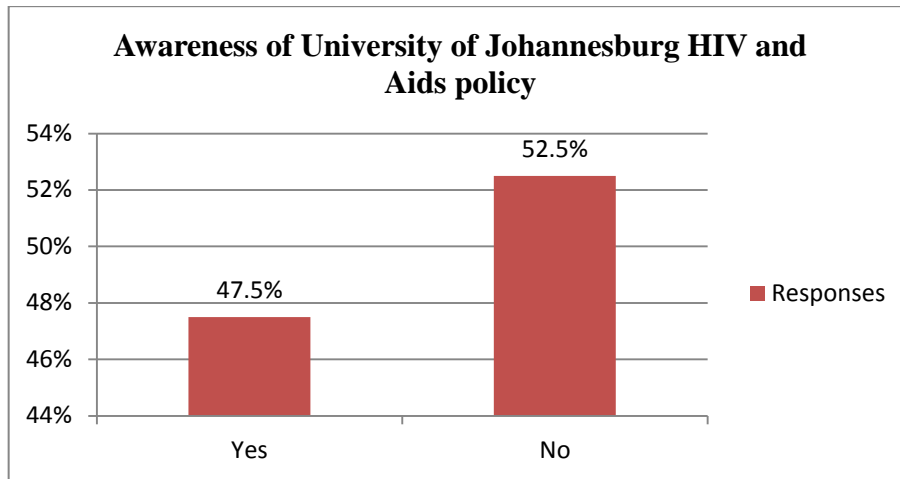
Of those who were aware of the UJ policy on people with disabilities (45%), only 37.5% had read the policy. On the other hand it means that 62.5% had not read the policy on people with disabilities.

**Figure 11: Accommodative and fairness of University of Johannesburg disability policy**



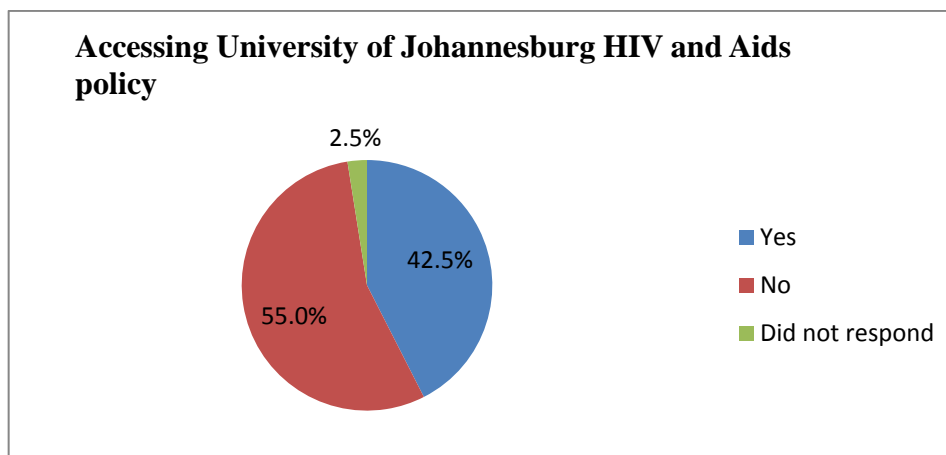
Of those who had read the policy, 35% said the policy was fair and accommodative. 20% of the participants did not respond to this question. It was surprising that 45% said the policy was not fair and accommodative, whereas they had indicated that they had not read the policy.

**Figure 12: Awareness of the University of Johannesburg HIV and AIDS policy**



Almost half (47.5%) of the participants indicated that they were aware of the University of Johannesburg HIV and AIDS policy, whilst 52.5% were not aware of the HIV and AIDS policy.

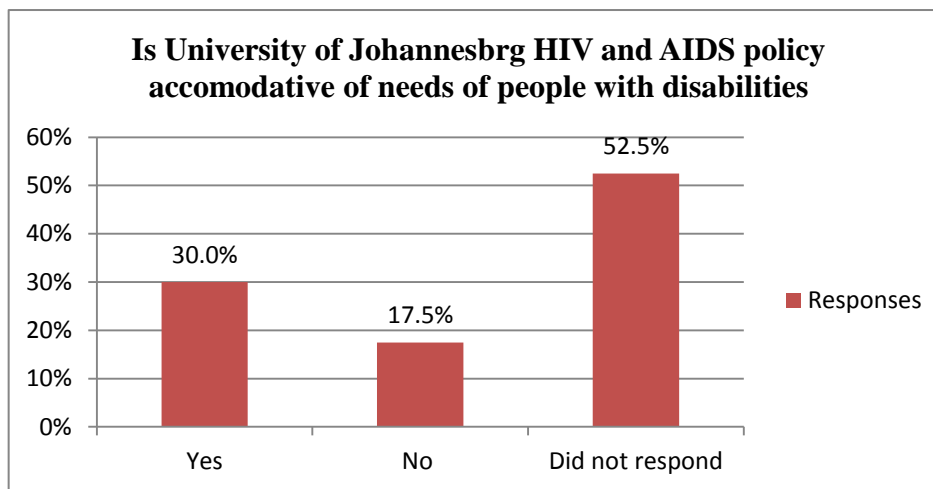
**Figure 13: Accessing the University of Johannesburg HIV and AIDS policy**



Of those who were aware of the UJ HIV and AIDS policy (47.5%), only 42.5% knew how to access the UJ HIV and AIDS policy. 55% of the participants did not know how to access the policy and 2.5% did not respond to this question.



**Figure 14: University of Johannesburg HIV and AIDS policy accommodation of the needs of people with disabilities**



30% of the participants indicated that the University of Johannesburg HIV and AIDS policy is accommodative of the needs of people with disabilities, whilst 17.5% indicated that the policy was not accommodative of the needs of people with disabilities. Most participants (52.5%) did not respond to this question. This could indicate that these may be the participants who were not familiar with the policy.

#### **4.3.8. Reasons for the University of Johannesburg HIV and AIDS policy not been accommodative of the needs of people with disabilities.**

The participants who indicated that the policy did not accommodate their needs, cited reasons for that, which were classified into two categories, namely:

##### **4.3.8.1 Detailed HIV and AIDS information on people with disabilities**

Four participants indicated that the policy was too generic and that it did not provide specific details on how people with disabilities would be accommodated on HIV and AIDS issues. One participant cited that “The policy is written in plain language without consideration for other disabilities like low vision”.

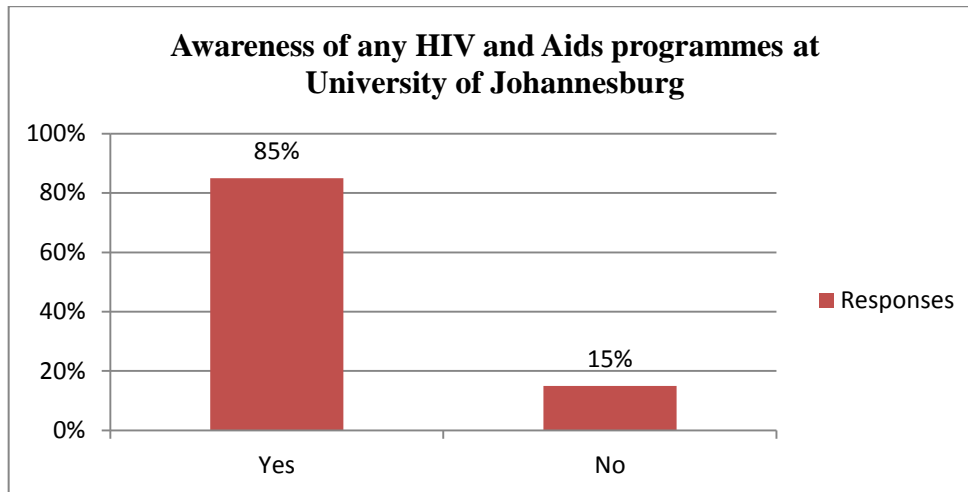
##### **4.3.8.2 Policy**

All 7 participants (17.5%) also indicated that they had never heard of such policies and never read them. One of the participants sadly said “I do not really know about the disability policy. I

don't know anything. I don't really care much to be honest; I believe I know enough to live without knowing the policies that are never accessible or in my face”.

