



UGANDA MANAGEMENT INSTITUTE

**FACTORS AFFECTING THE DELIVERY OF COMPREHENSIVE HIV/AIDS  
SERVICES AMONGST PERSONS WITH DISABILITIES IN UGANDA  
A CASE STUDY OF MASINDI DISTRICT**

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## **DECLARATION**

I, Kyohairwe Patience hereby declare that, to the best of my knowledge, this dissertation is my original work and has never been submitted to this University or any other institution of higher learning for an academic award or publication. I therefore submit it for the award of a degree of Masters of Management Studies (Project Planning and Management) of Uganda Management Institute.

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Date.....

## APPROVAL

We certify that Kyohairwe Patience carried out this study and wrote this dissertation under our supervision. Therefore this dissertation has been submitted for examination with our approval. Where it is obliged to the work of others, due acknowledgement has been given.

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## **DEDICATION**

This dissertation is dedicated to my beloved son Lyndon Ethan Abaasa for having endured my irregular presence at the times he needed me most. Also, without forgetting my dear parents, Mr. George and Mrs. Gladys Katebarirwe for their Financial support, constant prayers, love, and moral support. They constantly inquired about how i was doing with research and encouraged me to keep on track and finish. I also thank them for putting me in the best schools which gave me a good education background.

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# TABLE OF CONTENTS

Declaration.....	ii
Approval.....	ivi
Dedication.....	iv
Acknowledgement.....	v
Table of Contents.....	vi
Appendices.....	x
List of Figures.....	xi
List of Tables.....	xii
Abbreviations.....	xiii
Operation definition.....	xiv
Abstract.....	xvi
CHAPTER ONE.....	1
1.0 Introduction.....	1
1.1 Background to the study.....	1
1.2 Statement of the problem.....	6
1.3 General objective.....	7
1.4 Specific Objectives.....	7
1.5 Research questions.....	8
1.6 Hypothesis of the study.....	8
1.7 Conceptual framework.....	9
1.8 Significance of the study.....	11
1.9 Justification of the study.....	12

1.10 Scope of the study .....	13
1.11 Operational definitions.....	14
1.13 Dissemination of results.....	15
<b>CHAPTER TWO.....</b>	<b>16</b>
Review of Literature .....	16
2.0 Introduction.....	16
2.1 Theoretical Review .....	16
2.2 Delivery of comprehensive HIV/AIDS Service to PWDs .....	17
2.3 Socio-cultura factors and delivery of comprehensive HIV/AIDS Service .....	23
2.3.1 Poverty.....	23
2.3.2 Stigma and discrimination .....	25
2.4 Competence of Service Providers and delivery of comprehensive HIV/AIDS services .....	28
2.4.1 Skills of Health Providers.....	29
2.4.2 Attitudes of Health Providers.....	31
2.5 Modes of service delivery and comprehensive HIV/AIDS Service Delivery.....	33
2.5.1 Partnerships and Networking.....	33
2.5.2 Participatory service delivery.....	36
2.6 Conclusion .....	39
<b>CHAPTERTHREE.....</b>	<b>40</b>
Methodology.....	40
3.0 Introduction.....	40
3.1 Research Design.....	40
3.2 Location of the study.....	40

3.3 Study population.....	41
3.4 Sample size and selection.....	41
3.5 Sampling Techniques and procedure.....	42
3.6 Data collection methods.....	44
3.7 Data collection instruments.....	44
3.8 Validity of research instruments.....	45
3.9 Reliability.....	46
3.10 Procedure of data collection .....	46
3.11 Statistical analysis strategy .....	47
3.12 Feel for the data.....	48
3.13 Ethical considerations .....	48
<b>CHAPTER FOUR.....</b>	<b>50</b>
Presentation,Analysis and Interpretation.....	50
4.0 Introduction.....	50
4.1 Response rate.....	50
4.2 Social demographic characteristics.....	51
4.3 Impact of social-cultural factors on delivery of comprehensive HIV/AIDS services.....	58
4.4 Impact of Competence of service providers on the delivery of comprehensive HIV/AIDS services.....	64
4.5 Impact of Modes of service delivery and the delivery of comprehensive services HIV/AIDS services.....	70
<b>CHAPTER FIVE.....</b>	<b>76</b>
5.0 Summary, Discussion, Conclusion and Recommendation.....	76



5.1 Introduction.....	76
5.2 Summary of major findings.....	76
Discussion.....	80
Conclusion.....	99
Recommendations.....	103
Contribution and suggestions for Further study .....	109
REFERENCES.....	110
APPENDICES.....	125

## **APPENDICES**

Appendix i Questionnaire for PWDs.....	125
Appendix ii Interview guide for Key informants.....	126
Appendix iii Questions and responses from key informants.....	121
Appendix iv Observation Check List.....	136

## **LIST OF FIGURES**

Figure 1.1 Conceptual framework.....	9
Figure 1.2 Showing the type of disability.....	55
Figure 1.3 Indicating the type of services received.....	57

## LIST OF TABLES

<b>Table 3.1</b> Showing research respondents by category, sample size and sampling techniques.....	42
<b>Table 3.2</b> Showing number of respondents by sub-county.....	44
<b>Table 4.1</b> Showing the distribution of respondents by age and gender.....	51
<b>Table 4.2</b> Distribution of respondents by Education.....	52
<b>Table 4.3</b> Showing distribution of respondents' monthly incomes.....	53
<b>Table 4.4</b> Distribution of respondents by place of residence.....	54
<b>Table 4.5</b> Response on the effect of social cultural factors .....	58
<b>Table 4.6</b> Correlations Matrix for social- cultural factors and dependent variable.....	60
<b>Table 4.7</b> Regression output summary on social-cultural and delivery of comprehensive HIV/AIDS services.....	61
<b>Table 4.8</b> Response on the effect of competence of service providers.....	64
<b>Table 4.9</b> Correlation matrix for competence of service providers and delivery of comprehensive HIV/AIDS services.....	67
<b>Table 4.10</b> Regression out puts summary on competence of service providers and delivery of comprehensive HIV/AIDS services.....	68
<b>Table 4.11</b> Response on the effect of modes of service delivery.....	70
<b>Table 4.12</b> Correlations matrix for modes of service delivery and delivery of comprehensive HIV/AIDS services.....	72
<b>Table 4:13</b> Regression out puts summary on modes of service delivery and delivery of comprehensive HIV/AIDS services .....	73

## ABBREVIATIONS

AIC	AIDS Information Centre
ACP	AIDS Control Program
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARVs	Antiretroviral
CBOs	Community Based Organization
CRPD	Convention on the Rights of Persons with Disabilities
CDC	Centre for Disease Control
DDHS	Director of District Health services
DFID	Department For International Development
FGD	Focus Group Discussion
GHWA	Global Health Workforce Alliance
HCT	HIV Counseling and Testing
HIV	Human Immunodeficiency Virus
HBM	Health Belief Model
HRH	Human Resource for Health
JCRC	Joint Clinical research Centre
JLI	Joint Learning Initiative
MOH	Ministry of Health
MSF	Medicines San Frontier
NGO	Non Governmental Organization
NUDIPU	National Union of Disabled persons in Uganda
NFPDN	National Federation of People with Disabilities in Namibia
PHC	Primary Health Care
PLWHA	People living with HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission
PWD	Persons with Disabilities
TASO	The AIDS Support Organization
TBAs	Traditional Birth Attendants
UAC	Uganda AIDS Commission
UNAIDS	United Nations AIDS (Joint United Nations Programme on HIV/AIDS)
USAID	United States Agency for International Development
UK	United Kingdom
VCT	Voluntary Testing and Counseling
WHO	World Health Organization

## **OPERATIONAL DEFINITION**

**AIDS:** This is a chronic, life threatening condition caused by the presence of HIV which damages and destroys certain cells of the immune system particularly T-cells thus weakening the body's response to infection.

**Counseling:** Voluntary counseling is a confidential dialogue between the client and a care provider in order to help the client cope with stress and make an informed decision relating to the situation. It also helps in personal or psychological matters usually given by a professional person.

**Comprehensive healthcare services:** According to Mosby's Medical Dictionary, 8<sup>th</sup> Edition, 2009, it is a health care program that provides for preventive medical care and rehabilitative services in addition to traditional chronic and acute illness services. It involves a holistic health care or total patient care that considers the physical, emotional, social, Economical and spiritual needs of the person, his or her response to illness and the effect of the illness on the ability to make self-care needs. Comprehensive healthcare provides for all patients needs at all stages of life.

**Disability:** Disability is defined as "a complex system of social restrictions imposed on people with impairments resulting in a denial of rights and opportunities.

**FBOs:** Faith Based Organizations are religious organizations which depend on faith as a cornerstone for better leaving.

**HIV:** Human Immunodeficiency Virus is a virus that destroys the immune system's helper T-cells which a later cause AIDS.

**NGOs:** Non-Governmental Organization: both International and National organizations that are not run by the Government.

**PWDs:** Persons with different kinds of disabilities which include the deaf, blind and physical disability.

## **ABSTRACT**

The study set out to examine the factors affecting the delivery of comprehensive HIV/AIDS services to persons with disabilities in Masindi district. The objectives of the study were to assess; the effect of social- cultural factors, the impact of competence of service providers and the relationship between the modes of service delivery and delivery of comprehensive HIV/AIDS services to persons with disabilities.

The study was guided by the Social Cognitive theory. Pertinent literature from various sources including journals was reviewed to provide insights about the study variables.

A descriptive cross-sectional survey design was used to generate results. Both qualitative and quantitative approaches were used.

The findings revealed a positive correlation between independent and dependent variables which suggests that an improvement in the independent variables leads to delivery of comprehensive HIV/AIDS service amongst PWDs. The hypothesis was tested and the coefficient of all the independent variables was less than the p-value of 0.05 and this led to the rejection of the null hypothesis in favor of the alternative.

From the findings it was concluded that a positive significant relationship existed between the independent variables and the delivery of comprehensive HIV/AIDS services amongst PWDs.

The study recommends that the Social-cultural issues that surround disability and HIV/AIDS should be studied and interventions planned and the government's action should be more effective and matched with those of National and community-based NGOs. Health providers should be trained in special needs and different agencies should coordinate and needs of PWDs should be included in the development strategies. Disability agencies should also target disability and HIV/AIDS specifically and a closer relationship with NGO/FBOS should be enhanced.



# CHAPTER ONE

## 1.0 Introduction

This study is an examination of the factors affecting the delivery of Comprehensive HIV/AIDS services amongst persons with disabilities in Masindi District, Uganda. Factors that were considered in this study are Socio-cultural factors, Competence of Service providers and Modes of delivery as independent variables, while the delivery of comprehensive HIV/AIDS services (prevention and care) was the dependent variable.

This chapter also presents the background to the study, the statement of the problem, the general objective of the study, the specific objectives, the research questions, the hypotheses, the scope of the study, the significance, justification and operational definition of terms and concepts. The research ends by suggesting ways through which disability and HIV/AIDS can be tackled in order to reduce the exposure of persons with disabilities (PWDs) to HIV/AIDS.

### 1.1 Background of the study.

According to the HIV Counseling Manual, MOH, (2007), The Human Immune deficiency Virus is biological threat humanity has faced. HIV subversively undermines our immunity system, crippling the physiological resistance designed to protect humanity from infections. The dreadful effects of HIV take time to manifest into Acquired Immune Deficiency Syndrome (AIDS), allowing the innocent host to promote spread of infection. It should be noted that HIV has neither vaccine nor cure and is associated with a number of conditions, including frequent malaria, severe pains, and weight loss among others.

Disability is defined as “a condition when ones’ life is not in his or her hands, when ones physical or mental state is such that other people have to decide for him or her, what to do, where to go, what to eat and whom to associate with. In other words, you are just an object of pity and whatever opinion that you give can never be taken seriously. “Some people will treat you as if you were a child, even when you are well over 30 years” Disabled cobbler, Kampala, Uganda (cited in Lwanga-Ntale, 2003:6). Thomson et al, (2005), views disability as a physical or mental difficulty that substantially limits ones capacity to realize his or her full potentials.

Individuals living with disability do experience a lot of physical, economical and psychosocial challenges ranging from poverty, stigma and discrimination to social exclusion thus disabling them to have full participation in the societies they live in. According to International Policy Dialogue on HIV/AIDS and Disability (March, 2009), many PWDs are subject to what is known as the “Triple Burden” i.e. disability, poverty and HIV/AIDS. According to Wanda et al, (1997), the view on disability is what is disabling them and not the disabilities because it translates to unfair and unjust treatment of the disabled. The complex interplay between disabled and non-disabled people over the past century has made a commendable shift in power from the latter to the former, especially at the apex of society.

According to the (WHO, 2006) report, tackling HIV/AIDS is the world’s most urgent public health challenge. For every ten adults men living with HIV in sub-Saharan Africa, there are 14 women (UNAIDS, 2007). More still, almost three quarters (72%) of AIDS related deaths by 2006 have occurred in sub-Saharan Africa, and an estimated 25 million people are HIV positive in Sub-Saharan Africa today (UNAIDS, 2004b). Approximately, 4 million new HIV infections occurred in the region during 2000 (Centre for Disease Control, 2001). According to UNAIDS, over 33

million people are estimated to have been infected with HIV/AIDS by 2007 of which 22 million people live in the Sub-Saharan Africa (UNAIDS, 2008). Among the people severely affected by the scourge, the majority are poverty stricken, marginalized and socially excluded groups like People with Disabilities. In the last two decades, the HIV/AIDS pandemic has swept across sub-Saharan Africa with an increasing destructive force. According to UNAIDS and WHO, the epidemic has so far claimed over 14 million men, women and children south of Sahara (UNAIDS, WHO 2000). The recent increase in adult deaths in East, Central and South Africa countries can be attributed to HIV/AIDS infection, a case in point in Zimbabwe, adult mortality among men nearly tripled between 1988 and 1994 (Common wealth Region Health community Secretariat for East, Central and Southern Africa, 1999).

In the mid-nineties however, Uganda registered a declining prevalence rate, (Centre for Disease Control, 2001), the overall decline in adult HIV prevalence decreased from 14% in 1990, to 8% in 2000 (Centre for Disease Control, 2001), while in Masaka, Uganda, HIV prevalence among females aged 20-24 years, decreased from 20.9% to 13.8% from 1989-1997 (Kamali et al. 2000). This drop was attributed to mainly, declining incidence and partly due to AIDS related mortality, change in sexual behavior and a result of openness which characterized Uganda's national response hence contributing to the declining trend. Although Uganda has registered progress in bringing down the number of people infected with HIV, the war against this greatest threat to humanity is far from over .Uganda has lost people to Aids since the disease was diagnosed in 1980s in the country and more than 1 million people are estimated to be living with HIV/AIDS the majority being adults aged fifteen years and above. (STD/AIDS Control Program [ACP], 2003). Majority of Ugandans have been affected by this scourge and there is an increase in the number of orphans, and people infected with HIV/AIDS who need care, and support. However, the latest

information indicate that Uganda has a higher HIV/AIDS prevalence rate than previously thought because preliminary findings from 2005/06 Uganda HIV/AIDS sero-behavioral survey released by the Ministry of Health showed that 7% which is a representation of 800,000 adult Ugandans aged 15-59 years had HIV/AIDS compared to the previously known figure of 6.2% (Mukasa, 2005).

This latest survey is based on a nationwide sample of people who voluntarily gave their blood to be tested for HIV. However, Uganda's reported success in bringing down the HIV/AIDS prevalence rate is still doubted because of such arguments that HIV prevalence estimates is not giving a clear picture and even the presented results may be exaggerated since they are based on a few areas of intervention especially urban sites and there has been an over presentation of urban sites especially in early years (Parkhurst, 2005). In addition to this, there has also been a general poor record keeping with limited information on those who die especially in the rural areas where over 90% of Ugandans population live including PWDs.

Moreover, it has also been reported that AIDS statistics have suffered from serious under reporting (ACP, 2003). As this situation of HIV/AIDS intensifies, disabled people remain marginalized from the HIV information, education and communication (IEC) to which their non-disabled peers are exposed. Yet disabled people make up to 15 to 20 percent of the poor in the south (Elwan, 1999) and there is an estimated 80 million people living with a disability in Africa (UN, cited in World Bank, 2002), large numbers of whom reportedly live in isolated rural areas (UN, 1983). Although a lot is known about how the epidemic has affected special interest or vulnerable groups, little is known about its impact on people with disabilities. This is confirmed by the imprecise figures of people with disabilities who have the HIV virus, and hence a reminder that all disability

statistics need very careful interpretation because the term “disability” is by definition culturally and contextually dependent, (Miles, 1999:6).

The World Health Organization estimates that PWDs make up 10% of the world’s population (Nangendo, 2002; WHO in Owako, 2003), and yet the incidence and prevalence of HIV/AIDS amongst PWDs has been found to be very alarming, (Nsubuga-Muyonjo & Tumukunde, 2004). This shows that, there is an urgent need to understand fully the links between disability and HIV/AIDS in order to contribute to policy and programmes for this group (Groce, 2003a). Many PWDs lack access to preventive, curative, or rehabilitative services (Chermak, 2002) and often lack opportunities to engage in preventive health care activities and do not have adequate access to primary health care and long-term care services (DeJong et al, 1989).

In developing and resource poor countries including Uganda, sometimes individuals with disabilities are confined in settlements (Ministry of Health 1999; 2001; Ayeni, 1997), and policy makers and programme operators fail to carry out periodic assessment of the services available to PWDs especially those confined in settlements (Aderinto, 1997). The fact that PWDs are generally geographically scattered in both urban and rural areas in Uganda, has created accessibility problems in terms of mobilizing and sensitizing them for purposes of HIV/AIDS prevention activities. Those who live deep in the rural areas like Masindi where health care is insufficient find it difficult to access educational, health and other social services. This greatly affects their attitudes and their level of awareness in matters pertaining to HIV/AIDS and consequently increases their involvement in risky sexual behaviors thus increasing their vulnerability to the scourge.

It is also believed that negative attitudes and discrimination; continue to play a decisive role in shaping the lives of PWDs at all levels of social strata. Many decisions and therefore outcomes of disabled people's lives are a result of the social environment in which their disability was born and bred. Various social, mental and physical barriers limit participation by PWDs in their own development strategies as well as community development issues and as a result it is assumed that PWDs are protected from HIV, a disease that is often associated with interaction and participation. Therefore, such factors that hinder participation and integration of PWDs have made them more vulnerable to HIV/AIDS, and this has led to answered questions like; Are PWDs benefiting from, or contributing to the massive community, national and international response to the HIV/AIDS epidemic? A major concern of PWDs is that the strong and rapidly expanding fight against HIV/AIDS excludes them. Therefore, the situation that exhibits among PWDs has inspired the researcher to find out the factors that are affecting the delivery of comprehensive HIV/AIDS services amongst PWDs in Masindi district.

## **1.2 Statement of the problem**

According to International Policy Dialogue on HIV/AIDS and Disability (March, 2009), many PWDs are subject to what is known as the "Triple Burden" i.e. disability, poverty and HIV/AIDS. The most prevalent causes are lack of access to service provision, awareness of the disease, and the stigma that goes along with being disabled. According to NUDIPU report (2004), poverty, discrimination, and general stigmatization predispose PWDs to higher risk of contracting HIV in addition to psycho and socio-economic problems that further exacerbate their plight. PWDs are a group that is being largely ignored in efforts to stop the spread of HIV/AIDS in the global population including those with a physical, sensory, intellectual and mental health disability. In resource limited countries like Uganda, support for PWDs is minimal or does not exist at all, and

there are often barriers to accessing adequate food for maintaining health; rehabilitation services, assistive devices; and social support programmes. HIV/AIDS interventions such as voluntary counseling and testing, HIV sensitizations and health care services target the general populace with little or no attention given to PWDs needs. Despite of this big population, there seems to be less effort made to repackage and adapt systems and communication approaches into services that would improve access by the PWDs. Failure to address such anomalies put PWDs at a very great risk of acquiring HIV/AIDS.

### **1.3 General objective**

To examine the factors affecting the delivery of Comprehensive HIV/AIDS service amongst PWDs in Masindi district.

### **1.4 Specific Objectives**

1. To assess the effect of socio-cultural factors on the delivery of comprehensive HIV/AIDS services to PWDs in Masindi district.
2. To assess the impact of competence of health providers on the delivery of comprehensive HIV/AIDS services to PWDs in Masindi district.
3. To establish the relationship between modes of service delivery and the delivery of comprehensive HIV/AIDS services to PWDs in Masindi district.

## **1.5 Research questions**

1. To what extent do socio-cultural factors affect the delivery of comprehensive HIV/AIDS services to PWDs in Masindi district?
2. To what extent has competence of health providers affected the delivery of comprehensive HIV/AIDS services to PWDs in Masindi district?
3. What is the relationship between modes of service delivery and the delivery of comprehensive HIV/AIDS services amongst PWDs in Masindi district?

## **1.6 Hypothesis of the study**

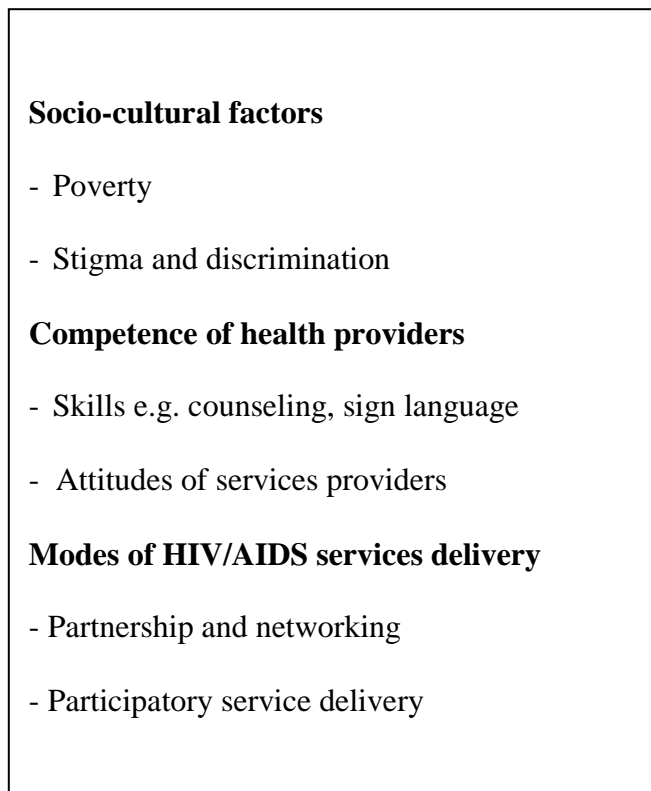
1. There is no relationship between Socio-cultural factors and delivery of comprehensive HIV/AIDS services to PWDs in Masindi district.
2. There is no relationship between competence of health providers and delivery of comprehensive HIV/AIDS services to PWDs in Masindi district.
3. There is a no relationship between the modes of service delivery and the delivery of comprehensive HIV/AIDS services to PWDs in Masindi district.



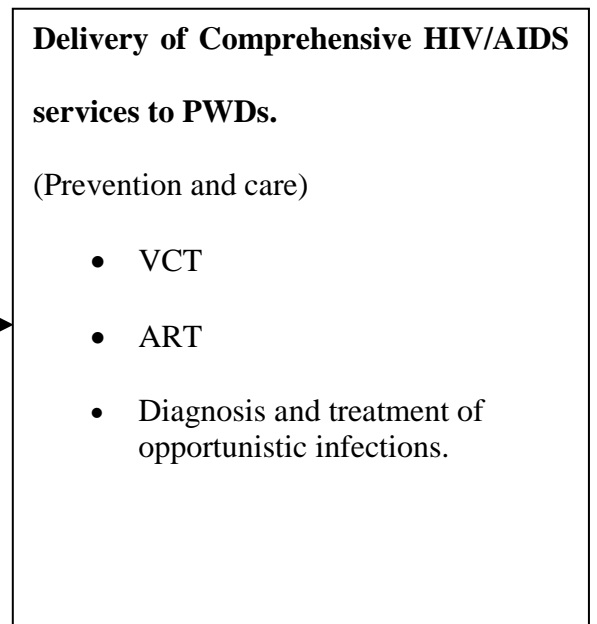
## 1.7 Conceptual framework

A conceptual framework showing factors affecting the delivery of comprehensive HIV/AIDS services amongst PWDs.

### INDEPENDENT VARIABLES



### DEPENDENT VARIABLE



**Source:** 1.1 Conceptual frame, adapted from Tshibumbu et al 2006

## **Explanation of Conceptual framework**

From the framework in figure 1.1, it was conceptualized that poverty, hinders persons with disabilities from seeking for HIV/AIDS services because of costs involved such as transport costs, and high costs of some prescribed drugs and user fee that is asked in some health units. On the other hand, stigma and discrimination towards PWDs that exist around communities where most PWDs live further discourage PWDs from seeking for HIV/AIDS services.

It was further conceptualized that lack of special skills like sign language amongst health providers affect the urge of PWDs to seek for HIV/AIDS care services. Special skills like sign language enable service providers to provide information and psychosocial support to PWDs with hearing/speech impairment. On the other hand, negative attitudes of service providers towards PWDs affect the response rate of PWDs in seeking for HIV/AIDS service.

It was further conceptualized that Partnership and Networking help in streamlining disability into HIV/AIDS service Organizations through disability awareness workshops and carrying out sensitizations about the rights of PWDs among others. On the other hand, it was further conceptualized that participatory service delivery facilitates inclusion of persons with disabilities in the health sectors and helps in highlighting issues that affect PWDs thus leading to making necessary accommodations for PWDs to seek for HIV/AIDS services such as VCT, ART, and diagnosis and treatment of opportunistic infections.

## **1.8 Significance of the study**

The findings of this study will be of major significance to the following groups of people;

### **Researchers**

The study findings will provide in depth knowledge on the factors affecting the delivery of comprehensive HIV/AIDS services amongst PWDs. The knowledge created out of this study will be beneficial and valuable to different researchers who will use it as a future reference.

### **Organizations**

Health institutions such as TASO, Masindi Hospital, JCRC and other HIV/AIDS service organizations will use the research findings in managing and supporting PWDs living with HIV/AIDS through inclusion methods of service delivery.

The study is important to primary care providers who need special training to better prepare them to identify, treat, and refer PWDs, and alternative service delivery strategies may be developed to address the health problems of PWDs in rural areas.

### **Government**

The study will be a guideline for policy makers in Governments and other NGOs to advocate for and strengthen HIV interventional strategies to encourage multi-sectoral approach to HIV/AIDS prevention and care amongst PWDs.

The study assesses the factors which affect the delivery of comprehensive HIV/AIDS to PWDs and therefore will enable main actors involved in management of HIV/AIDS to look at the gaps there in. The findings of this study will help to provide insights to enhance stakeholders get involved in HIV/AIDS education, control, and delivery of comprehensive HIV/AIDS services amongst vulnerable people like persons with disabilities.

The data obtained from this study will also produce bench mark indicators for monitoring the impact of future HIV/AIDS services and programs among vulnerable groups like PWDs, and will contribute to knowledge.

### **1.9 Justification of the study**

There are glaring gaps in our understanding of the general health challenges PWDs face in Uganda, and this becomes even more alarming when related to HIV/AIDS. It is against this background that the researcher carried out a study to investigate the factors affecting the delivery of comprehensive HIV/AIDS services amongst PWDs Masindi district in Uganda. Unless an empirical examination of the problem of HIV/AIDS, communication and access to health services by PWDs is done, it will not be possible to come up with valid and reliable facts to inform policy makers in favor of investing and improving these services for the inclusion of all PWDs.

At the moment, modes of service delivery of HIV/AIDS services remain the major thrust of HIV/AIDS control in Uganda because these services are accessible to only those who can hear without assistive devices, see and talk. Many are excluded because they have associated disabilities, this has led to PWDs rights and freedoms being abused and their lives sacrificed to

HIV/AIDS. This is all the same not worthwhile, since PWDs form part of the society and interact with others socially. The gaps that were identified by the study will call for attention especially in terms of addressing risky behaviors to help avert and reduce spread of HIV/AIDS among PWDs.

## **1.10 Scope of the study**

### **1.10.1 Content scope**

The study was limited to achieving these variables: the socio-cultural factors affecting the delivery of comprehensive HIV/AIDS services to PWDs; the competence of service providers and how this affects the provision of comprehensive HIV/AIDS services amongst PWDs and the modes of service delivery of comprehensive HIV/AIDS services to PWDs. The content scope also covered prevention and care services which include VCT, ART, diagnosis and treatment of opportunistic infections amongst PWDs.

### **1.10.2 Geographical scope**

The study was carried out in three sub counties of Nyangahya, Mirya and Masindi town councils in Masindi district including three health care institutions i.e., TASO Masindi, Joint Clinical Research Centre (JCRC) and Masindi main Hospital. The selection of these health institutions was because they have HIV/AIDS care services for all patients including counseling, psychosocial support, provision of food support, treatment and antiretroviral therapy (ART). In any case the findings from Masindi district will be generalized to represent the views and opinions of other PWDs in other districts.

### **1.10.3 Time scope**

The period of reference will be the last three years (2007-2009) to allow a relatively more accurate recollection of documents, views, attitudes of service providers and clients about factors affecting the delivery of comprehensive HIV/AIDS services amongst PWDs, from which conclusions can be drawn.

## **1.11 Operational definitions**

### **1.11.1 Disability**

The study defined disability as; “ *when your life is not in your hands, when your physical or mental state is such that other people have to decide for you what to do, where to go, what to eat and who to associate with. You are just an object of pity and whatever opinion that you give can never be taken seriously. Some people will treat you as if you were a child, even when you are well over 30 years*” Disabled cobbler, Kampala, Uganda (cited in Lwanga-Ntale, 2003:6) The definition encapsulates from a first person perspective the depth of exclusion experience as a result of having a disability in Uganda.

Disability is also defined as “a complex system of social restrictions imposed on people with impairments resulting in a denial of rights and opportunities” (Yeo, 2001: 3, emphasis added). Similarly, Yeo and Moore regard it as a socially constructed problem created by those who are non-disabled (Yeo and Moore, 2003). Miles, too, regards it as “a social construct which varies across culture and through time in the same way as gender or ethnicity” (Miles, 1999:9). This is supported by Nganwa et al who states how: “many decisions and therefore the outcomes of

disabled people' lives are a result of the social environment in which their disability was born and bred" Nganwa et al, 2002:188).

### **1.11.2 Comprehensive HIV/AIDS care and treatment.**

According to Mosby's Medical Dictionary, 8<sup>th</sup> Edition, 2009, it is a health care program that provides for preventive medical care and rehabilitative services in addition to traditional chronic and acute illness services. It involves a holistic health care or total patient care that considers the Physical, Emotional, Social, Economical and Spiritual needs of the person, his or her response to illness and the effect of the illness on the ability to make self-care needs. Comprehensive HIV/AIDS care and treatment in this study focused on medical and nursing care, psychological support, and socio-cultural support, involvement of PWDs and their families in HIV/AIDS prevention and care services. Comprehensive healthcare provides for all patients needs at all stages of life.

### **1.12 Dissemination of research findings**

The findings of the study will be submitted to the higher degrees of Uganda Management Institute in fulfillment of the requirement for award of a Master's Degree in Management studies and the institute may decide to display the results in the research Centre for people who may be interested in using them as unpublished research. The research findings will consequently be shared with the top management of the health units under study i.e. TASO Masindi, JCRC, and Masindi Hospital and other organizations for implementation of the recommendations and suggestions given.

## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **2.0 Introduction**

This chapter presents the literature that has been reviewed to lay the foundation for the research. In this section, the researcher examines the theoretical review, what has been written earlier about the delivery of comprehensive HIV/AIDS service to PWDs as a dependent variable, socio-cultural factors and delivery of comprehensive HIV/AIDS service, competence of health workers and delivery of comprehensive HIV/AIDS services and the modes of delivery of comprehensive HIV/AIDS services to PWDs as independent variables. This helped in answering the main research questions and confirming or refuting the proposition of the study.

#### **2.1 Theoretical Review**

The conceptual framework was drawn from several theories that include the Social cognitive theory (Tshibumbu et al 2006), Health Belief Model (Becker, 1974); Theory of Reasoned Action (Fishbein & Ajzen, 1975), the concept of self-efficacy from Bandura's Learning Theory (Bandura, 1977). The Health Belief Model (HBM) postulates that one's behavior in relation to health is related to their perceptions of the severity of the illness, their susceptibility to it (condition of disability) and the costs and benefits incurred in performing a particular behavior (Bowling, 1997). The self-efficacy concept, i.e. one's perceived ability to perform a particular behavior, will be included to account for an individual's control over his/her behavior. From the social cognitive theory, the concepts of environment and situation in theory refer to the objective factors that can affect a person's behavior but are physically external to that person and are external to the cognitive representation of the environment by that person (Tshibumbu et al 2006).



The HBM assumes that people make rational decisions before taking an action but this is not true in many occasions, as some PWDs, particularly adolescents have little control over their lives. Some PWDs behavior is not always voluntary or rational, and neither do they always plan what they want to do nor have control over their sexuality (Kim et al., 2001; UNICEF, 2001), hence, the inclusion of the self-efficacy concept. The Theory of Reasoned Action takes into consideration the individual's attitude toward a particular behavior and the subjective norms (i.e. social influence). The significant others play a significant role in the African context. The Lay Health Beliefs are important in explaining PWDs vulnerability to HIV/AIDS.

From the theoretical discussion above therefore, there is no single theoretical model that is adequate to explain peoples' behavior. Each model adds important factors that can affect behavior, but none is able to capture the whole experience of factors affecting delivery of HIV/AIDS health services among PWDs. Thus, the study's conceptual framework was based on the reviewed theoretical perspectives and other factors from empirical research.

## **2.2 Delivery of Comprehensive HIV/AIDS services to PWDs.**

At the United Nations General Assembly High Level Meeting on HIV/AIDS on 22 September 2003, the World Health Organization (WHO) declared lack of access to HIV/AIDS treatment a global health emergency and announced its commitment to lead the way towards an ambitious 3 by 5 target i.e. working with a wide range of partners including the Joint United Nations Programme on HIV/AIDS (UNAIDS) and WHO proposed to take urgent action to provide antiretroviral therapy (ART) to three million people by the end of 2005.

Voluntary Counseling and Testing (VCT) is the process by which an individual undergoes confidential counseling to learn about his/her HIV status and to exercise informed choices in testing for HIV followed by further appropriate action. A key underlying principle of the VCT intervention is the voluntary participation. Voluntary Counseling and Testing is a gateway to prevention and treatment, an essential tool in the control of HIV/AIDS epidemic. Prophylaxis commonly known as septrin in medical care is defined as a treatment for preventing disease (WHO, 2000). Prophylaxis has been found out to reduce the frequency of clinic visits and hospitalized of PLWHAs (Castetbon et al, 2001). HIV infected persons are more likely to suffer from opportunistic infections and die earlier than people without HIV (TASO, 2006). WHO and UNAIDS recommend the use of septrin prophylaxis in both adults and children living with HIV/AIDS in Africa as part of a minimum package of care which includes clinical management prophylaxis against opportunistic infections.

The introduction of antiretroviral therapy (ART) has in the recent past reined the fight against HIV/AIDS. ARVs are drugs that reduce the replication of HIV in the body (WHO, 2004). With 42 million people now living with HIV/AIDS – and 14 000 people newly infected and 8000 people dying of HIV/AIDS each day – expanding access to ART for those who urgently need it is one of the most pressing challenges in international health. Although Uganda has won international acclaim for its national fight and response against HIV/AIDS, many thousands of people who need ARVS including PWDs cannot get them. At the national level in 2005, of the 200,000 people who needed ARVS, only about 86,000 Ugandans had access to the drugs (Kihumuro, 2005). Article 25 of the Convention on the Rights of Persons with Disabilities states: “States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate

measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation”. However, PWDs in Uganda reported health services to be inaccessible and the attitudes of health workers to be discriminatory against disabled people.

In a study done by Opolot et al (2005), organizations were asked to state the estimated population of PWDs they served, the majority mainly the general health providers in most cases, stated that they served below 100 PWDs annually, whereas some of the specialized disability – run organizations claimed they served over 10,000 PWDs annually. This is followed by organizations serving between 1000 and 10,000 and in third place 500-1000 and the least numbers who served only 100-500 PWDs annually. In addition to their negative impact on quality of life (Sherbourne et al, 2000), disability has been consistently associated with increased HIV risk behavior (Hutton et al, 2004) as well as poor access and adherence to antiretroviral treatment for HIV/AIDS (Cook et al, 2002; Tucker et al, 2003). Although some disabilities are treatable, they must first be identified and individuals referred to appropriate services. Unfortunately, stigma and lack of knowledge about these disorders often prevent this from happening (Cooper et al, 2003). Clients resist seeking care for disability issues because they view them as personal weaknesses and do not want to be viewed as “crazy.”