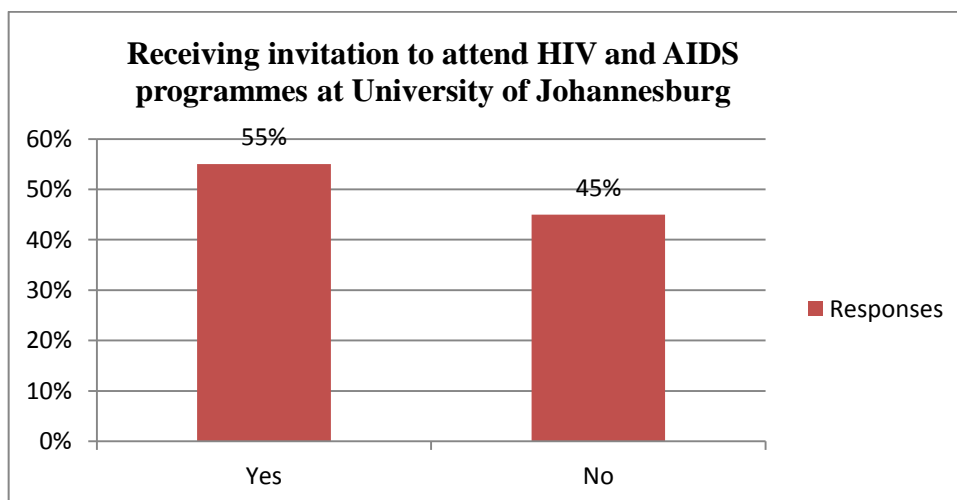
#### 4.4 AWARENESS OF EXISTING HIV AND AIDS PROGRAMMES

**Figure 15: Awareness of any HIV and AIDS programmes at University of Johannesburg**



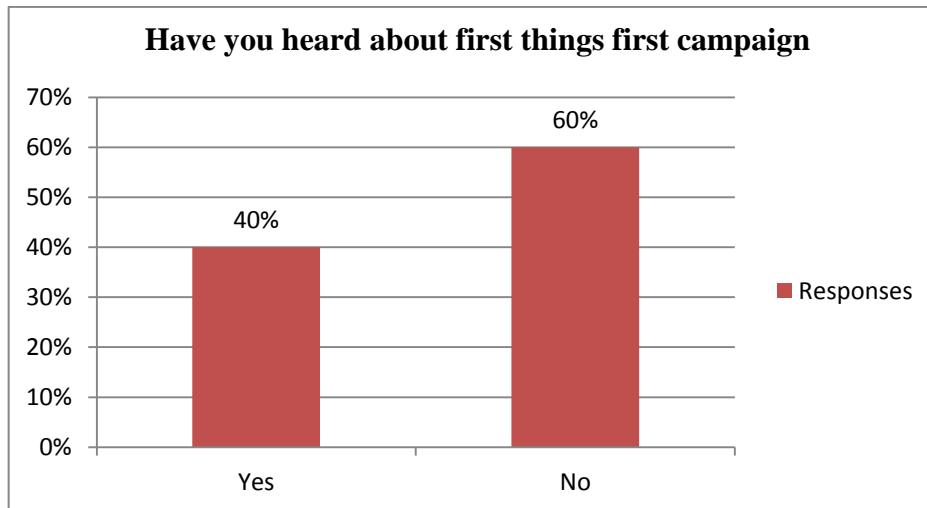
A significant number of participants (85%) were aware of the HIV and AIDS programmes at University of Johannesburg, compared to 15% who are not aware. This may imply that HIV and AIDS programmes at University of Johannesburg are visible.

**Figure 16: Invitation to attend HIV and AIDS programmes at University of Johannesburg**



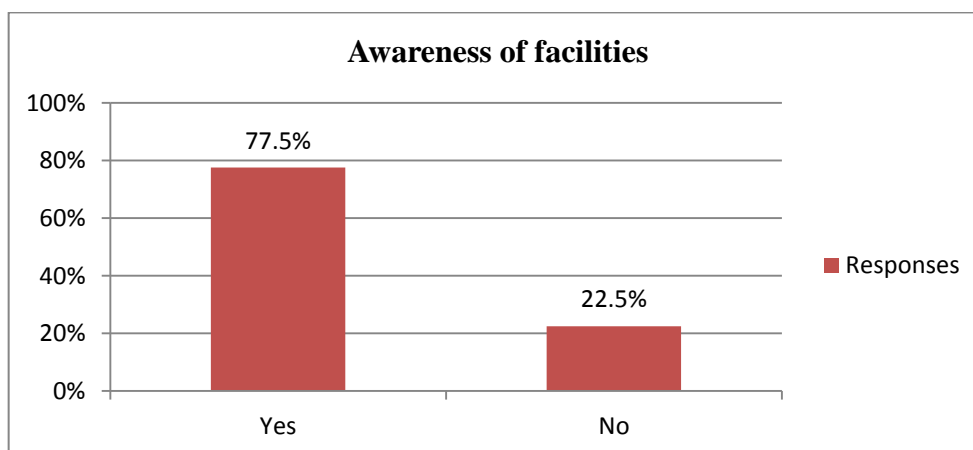
55% of participants indicated that they had never received an invitation to attend HIV and AIDS programmes at University of Johannesburg, in comparison with 45% who have received an invitation.

**Figure 17: Knowledge of first things first campaign**



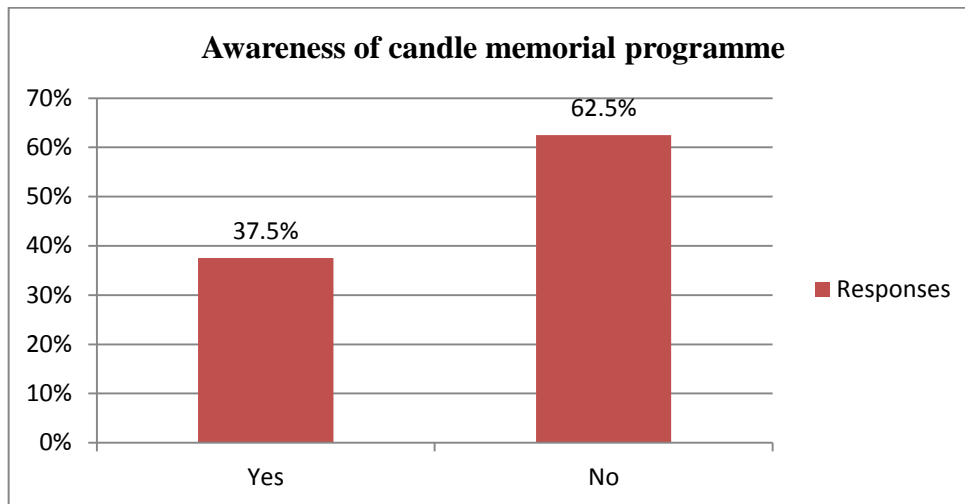
More than half of the participants (60%) have never heard of first things first campaign, while 40% have heard of the campaign.

**Figure 18: Awareness of facilities, resources and departments that offer HIV and AIDS services on campus**



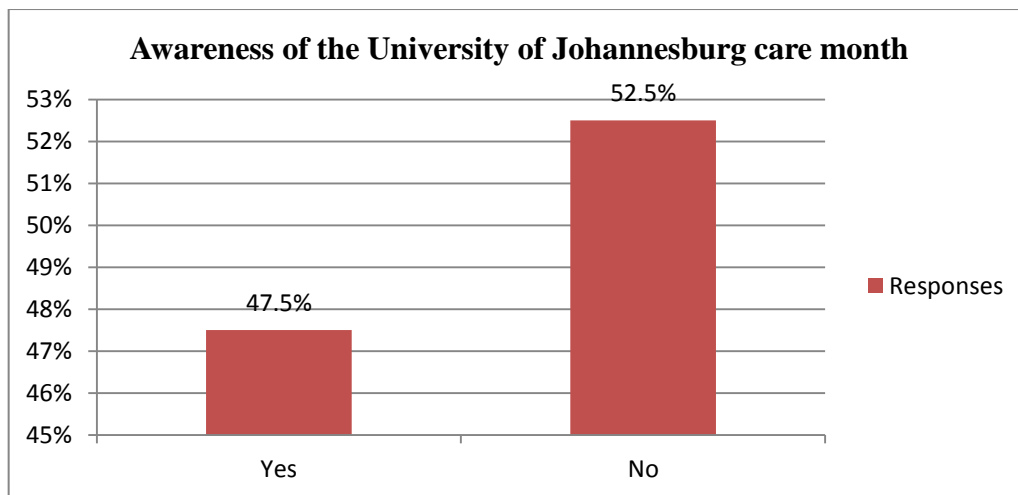
A significant number of participants (77.5%) were aware of other HIV partners on campus, as well as the resources offered, compared to 22.5% of participants who were not aware. This means that other HIV partners have marketed themselves well on campus.

**Figure 19: Awareness of HIV and AIDS candle memorial programme**



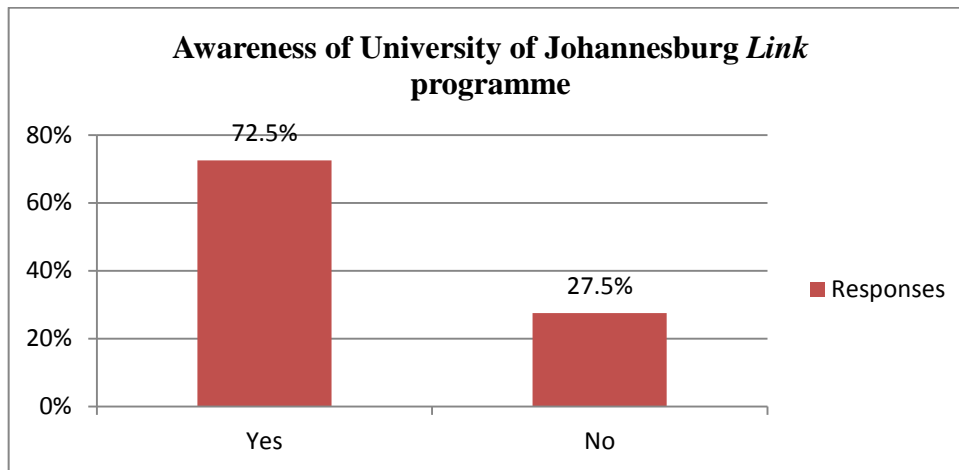
Many participants (62.5%) were not aware of the HIV and AIDS candle memorial programme, whilst 37.5% of participants were aware of the programme. This is concerning as this is a national programme commemorated every year in South Africa, and at the University of Johannesburg.

**Figure 20: Awareness of the care month at University of Johannesburg**



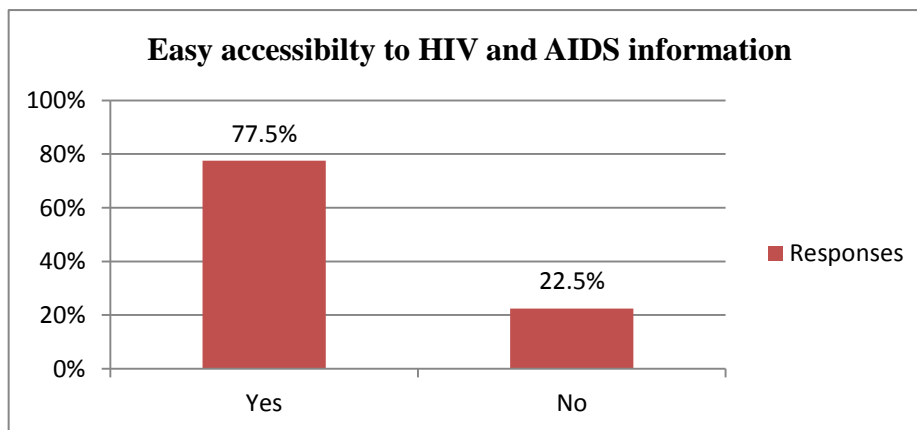
52.5% of the participants were not aware of the care month at UJ, compared to 47.5% who were aware. There was a very small margin between the awareness and lack of awareness of the care month at University of Johannesburg.