Basing on NUDIPU (2004) report estimates that Uganda has a population of 2.4 million PWDs; there is definitely low utilization of formal health institutions on the part of PWDs in the country. This confirms concerns that PWDs are often hidden in homes and not brought to obtain treatment at recommended health units and hospitals. Likewise, NUDIPU (2004) report states that PWDs feel they are discriminated against in health institutions; this feeling may lead many PWDs deliberately reject seeking treatment in formal health organizations in preference for alternatives

like self-medication in homes and/or even traditional medicines. In the African context, it has been successfully argued that people with disabilities have been left out of HIV/AIDS prevention and treatment programmes for far too long. In addition, the exclusion of PWDs is not an isolated phenomenon of HIV and AIDS service delivery. Persons with disabilities experience barriers while trying to access education and health services in general. Similar to other resource-poor settings, African countries experience challenges to make services accessible. However misconceptions about and ignorance towards disability leads to exclusion as well (Hanass-Hancock, 2008).

As described by Groce (2004), health services can be made accessible for PWDs through moving crucial services, such as voluntary counseling and testing to the bottom floor. Mobile clinics could use tents instead of caravans, and information could be made available on tapes if Braille is too expensive. PWDs should also be actively involved in service delivery, a fact given emphasis by the disability movement of the African continent (African Campaign on Disability and HIV & AIDS, 2008). However, in trying to access Treatment, Care and Support, PWDs may not benefit fully from HIV information and sexual and reproductive health services because of reasons such as service providers lacking knowledge about disability issues, and stigmatizing attitudes towards PWDs (Tororei, 2006). Services offered at clinics, hospitals and other health units may be physically inaccessible, lack of sign language facilities or failure to provide information in alternative formats such as Braille, audio or plain language.

In addition, as PWDs try to access HIV education, information and prevention services, they may be turned away from HIV education forums or may not even be invited by outreach workers, because of assumptions that they are not sexually active, or do not engage in other risky behaviors

such as injecting drugs (Groce & Trasi, 2004). Even where knowledge of HIV is high among PWDs, this does not always translate into use of HIV testing and counseling services (Munthali et al, 2004). Moreover, where PWDs are receiving HIV treatment, health professionals may not pay enough attention to potentially negative drug interactions between HIV treatment and the medications that PWDs are taking. Some medications may actually worsen the health status of persons with mental health conditions, including depression (Catalan, 2005). Most studies reveal that PWDs experience barriers to prevention, interventions and treatment (Mulindwa, 2003, Hanass-Hancock, 2008, Phillander & Swartz, 2006). Special schools are excluded from prevention campaigns or lack sex education (Hanass-Hancock, 2008). Clinics are physically inaccessible, and transport unaffordable or not suitable for wheelchair users (Otte et al, 2008; Rohleder, 2008). For persons with sensorial disabilities, certain channels of communication are inaccessible by PWDs. (Otte *et al* 2008) in Nigeria report that visually impaired people experience hospitals and billboards as inaccessible, and the Phillander and Swartz report (2006) participants emphasize that Braille and audiotapes are necessary to make AIDS services accessible to persons with visual disabilities.

According to Aidala et al. (2004), a patient under-recognition of problems is even more problematic with individuals who are also using drugs. Often people do not recognize the role disability problems have played in their drug use until they have maintained recovery for a prolonged period. In a study of a representative sample of HIV-infected New York City residents, Messeri et al (2002) found that clients' self-perception of disability problems and the need for treatment was the most significant predictor of accessing care. Unfortunately, the need for treatment is seldom acknowledged by those who need it. Three in four persons with mental health symptoms answered "no" to direct questions about emotional or psychological problems or the

need for mental health services (Aidala & Lee, 2001). The cost implications for the health budget have also been significant, this has been caused mainly by increased admissions, prolonged stay for AIDS patients, increased expenditure on drugs for treatment of opportunistic infections, purchase of HIV reagents, treatment cost of sick staff and expenses related to the funerals of health workers. A case study of the possible impact of HIV/AIDS estimated an increase of about 46% in costs for the same quality of health care due to the increased number of patients and other expenses such as diagnostic and treatment requirements (Gilks et al., 1998). A study in Uganda showed that HIV/AIDS has more than doubled the health sector's recurrent expenditures since the epidemic started (Jjemba, Madraa & Lutalo, 1998).

The challenges are great, the health sectors in many of the places most affected by HIV/AIDS are extremely weak, and health services are faced with severe shortages of human and financial resources. The growing impact of HIV/AIDS exacerbates an already difficult situation; this is clearly demonstrated in sub-Saharan Africa, where people with HIV/AIDS-related illness occupy more than 50% of hospital beds, and organizations and facilities providing care are overwhelmed by the demand. The hospitals have been forced to create HIV/AIDS counseling units by using the available nursing personnel, thus increasing their workload (Malecela-Lazaro et al., 2001). These general constraints affect scaling up ART and can constitute more serious bottlenecks as implementation progresses, especially as they can hamper expansion of the coverage beyond a certain threshold. Acknowledging this threat, the study focuses on overcoming the constraints in health policy, management and services delivery in the short and long term.

## **2.3 Socio-cultural factors and delivery of HIV/AIDS Service**

A number of studies worldwide have documented factors that make people more vulnerable to HIV infection; these include social-cultural factors such as poverty, stigma and discrimination. According to Philipettes et al (1998) disabled people are raised to believe they are less “human” due to their disabilities and the voices of PWDs on HIV/AIDS and vulnerability have not been properly documented.

### **2.3.1 Poverty and the delivery of comprehensive HIV/AIDS services**

Poverty is recognized as a predisposing factor for HIV (Yousafzi & Edwards 2004). The link between disability and poverty is well documented, both internationally (Groce, 2004) and in Uganda (Philpott & McLaren 1997), with the recognition that poverty is a cause of disability and disability in turn reinforces and deepens poverty. The World Bank estimates that disabled persons make up 20% of the world’s poor, due to lack of education and employment opportunities (Elwan, 1999). Situations of poverty frequently contribute to risky (sexual and other) behaviors in order to secure an income. PWDs are subjected to ridicule all their lives, to an extent that they believe what society says about them. This response to how society treats them is internalized, and as a result they often begin to react as helpless objects of pity in need of care and support, not able to do anything for them-selves, which in turn makes them charity cases, others react in an opposite manner by having multiple sexual partners. Women with disabilities are more exposed to being sexually exploited than their non-disabled peers and will rarely report the attack.

A case in point about the effects of poverty on disability was in the village of kisayani, south-east Kenya where a local disabled woman was raped and the family did not report the case but merely

asked for ‘compensation’ of some goats from the offender. When they interviewed the father, he stated that they were poor and there was little else that could be done. Further, as the head of the house, it was his decision to ask for such a compensation as the daughter is unable in any other way to make up for her disability and ever since she was a child, he has had to put money into caring for her whilst she cannot do anything productive for the family (source: adapted from Betts, 2004, as cited by Jacinta 2004). Here, the apparent worth of the daughter was made clear from the ‘penalty’ asked of the offender. This revealed an implicit acceptance of how disabled women in this part of sub-Saharan Africa are devalued. In addition to the legal barriers, (Groce and Trasi, 2004), making the incident public would further stigmatize a family that is already regarded as inferior due to having a ‘worthless’ family member (Rapuro, 1998).

Certainly, the link between poverty and disability is reinforced by the fact that more than 80% of persons with disabilities are unemployed (Inclusion International, 2004) and the most common form of employment for individuals with disabilities worldwide is begging. Indeed, disability and poverty are two sides of the same coin (DFID, 2000; McConkey and O’Toole, 1995). For example, the mean consumption of Tanzanian households in which there is one person with a disability is 60% lower than the average household (White, 1999). The relationship between poverty and disability has led to various ideas on how to alleviate the situation for disabled persons. Therefore, this study is in agreement with other research findings that concluded that: *“In most cases these treatment sources can be accessed by a social class that usually comprises the well-to-do and connected people. The poor in rural areas cannot access this treatment. Even when drugs are free patients may fail to have transport to carry them to where they will get treatments”* (Namagala, 2004: 13)



### **2.3.2 Stigma and discrimination and the delivery of comprehensive HIV/AIDS services**

Stigma has been defined as ‘an attribute that is deeply discrediting’ and that reduces the status of an individual possessing the undesirable characteristics in the eyes of society (Link & Phelan, 2001). The concept has been widely used and elaborated (Parker & Aggleton, 2003). Different components such as labeling, stereotyping, separating, emotional reactions, status loss and discrimination and dependence of stigma on power have been mentioned (Link et al, 2004). Similarly, different measures have been presented such as opinions about mental illness and community attitudes toward the mentally ill.

People Living with HIV/AIDS (PLWHA) are often discriminated against by others (Lau & Tsui, 2003). Such discrimination toward PLWHA would compromise the effectiveness of HIV prevention and care programs (Chesney & Smith, 1999). Experiencing discrimination or stigma also adversely affects the quality of life of these patients (Graf *et al.*, 2004). Few studies have, however, compared the degree of discrimination toward these two groups of patients (Walkup et al, 2004). Whilst one might argue that persons with disabilities are an inherent part of any of the aforementioned groupings, “disability should be mentioned as an issue of discrimination in its own right” (Miles, 1999: 3). Nganwa et al argue that there are social issues that lead to discrimination of PWDs and this leads to their vulnerability in terms of HIV/AIDS. In support of inclusion of PWDs, Nganwa et al posit that it is the very practice of excluding them, in their being prevented from associating with their non-disabled peers that increases their vulnerability to HIV/AIDS, (Nganwa et al 2002).

Other studies have also reported some diseases (e.g. malaria) which are interpreted as having a supernatural cause (Pilkington et al., 2005). With regard to HIV/AIDS, some people may regard

PLWHA as personally responsible for contracting the disease or being punished by the gods. Discriminatory attitudes toward PLWHA have therefore to be understood in a social–cultural context. Cultural interpretation of contagion of infectious diseases involves guiding principles that are related to social organization, supernatural powers, etc. and in some societies, there are ‘diseases of guilt’ and illness that expresses breach of a social rule (Caprara, 1998). HIV/AIDS is perhaps one of the most stigmatized medical conditions in the world (NSP, 2007-2011). Groce (2004) explores both the stigma associated with disability and the stigma associated with HIV/AIDS, and concludes that disabled persons who become HIV/AIDS positive are “doubly stigmatized, particularly within the “charity model” framework”. This model reflects a tendency for other people to make decisions about the lives of disabled persons, thereby contributing to a sense of powerlessness and hopelessness. Adding to the predicament is the view that many disabled persons in the developing world are not aware of their reproductive health rights (DFID, 2004a), another factor that puts them at risk of infection and sexual exploitation.

In addition, families and communities may also be accountable for the invisibility of persons with disabilities where by the stigma attached to giving birth to a disabled child in many societies makes a family want to hide that child (Rupuro, 1998; Narib, 2003). The child therefore becomes invisible and less valued as a person. Unsurprisingly, those disabled children who are not exposed to or welcomed by their community grow up unrecognized by their non-disabled peers; this in turn leads to lack of recognition of their rights as human beings which in turn leads to low self-esteem (Yeo and Moore, 2003).

According to Goffman and other researchers, diseases associated with the highest degree of stigma share common attributes. The person with the disease is seen as responsible for having the illness,

the disease is progressive and incurable, the disease is not well understood among the public and the symptoms cannot be concealed (Goffman, 1963). HIV infection fits the profile of a condition that carries a high level of stigmatization (Herek, 2002). First, people infected with HIV are often blamed for their condition and many people believe HIV could be avoided if individuals made better moral decisions. Second, although HIV is treatable, it is nevertheless a progressive, incurable disease (Herek, 2002). Third, HIV transmission is poorly understood by some people in the general population, causing them to feel threatened by the mere presence of the disease. Although asymptomatic HIV infection can often be concealed, the symptoms of HIV-related illness cannot. HIV-related symptoms may be considered repulsive, ugly, and disruptive to social interaction (Herek, 2002).

Other studies also provide evidence that stigma is associated with delays in HIV testing among individuals who are at high risk of being infected with HIV (Stall et al., 1996). In a study of gay and bisexual men who were unaware of their HIV status, two-thirds of the participants expressed a fear of discrimination against people with HIV and said it was a reason for not getting tested (Stall et al., 1996). Earlier in the epidemic, HIV stigmatization was shown to influence the way in which at-risk populations approached HIV testing. People at risk for HIV infection were more likely to seek testing that was offered anonymously (i.e., no names were recorded) than testing that was offered confidentially (i.e., names were kept in confidential files) (Johnson et al., 1998). Also apparent, is the dependency of PWDs on care takers to accompany them and tell them their HIV status. There is a frequent lack of confidentiality of a person's status as a result, a blatant rejection of Article 17 of the International Covenant on Civil and Political Rights (UNHCR, 1976).

In Uganda, Birabi joins others in highlighting the entrenched stigmatization of persons with disabilities (Birabi, 2003). How can we then ensure that health institutions are divorced from these practices as soon as possible in order to ensure equitable health for all, regardless of disability? Some of these questions beg for structural and therefore institutional reforms of the health sector and its physical and human systems. However, as Subrahmanian pointed out, given the inherent exclusionary potential of institutions and processes against PWDs, a policy approach that seeks to be inclusive needs to be mindful of all ways in which institutions exclude and ask if the proposed reform is structural enough to ensure inclusion. The point raised above calls for a detailed examination of the governance structures that determine health services delivery in Uganda and the structural impediments that affect their ability to fully support PWDs health requirements (Subrahmanian, 2003).

#### **2.4 Competence of Health Providers and delivery of comprehensive HIV/AIDS services**

Strategic HR leadership and managing people as strategic resources pose a significant challenge for most ministries of health as well as non-governmental organizations (NGOs) working in health because there are no trained, professional cadres of human resource management, and HR management policies and practices are under-developed, and if developed, these policies and practices are not universally implemented, monitored, and evaluated (MSH 2003, 2004, and 2005). In this context, professionals treat persons with disabilities with insufficient respect or simply forget about them as they falsely believe that these people are asexual (Wazakili et al, 2006).

#### **2.4.1 Skills of service providers and delivery of comprehensive HIV/AIDS services**

Numerous studies identify lack of training of health professionals in dealing with disability as a factor contributing to the lack of attention to HIV/AIDS prevention for disabled persons, and the lack of awareness of the needs of disabled people. Health practitioners often lack the necessary skills for dealing with disabled persons. The dimensions of the human resource (HR) crisis in health have been reported in stark terms in publications and studies by the Joint Learning Initiative, (JLI, 2005) and the World Health Organization (WHO, 2006), among others. The limited numbers also confirm the earlier concerns of ADD (1996) and Murangira (2003), that the general health providers predominate in the country but may lack the specific skills to address PWDs-special needs in HIV/AIDS services and health in general. The limited PWDs focused health services reflect on the wider failure of Uganda's health system to cater for PWDs special communication and mobility requirements within health institutions. The literature confirms the extent to which health organizations lack the capacity to provide sufficient communication facilities and services for the deaf and or of difficulty of hearing, visually impaired and easy mobility to service points within health organizations for those with physical disability.

However, with the formation of the Global Health Workforce Alliance (GHWA) and the commitment of multi-national institutions and bilateral donors such as World Health Organization (WHO), the US Agency for International Development (USAID), the UK Department for International Development (DFID), and others, mechanisms have been put in place to provide leadership on the human resources for health (HRH) crisis at the global level. However, increasing the number of health workers, will not always improve health system performance or health outcomes. Moreover, some of these health providers lack skills in counseling, testing and psycho-

social support for disabled persons. Although PWDs often depend on health professionals for sex education, many are insufficiently trained and uncomfortable with raising issues of sexuality.

Other studies reveal that volunteer counseling and testing staff, practitioners, nurses and police officers are not able to communicate with deaf people (Groce, 2004) and confidentiality is therefore often compromised. In addition, sex education in Africa is often dominated by abstinence messages, which might be detrimental to persons with disabilities, which at times may need special intervention, demonstrations and explanations that go beyond conservative imagination (Rohleder & Leslie Swartz, 2009). A blind person might need to touch and feel, a deaf person needs signs, and a person with intellectual disabilities needs plain and direct instruction with pictures that leave no room for false interpretations. This might become very uncomfortable for health care providers or educators who most likely need support themselves to perform this special task (Mallinson, 2004).

Important to note also, the signs for AIDS in some places has not been fully-developed or used, notably in Kenya sign language where signs for sexuality were only developed in 2003. This is not to say that people with other disabilities are not marginalized; physical access to HIV/AIDS information venues is clearly a problem. An example in Uganda as cited by Yousafzai and Edwards, “Your movement may be difficult, some of the paths are also difficult to locate. You cannot pass there without a guide. So this has made it to be difficult to get to the centers” (Yousafzai and Edwards, 2004:43). What is also evident is a difference in how people with specific disabilities are able to access information. This is further exemplified by the situation in Rwanda, where radios are the most common means of information; not only does this exclude deaf people from a key means of information on HIV/AIDS but many persons with disabilities in

rural areas cannot afford this means of communication and “The majority of participants felt that persons with disabilities had less information than their non-disabled peers” (Yousafzai and Edwards, 2004: 53).

Peterson and Quarstein utilize the simulation of disabilities in disability sensitivity training for professionals working with deaf and blind PWDs with HIV/AIDS, whereby participants were required to perform cooking and life skills chores as a team, whilst simulating a disability. These authors claim positive results, although these did not include an increased awareness not to disempower persons with multiple disabilities, including sensory and communication disabilities, (Peterson and Quarstein, 2001). In addition, subjects reported disliking being ‘confined’ to a wheelchair, feeling isolated and frustrated. Considering, Peterson and Quarstein were attempting to improve attitudes toward disabled persons through sensitivity training; these authors not only use inappropriate language (for instance, wheelchair bound, p. 45) but also claim ‘positive results’ despite having no real basis for this conclusion, having used only self-evaluation and group discussion after the exercise.

#### **2.4.2 Attitudes of service providers and delivery of comprehensive HIV/AIDS services**

Health practitioners often have negative attitudes towards the disabled persons. Some of them may stigmatize and discriminate against PWDs due to negative perceptions towards them. In addition, services are rarely modified to suit the needs of some disabilities like the visually-impaired. If a disabled person is infected with HIV, there is little support from the community due to social stigma and negative attitudes and perceptions towards PWDs. This may accelerate immunity deficiency and reduce life expectancy. The attitudes of health professionals are a reflection of the perception of PWDs in the general population.