**Figure 21: Awareness of the University of Johannesburg *Link* programme**



A significant number of participants (72.5%) were aware of the University of Johannesburg *Link* programme, compared to 27.5% who were not aware. The *Link* programme is a student peer education programme. The high level of awareness signifies the visibility of link members on campus.

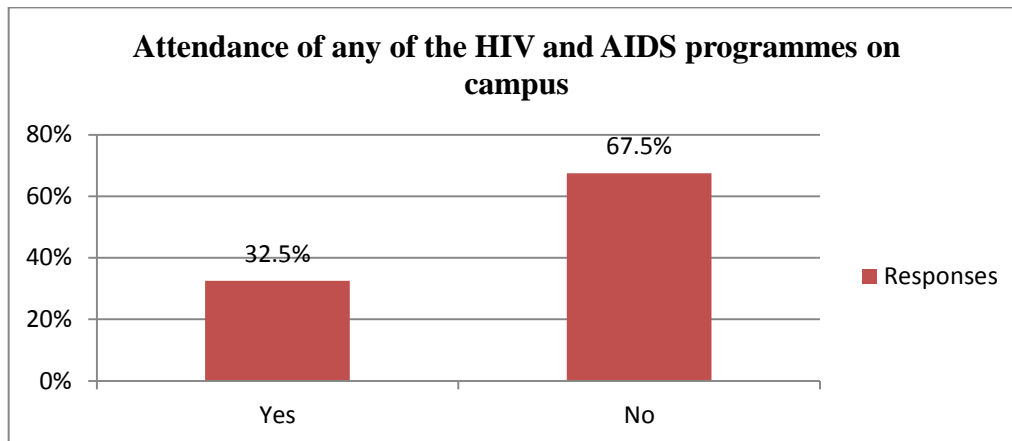
**Figure 22: Easy accessibility of HIV and AIDS information at University of Johannesburg**



A significant number of participants (77.5%) find it easy to access HIV and AIDS information at University of Johannesburg, compared to 22.5% who do not find it easy to access such information. This signifies that the HIV and AIDS information is visible.

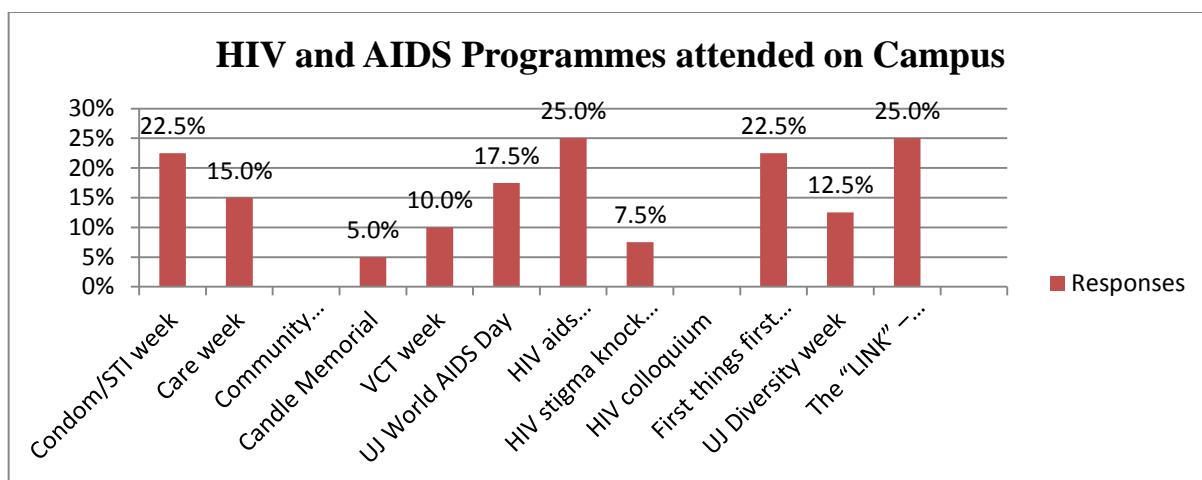
#### 4.5 LEVEL OF PARTICIPATION

**Figure 23: Attendance of any of the HIV and AIDS programmes on campus**



Only 32.5% of the participants have attended any of the HIV and AIDS programmes on campus, compared to a staggering 67.5% who have not attended any of the HIV and AIDS programmes. Although 85% of participants had indicated that they are aware of HIV and AIDS programmes at University of Johannesburg, it is shocking that only 32.5% of them have attended such programmes.

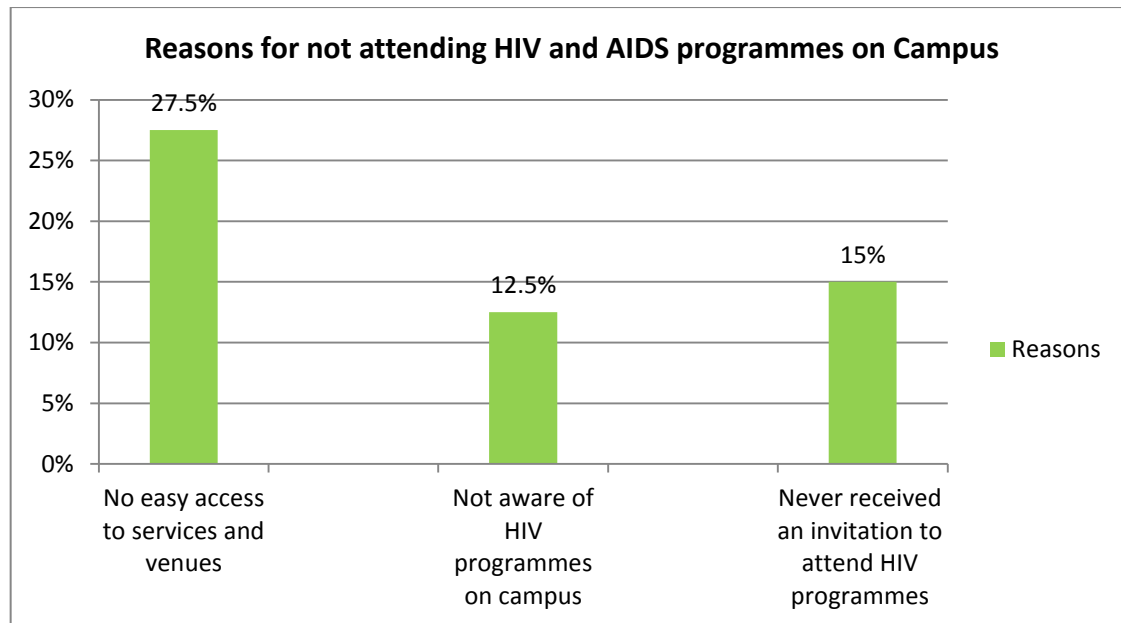
**Figure 24: Specific HIV and AIDS programmes attended on campus**



The figure above shows the specific HIV and AIDS programmes that have been attended by the participants. The most popular programmes attended was the *Link* programme and HIV and AIDS workshop at residences, both at 25% despite the fact that 72.5% were aware of the programme. This was followed by the condom/STI week and first things first campaign at a low

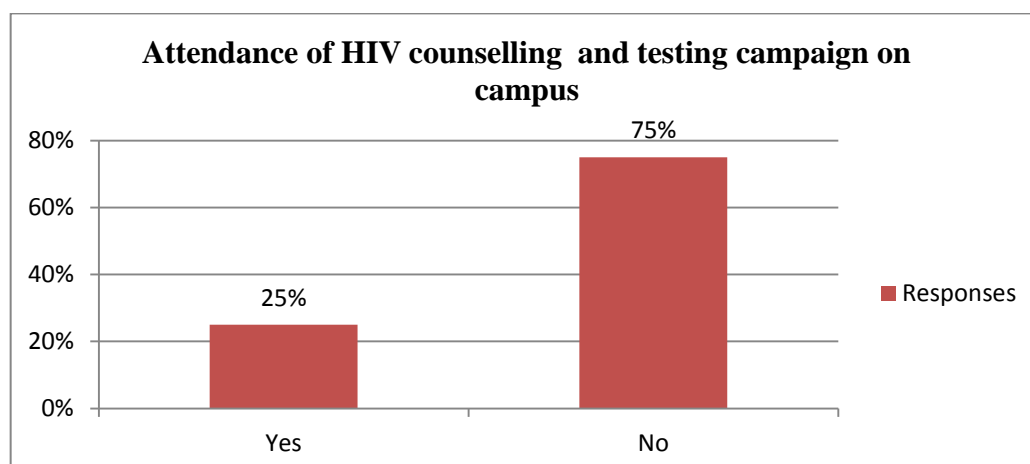
of 22.5% each. This was followed by the UJ World AIDS day (17.5%) and care week (15%). Other programmes that were attended at a very low rate are UJ Diversity week (12.5%), VCT (10%), HIV stigma knockout tournament (7.5%), candle memorial (5%) and HIV and AIDS workshop at residences (2.5%). The programmes that were not attended by the participants at all were the community outreach programmes, as well as the HIV colloquium.

**Figure 25: Reasons for not attending HIV and AIDS programmes on campus**



Reasons given for not attending HIV and AIDS programmes on campus, ranged from no easy access to services and venues (27.5%) to lack of awareness of such programmes (12.5%) as well as mentioning that they had never received an invitation to attend the programmes (15%).

**Figure 26: Attendance of HIV counselling and testing campaign on campus**



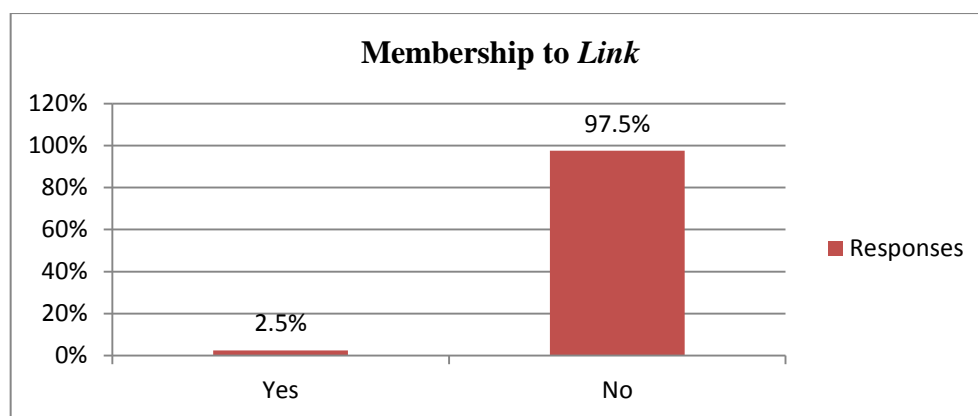
75% of the participants have never attended the HIV counselling and testing campaign on campus, compared to 25% who have attended such a campaign. This means that approximately 75% of the participants might not know their HIV status.

**Table 1: Resource where HIV counselling and testing campaign attended**

Responses	Frequency	%
At campus during HCT week	3	7.5
At campus during first things first campaign	3	7.5
At campus during UJ World AIDS day	1	2.5
At campus clinic, out of my own initiative	2	5
At campus during the Candle Memorial day	1	2.5

Those that have participated in the HIV and AIDS testing campaign have done so at the following events/resources, HCT week (7.5%), first things first campaign (7.5%), University of Johannesburg World AIDS day campaign (2.5%), campus clinic (5%) and candle memorial day (2.5%).

**Figure 27: Membership to *Link* programme**



An overwhelming 97.5% of participants are not members of the *Link* programme. Only one participant (2.5%) was a member of “Link” programme. Even though 72.5% had indicated that they were aware of the “Link” programme, only 25% have attended the programme and the membership of participants is only 2.5%, which is very worrying.

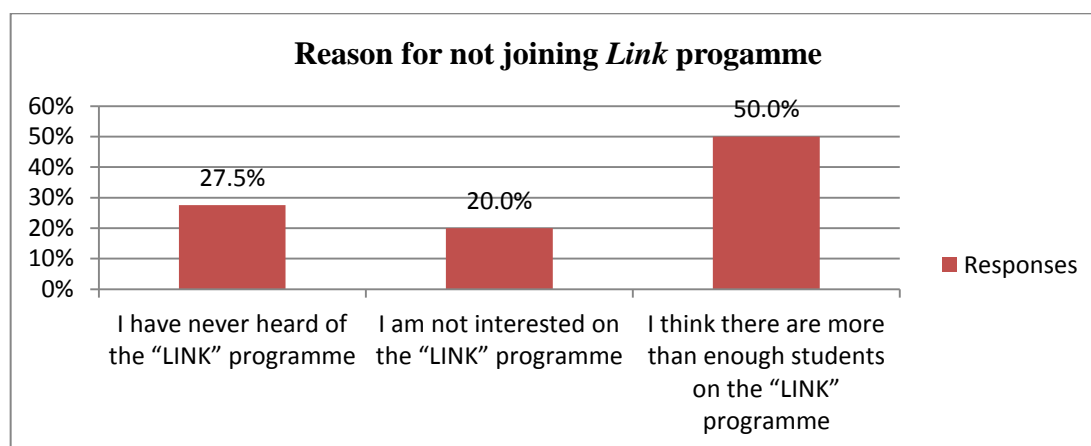


**Table 2: Motivation to join the *Link* programme**

Responses	Frequency	%
I am passionate about educating my peers about HIV and AIDS		
I want to represent people with disabilities on HIV and AIDS programmes	1	2.5
I want to offer support to family and friends that are HIV positive		

The motivation for the one participant (2.5%) to become a *Link* member is because he/she wants to represent people with disabilities on HIV and AIDS programmes.

**Figure 28: Reason for not joining the *Link* programme**

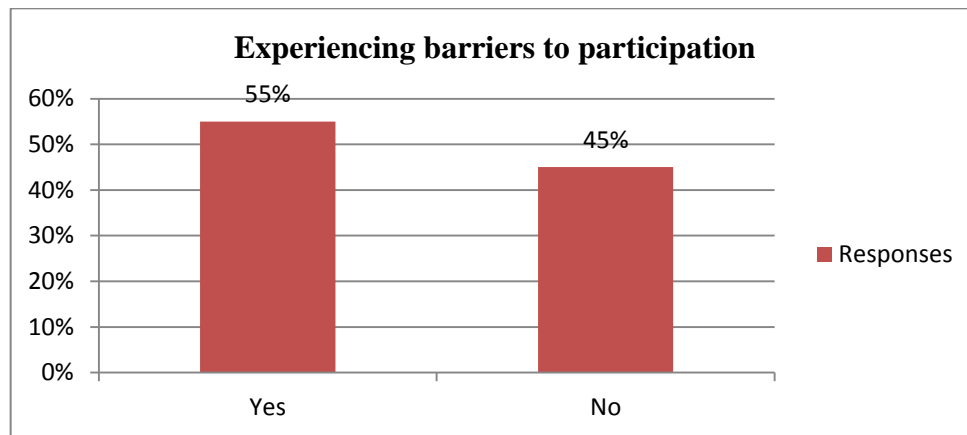


Participants had various reasons for not joining the *Link* programme, such as:

27.5% of participants had never heard of *Link* programme, 20% of participants were not interested in the *Link* programme and half of the participants (50%) thought there were more than enough students on the *Link* programme.

## 4.6 BARRIERS TO PARTICIPATION

**Figure 29: Experiencing barriers to participate in HIV and AIDS programmes at University of Johannesburg**

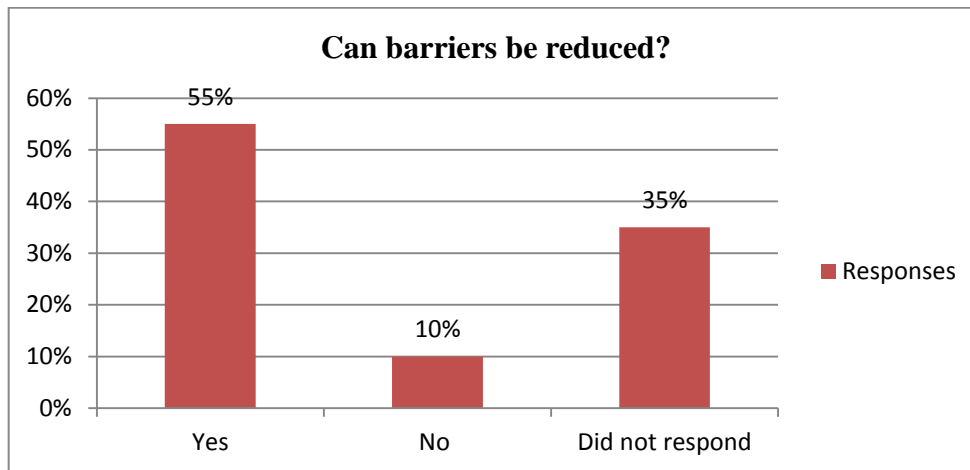


More than half of the participants (55%) indicated that they experience barriers to participate in HIV and AIDS programmes, compared to 45% who did not experience barriers to participate. The margin was very low.

**Table 3: Type of barriers experienced**

Responses	Frequency	%
Physical barriers (e.g. Accessibility and facilities)	10	25
Communication barriers (e.g. format of material)	8	20
Policy barriers (e.g. HIV policy not inclusive of people with disabilities)	7	17.5
Transportation barriers (e.g. not conducive to accommodate needs of people with disabilities)	3	7.5
Institutional barriers (e.g. no representation in HIV structures)	9	22.5
Attitudinal barriers (e.g. stereotypes from others)	18	45

Almost half of the participants (45%) indicated that they experienced attitudinal barriers. Other barriers experienced were physical barriers (25%), communication barriers (20%), policy barriers (17.5%), transportation barriers (7.5%) and institutional barriers (22.5%).

**Figure 30: Can barriers be reduced?**

Many participants (55%) believe that some things can be done to reduce the barriers, whilst 10% of the participants don't seem to think so. 35% of the respondents did not respond to this question.