Some of the PWDs indicated that challenging the atrocious attitudes of health workers often landed them in worse situations. Disabled women reported being told by nurses that they like men and sex. They are labeled as “having an attitude” or being troublemakers (Groce, 2004; Swartz et al, 2006). An example of how women with disabilities are subjected to situations as a result of their disability is displayed in a study of low status of girls and women in Zimbabwe (Nganzi and Matonhodze, 2003). This study found that actually there was a higher incidence of abuse due to the myth that sex with a disabled female cleanses the male of the HIV virus. Supporting this, Yousafzai et al’s study which found that only women with disabilities talked of “*abuse, sex exploitation and lack of power to determine their own sexual well-being*” (Yousafzai et al 2004, forthcoming). Indeed, it is the invisibility arising from lack of self-esteem and rights-awareness which may partly explain why women with disabilities are two to three times more likely to be sexually abused (DFID, 2000) and their risk of contracting HIV/AIDS therefore increased.

Governments generally have traditionally given disability very low priority. For instance, the Kenyan National condom policy and strategy clearly states its target groups to be youths aged 15-24, sex workers, people living with HIV/AIDS and “people who frequent bars and other drinking places” (Ministry of Health, 2001: 5). In this way, persons with disabilities, also a sexually active group and there as much at risk of contracting HIV/AIDS are invisible, (Miles, 1999). This study therefore promotes the view that while it is crucial that excluded groups are integrated, the root causes must be understood before more immediate symptoms can be dealt with in relation to how persons with disabilities are excluded in reference to HIV/AIDS. Miles’ view was supported by those in favor of mainstreaming disability programmes of international development agencies. This might help the fight against HIV/AIDS given that “*traditional coping mechanisms to combat HIV/AIDS-related disasters have been stretched to breaking*’ (Nganwa et al, 2002: 186).



Many International Development agencies however, have tended to treat disability as a “specialist” issue, perhaps because of the ongoing marginalizing of disability that portrays disability as such. Yeo (2003) posits that this is an excuse used by organizations to explain why they do not integrate disability into their everyday work, many NGOs leave disability to organizations who work on it full-time and yet specialist NGOs try to mainstream disability as an integral aspect of development but are assisted in this by their mainstream development counterparts. Despite the existence of National Building Regulations (1988) which make provision for ramps, accessible toilets, wheelchair accommodation in auditoriums and access to buildings from parking areas, current health facilities still are not accessible to disabled people.

## **2.5 Modes of service delivery and comprehensive HIV/AIDS Service to PWDs**

At the health services level, shortages of infrastructure, equipment and human resources constitute the most important bottlenecks when delivering HIV/AIDS services. The biggest problems have been identified as, very limited geographical accessibility, financial shortages, poor quality of services, shortage of human resources and low motivation of health workers. There is also a huge gap in both initial and continuing professional training, weak institutional capacity for the management of the health system, and insufficient support structures at central, regional and local levels as indicated by (Ranson et al., 2003; Wyss, Moto & Callwaert, 2003).

### **2.5.1 Partnerships and Networking and delivery of comprehensive HIV/AIDS services**

At the United Nations General Assembly High Level Meeting on HIV/AIDS on 22 September 2003, the World Health Organization (WHO) declared the lack of access to HIV/AIDS treatment a global health emergency and announced its commitment to lead the way towards working with a

wide range of partners including the Joint United Nations Programme on HIV/AIDS (UNAIDS). WHO proposed to take an urgent action to provide antiretroviral therapy (ART) to three million people by the end of 2005. To make this ambitious but necessary vision a reality, WHO developed a detailed strategy that was announced on World AIDS Day, on 1st December, 2003. However, the biggest challenge for most health systems is the integration of different stakeholders into the system, such as the private sector, NGOs and communities. Contracting out some health services in low- and middle-income countries to private-sector providers is sometimes suggested as a mechanism to increase coverage and efficiency.

However, the need would then arise for development of mechanisms for contracting and for strengthening the regulatory framework, both of which have proved problematic. It is clear from this sample that PWDs run health organizations are very few compared to the general health infrastructure in low developed countries like Uganda. In response to some of these challenges, the National Federation of persons with disabilities in Namibia (NFPDN) in 2003 chose to work with the concept ‘of *double mainstreaming*’: to mainstream disability into HIV/AIDS service organizations through a series of disability awareness workshops and to mainstream HIV/AIDS into disability organizations also through workshops, both at the same time. The rationale for this two-pronged approach is that you can make persons with disabilities aware of HIV/AIDS, but if service providers are not open to their needs, this is of little use.

Therefore, the view of Nganzi & Matonhodze (2003) on the exclusion of persons with disabilities from the mainstream HIV/AIDS services is that this clearly exacerbates the situation. A sound HIV/AIDS programme must work through effective PWDs embracing community action in setting priorities, making decisions, planning and implementing strategies to achieve better health.

The increasing availability of antiretroviral therapy means many people living with HIV live longer. Some of these people experience activity limitations or participation restrictions as a result of progress of the disease or side effects of treatment (Rusch et al, 2004). However, this may be on a temporary, episodic or permanent basis. Health-related rehabilitation is increasingly important in the continuum of HIV care and can slow deterioration of the individual's condition and enable the person to achieve and maintain independence. This involves assisting those living with HIV in self-care and other day-to-day activities that can minimize the impact of the virus on their health through partnerships and networking. Rehabilitation professionals play a key role in accurately assessing and addressing the complex disabilities people living with HIV may experience.

At the national level, lack of service provision for persons with disabilities within the HIV/AIDS programme has been one of the gaps identified in a proposal for the Global Fund. In 2005, the NFPDN started several new initiatives to educate its members about HIV/AIDS, including a peer education programme and a training programme for HIV/AIDS counselors. Groce advised that the goal of a partnership building strategy in responding to this challenge is to scale up solidarity for HIV and AIDS responses for PWDs in Africa and beyond (Groce, 2004). The objectives of this strategy include; building the critical constituency or alliances for advocacy and influencing for inclusive policy, decision making, programming and legislation on disability and HIV and AIDS, building solidarity among all actors in response to HIV/AIDS and disability, promoting services needed by enhancing learning and information exchange among stakeholders, optimizing usage of the scarce resources available in the disability and HIV/AIDS sectors, and building synergy among stakeholders to avoid duplication of efforts. At the heart of this process is the

empowerment of the PWDs communities, their ownership and control of their own endeavors and destinies, Ndeezi (2004) called this ‘solidarity not charity or pity.

### **2.5.2 Participatory service delivery**

Governments generally have traditionally given disability very low priority. For instance, the Kenyan National condom policy and strategy clearly states its target groups to be youths aged 15-24, sex workers, people living with HIV/AIDS and “people who frequent bars and other drinking places” (Ministry of Health, 2001: 5). In this way, persons with disabilities, also a sexually active group and therefore as much at risk of contracting HIV/AIDS are invisible, (Miles, 1999). This study therefore promotes the view that while it is crucial that excluded groups are integrated, the root causes must be understood before more immediate symptoms can be dealt with in relation to how persons with disabilities are excluded in reference to HIV/AIDS. Miles’ view was supported by those in favor of mainstreaming disability programmes of international development agencies. This might help the fight against HIV/AIDS given that “*traditional coping mechanisms to combat HIV/AIDS- related disasters have been stretched to breaking*’ (Nganwa et al, 2002: 186).

To further campaigns on HIV/AIDS and disability while drawing from the UN convention, a number of countries have joined regional campaigns to advocate for the inclusion of disabled persons and their rights into existing health related protocols. The objective of these campaigns is to ensure equal access to HIV information and services, and to coordinate national HIV/AIDS policies and programmes. For instance in Africa, the African Campaign on HIV/AIDS and disability has been established to advocate for the inclusion of disabled persons in health related matters. This campaign has brought together a number of African countries including Algeria,

Cameroon, Congo, Ethiopia, Kenya, Malawi, Namibia, Nigeria, Rwanda, South Africa, Swaziland, Tanzania, Uganda and Zimbabwe. Particularly in Zimbabwe, a study by Nganzi and Matonhodze (2004) found out that the majority of respondents (80%) were not aware of any policies related to disability and HIV/AIDS. However, (20%) knew about the disability policy, they talked of non-discrimination as the key issue in the policy but they said it was not addressing HIV/AIDS issues. All the respondents were not aware of the National HIV/AIDS Policy.

An analysis of the national AIDS policy revealed that there is no mention of the disability issues in relation to HIV/AIDS. To integrate PWDs in HIV/AIDS management would require that we draw on their existing human and material resources to enhance self-help and social support, and develop flexible systems for strengthening their visibility, participation and direction of health and in particular HIV/AIDS matters. This requires full and continuous access to information, learning opportunities for health and funding support. Thus, a lot of caution is called to interpret and assess ‘exclusions and ‘inclusions of PWDs in health settings. UN Convention on the Rights of Persons with Disabilities was developed in 2006 and it marked a “paradigm shift” in attitudes and approaches to PWDs. The Convention was intended as a human rights instrument with an explicit, social development dimension. It adopts a broad categorization of PWDs reaffirming that all PWDs must enjoy all human rights and fundamental freedoms. It clarifies and qualifies how all categories of rights apply to PWDs, identifies areas where adaptations have to be made for PWDs to effectively exercise their rights ,areas where their rights have been violated, and where protection of rights must be reinforced (United Nations Enable, 2006).

In a study done by Nganzi and Matonhodze (2004), many PWDs expressed that mainstream HIV messages and services were unlikely to reach the majority of PWDs living in Nagaland and

Manipur. Various reasons were cited, e.g., being 'hidden' and housebound, the role of gatekeeper, non-engagement in the community, perceived inconvenience or stigma related to seeking services, and type of disability. It was suggested that an outreach service may be an appropriate way to identify PWDs in the community and educate and develop trust with gatekeepers, who play a crucial role in providing access, as well as protection for the most vulnerable PWDs. In addition, most persons with hearing disabilities in these states cannot read or use sign language; service providers felt simple visual materials and education of gatekeepers were most desirable. The high rate of illiteracy among PWDs in general creates a need for varied and creative approaches. Silver makes the point that “*exclusion arises from the interplay of class, status and political power*”, meaning that the excluded are both “outsiders and dominated” (Silver 1994:543, emphasis added).

Whilst literature on disability generally focuses on the place of disability in more broadly, very recent research has indicated that the relationship between HIV/AIDS and the social exclusion of disabled persons exist and is worth for further study. This is exemplified in a comparative study of disabled and non-disabled youths in Uganda and Rwanda (Yousafzai and Edwards, 2004). The study focused on the difference in knowledge concerning HIV/AIDS between the two groups. Its conclusions were that the disabled youths in these countries are in need of much more HIV/AIDS IEC and this is supported by the research in Swaziland (Yousafzai et al, 2004) of disabled persons’ perceptions regarding HIV/AIDS.

## **2.6 Conclusion**

From the literature review, it is apparent that PWDs are less likely to seek for HIV/AIDS services because of a complexity of factors like socio-cultural factors, competence of service providers and modes of service delivery. It has also been mentioned that accessibility of these services by PWDs has posed a great hindrance for PWDs to seek for these services because of mobility problems.

However, much as the Literature shows some good experience in studying factors affecting the delivery of HIV/AIDS amongst PWDs in general, nothing much has been mentioned about the factors responsible for the low uptake of HIV/AIDS services by PWDs.

# **CHAPTER THREE**

## **METHODOLOGY**

### **3 Introduction**

This chapter presents the methods that were used in this study as well as the systematic approach and underlying procedures in the research process. The chapter covers the research design, study area and location, study population, sample size and selection, sampling techniques and procedures, data collection methods and instruments, validity, reliability, and data analysis.

#### **3.1 Research Design**

The study used a descriptive cross-sectional survey design to collect information from a sample of the population. According to Neuman (2000), a cross sectional survey design is simple, less time consuming and usually cheaper. According to Ezean (1998), the purpose of descriptive surveys is to collect detailed and factual information that describes an existing phenomenon. The study combined both qualitative and quantitative approaches. In qualitative approach, the researcher explored using key informant interviews and observation check list while in the quantitative approach, questionnaires were administered.

#### **3.2 Location of the study**

The study covered the three sub counties of Nyangahya, Mirya and Masindi town council in Masindi district. These included three health care institutions i.e. TASO Masindi branch, Joint Clinical Research Centre (JCRC) and Masindi main Hospital. The selection of these health



institutions was because they provide HIV/AIDS services including, psychosocial support, counseling, food support, treatment and antiretroviral therapy (ART).

### **3.3 Study population**

The primary population consisted of PWDs including: visual and physical disabilities. The researcher only included those who could speak and communicate well using sign language. The key informants included; HIV Counselors, Nurses, PWDs living with HIV/AIDS by virtue of their designation and experience, District HIV/AIDS focal person, Medical Superintendent, HIV/AIDS Clinic In-charge, Medical coordinators, Client council members, and Counseling coordinators.

### **3.4 Sample size and selection**

At the time of data collection, there were 317 registered PWDs according to Masindi District 5-Year Development Plan of 2005. However, in the three sampled sub counties of Nyangahya, Mirya, and Masindi town council, there were 140 PWDs registered according to these registers. According to Sekaran (2003), a sample is selected based on the experience and knowledge of the group. Therefore, the key informants were purposively selected, using purposive sampling technique; the researcher chose informants that were thought of to have the required information with respect to the objective of the study.

**Table 3.1: Showing research respondents by category, sample size and sampling techniques**

<b>Respondent category</b>	<b>Target population[N]</b>	<b>Sample size [S]</b>	<b>Sampling techniques</b>
PWDs	140	103	Systematic sampling
TASO Staff	30	20	Purposive sampling
JCRC Staff	14	10	Purposive sampling
Masindi Hospital	12	8	Purposive sampling
DDHS	10	6	Purposive sampling
<b>Total number of respondents</b>	<b>TOTAL [N] =206</b>	<b>TOTAL [S] =147</b>	

The sample size was determined using Kish and Leslie (1965) a formula for calculating sample size for cross-sectional survey.

$$n = \frac{N}{1 + N(e)^2}$$

Where, n is the sample size,

N is the accessible population,

e is the level of significance, (Mugenda and Mugenda, 2003 pp44).

Therefore; if

$$N = 206$$

e = 0.05 or 5% level of significance (Margin of error)

Therefore, the sample size for the study will be calculated as below;

$$n = \frac{206}{1 + 206(0.05)^2}$$

$$n = \frac{206}{1 + 206 * 0.0025}$$

$$n = \frac{206}{1.515}$$

$$n = 136$$

Therefore, the target population is 206 from all the categories listed above but the total accessible population is 136 respondents for all categories as shown above.

### **3.5 Sampling techniques and procedure**

Out of 103 PWDs that were sampled for the study, 92 respondents representing 65.7% were successfully interviewed, and the balance of 11 respondents that were not interviewed had special cases like some being mentally disturbed and others had communication barriers. The key informants were purposively selected from TASO, JCRC, and Masindi hospital and DDHS. The researcher chose informants that were thought to have the required information with respect to the objectives of the study. As noted by Sekaran (2003), that a sample is selected based on experience and knowledge of the group. The key informants included medical practitioners, counselors' administrators and clients' council members by virtue of their designation and experience. Using Snowball sampling technique, the researcher involved key informants to identify others who were contacted to provide enhanced information in regard to aspects of interests in this study.

Using quota sampling technique, the population was divided into sub populations such that the elements within each sub population were homogeneous giving the researcher an opportunity to access information from a well-defined representation of the quotas in the table below.

**Table 3.2: Number of PWDs by Sub County**

<b>Sub-County</b>	<b>No. of PWDs</b>
Nyangahya	46
Miirya	42
Masindi Town council	52
Sub-total	140 PWDs

The various sample size in the strata shall be proportionately determined from the total sample size as calculated below;

Nyangahya sub county  $46/140*92 = 33$  respondents.

Mirya sub county  $42/140*103 = 30+2=32$  respondents

Masindi town council  $52/140*103 = 38$  respondents

Total = 103 Respondents

### **3.6 Data collection methods**

Data collection methods used included use of questionnaires, key informants interviews, and observation.

### **3.7 Data collection instruments**

#### **3.7.1 Questionnaire**

These were used to gather responses from 103 PWDs. Some questions were translated into the local dialects (Runyakitara) because some respondents were more conversant with their mother tongue than English, and sign language was used for some respondents with speech/hearing disability. The questionnaires were the most convenient way of collecting quantitative data within a short time from a large number of respondents.

### **3.7.2 Key informant interviews guide**

The interview method was suitable because of the qualitative nature of the study. It provided in-depth data which complimented quantitative data and risks of confusing questions were minimized and it was flexible to suit the situation as pointed out by Sekaran (2003). Interviews were conducted to gather qualitative data using a semi-structured key informant interview guide from 20 staff from TASO Masindi, 10 staff from JCRC, 8 from Masindi hospital and 6 from Director of District health services (DDHS). This method was instrumental and allowed flexibility of the members to freely discuss issues under the study and allowed frankness, sincerity, truthfulness and the researcher discussed meanings to the questions to eliminate ambiguity and this provided an opportunity to correct any misunderstandings by some respondents.

### **3.7.3 Observation check list**

Observation was also employed to enrich data that was collected using the above two methods, using the observation checklist (Appendix V). The method was used at service centers to observe what PWDs go through while accessing services like Medication, Counseling and Treatment. This provided the researcher an opportunity to compare data collected using other methods and what actually PWDs went through and the existing structures independent of the participants.

## **3.8 Validity of research instruments**

Validity of the instruments was ensured through discussing with colleagues especially counselors, medical officers, pilot respondents and fellow participants of Masters of Management studies about what the instruments intended to measure by asking them whether these instruments were designed to capture the required data. De Vos (2002) describes content validity as a judgmental

process whereby colleagues establish the validity of the content. To enhance validity, vague questions like unnecessary open/close ended questions were removed and comments and suggestions given by the respondents during the pre-test were considered and incorporated. More so, deficiencies in the questionnaire like insufficient space to write the responses were reviewed and corrected before the data collection exercise.

### **3.9 Reliability**

Reliability describes the degree of consistency or agreement between two independently derived set of scores and the extent to which independent administrations of the same instrument yield the same (or similar results) under comparable conditions, (De Vos, 2003:168). To ensure reliability of the instruments, questionnaires and interview guide were designed and pre-tested at TASO Masindi during the clinic days and their characteristics were thought to be a good representative of PWDs in Masindi district. A test-retest was done in time lapse of 2 weeks to establish consistence in responses. Amin (2005) ascertains that test-retest reliability can be used to measure the extent to which the instrument will produce consistent scores when the same group of individuals is repeatedly measured under the same conditions. The results from the pretest were used to modify the items in the instruments.