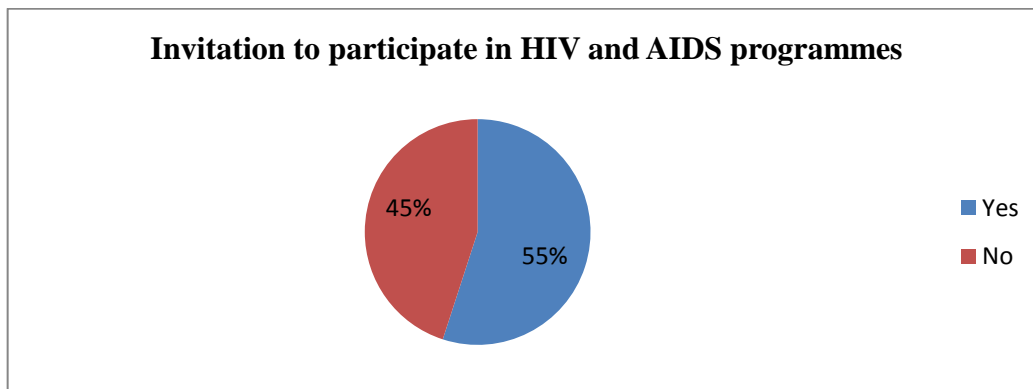
**Table 4: How to reduce barriers**

Responses	Frequency	%
Involving people with disabilities in HIV committees	22	55
Participation in HIV activities	12	30
Joining the "Link" club	8	20
Making venues accessible for people with disabilities	10	25
Improving communication barriers to accommodate our needs	8	20
Sensitize students and employees about disability issues	24	60

The table above indicates that various things can be done to reduce barriers to participate in HIV and AIDS programmes, namely sensitizing students and employees about disability issues (60%). This also ties in with the participants (45%) who indicated that attitudinal barriers were the main issue. There was also a strong indication (55%) that people with disabilities should be involved in HIV committees. 30% of the participants indicated that participating in HIV activities can reduce barriers. Equally 20% of the participants indicated that barriers can be reduced by joining the *Link* programme and improving communication barriers to accommodate the needs of people with disabilities.

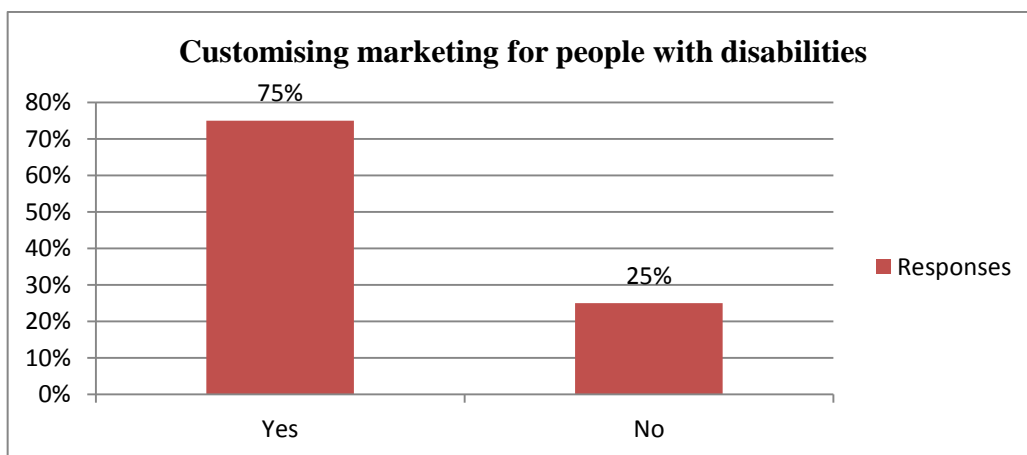
#### 4.7 ENCOURAGING PARTICIPATION

**Figure 31: Invitation to participate on HIV and AIDS programmes**



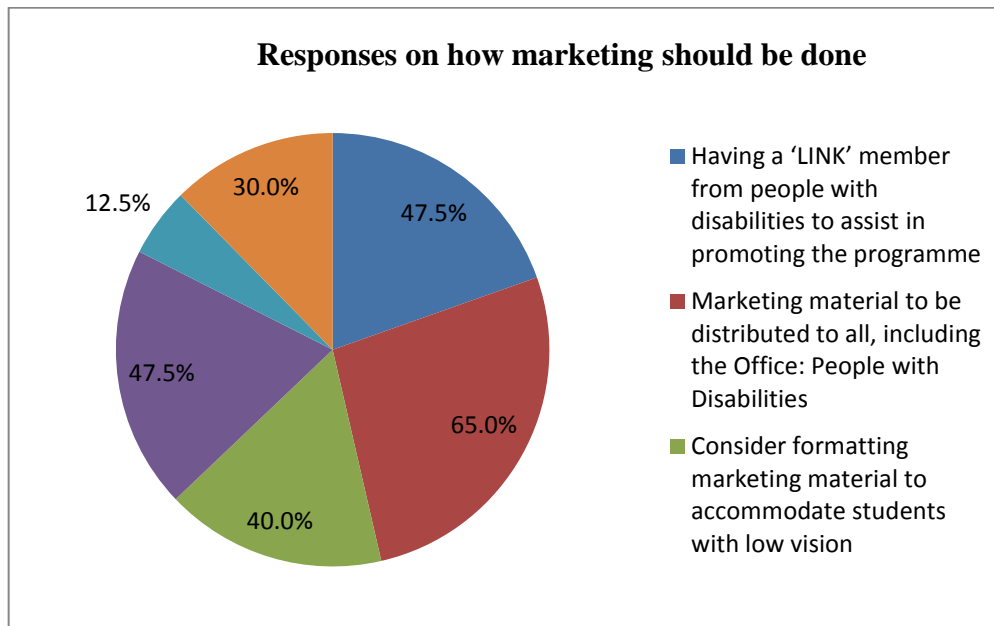
More than half of the participants (55%) acknowledged that they have been invited to an HIV and AIDS programme and encouraged to attend, whilst others (45%) say they have never received such an invitation.

**Figure 32: Customizing medium of marketing for people with disabilities**



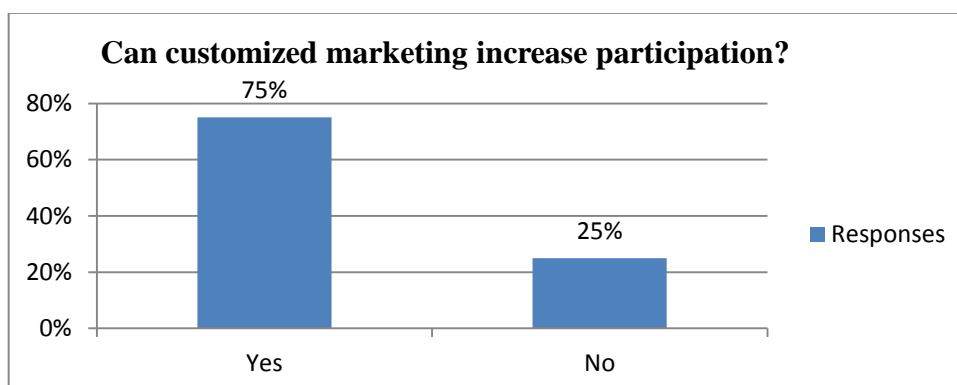
An overwhelming number of participants (75%) indicated that the medium of marketing should be customized for people with disabilities, whilst 25% of the participants felt differently. This may be a strong indication that people with disabilities want to feel part of the HIV and AIDS programmes.

**Figure 33: Marketing the HIV and AIDS programme to attract people with disabilities**



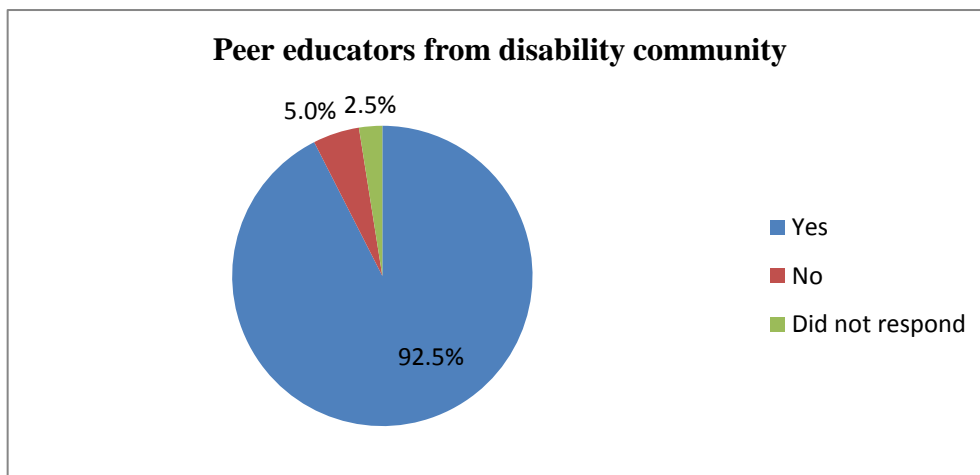
The figure shows participants' response regarding ways to attract people with disabilities to the HIV and AIDS programme. Participants (65%) indicated that marketing material should be distributed to all, including the office of people with disabilities. Several participants (47.5%) indicated that some people with disabilities should join the "Link" programme so as to assist in promoting the problem, as well as distributing marketing material to the forum for people with disabilities (DARE). Others (30%) felt that attitudinal barriers should be addressed.

**Figure 34: Increasing customized marketing to attract people with disabilities**



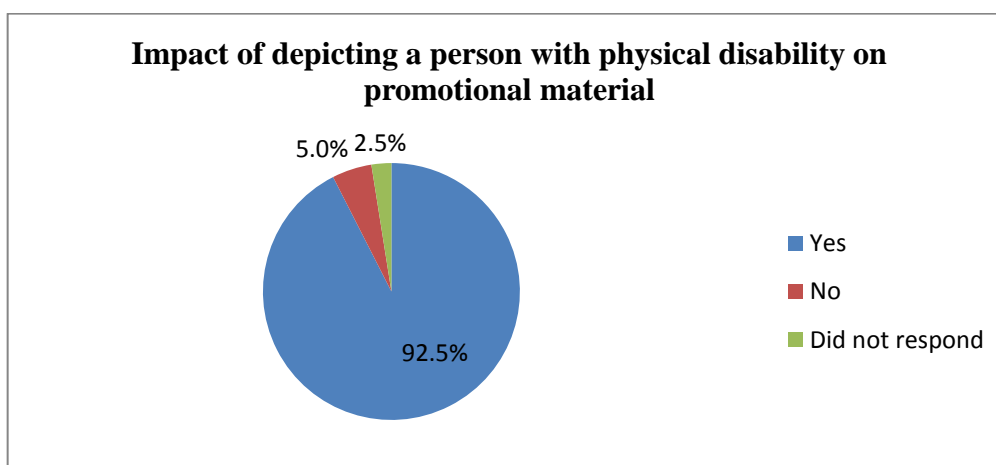
An overwhelming number of participants (75%) indicated that customized marketing can increase the participation of people with disabilities on HIV and AIDS programmes, whilst a low 25% didn't think so.