### **3.10 Procedure of data collection**

A researcher obtained a letter from the Uganda Management Institute introducing her to health institutions identified and Masindi district officials seeking permission to allow the researcher to carry out research study in Masindi district (Appendix V1). All questionnaires had an introductory section explaining the purpose of the study in order to encourage respondents to cooperate. The

respondents were informed of the significance of the study, and the confidentiality of the information they provided. Two research assistants were recruited and taken through basic training for two days. The questionnaires were administered to individual respondents and those who were not conversant in English were guided by the research assistants and those who needed a sign language interpreter were handled by the researcher herself. An average of 5 key interviews lasted about thirty minutes each and these were conducted on one to one basis by research assistants while other key informant interviews were given to respondents to fill them at their own free time and were collected later on by the researcher herself. The researcher also used observation check list to visit the health centers used for the study and findings were noted in the note book.

### **3.11 Statistical analysis strategy**

Data was analyzed using both qualitative and quantitative methods.

#### **3.11.1 Qualitative Data Analysis**

Qualitative data from the key informant interviews and observation check lists was arranged into themes according to the stated research objectives. Information of the same category were assembled together in a summary report and interpreted by composing explanation or description from the responses. A content analysis process was used to identify main ideas, recurring themes and relationships between concepts and was presented in a narrative form.

#### **3.11.2 Quantitative Data Analysis**

Quantitative data from questionnaires was sorted, classified and computed into percentages and frequency distribution tables to interpret the results. This involved use of a software called Statistical Package for Social Scientists (**SPSS 10.0**), the most recommended data analysis

package (Amin, 2005). Data collected was analyzed under themes based on objectives of the study. Descriptive statistics was involved using percentages used to study the relationships between the independent variables and dependent variable. Pearson's correlation coefficient R was used to determine the direction and relationship of the variables and a significance of  $p = 0.05$  which is generally acceptable in conventional level in social research. R square ( $R^2$ ), refers to the amount of variations explained by the independent variable or variables and explains the proportion of the total variability in the dependent variable that can be explained by the independent variables. In addition, a regression analysis was determined to show which of the components of the constructs had a stronger relationship and to establish whether the independent variables would predict the dependent variable using coefficient determination ( $R^2$ ).

### **3.12 Feel for the data**

To have a feel for the data, the researcher established the mean and standard deviation to generate an idea how the respondents reacted to the items in the questionnaires. With the use of frequency distributions, visual displays were generated through histograms, bar graphs and pie charts. On the whole, this helped the research to obtain the range, dispersion levels and variances within variables.

### **3.13 Ethical Considerations**

This study was approved by the higher degrees department of Uganda Management institute (UMI). The following ethical issues were taken into consideration when conducting this study. Clear explanation of the purpose and objectives of the study was given to the respondents to avoid misinterpretation or misunderstanding and all information gathered was handled with utmost



confidentiality. Participation in the study was voluntary and oral and written consents of Health Workers and disabled persons in the different research settings were sought and obtained. Their respective approvals enabled the researchers to collect information uninhibited.

# CHAPTER FOUR

## PRESENTATION, ANALYSIS AND INTERPRETATION

### 4.0 Introduction

This chapter presents the research findings, the response rate, analysis and interpretation in the context to the objectives, research variables and research hypotheses as they were presented at the beginning of the study. The general objective of the study was to examine the factors affecting the delivery of comprehensive HIV/AIDS services amongst PWD in Masindi district.

In order to provide focus and direction, null hypotheses were formulated in relation to specific objectives;

*Ho 1: There is no relationship between social cultural factors and the delivery of comprehensive HIV/AIDS services amongst PWDs in Masindi district.*

*Ho 2: There is no relationship between competence of service providers and delivery of comprehensive HIV/AIDS services amongst PWDs in Masindi district.*

*Ho 3: There is no relationship between modes of service delivery and delivery of comprehensive HIV/AIDS services amongst PWDs in Masindi district.*

### 4.1 Response rate

The response rate is the frequency or proportion of respondents in relation to the whole. A total of 103 questionnaires were issued to the sampled PWDs in the selected three sub-counties of Nyangahya, Mirya and Masindi town council. Out of 103 questionnaires, 92 were filled correctly,

and were valid and usable. This great success was attributed to research assistants who were able to probe clearly and explain to the respondents the questions and the willingness of PWDs to participate in the study. However, 11 respondents out of 103 were unable to respond to questions correctly because of their conditions, and some of these were mentally ill so these questionnaires were discarded.

## 4.2 Social-Demographic characteristics of respondents

The demographic characteristics of respondents in the study included gender, age, educational back ground, monthly incomes, place of residence, type of disability and health services ever received.

### 2.2.1 Age and Gender distribution of respondents

**Table 4.1 showing the distribution of respondents by age and gender.**

Age	Gender		Total
	Male	Female	
Below 20 yrs	12.0%(11)	5.4%(5)	17.4%(16)
21 - 30 yrs	20.7%(19)	22.8%(21)	43.5%(40)
31 - 40 yrs	13.0%(12)	9.8%(9)	22.8%(21)
Above 40 yrs	5.4%(5)	10.8%(10)	16.3%(15)
<b>Total</b>	<b>51.1%</b>	<b>48.8%</b>	<b>100.0%</b>

According to table 4.1 above, it was established that the majority of the respondents i.e. 43.5%(40) were in the age bracket of 21-30 years and among these, females were 22.8%(21) and men were 20.7%(19). The fact that the majority are in this age group which is the reproductive age, this means that most of them could be sexually active which could put them at the risk of acquiring

HIV or spreading it to their partners. The second largest were in the age bracket of 31-40 years and men were the majority 13.0%(12), and females were 9.8%(9) of the respondents which is still the age group that could be engaging in sexual activities for reasons like producing children and seeking for financial support. The third category of respondents were below 20 years of age and among these, males were the majority with 12.0%(11) years and females were 5.4%(5), some of these have already engaged in sexual activities and others may be taken advantage of by people who live around them hence need HIV IEC materials to better prepare them for safer reproductive health and HIV/AIDS prevention strategies. The least number of respondents were in the age group of 40 and above and they were made up of 5.4 %( 5) males and 10.9 %( 10) females. Most of these are care takers of others including HIV patients and therefore would need preventive measures to better take care of HIV/AIDS patients without contracting it, others are still sexually active and would need HIV/AIDS IEC materials packaged in the best way they would understand them.

#### 4.2.2 Education level of respondents

**Table 4.2 Distribution of respondents by Education**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	None	4	4.3%	4.3%	4.3%
	Primary	19	20.7%	20.7%	25.0%
	Secondary	29	31.5%	31.5%	56.5%
	Vocational	22	23.9%	23.9%	80.4%
	University	17	18.5%	18.5%	98.9%
	Post graduate	1	1.1%	1.1%	99.9%
	Total	92	99.9%	99.9%	

From table 4.2 above, it was established that the majority 31.5%(29) of the respondents had reached secondary level, which means that these could use HIV/AIDS IEC materials if they are packaged in the best way they understand them. These were followed by 23.9%(22) of the respondents who had finished vocational training; still these ones are capable of understanding the HIV/AIDS messages if they are conveyed in the way they understand like use of sign language for the deaf and braille for the blind. Those who had stopped in primary level were 20.7 %(19) and 4.3%(4) of respondents did not go to school; these may need information that is interpreted well to suit their level of understanding. 18.5%(17) had gone up to the university level and 1.1%(1\_ of respondents made it to a post graduate level and these have a lot of knowledge about HIV/AIDS though they need information regarding the importance of seeking for HIV/AIDS care and prevention. It was thought that low levels of education among some PWDs were directly proportional to the level of incomes as indicated in table 4.3 below. Since assessment of risk is likely to depend on the quality of ones' knowledge about HIV, the results were of interest predicting the likely trend of HIV infections among PWDs.

#### 4.2.3 Monthly incomes of respondents

**Table 4.3: Showing distribution of respondents' monthly incomes**

	Monthly incomes	Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Less than 50,000	13	14.1%	14.1%	14.1%
	50,000 -100,000	25	27.2%	27.2%	41.3%
	100,000- 500,000	35	38.0%	38.0%	79.3%
	500,000-1,000,000	19	20.7	20.7%	60.4%
	<b>Total</b>	<b>92</b>	<b>99.9%</b>	<b>99.9%</b>	<b>99.9%</b>

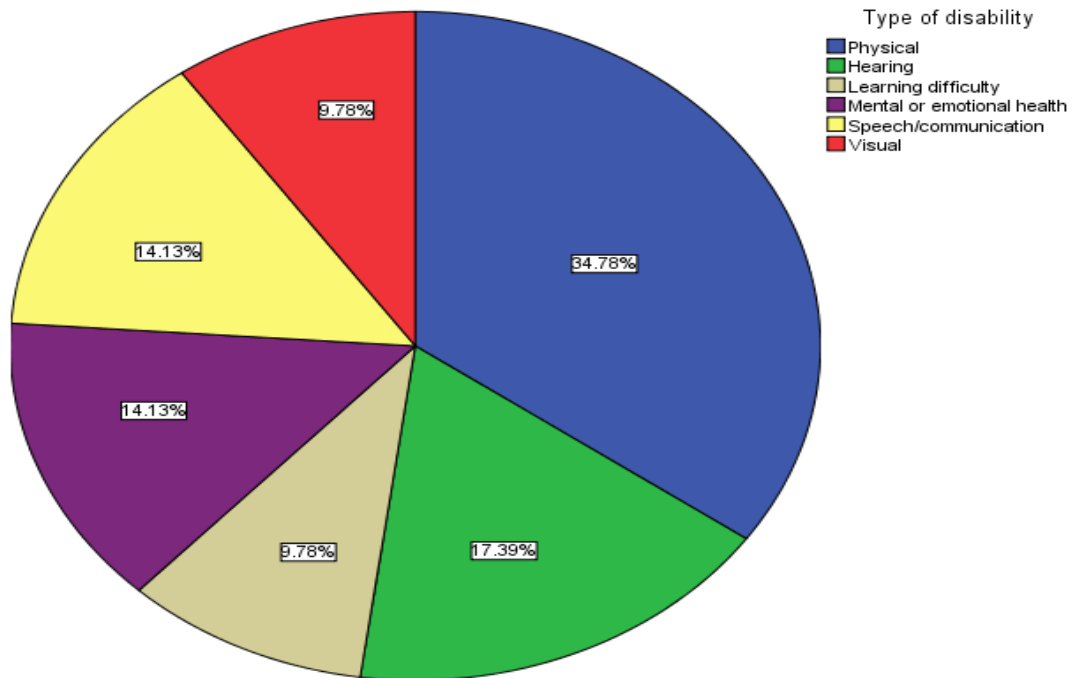
Table 4.3 indicates that the majority of the respondents i.e. 38% (35) were earning between 100,000 -500,000/ per month, most of these were graduates and were employed in some organizations in Masindi and could easily access HIV/AIDS services. These were followed by 27.2%(25) of respondents who were earning between 50,000 -100,000/ monthly and most of these had stopped in primary school and were engaged in small scale enterprises like making local brew and selling food stuffs by the roadside for a living, these ones find it a bit challenging to seek for HIV/AIDS services because of accessibility problems and low incomes they get per month. 20.7% (19) were earning between 500,000-1,000,000/ in a month, most of these have families and find it easy to access HIV/AIDS services. 14.1%(13) of the respondents were earning less than 50,000/, most of these were engaged in activities like begging, carrying people’s luggage and some were totally depending on their families and care takers. These found it hard to reach the health centers because of accessibility problems, having low or no incomes of their own to transport them and fear of negative attitudes of service providers and therefore they had little or no information regarding HIV/AIDS prevention and care services.

**Table 4.4: Distribution of PWDs respondents by the place of residence in Masindi district**

Valid	Place of Residence	Frequency	Percent	Valid Percent	Cumulative Percent
	Urban	39	37.8%	37.8%	75.6%
	Peri-urban	39	37.8%	37.8%	75.6%
	Rural	25	24.3%	24.3%	48.6%
	Total	103	99.9%	99.9%	

Table 4.4 shows that 37.8%(39) of the respondents were residing around Masindi town and these were carrying out businesses like local brew selling, food stuffs and some women revealed that they were depending on the little incomes they got from men as a result of exchange for sex. 37.8% (39) of the respondents were staying in the peri-urban areas of Masindi town and most of these depended on agricultural activities where they sold some of the produce for a living. 24.3% (25) of the respondents were residing in the rural areas in Masindi district and totally depended on agricultural activities, others were total dependents on their families and caretakers and could not afford to do anything on their own because . According to the research findings, the majority were staying around Masindi town where most of them were carrying out small scale businesses such as shoe repairing, tailoring, prostitution and local brew selling for a living.

**4.2.5: Figure 1.2 showing distribution of respondents by type of disability**



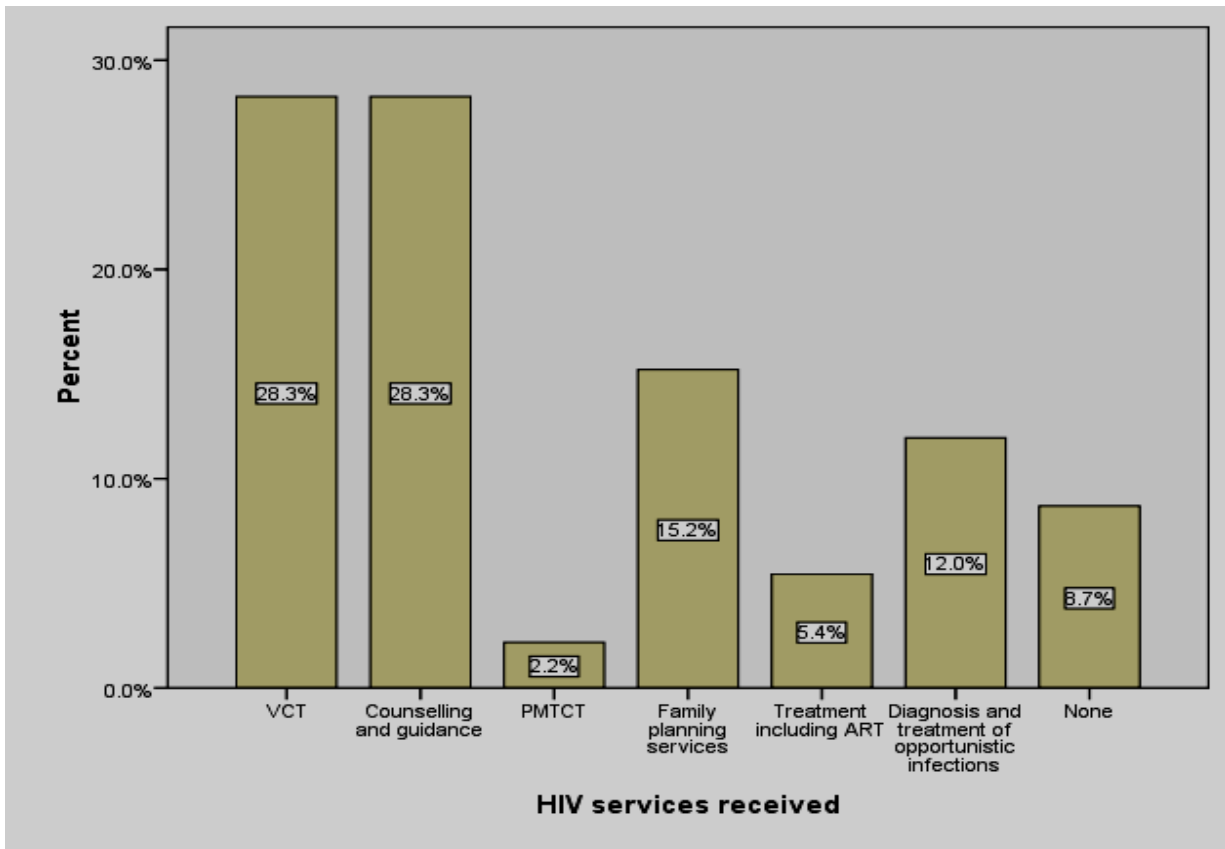
**Figure 1.2: Showing the type of disability**

From the above figure 1.2, the majority of the respondents i.e. 34.78% (32) had a physical disability which means that mobility to health units could be a challenge if they are not supported by their caretakers; unfortunately, some of these caretakers believe that since PWDs are not sexually active, they may not need HIV/AIDS services like VCT and prevention messages. 17.39%(16) had a hearing disability which means that they may needed a sign language interpreter in order to receive HIV/AIDS prevention and care services at Health units they visit, however, research findings found out that most health providers have no skills in sign language and give general care and treatment without giving special attention to these PWDs' needs.

Even while prescribing for them treatment, it was found out that most times service providers guess the kind of illness they may be having which sometimes may not be right. 9.78% (9) had a learning disability, which means that they would need a lot of patience while giving them care and treatment, however, research has found out that most service providers have no such time to dedicate to such people because of overwhelming numbers that turn up on clinic days. 14.13% (13) had a mental or emotional disability which means that they would also need more patience and skills while caring for them which most health providers don't have. 14.13% (13) had a speech/communication disability and also needed a lot of attention and sometimes a sign language interpreter to convey the message to them, while 9.78% (9) had a visual disability which meant that they would need a guide to reach health centers and those who failed stayed in their homes with no care and information regarding HIV/AIDS.



#### 4.2.6: Distribution of respondents by type of service



**Figure 1.3: Type of services**

From figure 1.3 above, 56.6% (52), the majority of the respondents received VCT and Counseling and guidance services, which meant that of the PWDs who managed to reach health units, the majority sought for VCT services and counseling and guidance services. 15.2% (14) sought for Family planning services which confirmed that PWDs are also sexually active contrary to the research findings that some service providers and community members believed that PWDs were not sexually active. 12.0% (11) sought for diagnosis and treatment of opportunistic infections which means that these had tested HIV positive and were already receiving care and treatment including prophylaxis. 5.4% (5) were already enrolled on ART and needed a lot of support in

order to adhere on these drugs, and 2.2 % (2) were receiving PMTCT which means that they were either in a relationship or were already and could infect their babies with HIV if they didn't take precaution. 8.7% (8) had never received any of these HIV/AIDS services, therefore were at a great risk of catching HIV and spreading it to their partners without even knowing and in the end die without any HIV/AIDS care and treatment.

### 4.3 The impact of social-cultural factors on delivery of comprehensive HIV/AIDS services

#### Objective 1

The first objective was to assess the effect of social-cultural factors on the delivery of comprehensive HIV/AIDS services to PWDs in Masindi district. Social-cultural dimensions were poverty, stigma and discrimination and the results from the respondents are presented in table 4.4 below:-

**Table 4.5: Response on the social cultural factors**

<b>Factors</b>	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Not sure</b>	<b>Agree</b>	<b>Strongly agree</b>	<b>Total</b>
<b>Poverty</b>						
Poverty predisposes PWDs to HIV infection	0.0%(0)	1.1%(1)	6.5%(6)	48.9%(45)	43.5%(40)	100%(92)
Poverty leads PWDs not access education	1.1%(1)	6.5%(6)	9.8%(9)	53.3%(49)	29.3%(27)	100%(92)
Poverty increases risky sexual behaviors amongst PWDs	3.3%(3)	13.0%(12)	16.3%(15)	46.7%(43)	20.7%(19)	100%(92)
<b>Stigma and Discrimination</b>						
Society looks at PWDs as objects of pity and hopeless	0.0%(0)	12.0%(11)	4.3%(4)	55.4%(51)	28.3%(26)	100%(92)
PWDs not involved in society activities due their disabilities	6.5%(6)	23.9%(22)	7.6%(7)	51.1%(47)	10.9%(10)	100%(92)
PWDs are given info regarding condoms use and reproductive health	3.3%(3)	9.8%(9)	7.6%(7)	56.5%(52)	22.8%(21)	100%(92)

In the table 4.5 above, the majority of respondents, 92.4 % (85) agreed that poverty predisposes PWDs to HIV infection. Only 1.1% (1) was in total disagreement to the statement, and 6.5% (6) of the respondents were not sure. Results further showed that the majority of respondents 82% (76) believed that poverty leads PWDs not accessing education while only 7.6% (7) disagreed with the statement and 9.8% were not sure. Further, the results showed that the majority of respondents 67.4% (62) agreed that poverty increases risky sexual behaviors as opposed to 16.3% (15) who disagreed with the statement and 16.3% (15) were not sure. The above results imply that the majority believed that poverty as a social-cultural factor has contributed to PWDs failing to acquire education and which in return has led them in engaging in risky sexual behaviors which has exposed them to high HIV infection.

From table 4.5 above, the majority of respondents 83.7% (77) believed that the society looks at PWDs as objects of pity and hopeless as opposed to 12.0% (11) who disagreed and 4.3% (4) were not sure. The results further showed that the majority of the respondents 62% (57) agreed that PWDs are not involved in society activities due to their disabilities as opposed to 30.4 (28) who disagreed with the statement and 7.6% (7) of respondents were not sure. Finally, table 4.4 shows that 79.3% (73) the majority of the respondents agreed that PWDs are given information regarding condom use and reproductive health, the minority of respondents 13.1% (12) disagreed and 7.6% (7) were not sure and these were mostly the deaf/dumb clients who wouldn't hear the information that was given at health units.

### **Hypothesis testing**

The first objective was to assess the effect of social-cultural factors on the delivery of comprehensive HIV/AIDS to PWDs in Masindi district. The degree of strength and the direction

of the relationship were determined using Pearson’s correlation coefficient as presented in table 4.6 below.

**Table 4.6 Correlations Matrix for social-cultural factors and dependent variable**

		Delivery of comprehensive HIV/AIDS services	social cultural factors
Delivery of comprehensive HIV/AIDS services	Pearson Correlation	1.000	.283**
	Sig. (2-tailed) N	. 92	.006 92
social cultural factors	Pearson Correlation	.283**	1.000
	Sig. (2-tailed) N	.006 92	. 92
** Correlation is significant at the 0.01 level (2-tailed).			

From table 4.6 results showed a correlation coefficient of 0.283 at the level of significance of 0.006 and this shows that there is a significant positive relationship between social cultural factors and delivery of comprehensive HIV/AIDS services. The results showed that poverty, stigma and discrimination negatively affect the delivery of comprehensive HIV/AIDS services among PWDs in Masindi district. Therefore, the null hypothesis was rejected and the alternative hypothesis substantiated.

Further analysis was done using a regression to determine the strength of this relationship and to show how much of the variance in the dependent variable would be caused by social-cultural factors as illustrated in table 4.7 below.

**Table 4.7 Regression output summary on social-cultural and delivery of comprehensive HIV/AIDS services**

**Model Summary**

	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
Model					R Square Change	F Change	df1	df2	Sig. F Change
1	.283	.080	.070	.5406	.080	7.818	1	90	.006
a Predictors: (Constant), Social-cultural factors									

The coefficient of determination (adjusted R square) of 0.070 shows that social-cultural factors explain 0.7% of the variance in delivery of comprehensive HIV/AIDS services to PWDs at the significant level of 0.006. This is in disagreement with the null hypothesis that was projected and therefore the alternative hypothesis substantiated

During the interviews with key informants, it was pointed out that poverty predispose PWDs to HIV/AIDS especially disabled women who have many partners who use them sexually by giving them a small token as a means of survival but some of these partners usually do not use condoms believing that PWDs women are less sexually active and free from HIV infection. The key informants also agreed that poverty limits persons with disabilities who may wish to have an HIV test because they do not have money to transport them to the health units providing such services and as a result they do not seek for these services because of accessibility problems. This was in line with 92.4% (85) the majority of the respondents who strongly agreed that indeed poverty predisposes PWDs to HIV/AIDS because many of them who do not access such services like information and care leave in ignorance and suffer with the disease. The majority of the key informants also reported that there is a negative mentality towards persons with disabilities in the communities they lived in. Key informants pointed out that even in health units where PWDs go

for such services like HIV blood test or buying condoms, some service providers still take it to be strange and believe that PWDs could not be sexually active and needed no condoms for protection or HIV test. This is in agreement with Yousafzai and Edwards (2004, 42-57) that people take it for granted that issues concerning protection and prevention are for non-disabled and yet persons with disabilities are also human beings and are sexually active.

It was further highlighted by the majority of the key respondents that disabled women in Masindi were known to have multiple partners and most cases do not use condoms. During the individual sessions with the PWDs, one disabled lady acknowledged that *“I have been involved with several men, but I have never used a condom, the men who have sex with me do not want to use condoms”*. Indeed, some respondents mentioned that even those women who decided they do not want to be sexually active, they may be forced into it as a livelihood because of poverty. The reality of unprotected sex can result into a disabled person involved wish to have a test but may not afford it. For example, another disabled female stated that *“sometimes even the disabled persons wish to go for HIV/AIDS testing but they don’t have money for transport”*. Similarly, deaf persons reported that they resist going to hospital because they would need an interpreter, whom they may not ably get because sometimes their caretakers are too busy and hiring someone to go with is costly, consequently many either diagnose themselves or use some form of medication. This indicates that access to HIV/AIDS resources for people with disabilities is inadequate.

In addition, the clients’ council chairperson at TASO Masindi commented that he believed the attitudes of the service providers was a hindrance for PWDs seeking for HIV/AIDS services and gave an example that; *“One day, there was an HIV testing and sensitization in the nearby village, then a crippled woman went to test her blood and the nurse told her that she was not going to test*

*her blood because she was lame and couldn't have sex to get exposed to HIV*". This was in agreement with 83.7% (77) of respondents who believed that society looks at them as objects of pity and 42.4% (39) of the respondents said that PWDs were prohibited from seeking HIV/AIDS services by their families and care givers because they believed they were not sexually active. The findings stressed how attitudinal discrimination was a significant factor in preventing disabled people from accessing facilities they need in order to get HIV/AIDS information, care and treatment.

Following the observation checklist, the researcher observed that there was a general VCT register book for all clients who visited all of the health units i.e. TASO, JCRC and Masindi hospital for HIV tests, care and treatment. Unfortunately the information asked at registration was not capturing the different types of disabilities that some clients may have had for better management. This implies PWDs with special needs like sign language interpreters and ramps for wheel chair users were not put into consideration. Therefore, the health facilities were not user friendly to some PWDs who needed such special care, and the toilet facilities were not accessible to some PWDs hence some may fear to visit such health units for fear of being stigmatized and not being helped. Therefore, physical access to HIV/AIDS information venues is clearly a problem like one respondent put it that; *'Your movement may be difficult, some of the paths are also difficult to locate, you cannot pass there without a guide and this has made it difficult to get to the centers'*.

#### 4.4 The impact of competence of service providers on the delivery of comprehensive HIV/AIDS services

##### Objective 2

The second objective was to assess the impact of competence of service providers on the delivery of comprehensive HIV/AIDS services amongst PWDs in Masindi district. Competences of service providers' dimensions were skills e.g. sign language and perceptions of service providers.

**Table 4.8: Response on the competence of service providers**

<b>Factors</b>	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Not sure</b>	<b>Agree</b>	<b>Strongly agree</b>	<b>Total</b>
<b>Skills e.g. sign language</b>						
Health providers put into consideration the needs of PWDs	4.3%(4)	30.4%(28)	13.0%(12)	44.6%(41)	7.6%(7)	<b>100%(92)</b>
Service providers have the knowledge and skills in HIV/AIDS	2.2%(2)	14.1%(13)	12.0%(11)	53.3%(49)	18.5%(17)	<b>100%(92)</b>
Service providers are able to communicate using sign language	3.3%(3)	16.3%(15)	26.1%(24)	42.4%(39)	12.0%(11)	<b>100%(92)</b>
<b>Perceptions of service providers</b>						
Attitude of service providers is a hindrance for PWDs to seek for HIV/AIDS services	5.4%(5)	38.0%(35)	18.5%(17)	23.9%(22)	14.1%(13)	<b>100%(92)</b>
Service providers willingly assist HIV/AIDS PWDs by giving them priority	7.6%(7)	16.3%(15)	15.2%(14)	45.7%(42)	15.2%(14)	<b>100%(92)</b>
Service providers willingly give out condoms to PWDs	6.5%(6)	23.9%(22)	12.0%(11)	34.8%(32)	22.8%(21)	<b>100%(92)</b>

**Source: Primary data.**



Table 4.8 shows that the majority of the respondents 52% (48) agreed that service providers put into consideration the needs of PWDs. However, a question remains, how do they do this when they are not capturing information about different disabilities and taking note of special needs of some clients at registration? Besides that do service providers have special skills like sign language to communicate with the deaf/dumb? 34.7% (32) of the respondents disagreed saying that service providers were not putting into consideration specific needs like use of sign language for the deaf hence they used guess work to treat such clients. 13.0% (12) were not sure which means that they were either keeping quiet about such things that affected them at the health units or they felt they had no choice but to take what they were given.

Furthermore, 71.8% (66) which is the majority believed that service providers have knowledge and skills in HIV/AIDS which means they were comfortable with the care and treatment the service providers were giving them. However, 16.3% (15) of the respondents disagreed with the statement saying that some service providers acted rudely and lacked skills to pass on information especially to the deaf and blind PWDs who needed more time and special care. Responses on the service providers having skills to communicate using sign language, 54.4% (50) agreed that service providers could be having special skills like sign language because they managed to treat the deaf/dumb, 19.6% (18) were sure that service providers didn't have such skills but just guessed and gambled whenever they were handling such clients and 26.1% (24) were not sure since each client would be handled alone in the medical /counseling rooms.

Table 4.8 further shows the responses on the perceptions of service providers, 38% (35) agreed that the attitudes of service providers were a hindrance for PWDs in seeking HIV/AIDS services since they believed that they would be blamed for having contracted the disease while the majority

of respondents 43% (40) disagreed that service providers' attitudes were not a hindrance and believed that they treated all patients the same way while 18.5% (17) were not sure and this could have been as a result of fear of being snubbed by service providers if they got to know that was how PWDs felt about their services.

Table 4.8 further shows that the majority of respondents 60.9% (56) of the respondents believed that service providers willingly assisted HIV/AIDS PWDs by giving them priority when they visited the health units, 23.9% (22) believed that PWDs were not given priority depending on their conditions but were treated like any other able bodied patient while 15.2% (14) were not sure of how are treated, this could be as a result of fearing to lose the relationship they had with some service providers who cared about them. The majority of the respondents 57% (53) strongly agreed that service providers willingly gave out condoms to all PWDs without questioning their ability to use them, while 30.4% (28) disagreed saying that some service providers believed that PWDs were not sexually active and only gave them condoms after a lot of probing to find out if they had sexual partners and would actually use them, 12.0%(11) of respondents were not sure about service providers' feelings as they gave them these condoms.

### **Hypothesis testing**

The second objective was to assess the impact of competence of service providers on the delivery of comprehensive HIV/AIDS services to PWDs. The dimensions were skills and attitudes of service providers and Pearson's correlation coefficient was used to establish the degree and the direction of the relationship as illustrated in table 4.8 below;

**Table 4.9: correlation matrix for competence of service providers and delivery of comprehensive HIV/AIDS services**

		Delivery of comprehensive HIV/AIDS services	competence of health providers
Delivery of comprehensive HIV/AIDS services	Pearson Correlation	1.000	.224*
	Sig. (2-tailed)	.	.031
	N	92	92
competence of health providers	Pearson Correlation	.224*	1.000
	Sig. (2-tailed)	.031	.
	N	92	92
* Correlation is significant at the 0.05 level (2-tailed).			

Results showed a correlation coefficient of 0.224 at 0.031 level of significant meaning that there is a weak but positive relationship between competence of service providers and the delivery of comprehensive HIV/AIDS services for PWDs in Masindi district. Since the results showed that the majority of the respondents 71.8% (66) believed that service providers have the knowledge and skills in HIV/AIDS and 60.9% (56) the majority of the respondents believed that service providers assisted PWDs by giving them priority when they visited health units, therefore the competence of service providers had an insignificant negative effect on delivery of comprehensive HIV/AIDS to PWDs in Masindi district.

Further analysis was done using a regression to explain how much the variance in the dependent variable would be caused by competence of service providers as illustrated in the table 4.10 below;

**Table 4.10: Regression out puts summary on competence of service providers and delivery of comprehensive HIV/AIDS services**

**Model Summary**

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. Change
1	.224	.050	.040	.5493	.050	4.775	1	90	.031
a Predictors: (Constant), competence of health providers									

From the regression analysis, the adjusted R<sup>2</sup> value of 0.040 implies that competence of service providers explains 4.0% of the variation in delivery of comprehensive HIV/AIDS services among PWDs in Masindi district at the level of significance of 0.031. Therefore, the null hypothesis was rejected and the alternative hypothesis was substantiated.

Information obtained from key informants however revealed that service providers have general skills to care for PLWHA like counseling and guidance but not specific skills like sign language to communicate with the deaf/dumb persons. However, this becomes a barrier to crucial information concerning HIV/AIDS for disabled persons especially the deaf. Indeed some key informants during the interviews agreed that it was common that the deaf persons in particular faced barriers specific to their impairments.

Although a counselor at TASO shared that the organization through partnership with NUDIPU and UNAD has trained two counselors in sign language who could ably communicate with the deaf/dumb clients using sign language, she noted that the challenge was that most deaf/dumb persons have not gone to school to learn these signs so communication was still hard with such

clients. A counselor at JCRC also noted that there was lack of confidentiality where by some PWDs were escorted by their caregivers in the medical/counseling rooms in order to support them and had to hear their issues which should have been kept to themselves which made them not comfortable; “*A deaf lady told us that...going for a test is not bad but you know the testing has to be secret, but by the time you go with the interpreter, then you are three people (you, counselor, and interpreter)*”. This implies that some PWDs especially the deaf/dumb do not come for HIV/AIDS because of lack of confidentiality which discourages them and they express their concerns that service providers carrying out HIV tests should at least be trained in sign language so that they give them results in privacy and also give them a chance to freely with them issues that may affect them as deaf/dumb persons.

During the key interviews, one of the respondents admitted that she was not providing information concerning HIV/AIDS to some PWDs because she felt they wouldn't need it since she believed they were not sexually active. This reinforced the idea of PWDs as passive recipients and the perceptions of service providers are a significant factor in preventing disabled persons from accessing facilities they needed. This was in agreement with 38% (35) of the respondents who agreed that the attitude of service providers was a hindrance for PWDs to seek for HIV/AIDS services.

The researcher observed that during the clinics, all clients were gathered in one waiting room where general HIV/AIDS information was given regardless of special needs of some clients like the deaf/dumb that wouldn't hear these messages and needed sign language interpreters. Therefore some PWDs felt that their only choice was to depend on general information, despite it being inappropriate to their peers.

**4.5. The impact of modes of service delivery and the delivery of comprehensive services HIV/AIDS services.**

**Objective 3**

The third objective was to establish the relationship between the modes of service delivery and the delivery of comprehensive HIV/AIDS services in Masindi district. The dimensions of modes of service delivery were partnership and networking and participatory service delivery.

**Table 4.11: Response on the effect of modes of service delivery**

<b>Factors</b>	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Not sure</b>	<b>Agree</b>	<b>Strongly agree</b>	<b>Total</b>
<b>Partnership and networking</b>						
CBOs help PWDs in building partnerships and networking	3.3%(3)	7.6%(7)	8.7%(8)	64.1%(59)	16.3%(15)	<b>100%(92)</b>
Public-private partnerships help make health care services accessible to PWDs	2.2%(2)	17.4%(16)	10.9%(10)	57.6%(53)	12.0%(11)	<b>100%(92)</b>
<b>Participatory service delivery</b>						
I am satisfied with the involvement of PWDs in the mainstream development issues	13.0%(12)	22.8%(21)	5.4%(5)	43.5%(40)	15.2%(14)	<b>100%(92)</b>
Existing policies are structured to ensure inclusion of PWDs	2.2%(2)	10.9%(10)	19.6%(18)	55.4%(51)	12.0%(11)	<b>100%(92)</b>

From table 4.11 above, results showed that the majority of respondents 80.4% (74) believed that CBOs were important in building partnerships and networking as opposed to 10.9% (10) of respondents who disagreed that CBOs were not important in building partnerships and networking, 19.6% (23) were not sure and these were basically getting services from government

health units where most services are still free with no user fee charged. This has an effect on the quality of services provided for instance when there are drug stock outs, some go without drugs and are referred to drug shops, since most of those who go for such free services are the poorest, they cannot afford to buy such drugs hence stay with their illnesses. Further results showed that 69% (64) believed that public-private partnerships were important in helping make health care services more accessible to PWDs and providing the necessary equipment like ramps for wheel chairs, training of service providers in special skills like sign language and making sure the all the drugs are available.

Table 4.11 also shows that 58.7% (54) agreed that they were satisfied with the involvement of PWDs in the mainstream development issues as opposed to 35.8% (33) of respondents who said that they were not satisfied and they expressed that the negative attitudes towards PWDs still existed and they were eliminated in certain activities thinking that they would not manage them because of being disabled. 5.4% (5) were not sure and 67.4% (62) believed that the existing structured policies ensured inclusion of PWDs needs and addressed their concerns though some were still not yet put in action. 13.1% (12) believed that existing structures do not ensure inclusion of all the needs of PWDs and the few that are included are not put in action. 19.6% (18) were not sure whether PWDs needs were included in the existing policies because they never have a chance to look at those policies but depended on general information they were given.

### **Hypothesis testing**

The third objective was to establish the relationship between modes of service delivery and delivery of comprehensive HIV/AIDS services to PWDs in Masindi district. The dimensions that were considered are partnership and networking and participatory service delivery. Pearson's

coefficient was used to measure the degree and the direction of the relationship as illustrated below in table 4.12.