**Figure 35: Peer educators with disability to increase participation on HIV and AIDS programmes**



A vast number of participants (92.5%) thought that having a peer educator with a disability can increase the participation of people with disabilities on HIV and AIDS programmes, whilst 5% of participants did not think so. 2.5 % of participants did not respond to this question.

**Figure 36: Depicting a person with a physical disability on promotional materials**



An overwhelming response of 92.5% of participants believe that portraying a person with physical disability on promotional materials can certainly encourage people with disabilities to participate on HIV and AIDS programmes. One participant (2.5%) did not respond to this question.

## **4.8 CONCLUSION**

This section presented findings of data collected from forty participants. What emerged from these findings is that although a number of students with disabilities have a high level of awareness of HIV and AIDS programmes at the University of Johannesburg, their level of participation to the HIV and AIDS programmes at the University of Johannesburg is very low.

Despite knowing about the HIV and AIDS programmes, there is still general lack of knowledge of policies on people with disabilities, as well as HIV and AIDS.

## **5. DISCUSSION**

### **5.1 INTRODUCTION**

This section focusses on the summary of the findings, thus bringing conclusion on this research assignment. The aim of the study was to determine whether students with disabilities at the University of Johannesburg do participate on HIV and AIDS programmes on campus. In responding to that research question, five themes emerged that will be used to discuss the findings.

Most of the participants had been at the University of Johannesburg for at least more than one year. In fact, the majority of the participants (32.5%) had been at the University of Johannesburg for three years, whilst 7.5% of them had been at the University of Johannesburg for more than five years.

### **5.2 SUMMARY OF FINDINGS AND DISCUSSION**

#### **5.2.1 FINDINGS RELATING TO KNOWLEDGE ABOUT EXISTING POLICIES**

There was a small margin between those who were aware of the University of Johannesburg disability policy and those who were not aware (5%). As a vulnerable group and a group that considers themselves marginalized, they should make it their duty to familiarize themselves with this policy that focus on their rights. Even though some were aware of the policy, most of the students with disabilities (62.5%) have not even read the policy. Students with disabilities may be aware of the University of Johannesburg policy on people with disabilities, but they are not familiar with its contents/details, therefore, they are unable to evaluate its fairness. According to

Nduta et al (2009) people with disabilities must be “involved in policy formulation in order to identify their needs properly and decide how these needs can be addressed through policies”.

There was again a small margin between those who were aware of the University of Johannesburg HIV and AIDS policy and those who were not aware (2.5%). Of the 47.5% who were aware of this policy, 42.5% of them knew how to access this policy. Those who indicated that the UJ HIV and AIDS policy did not accommodate their needs indicated that the policy was too generic, and that it did not provide detail on how people with disabilities are accommodated. There were also quite a few (17.5%) who indicated that they had never heard of such policies. Their awareness of the two policies is non-existent, but if there is an expectation for students with disabilities to participate on HIV and AIDS programmes on campus, awareness without knowledge of details is not enough.

### **5.2.2 FINDINGS RELATING TO AWARENESS OF EXISTING HIV AND AIDS PROGRAMMES**

Quite a number of participants (85%) are aware of the HIV and AIDS programmes at the University of Johannesburg, and more than half have received an invitation to attend the programmes. Most participants (77.5%) are aware of the facilities, resources and departments that offer HIV and AIDS services on campus. Most participants (60%) had not heard of the first things first campaign. This is a campaign targeted mostly at first year students. This could be attributed to the fact that most of the participants were in their second year of study and above. Having said that, most participants find it easy to access HIV and AIDS information. This outcome is supported by the study by Yousafzai, Dlamini, Groce & Wirz (2004) on knowledge, personal risk and experiences of HIV and AIDS among people with disabilities in Swaziland, which concluded that awareness of HIV and AIDS services was high amongst people with disabilities.

### **5.2.3 FINDINGS RELATING TO LEVEL OF PARTICIPATION**

Despite the high level of awareness of the existing HIV and AIDS programmes, a staggering 67.5% of participants have not attended any such programmes. The most popular programmes attended by a few participants are the *Link* programmes and HIV and AIDS workshops at residences (25%). Sadly, none of the participants have participated on community outreach projects and the HIV colloquium. Participants cited lack of easy access to services and venues, as



well as not receiving invitations as reasons for not attending the HIV and AIDS programmes on campus.

Of particular concern was that only 25% of participants had attended HIV counselling and testing campaigns on campus, despite their high level of awareness on HIV and AIDS programmes, and these have been mostly attended during the HCT week and first things first campaign. According to UNAIDS, WHO & UNHR (2009) high knowledge of HIV amongst people with disabilities doesn't necessarily translate into use of HIV testing and counselling services. Hence this finding is similar to the finding of a study done in Malawi on effective HIV and AIDS and reproductive health information to people with disabilities, where it was found that 94% of the respondents knew about HIV, but only 10% had tested for HIV.

Although the *Link* programme seems to be popular amongst the participants, only 1 participant (2.5%) was a member of the "Link" programme. In other words, of all the participants, only one person was a peer educator, and his/her reason for joining the *Link* programme was to represent the interests of the people with disabilities on HIV and AIDS programmes. Nduta et al (2009) say that involving people with disabilities not only as recipients, but also as participants adds value, because been seen at the forefront fighting against HIV and AIDS can make the programme more acceptable, especially in the community of people with disabilities.

#### **5.2.4 FINDINGS RELATING TO BARRIERS TO PARTICIPATION**

Quite a number of participants (55%) experienced barriers to participate on HIV and AIDS programmes at the University of Johannesburg and the barriers experienced are attitudinal, stereotypes from others, physical, institutional, communications and policy barriers (in that order). The Human Rights Watch (2012) says such barriers exposes people with disabilities to the risk of HIV and hinder their access to treatment and care. Participants believe that these barriers can be reduced in a number of ways, for example, by sensitizing students and staff about disability issues, by involving people with disabilities in HIV committees and by participating in HIV and AIDS activities in general.

#### **5.2.5 FINDINGS ON ENCOURAGING PARTICIPATION**

In order to encourage participation on HIV and AIDS programmes, an overwhelming number of participants (75%) believe that marketing material and AIDS messages should be customized to meet the needs of people with disabilities. They strongly believe that marketing material should

also be distributed to the DARE group and office of people with disabilities. This is the office they frequently access for reasonable accommodation and other disability related issues. According to CBM (2012) one way of encouraging people with disabilities to participate on HIV and AIDS programmes, is to work with disabled people's organizations. In the case of the University of Johannesburg, it will be for the HIV office to work with the office of people with disabilities, in order to raise awareness on HIV and AIDS risk factors.

They are also of the opinion that representation on the "Link" programme will be to their advantage. In other words, peer educators from the community of students with disabilities can help encourage the level of participation on HIV and AIDS programmes on campus. Peer educators help "to encourage isolated and marginalized people with all disabilities to get informed about HIV and AIDS, go for testing and know their status".

An overwhelming majority of participants (92.5%) believe that marketing materials such as posters and pamphlets should also portray figures of people with disabilities. CBM (2012) says this should be used not only to target people with disabilities, but also as part of the general population. This will send a message that people with disabilities are not excluded from HIV and AIDS programmes on campus. There were also suggestions that marketing material should be formatted to accommodate students with low vision.

### **5.3 IMPLICATIONS OF THE RESULTS**

There is no doubt that the South African government is making progress in responding to the needs of people with disabilities, especially at national level. The South African government has one of the best policy frameworks on disability and HIV and AIDS, and they have also integrated disability on its HIV, AIDS & STI national strategic plan (2012-2016). Despite that progress, there are still gaps in practical implementation, especially at local levels. The implications of the results therefore, is that there is still more to be done and the responsibility now lies with the HIV and AIDS programme managers in collaboration with disability unit at the University of Johannesburg to ensure the mainstreaming of disability on HIV and AIDS programmes.

### **5.4 LIMITATIONS OF THE STUDY**

As a result of the Protection of Personal Information Act, the researcher could not access the email addresses of students with disabilities for administering questionnaires to target all types of disabilities. Neither the office of people with disabilities nor the DARE group could provide the

researcher with email addresses, without getting the written consent from the people involved, therefore, the researcher was unable to sample two (Disabled, but unspecified and multiple disabilities) of the eight disability types. The researcher relied on the DARE group, the library services and the primary health care clinics to administer the questionnaires randomly.

Furthermore, due to delays whilst negotiating for access to student email addresses, and conducting the study during study and exam period, it was difficult to locate students with the two types of disabilities that were not covered in the study.

Therefore the findings relate to all types of disabilities at the University of Johannesburg, except the disabled, but unspecified and multiple disabilities.

## 5.5 CONCLUSION

The key research question was “do students with disabilities at the University of Johannesburg participate in HIV and AIDS programmes on campus”?

Most participants are aware of the existing HIV and AIDS programmes on campus, and they also find it easy to access HIV and AIDS information. This implies that the University of Johannesburg’s HIV and AIDS programmes have been well marketed on campus. Despite this finding, the conclusion that can be drawn from the study is that the level of participation on HIV and AIDS programmes by students with disabilities at the University of Johannesburg is very low.

The outcome of this study validated various literature that indeed, people with disabilities do not participate on HIV and AIDS programmes (Chireshe, Rutondoki & Ojwang, 2010) on perceptions of the availability and effectiveness of HIV and AIDS awareness and intervention programmes by people with disabilities in Uganda, as well as Yousafzai et al (2005) on a study in Gauteng, Western Cape and Kwazulu-Natal, which found that people with disabilities had less access to HIV and AIDS services compared to the general population.