**Table 4.12: Correlations matrix for modes of service delivery and delivery of comprehensive HIV/AIDS services**

		Delivery of comprehensive HIV/AIDS services	Modes of service delivery
Delivery of comprehensive HIV/AIDS services	Pearson Correlation	1.000	.112
	Sig. (2-tailed) N	. 92	.286 92
Modes of service delivery	Pearson Correlation	.112	1.000
	Sig. (2-tailed) N	.286 92	. 92

Results show a correlation coefficient of 0.112 which means that there is a weak but positive relationship between modes of service delivery and delivery of comprehensive HIV/AIDS services which is not statistically significant.

Further analysis was done using a regression to show how much of the variance in the dependent variable would be caused by modes of service delivery as explained in the table 4.13 below.



**Table 4:13: Regression out puts summary on modes of service delivery and delivery of comprehensive HIV/AIDS services**

**Model Summary**

	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics					
Model					R Square Change	F Change	df1	df2	Sig. Change	F
1	.112	.013	.002	.5601	.013	1.152	1	90	.286	
a. Predictors: (Constant), Modes of service delivery										

From the regression analysis above, the adjusted R<sup>2</sup> value of 0.02 means that modes of service delivery explains 0.2% of the variation in delivery of comprehensive HIV/AIDS services to PWDs at the significance level of 0.286. Therefore, since the p value (F) is 0.286 which is greater than the level of significance of 0.05, the null hypothesis was maintained.

It was noted during interviews that there are community based organizations in Masindi district including main hospital, and TASO that have come in a partnership under Masindi NGO forum to help PWDs come out and access HIV/AIDS services. The HIV focal person at the district reported that some PWDs have received some wheelchairs donated by Rotary club of Masindi and other NGOs which have eased their movement to health units. However, the counseling coordinator at TASO mentioned that they have identified all HIV/AIDS clients with disabilities and have formed a disability and HIV support group and a counselor trained in sign language has been put in charge of all PWDs clients and this has helped the organization to meet some of the challenges of PWDs. Through partnership and networking with other stakeholders like banks and other NGOs dealing with vulnerable groups, appropriate referrals have been made where necessary. In addition, the HIV/AIDS clinic in charge at JCRC submitted that some PWDs whose disability is less severe are involved in HIV/AIDS awareness and prevention strategies. However he commented that there is

still a challenge of stigma attached to persons with disabilities and living with HIV/AIDS in the communities where they live and this has discouraged some of them from participating in prevention campaigns and seeking for care and treatment.

During the key interviews, the district health inspector said that the existing policies are structured to ensure inclusion of PWDs needs and they ensure that PWDs are represented during policy formulation and community development issues. This is in agreement with 67.4% the majority of the respondents in the questionnaire who agreed that the existing policies were structured to ensure inclusion of PWDs. However, the over protection by the family was identified as an important factor in limiting PWDs especially adolescents from sex education whether this includes traditional initiation ceremonies or the more modern skills for life training. One counselor at TASO commented that “*parents view their disabled adolescent as a perpetual child who does not require sex related education and must be protected from advance of opposite sex*”. This leads to disabled adolescents who are protected by their parents to miss out on information about safer sex and reproductive health hence they are exploited due to their lack of information on prevention measures.

The researcher observed that the HIV positive PWDs who visited all the three health centers on clinic days were only adults above eighteen years and the registration forms used were capturing information regarding adulthood experience and these forms did not have a provision for recording the type of disability one had for better management. This means that children who could have been born with HIV and are disabled and the sexually active disabled adolescents are still hidden in their homes and denied the chance to receive HIV/AIDS care and treatment at an early age. More still, the researcher observed that the deaf/dumb persons were not given sufficient

attention since some of these health units have no sign interpreters and even those who have like TASO face the challenge of communicating with some of the deaf/dumb persons who did not have skills in sign language and some who have not attained formal education find it hard to communicate with right signs.

## **CHAPTER FIVE**

### **SUMMARY, DISCUSSION, CONCLUSION AND RECOMMENDATION**

#### **5.1 Introduction**

This chapter presents summary of the findings and these findings will help work out logical on which recommendations will be built in line with the significance of the study.

#### **5.2 Summary of major findings**

A cross-sectional descriptive study was carried out to examine the factors affecting the delivery of comprehensive HIV/AIDS amongst PWDs in Masindi district. Both quantitative and qualitative methods were used to assess the impact of social-cultural factors, competence of service providers and modes of service delivery on delivery of comprehensive HIV/AIDS services. The direction of the relationship and the degree of strength were determined by Pearson's correlation and regression analysis.

There was statistically a significant positive relationship between social cultural factors and delivery of comprehensive HIV/AIDS services with a correlation coefficient of 0.283 at level of significance of 0.006. A regression analysis, (adjusted R<sup>2</sup>) of 0.070 explained 7% the variation of delivery of comprehensive HIV/AIDS services. Findings from the field revealed that the majority of the primary respondents said that poverty pre-disposed PWDs to HIV/AIDS because of reasons like engagement in sex for money by PWDs. Also, the majority believed that poverty causes disability because some people who cannot get meaningful employments as a result of low

education tend to get engaged in heavy work load like lifting heavy loads which make them disabled.

More still the majority of the respondents believed that poverty is the biggest reason as to why many PWDs have not gone to school because most of them are total dependents on their families. In addition, the majority believed that poverty led many PWDs into engaging in risky sexual behaviors like prostitution in order to earn a living since some cannot get meaningful employment because of their conditions. Further, the majority felt that society looks at them as objects of pity and hopeless, while others revealed that some PWDs are prohibited from seeking HIV/AIDS services because they are believed to be asexual. More so, research findings showed that some PWDs are not involved in society activities due their inability to perform certain duties and others revealed that they preferred self-medication because they fear going to health units where service provider blame them. Some PWDs revealed that they are treated unfairly by members of society where they lived; however, the majority said they received information regarding condom use and its importance.

There was a statistically a positive relation between competence of health providers and delivery of HIV/AIDS services. A Pearson's product moment correlation coefficient of 0.224 at 0.031 at a level of significance was established. The regression analysis showed the adjusted  $R^2$  of 0.040 which meant that competence of service providers explained 4% of the variation in delivery of comprehensive HIV/AIDS services amongst PWDs in Masindi district. It was established that majority agreed that service providers put into consideration the needs of PWDs while serving them and believed they have the knowledge and skills in HIV/AIDS. Others revealed that the attitudes of service providers was a hindrance of some PWDs not seeking HIV/AIDS for fear of

blame, however others said that service providers assisted them when they visited health units by giving them priority to pass through the health care path way. The majority also revealed that service providers willingly gave them condoms without questioning their ability to use them.

In addition, the results showed a statistically very weak but positive relationship between modes of service delivery and delivery of comprehensive HIV/AIDS services as derived from Pearson's correlation coefficient of 0.112 at 0.286 level of significance and adjusted R<sup>2</sup> of 0.002 means that modes of service delivery of HIV/AIDS services explains 0.2% variations in delivery of comprehensive HIV/AIDS services. Research findings showed that partnership and networking helped in bridging the gap between different health providers, also the majority mentioned that PWDs were involved in mainstream development issues and that existing policies were structured to ensure inclusion of PWDs needs. Therefore the research findings showed that modes of service delivery had a less effect on the delivery of comprehensive HIV/AIDS services.

Throughout this study, it has been argued that the situation regarding disability and HIV/AIDS in sub-Saharan Africa is in need of more attention. Chapter one justifies why this is the case and chapter two presented an overview of the literature on factors affecting delivery of comprehensive HIV/AIDS to PWDs, disability and HIV/AIDS. This chapter drew the debate over definitions of disability and reviewed the link between disability and social-cultural factors, competence of service providers and modes of service delivery how these affect the delivery of HIV/AIDS services to PWDs. It further underlined how person with disabilities, particularly disabled women, are more exposed to HIV/AIDS as a result of sexual exploitation. Situations were depicted in which disabled women are sexually abused, thereby adding to the argument that disabled persons are more exposed to HIV/AIDS than their non-disabled peers (Groce, 2004). Various scenarios

presented the overlap between poverty and disability, the inaccessibility of HIV/AIDS IEC materials and attitudinal discrimination towards disabled persons.

In this chapter, it is intended that the research questions with which this study began are addressed. The chapter will then explore the way forward through a critique of the stakeholders response thus far and by considering what more that needs to be done in order the situation regarding disability and HIV/AIDS in sub-Saharan Africa particularly in Masindi district can be improved. This chapter will end by concluding on the research as a whole.

## **Discussion**

### **5.3. Social cultural factors and delivery of comprehensive HIV/AIDS services to PWDs.**

#### **Hypothesis 1**

The first hypothesis stated that there was no relationship between social cultural and delivery of comprehensive HIV/AIDS services amongst PWDs in Masindi district. However, the results showed that there was a positive statistically significant relationship between social-cultural factors and delivery of comprehensive HIV/AIDS services among PWDs in Masindi District. Therefore the null hypothesis was rejected and the alternative hypothesis substantiated.

#### **5.3.1 Poverty**

Poverty is recognized as a predisposing factor for HIV as highlighted by Yousafzi & Edwards (2004). The link between disability and poverty is well documented, both internationally (Groce, 2004) and in Uganda (Philpott & McLaren 1997), with the recognition that poverty is a cause of disability and disability in turn reinforces and deepens poverty. Disability has been highlighted as a development issue by the Health link Worldwide who stated that “the Millennium Development Goal of having poverty cannot be addressed without responding to the needs of persons with disabilities across sub-Saharan Africa’ (Health link Worldwide, 2004). Indeed poverty and disability are two sides of the same coin whose relationship has led to various ideas on how to alleviate the situation for disabled persons. The rejection of women with disabilities was particularly evident in this study, while persons with disabilities may be described as doubly exposed; there is a triple jeopardy in the case of being a female, disabled and financially poor.



The research findings further exhibit De Haan's argument (De Haan, 1999), that the elements of deprivation in this case poverty, disability and gender overlap. It is commonly accepted that disability and HIV/AIDS is rendered invisible because many of those who are affected by disability are poor (DFID, 2000), this leads to double discrimination. Evidence from respondents supports the argument that people who are both poor and disabled are not a priority for the society. This also is exemplified by some respondents who admitted to be carrying out prostitution sometimes without using protection in order to support themselves financially. Having a disability and experiencing poverty renders one powerless, this leads disabled persons to being marginalized in the fight against AIDS since they are in other arrears of their lives.

DFID seemed to be striding ahead on formalizing the relationship between disability and poverty (DFID, 2000). Its twin-track approach consists of "addressing inequalities between disabled and non-disabled persons in all strategic areas" whilst "supporting specific initiatives to enhance the empowerment of persons with disabilities" (DFID, 2000: 11). With such donors, and other partners working hand in hand, schools for different disability persons have been built a case in point is Bujenje school for the deaf in Masindi district which admits over two hundred deaf children per year. In addition, a white paper supporting an integrated National disability strategy was published in 2000 (Narib, 2003), this paper states that both Government departments and state bodies must provide as, far as possible, access to rights for persons with disabilities in the same way as they would for those who have no disability (Narib, 2003). This is exemplified by the fact that literacy rates of PWDs in sub-Saharan Africa are lower than the rest of a given population (DFID, 2000) and the global adult literacy rate of disabled persons is 3% (Groce, 2003a). Such a low rate therefore means that communication of HIV/AIDS IEC is difficult (Groce, 2003a). The study findings further confirmed that lack of knowledge about sex and HIV/AIDS greatly

constrains young people's ability to protect them from infection. Although it is true that knowledge about prevention is not enough to bring about behavior change, it is also true that there are many individuals, particularly young women, who are seriously disadvantaged in this epidemic because of a lack of knowledge.

The findings further showed that the perception of disability as a problem of the one with a disability continues to pervade societies because the alternative commands much effort a real shift in understanding as reported that "disability is a matter that many people would rather not consider: it is uncomfortable, and calls into question many of our assumptions about what a 'normal' life is" (*The Lancet*, 1999). Besides, a discussion of HIV/AIDS in sub-Saharan Africa is still a taboo in many areas. Therefore, two subjects with whom society is generally uncomfortable have to be reconciled and brought to the fore, though it is not an easy task. However, it is only through discussion of each that these concepts can be understood more precisely.

Evidence suggests that in developing countries poverty and lack of economic and educational opportunities, as often experienced by PWDs, influence HIV vulnerability. Despite this theoretical link, there is a dearth of research that documents HIV prevalence, risk and vulnerability among PWDs, the adequacy of service provision, and the extent to which HIV programs have addressed their needs. Organizations working in the field of disability claim that the strong stigmatization of disability in Ugandan society results in an underestimation of its prevalence.

In response to some of the PWDs challenges, the resource entitled 'Stepping Stones' has been used in many countries across sub-Saharan Africa including Uganda and the southern Africa regional office has been seeking for funds to translate the manual into Braille. So far, the manual

has been adapted by the National Association of Disabled People in Uganda. It has also been used in Zambia for HIV/AIDS education and life skills training of the deaf where the programme used a signer as well as the usual facilitator (Welbourne, 2004). In this way, standard HIV/AIDS resources were made and hopefully they will help in tackling some of the challenges especially regarding HIV/AIDS information giving.

### **5.3.2 Stigma and Discrimination**

People Living with HIV/AIDS (PLWHA) are often discriminated against by others as cited by Lau & Tsui, (2003). Such discrimination toward PLWHA would compromise the effectiveness of HIV prevention and care programs. Experiencing discrimination or stigma also adversely affects the quality of life of these patients (Graf *et al.*, 2004). Whilst one might argue that persons with disabilities are an inherent part of any of the aforementioned groupings, “disability should be mentioned as an issue of discrimination in its own right”. Disability is often interpreted as a social and cultural issue instead of a medical one. In this situation, “the issue of interpretation of disability moves from one of health to one of human rights” (Groce, 1999:354). Thus the emphasis is on breaking down stigma and discrimination of persons with disabilities so that they have equal opportunities. This is in relation to the research findings where the majority of the respondents confirmed that PWDs do not have equal opportunities as their able bodied counterparts. Therefore the view of De Haan (1999) is right that an understanding of the social relations of deprivation is necessary and can be applied to understanding social exclusion of person with disabilities in particular.

The research findings also are in line with Coleridge argument that PWDs need to play an active role in development process to overcome social exclusion, while Helander (1992) believes that

“many of the reasons behind the problems facing disabled persons can be found in deep-rooted prejudices” (Helander, 1992:7). This is in line with the results that which revealed that PWDs are excluded from certain activities because of their inability to perform certain duties, the findings also confirmed that different societies have different ways of excluding people so that the “poor of different times and places differ between themselves in virtually every aspect of their condition”.

In a related situation that reinforces the invisibility of disability and HIV/AIDS is where women with disabilities who are sexually abused are socially excluded, particularly by other women, and resented instead of supported, these are forms of symbolic devaluation that are reproduced in everyday social practice. The stigma attached to having a disability means that disabled persons are often refused participation and are therefore socially excluded from social, religious and political affairs of their community (World Bank, 2003). This was confirmed by the research findings which revealed that PWDs are hidden in their homes which deprive them of opportunities to participate in society activities including the efforts to fight against HIV/AIDS. Indeed the view inherent in believing that disabled persons are not sexually active and that they are sexless, unattractive and therefore cannot “secure” a partner encapsulates how they remain highly stigmatized in many sub-Saharan countries including Uganda. The majority of the respondents mentioned that they did not know the various modes of HIV transmission and the facts related to this disease. Many confessed they have not touched a condom, and a few confessed to having sex indiscriminately and using no precautionary measures.

Further, research findings showed that disabled persons themselves exhibit elements of self-stigmatization where by the interpreter of the deaf person may not tell that person directly if he/she is found to be HIV positive, instead that person may only find out from his/her peers in the deaf

community. This is confirmed by (Ombara, 2004), that “Even among deaf persons, AIDS carries a stigma”. This is not to say that persons with other disabilities are not marginalized, physical access to HIV/AIDS information venues is clearly a problem. Yousafzai and Edwards substantiate that in Uganda, “Your movement may be difficult, some of the paths are also difficult to locate. You cannot pass there without a guide. So this has made it difficult to get to the centers” (Yousafzai and Edwards, 2004:43), and many blind respondents complained of VCT centers not being ‘blind-friendly’.

Another example of social exclusion can be cited in Rwanda where radios are the most key means of information; not only does this exclude deaf people from a key means of information on HIV/AIDS but also the majority of respondents confirmed that they could not afford this means of communication and the majority felt that persons with disabilities had less information than their non-disabled peers as cited by Yousafzai and Edwards (2004: 53). This lack of information can lead PWDs have more misconceptions about HIV/AIDS than their non-disabled peers. This was confirmed by some respondents who said that one could acquire the virus from sharing toilets, kissing and sharing utensils and a small number of respondents mentioned that testing was necessary to find out if one were HIV positive.

#### **5.4 Competence of service providers and the delivery of comprehensive HIV/AIDS services.**

##### **Hypothesis 2**

The second hypothesis stated that there was no relationship between competence of health providers and the delivery of comprehensive HIV/AIDS services to PWDs in Masindi district. However the results from the study showed that there was a positive significant relationship between competence of service providers and delivery of comprehensive HIV/AIDS services to

PWD in Masindi district. Therefore, the null hypothesis was rejected and an alternative hypothesis substantiated.

#### **5.4.1 Skills of Service Providers**

“ A key group that is being largely ignored in efforts to stop the spread of AIDS is the global population of 600 million people who live with a physical, sensory, intellectual, or mental health disability” (World Bank, 2003:1).

Given the lack of precision on disability statistics, it is unsurprising that the statistics do not exist on how many PWDs are currently living with the virus or have died of AIDS-related illnesses. Thus the relationship between disability and HIV/AIDS in development has been given minimal attention, particularly in sub-Saharan Africa (Banda, 2003). The United Nations General Assembly Special Session on HIV/AIDS, a member state committed to “ensure that by 2015 at least 90 percent of young men and women aged 15-24 have access to the information and education necessary to develop the life skills required to reduce their vulnerability to HIV” (United Nations, 2001). In addition, since often there is no any other means of informing and educating persons with disabilities, the rights of all people to be informed and educated, as stated in Article 19 of the Universal Declaration of Human Rights, is frequently denied them. Whilst current efforts to establish a Global Partnership on Disability and Development (World Bank, 2004a) and a new international human rights convention for disabled persons highlight a degree of willingness by the international community to raise the profile of disability within development.