The Institutional Office for HIV and AIDS (IOHA) at University of Johannesburg should capitalize on the popularity of the *Link* programme, and ensure that their current peer educators reach out to as many students with disabilities as possible. Equally so, more students with disabilities should be recruited as peer educators to the *Link* programme. Ivom (2009) summarizes it well, “Train people with different impairments as HIV peer educators to inform and support other people with disabilities on HIV awareness and information”.

IOHA and the office of people with disabilities should work in collaboration with each other, in order to enhance the participation of students with disabilities in HIV and AIDS programmes. Thus the involvement and participation of students with disabilities in HIV and AIDS activities can be optimized. Involving students with disabilities in HIV and AIDS committees, making HIV and AIDS policies fair and recruiting students with disabilities as peer educators, can help encourage participation of people with disabilities on HIV and AIDS programmes on campus.

Marketing of HIV and AIDS programmes should be improved to also portray people with disabilities, so as to show inclusivity of all.

## **5.6 RECOMMENDATIONS**

### **5.6.1 FOR STUDENTS WITH DISABILITIES**

Although the students with disabilities are aware of the policies on people with disabilities and HIV and AIDS, it is recommended that they should familiarize themselves with the content of the policies, so that they can give valuable input on these policies and see to its applicability. Students with disabilities should get involved in HIV and AIDS structures and committees at the University of Johannesburg. They could use the DARE group as a basis from which they can get involved.

### **5.6.2 FOR INSTITUTIONAL OFFICE FOR HIV AND AIDS (IOHA)**

The department dealing with HIV and AIDS programmes – (IOHA) needs to market the HIV and AIDS policy vigorously to the community of students with disabilities.

The *Link* programme at the University of Johannesburg seems to be very popular to the participants; therefore the link programme champions need to capitalize on this programme in order to attract students with disabilities to the HIV and AIDS programme. Furthermore, students with disabilities should be recruited to the *Link* programme, so that they can become peer educators and reach out to their fellow peers.

The Institutional office for HIV and AIDS should ensure that invitations to HIV and AIDS programmes reach people with disabilities through other means, such as their structures and offices aligned to them. Furthermore, IOHA needs to improve marketing formats to attract people with disabilities to the HIV and AIDS programmes.

### **5.6.3 FOR OFFICE OF PEOPLE WITH DISABILITIES**

The office of people with disabilities should market their policy vigorously to the community of students with disabilities. Furthermore, the student and staff population should be educated and sensitized on attitudes and stereotypes towards people with disabilities.

### **5.7 RECOMMENDATIONS FOR FURTHER RESEARCH**

It would seem as if a lot has not been explored on people with disabilities with regards to HIV and AIDS programmes, at least at the University of Johannesburg. Based on the findings of the study, the following is recommended for future research:

Peer education is one of the successful HIV and AIDS prevention programmes at the University of Johannesburg, and it also seems to be popular amongst the participants. The participants themselves also indicated that one way of encouraging participation of people with disabilities on HIV and AIDS programmes, is through peer education by people with disabilities themselves. It is therefore recommended that there should be studies focusing on the effectiveness of peer education interventions for HIV and AIDS prevention and support by people with disabilities.

This study has focused on people with different disabilities to ascertain whether they participate on HIV and AIDS programmes at University of Johannesburg. To take it further, it is recommended that focus should be on a specific disability to determine what specific programmes are needed to encourage their participation, so that there is no generalization when packaging HIV and AIDS programmes for people with different disabilities.

Last, but not least, as much as people with disabilities have aired their opinions on participation in HIV and AIDS programmes, there is a need to explore the opinions of HIV and AIDS programme managers i.e. all units dealing with HIV and AIDS on campus, and ascertain what their take is, regarding participation or lack thereof, of people with disabilities on the HIV and AIDS programmes.

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*Annexure A: Questionnaire*

**Investigation into the participation of students with disabilities in HIV and AIDS programmes at the University of Johannesburg**

*Private & Confidential*

Thank you for taking time to complete this questionnaire on HIV and AIDS programmes and students' participation. The aim of the study is to investigate the participation of students with disabilities in HIV and AIDS programmes on campus. The questionnaire is totally anonymous, no name is required. All information will be treated in strict confidentiality. The information gained from this questionnaire will be analysed and submitted to Stellenbosch University as part of my requirement to pass the MPhil in HIV and AIDS Management.

Please answer all the questions as honest as you can. There are no wrong or right answers, the whole idea is to gain an understanding on your perceptions regarding participation in HIV and AIDS programmes.

**The following questions relate to general information of the participants**

GENERAL INFORMATION	
Age group	<input type="checkbox"/> 18-30 <input type="checkbox"/> 31-40
Gender	<input type="checkbox"/> Male <input type="checkbox"/> Female
Marital status	<input type="checkbox"/> Single <input type="checkbox"/> Married <input type="checkbox"/> Living together  <input type="checkbox"/> Divorced <input type="checkbox"/> Widowed
Year of study	<input type="checkbox"/> First <input type="checkbox"/> Second <input type="checkbox"/> Third  <input type="checkbox"/> Fourth <input type="checkbox"/> Post Graduate
Campus	<input type="checkbox"/> Kingsway <input type="checkbox"/> Doornfontein <input type="checkbox"/> Bunting Road <input type="checkbox"/> Soweto
Nature of your impairment	<input type="checkbox"/> Physical <input type="checkbox"/> Learning <input type="checkbox"/> Low vision <input type="checkbox"/> Emotional  <input type="checkbox"/> Hearing <input type="checkbox"/> Communication <input type="checkbox"/> Disabled, but unspecified <input type="checkbox"/> Multiple
How long have you been at UJ?	<input type="checkbox"/> 1 year <input type="checkbox"/> 2 years <input type="checkbox"/> 3 years <input type="checkbox"/> 4 years <input type="checkbox"/> More than 5years

The following questions relate to knowledge about existing policies and their applicability

<b>KNOWLEDGE ABOUT EXISTING POLICIES</b>		
	<b>Yes</b>	<b>No</b>
1. Are you aware of the UJ disability policy?		
2. Do you know how to access the UJ disability policy?		
3. Have you read the policy on people with disabilities?		
4. Is the UJ disability policy fair and accommodative?		
5. Are you aware of the UJ HIV and AIDS policy?		
6. Do you know how to access the UJ HIV and AIDS policy?		
7. Is the UJ HIV and AIDS policy accommodative of the needs of people with disabilities		
8. If you answered "No" to the above question, please explain		

The following question relate to awareness of existing HIV and AIDS programmes at UJ

<b>AWARENESS OF EXISTING HIV and AIDS PROGRAMMES</b>		
	<b>Yes</b>	<b>No</b>
9. Are you aware of any HIV and AIDS programmes at UJ?		
10. Have you ever received an invitation to attend HIV and AIDS programmes at UJ?		
11. Have you ever heard about the first things first campaign?		
12. Are you aware of the facilities, resources and departments that offer HIV and AIDS services on campus?		
13. Are you aware of the HIV/AIDS candle memorial programme?		
14. Are you aware of the care month at UJ?		

15. Are you aware of the UJ “Link” programme?		
16. Do you find it easy to access HIV and AIDS information at UJ?		

The following questions relate to level of participation in the HIV and AIDS programmes

LEVEL OF PARTICIPATION		
	Yes	No
17. Have you attended any of the HIV and AIDS programmes on campus?		

18. If yes, please tick which programmes

Condom/STI week	
Care week	
Community outreach projects	
Candle Memorial	
VCT week	
UJ World AIDS Day	
HIV aids workshop at residences	
HIV stigma knock out tournament	
HIV colloquium	
First things first campaign	
UJ Diversity week	
The “LINK” – student volunteer and peer educator programme	

19. If no, please tick why not:

No easy accessibility to services and venues	
I am not aware of HIV programmes on campus	
I have never received an invitation to attend HIV programmes	

	Yes	No
20. Have you attended the HIV counselling and testing campaign on campus?		

21. If yes, please indicate by means of a tick

At campus during HCT week	
At campus during first things first campaign	
At campus during UJ World AIDS day	
At campus clinic, out of my own initiative	
At campus during the Candle Memorial day	

	Yes	No
22. Are you a member of the "LINK" programme		

23. If yes, please indicate by means of a tick what motivated you to join the programme

I am passionate about educating my peers about HIV and AIDS	
I want to represent people with disabilities on HIV and AIDS programmes	
I want to offer support to family and friends that are HIV positive	

24. If no, please indicate why not, by means of a tick

I have never heard of the "LINK" programme	
I am not interested on the "LINK" programme	
I think there are more than enough students on the "LINK" programme	

The following questions relate to barriers to participation in HIV programmes at UJ

<b>BARRIERS TO PARTICIPATION</b>		
	<b>Yes</b>	<b>No</b>
25. Do you experience barriers to participate in HIV and AIDS programmes at UJ?		

26. If yes, please indicate which barriers

Physical barriers (e.g. Accessibility and facilities)	
Communication barriers (e.g. format of material)	
Policy barriers (e.g. HIV policy not inclusive of people with disabilities)	
Transportation barriers (e.g. not conducive to accommodate needs of people with disabilities)	
Institutional barriers (e.g. no representation in HIV structures)	
Attitudinal barriers (e.g. stereotypes from others)	

	<b>Yes</b>	<b>No</b>
27. Is there anything that can be done to reduce the barriers?		

28. If yes, please indicate what can be done, by means of a tick

Involving people with disabilities in HIV committees	
Participation in HIV activities	
Joining the "LINK" club	
Making venues accessible for people with disabilities	
Improving communication barriers to accommodate our needs	
Sensitize students and employees about disability issues	

The following questions relate to ways to encourage participation on UJ HIV and AIDS programmes

<b>ENCOURAGING PARTICIPATION</b>		
	<b>Yes</b>	<b>No</b>
29. Have you been invited to an HIV and AIDS programme and encouraged to attend?		
30. Do you think the medium of marketing HIV and AIDS services should be customized for people with disabilities?		

31. If yes, indicate how marketing of HIV services should be done to attract people with disabilities to the Programme

Having a 'LINK' member from people with disabilities to assist in promoting the programme	
Marketing material to be distributed to all, including the Office: People with Disabilities	
Consider formatting marketing material to accommodate students with low vision	
Distributing marketing material to the forum for people with disabilities "DARE"	
Institutional (e.g. no representation in HIV structures)	
Attitudinal (e.g. stereotypes from others)	

	<b>Yes</b>	<b>No</b>
32. Do you think customized marketing can increase participation of people with disabilities on HIV and AIDS programmes?		
33. Do you think having a peer educator from the disability community can increase participation of people with disabilities on HIV and AIDS programmes?		
34. Do you think depicting a person with a physical disability in promotional materials; will encourage participation to HIV and AIDS programmes by people with disabilities?		

**Thank you for you for your time**

*Annexure B: Permission letter from Stellenbosch University's ethics committee*



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**Approval Notice**

**Stipulated documents/requirements**

16-Sep-2013

RAMAFOLA, Pearl Berlinda

**Proposal #: DESC\_Ramafola 2013**

**Title: Investigation into the participation of students with disabilities in HIV and AIDS programmes at the University of Johannesburg**

Dear Ms Pearl RAMAFOLA,

Your **Stipulated documents/requirements** received on **13-Sep-2013**, was reviewed by members of the **Research Ethics Committee: Human Research**

**(Humanities)** via Expedited review procedures on **16-Sep-2013** and was approved.

Sincerely,

Susara Oberholzer

RECCoordinator

Research Ethics Committee: Human Research (Humanities)

*Annexure C: Permission letter from University of Johannesburg*

**MEMORANDUM**

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To: Ms Pearl B Ramafola

From: Prof CM Fourie

Date: 8 August 2013

Subject: Permission to conduct research at UJ

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Dear Ms Ramafola

After carefully studying all the submitted documents it is my privilege to inform you that permission is granted that you may conduct your research at the University of Johannesburg.

Should you need any further clarification feel free to contact me.

Regards



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(Prof) C.M Fourie  
Head: Institutional Research Unit.

Tel: 011 559 2093  
Email: [nfourie@uj.ac.za](mailto:nfourie@uj.ac.za)

OFFICIAL ADDRESS | Cnr Kingsway and University Road Auckland Park  
PO Box 524 Auckland Park 2006 | Tel +27 11 559 4555 | [www.uj.ac.za](http://www.uj.ac.za)  
Auckland Park Bunting Campus | Auckland Park Kingsway Campus  
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*Annexure D: Letter of intent*



AFRICA CENTRE FOR HIV/AIDS MANAGEMENT

08 May 2013

The Ethics Committee  
University of Johannesburg

Dear Sir/Madam

**RE: Intention to conduct a research project at the University of Johannesburg**

Ms. Pearl Ramafola, a Master of Philosophy student in HIV and AIDS Management (Student Number: 17439469), at the Africa Centre for HIV/AIDS Management at Stellenbosch University intends to conduct research at the University of Johannesburg on the "Investigation into why students with disabilities do not participate in HIV and AIDS programmes at the University of Johannesburg".

The target group will be students with disabilities from all four campuses of the University of Johannesburg. The sample size will be a total of 40 students with various disabilities. Participants will be selected randomly within each disability group. The researcher will use the quantitative method and participants will be requested to complete an anonymous self-administered questionnaire that consists mainly of closed-ended questions and a limited number of open-ended questions to collect data. This is because the researcher will be targeting a large population of respondents, most of whom are able to complete questionnaires themselves. Due to the nature of different disabilities, participants who need assistance with completion of questionnaires will be duly assisted.

The researcher will first consult with the Office of People with Disabilities (O: PwD) to get a clearer understanding of the nature of disabilities as classified, so that she can design the questionnaires in the appropriate format (accommodative of all disabilities). The information to be covered on the questionnaire is on the following:

- Knowledge about the existing policies and their applicability (HIV/AIDS policy, as well as the policy on people with disabilities)

- Awareness and knowledge of existing HIV and AIDS programmes at UJ
- Participation on HIV initiatives
- Barriers experienced by students in participation
- Ways to encourage students to participate in HIV initiatives

All the data collected from this study will be safely stored to ensure that no other person has access to them. The research is primarily academic but the results of the study will also be submitted to the University of Johannesburg's HIV committee.

We therefore kindly request permission for Pearl Ramafola to carry out this study at the University. The study should run from August 2013 until January 2014. The student will apply for ethical clearance from the Stellenbosch University Ethics Committee in July 2014. Feel free to contact us if you have any further questions.

Kind Regards,



Burt Davis

Lecturer

Africa Centre for HIV/AIDS Management

STELLENBOSCH UNIVERSITY | Private Bag X1 | Matieland 7602 | RSA T:  
+27 21 808 3006 | F: +27 21 808 3015

E: [burt@sun.ac.za](mailto:burt@sun.ac.za) | W: [www.aidscentre.sun.ac.za](http://www.aidscentre.sun.ac.za)



Industrial Psychology Building • Private Bag X1, Matieland, 7602 • South Africa

Tel: (+27) 21 808 3002 • Fax: (+27) 21 808 3015 • e-mail: [pdm@sun.ac.za](mailto:pdm@sun.ac.za) [www.aidscentre.sun.ac.za](http://www.aidscentre.sun.ac.za)

*Annexure E: Informed consent form*



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**CONSENT TO PARTICIPATE IN RESEARCH**

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**Investigation into the participation of students with disabilities in HIV and AIDS programmes at the University of Johannesburg**

You are asked to participate in a research study conducted by Pearl Ramafola, a Master of Philosophy student in HIV and AIDS Management (student number: 17439469) at the Africa Centre for HIV/AIDS Management at Stellenbosch University. The information gained from this questionnaire will be analyzed and submitted to Stellenbosch University as part of my requirement to pass the MPhil in HIV and AIDS Management. You were selected as a possible participant in this study because the investigation of the study focuses on people with disabilities.

**1. PURPOSE OF THE STUDY**

The purpose of the study is to investigate the participation of students with disabilities in HIV and AIDS programmes on campus.

**2. PROCEDURES**

If you volunteer to participate in this study, we would ask you to do the following things:

To complete the questionnaire provided as honest as you can, and to submit the completed questionnaire in a drop off box to be provided.

The questionnaire should not take more than 15 minutes to complete, and questionnaires can be completed at your convenient venue.

### **3. POTENTIAL RISKS AND DISCOMFORTS**

Participation in this study is voluntary. If, for any reason you feel uncomfortable, you may also choose not to participate or choose to withdraw your participation at any time during the study. You will not be required to use your academic time to participate in this study; questionnaires can be completed at your own convenience.

The data provided will be used for research purposes only, and the results will be shared with Africa Centre for HIV & AIDS, the UJ HIV & AIDS committee, the participants of this study, and possibly be published in an academic journal. No participant will be linked to the results.

### **4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY**

Conducting this study will be beneficial to people with disabilities as they will feel part of the solution to the HIV problem, by participating in HIV interventions at the University of Johannesburg, as well as providing solutions that are applicable to them as a designated group. As people who understand their own disabilities, they will influence policy change and drive towards HIV programme inclusivity.

The findings from this study will also assist the University of Johannesburg in implementing an all-inclusive HIV and AIDS programme and can also serve as a model for other higher learning institutions and workplaces. The findings will also assist the South African government towards "getting to zero" (zero new HIV, STI & TB infections, zero AIDS-related deaths, zero new infections due to mother-to-child transmission and zero stigma).

### **5. PAYMENT FOR PARTICIPATION**

Participants will not be remunerated for participating in this study.

### **6. CONFIDENTIALITY**

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of the following:

You will not be required to complete your names on the questionnaire. Identifying information will be limited to age group category, gender, campus of study, year of study, marital status, and type of disability. This information will make it impossible to link it to a person. Completed questionnaires will be put in a lockable information box, which can be easily accessed by the participants, and the box will only be opened by the researcher. Once questionnaires have been collected, they will be stored in a lockable cabinet in the researcher's office which is also lockable. After all the analysis has been done, the researcher will dispose all the questionnaires by shredding them.

## **7. PARTICIPATION AND WITHDRAWAL**

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so. (If the participant is the programme coordinator for HIV & AIDS programmes at the University of Johannesburg)

## **8. IDENTIFICATION OF INVESTIGATORS**

If you have any questions or concerns about the research, please feel free to contact the following research personnel

Pearl Ramafola – Principal Investigator

Tel: 011 559 4032

E-mail: [pearlra@uj.ac.za](mailto:pearlra@uj.ac.za)

Ms Anja Laas – Supervisor

Tel: 021 808 2964

E-mail: [aids@sun.ac.za](mailto:aids@sun.ac.za)

## **9. RIGHTS OF RESEARCH SUBJECTS**

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study.

If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

**SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE**

The information above was described to me by Ms Pearl Ramafola in English and I am in command of this language. I was given the opportunity to ask questions and these questions were answered to my satisfaction. I hereby consent voluntarily to participate in this study. I have been given a copy of this form.

\_\_\_\_\_

**1 Name of Subject/Participant**

\_\_\_\_\_

**2 Signature of Participant**

**Date**

\_\_\_\_\_

**SIGNATURE OF INVESTIGATOR**

I declare that I explained the information given in this document to \_\_\_\_\_ and/or representative \_\_\_\_\_. He/she was encouraged and given ample time to ask me any questions. This conversation was conducted in English and no translator was used.



13 June 2013

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