Research findings on disability and HIV/AIDS pointed out that many health providers have a common belief that PWDs are not sexually active, this is confirmed by similar findings that

having a disability is synonymous with being asexual (DFID, 2000) and that disabled people are therefore in little need of HIV/AIDS education (World Bank, 2004a). Other related research findings also suggest that programmes to change behavior and promote condoms can be effective in preventing the spread of HIV (Lamprey, 2002). Yet persons with disabilities are often denied access to these initiatives. In this way, the link between disability and HIV/AIDS remains invisible. In particular, little attention has been paid to HIV/AIDS and the sexual abuse of women with disabilities in sub-Saharan Africa.

Research findings further showed that disabled women were more prone to HIV/AIDS because of lack of information regarding the disease and their sexual reproductive health. This is in line with Groce's research findings that there is an increasing evidence suggesting that women with disabilities are more susceptible to HIV virus as a result not only of lack of access to HIV/AIDS information, education and communication (IEC) but also because of sexual exploitation (Groce et al, 2004). Indeed, it is a common view that deaf persons in particular face more barriers specific to their impairment (Stevens, 1998). Deafness, sometimes viewed as an invisible disability often provokes even less attention (Stevens, 1998). Yet the results highlight just how acute the need is for appropriate HIV/AIDS information, education and crucially, communication. "Physical and blind persons get more information about AIDS whereas the deaf are always left out" (cited in Yousafzai et al, 2004 forthcoming: 2).

#### **5.4.2 Attitudes of service providers**

Health providers at the health centers most times are not trained in the skills required to handle disabled person. The blind have been accused of asking offending questions and service providers sometimes wonder loudly whether blind persons can engage in sexual intercourse. "The sighted

members of society have always thought that blind persons do not engage in sexual activities”. The attitudinal discrimination is a significant factor in preventing disabled persons from accessing facilities they need in order to inform themselves about prevention of HIV and/or their own status. Research findings further showed that PWDs were very much aware of these attitudes, as highlighted by one disabled male that “*they do not know that our penises are working and they may call us that our body is all disabled whereas our penises may be working*” (cited in Yousafzai and Edwards, 2004: 45, emphasis added). Yet another attitude is summed up in the following retort to the suggestion that a disabled person seek methods of prevention: “A disabled person going to buy condoms (in Rwanda). It is right and understandable but in the society, it cannot look good” (cited in Yousafzai and Edwards, 2004:57). Some disabled persons feel that their only choice is to depend on general information, despite it being inappropriate to their needs. This is what is happening at all health service centers that were included in this study and research findings actually confirmed that service providers lack skills that would enable them handle different disability needs therefore, they give general information to all clients that visit the health units despite of their differences.

The attitude of society towards persons with disabilities in believing, among other things that disabled persons cannot be sexually active are a form of ‘social exclusion’, and do not fit into those able-bodied norms established by a society and are therefore ousted. Social exclusion is defined as “the process through which individuals or groups are wholly or partially excluded from full participation in the society within which they live”. European Foundation, 1995, cited in Francis, (2002:74). This is in line with what was stated in chapter two that, one reason for the invisibility of disability and HIV/AIDS is the common view that disabled persons do not need HIV/AIDS IEC because they are not sexually active.



In addition, accessibility has remained a big problem as showed by the results and this is partly because of the invisibility of disability and HIV/AIDS. This is in the form of both “apartheid by design” as reported by (Imrie, 1996, cited in Yeo and Moore, 2003: 572) and access to a confidential service. Moreover in each, the lack of access to HIV/AIDS IEC is the result of disabled persons being socially excluded. If a given society’s standard is that one must be able-bodied, then anyone who falls outside of this standard is deviant and therefore less important. What is evident here is a difference in how persons with specific disabilities are able to access information and the lack of skills on the side of the service providers as exhibited in the research findings. Moreover, when access is available, it is not always confidential. This was evident in the interview with one of the counselors at JCRC as reported in chapter four that some PWDs are not seeking for HIV/AIDS services of the need to use interpreters. This implies that some PWDs especially the deaf/dumb do not come for HIV/AIDS because of lack of confidentiality which discourages them and this calls for service providers to be trained such skills like sign language.

Yousafzai and Edwards, (2004:43) emphasized the above point that those who are working on testing should be trained in sign language. Indeed in terms of access to communication, even the signs for AIDS in some places have not been fully-developed or used. Notably in Kenya, sign language signs for sexuality were only developed in 2003 as noted in chapter two. This is apparently common in places throughout sub-Saharan Africa. Also in Uganda, it is reported that there is no word in many local dialects for disability (Lwanga-Ntale, 2003). These examples demonstrate the gap in the conceptualization of disability and therefore leave room for improvement in this area.

## **5.5 Modes of service delivery, and delivery of comprehensive HIV/AIDS service.**

### **Hypothesis 3**

The third hypothesis stated that there was no relationship between the modes of service delivery and the delivery of comprehensive HIV/AIDS services to PWDs in Masindi district. Results showed a correlation coefficient of 0.112 at the level of significance of 0.286 which means that there is a very weak but positive relationship between modes of service delivery and delivery of comprehensive HIV/AIDS services. Therefore, since the p value (F) is 0.286 which is greater than 0.05, the null hypothesis was maintained.

#### **5.5.1 Partnership and Net working**

The United Nations Decade of Disabled Persons (1983-1992) initiated some of the first steps in raising wide – scale awareness of disability but gained little, save to introduce the 22 Standard Rules on the equalization of opportunity for persons with disabilities, created in 1993 (UN, 1993). These provided a framework for states to follow up their pledge to equal rights for disabled persons. Since the rules are not legally binding, they need to be “delivered with more energy and commitment” (DFID, 2000: 6).

In addition, World Bank is increasingly focusing on disability and development with its Global Partnership for Disability and Development (GPDD). The GPDD advocates a disability dimension to all economic programmes. This approach reinforces the point made in chapter one, that persons with disabilities are vital to the economy of countries (Yeo, 2001). More specifically, a global survey on HIV/AIDS and Disability (Groce, 2003b) has been conducted and its conclusions corroborate what had until recently only been recorded sketchily, persons with disabilities are not included in HIV/AIDS IEC; moreover, PWDs are sexually active and are victims of sexual abuse.

The research findings underline the point that HIV/AIDS is of concern to Persons with Disabilities. Putting disability in the context of the UN's fight against HIV/AIDS, the Declaration of Commitment on HIV/AIDS stated it would *“enact, strengthen or enforce...measures to eliminate all forms of discrimination against...members of vulnerable groups, in particular to ensure their access to...social and health services...while respecting their privacy and confidentiality”* (UNAIDS, 2003b:34). This covert reference to disabled persons as one of the vulnerable groups exposed to HIV/AIDS will hopefully be strengthened by UN efforts to establish a disability and human rights convention.

Research findings confirmed that the majority of the respondents that PWDs were hidden in their homes and this made them stay invisible and eventually their rights are violated in one way on the other. This view is supported by Disabled Persons International and is reminiscent of Miles' view that persons with disabilities must have their own forums and should not be assumed to be part of a broader category of 'vulnerable groups' (Miles, 1999). The study is therefore, vital to the international response to disability and HIV/AIDS; it highlights to the Bank's global audience, how those risks linked to HIV/AIDS such as stigma, poverty, lack of education and rape (of women in particular) are increased for PWDs; they must therefore be understood and dealt with appropriately. Remarkably, the study confirms the gaps in existing knowledge, and understanding of what works and why in terms of disability and HIV/AIDS, IEC and formal monitoring and evaluation of those projects already in existence (Groce et al, 2004). The findings further indicated that working in partnership would help in identifying such gaps and solutions to such gaps would be sought of. Overall, World Bank's approach is to mainstream disability into economic development (World Bank, 2004c) by *“understanding that an inclusive development approach is as important as disability-specific interventions”* (Heumann et al, 2004:6). This is also being

applied to the Bank's approach to disability and HIV/AIDS specifically (Groce, 2003b). The approach also bears resemblance to that advocated by the UK Department for International Development in its 2000 issues paper on poverty and disability (DFID, 2000).

In any case, governments cannot act in a vacuum: a stronger national effort to combat HIV/AIDS and disability in any country must be complimented by NGOs-international, national and community-based, all of whom must work towards the same goal as the respective government. An example of this is the collaboration between the government of Kenya, VSO, and AMREF, where the government has been developing a 'National Plan for implementing the Continental Plan of Action for the Decade of Persons with Disabilities' (East African Standard, 2004) following its collaboration with VSO and AMREF to launch the 'Kenyan National Conference on the African Decade of Persons with Disabilities' in January, 2004 (VSO, 2004).

### **5.5.2 Participatory service delivery**

UNAIDS (2004a: 11) asserts that "*prevention programmes are not reaching the people who need them...AIDS education is still far from universal*". Gradually, the realization is drawing on key actors that people with disabilities have been socially excluded and therefore further exposed to HIV/AIDS virus. Access for all, regardless of disability or geographical location is human right, though even the most recent UNAIDS document does not mention people with disabilities as a target group in its exclusive summary (UNAIDS, 2004b).

The Government of Uganda is notable for its apparent commitment to PWDs in particular, "persons with disabilities who have achieved greater representation in any other country" (DFID, 2000: 9). For example the constitution of Uganda has been designed so that the disability

movement is represented at all administrative levels. Additionally, there are five seats in the parliament for PWDs; this has been designed to accommodate one person with a disability from each of the four regions of Uganda and one woman with a disability. Furthermore, a space is reserved in every election to allow one person with a disability canvas (DFID, 2000). Further still, the Government advocates inclusive education. It is now compulsory for families to send disabled children as part of the project which funds four children, two of whom must be girls, from every family. In so doing, this strategy acknowledges the tendency of many families to otherwise send only non-disabled sons to school, thereby maintaining the invisibility of their disabled children (DFID, 2000).

Furthermore, the biggest disability NGO in UK, Action for Disability and Development (ADD) follows the social exclusion model of disability, focusing on the empowerment of PWDs rather than on service delivery for them. Whilst they advocate access for disabled persons to health services in general, their work is more extensive in some places including Uganda than in others and, with reference to HIV/AIDS and disability. In addition, the move away from project funding to overall work in a given country has meant that no specific funding is currently allocated to tackle HIV and disability specifically. This confirms the views of some key informants that one of the challenges that service providers face is lack of enough funds to carry out some programmatic activities which include disability action plans in relation to HIV/AIDS.

More important also, other international NGOs are also making strides in mainstreaming disability as a key issue. An example is VSO, who has published a position paper on disability and poverty (Enfield, 2001), and states disability as one of its six goals. Also, VSO has developed a regional focus on disability through its Regional Aids Initiative for Southern Africa (RAISA). Of

particular, relevance is the 2003 conference on disability and HIV/AIDS (Narib, 2003) attended by the Namibian Prime Minister and PWDs from national and community-based NGOs. In this conference, people with different disabilities expressed how they are excluded from HIV/AIDS IEC as already been confirmed by the majority of the respondents. The conference also formally reported to a wide audience the sexual abuse of women with disabilities in particular and the report was therefore able to document, for official follow-up, the needs of PWDs regarding their exposure to HIV/AIDS. The key findings were the difficulties caused by lack of access to IEC and societal attitudes especially the service providers and this even discouraged some of the PWDs from seeking for HIV/AIDS services as confirmed by the majority of the respondents.

Important to note also is that the Government of Uganda's action on disability like some other Governments in sub-Saharan Africa more broadly is along with Coleridge's recommendation of three-pronged strategy to have Community Based Rehabilitation (CBR) alongside the integration of disability within education, equal opportunities and awareness-raising of disability. An example is the government of Namibia, even as there was no absolute government initiative at the time of writing on disability and HIV/AIDS, the fact that the Prime Minister, rather than a junior minister, attended the VSO 2003 conference on disability and HIV/AIDS signals the government's acknowledgement of the escalating importance of the issue in the country.

Indeed, all governments referred to exemplify elements of willingness to produce policy documents apparently written through a social model lens. Though, while there may be elements of change such as National AIDS Control Councils and Disability Acts, the two should be brought together since any policy that is formulated should be implemented. In response therefore, the government's action should be more effective and matched with that of National and community-

based NGOs. This study has found scant evidence about this, governments pledging to work with NGOs on HIV/AIDS programme often only do so until funding is secured after which they fail to collaborate as confirmed by UNAIDS, (2004b). However, various NGOs have started to bring the issue of disability and HIV/AIDS into the fore with varying approaches to tackling disability and HIV/AIDS.

From this perspective, disability still has to be mainstreamed within development before its constituent parts, of which one is HIV/AIDS amongst persons with disabilities, VSO's action of strategic decision as a mainstream development organization to integrate disability, amongst other areas appears to be bridging the gap between agencies and non- disability agencies, reminiscent of Yeo's point on this topic (Yeo 2003). Therefore, different agencies should coordinate and include the needs of PWDs in the development strategies. Whilst some governments, NGOs, and donors action as described in this study appear to acknowledge the beginning of an inclusive approach concerning persons with disabilities, it is nonetheless under-developed, with policies more integrated in some places than others. Once more, it is important to reflect on the extent to which the promises remain as rhetoric; *"Having an action plan is one thing, but its implementing is a different issue altogether"* (Phiri, 2004: 1). So it is important that the plans are put into action rather than just mentioned and action is never done.

Another way of responding to the consequences of social exclusion and re-conceptualizing disability is through promotion of the social model *"Rather than PWDs having to change to fit society. Society must make room for them and uphold their rights"* (DFID, 2000:7). It is up to society to empower disabled persons to act, many PWDs run initiatives that are "disability specific and user-friendly" (Serenata, 2001: 1). This should be extended to deal more effectively with

HIV/AIDS through peer support and counseling. The adaptation of the stepping stone approach, as detailed in chapter five, highlights that resources definitely can be adapted to the needs of persons with varying disabilities. All stakeholders should therefore be “actively incorporating disability dimensions in their programmes” (Narib, 2003: 9).

Basically, PWDs are sexually active and this should be taken much more seriously, since a significant number of populations in sub-Saharan Africa including Uganda continue to be exposed to the HIV virus. The results of such social exclusion militate against the visibility of HIV/AIDS and disability. The fact that disabled persons are subjected to humiliation while trying to access information about HIV/AIDS, this leads to disillusionment. Therefore, the logical resort is to avoid accessing it whilst continuing to be sexually active. In this way, HIV/AIDS virus continues to weave its way through a population that needs not be exposed. In turn, this has implication for the economic and social development in the whole of sub-Saharan Africa.

Furthermore, it would be advisable for mainstream development agencies to take on disability, and disability agencies should target disability and HIV/AIDS specifically. Particularly, initiatives to promote the needs of women with disabilities are lacking as per research findings, moreover, there remains a distinct lack of rural-based initiatives given the number of disabled persons reported to be living outside towns. Also, there is a lack of social marketing focused on disability and HIV/AIDS as noted by (Narib, 2003: 9). This is essential along with formal monitoring and evaluation for disability and HIV/AIDS activities and projects, as stated by (Groce et al, 2004). Another important step is the adoption of the social model which would mean that Imrie’s ‘apartheid by design’ would belong in the past and physical solutions such as ramps would be automatically constructed; this is not impossible given Wolfensohn’s estimate of only a 3% increase on the cost of constructing buildings to accommodate this (Wolfensohn, 2002).



More still, emphasis should be put on the concept of social inclusion rather than social exclusion; the duality of inclusion and exclusion should not be over-simplified (Francis, 2002) and is a case to be debated beyond the submission of this study. Nevertheless, persons with disabilities have a right to participate in their societies at all levels i.e. socially, religiously, economically and politically. One of the ways to do this is to integrate the social model of disability throughout disability debates. Many communities in Africa have responded to epidemics with community initiatives that take the sick with HIV.

Community Based Rehabilitation (CBR) should be an entry point for PWDs to access HIV prevention programmes. The CBR programmes need to ensure that PWDs who have AIDS, have access to the services provided by community based AIDS support Organizations. For example, CBR should challenge HIV projects to provide information packaged for different disability groups. The dissemination of this material can be done by HIV prevention Organizations with CBR programme playing a contact or facilitatory role. More difficult, but just as important, is the need for CBR to address the need for communities to protect PWDs from sexual exploitation.

There is a need to awaken social consciousness to the plight of women with disabilities. Some of the more vulnerable disability groups such as the blind, deaf and mentally handicapped persons need special attention. Although, CBR should spearhead the protection of PWDs, care needs to be taken to avoid hindering the opportunities to have children. Where disabled orphans are concerned, the CBR workers need to ensure accessibility and integration of these children in their new homes. District Probation Officers (DPO), together with CBR programmes should network with the district, regional and National HIV organizations (government and NGOs), to ensure that PWDs and their families access and participate in HIV prevention and treatment interventions.

Social-cultural issues that surround disability and HIV/AIDS need to be studied and interventions planned. In this case, the role of CBR may not be in conducting the actuarial research, but to bring the disability issue to the attention of researchers in HIV.

## **Conclusion**

The study set out to examine the factors affecting the delivery of Comprehensive HIV/AIDS service amongst PWDs in Masindi district. Basing on the research findings and findings by other researchers in the related fields of study, the following were conclusions as per objective of the study.

### **5.6 Objective1**

The first objective was to assess the effect of socio-cultural factors in the delivery of comprehensive HIV/AIDS services to PWDs in Masindi district. The results showed that there was a positive significant relationship between social-cultural factors and delivery of comprehensive HIV/AIDS services among PWDs in Masindi District. This means that social cultural factors affect the delivery of comprehensive HIV/AIDS services.

#### **5.6.1 Poverty**

The results confirmed that poverty affects the delivery of comprehensive HIV/AIDS services amongst PWDs in Masindi district. The majority of the respondents believed that poverty is the biggest reason as to why many PWDs have not gone to school. With high illiteracy rates amongst PWDs in sub-Saharan Africa as compared to the rest of a given population, this has led many PWDs be exposed to HIV infection as confirmed by the majority of respondents since information about HIV/AIDS through IEC materials has been a challenge to PWDs. Basing on this fact, it is concluded that if poverty amongst PWDs can be reduced through provision of such things like grants, donations and working with other supportive systems, PWDs would be empowered to seek for HIV/AIDS services in Masindi district.

### **5.6.2 Stigma and discrimination**

Research findings confirmed that People Living with HIV/AIDS (PLWHA) are often discriminated against by others and such discrimination compromises the effectiveness of HIV prevention and care programs. Experiencing discrimination or stigma also adversely affects the quality of life of HIV patients; however, comparing the degree of discrimination towards PWDs HIV patients, it has been mentioned that disability is an issue of discrimination in its own right. It was further confirmed that there are social issues that lead to discrimination of PWDs and these issues lead to their vulnerability in terms of HIV/AIDS. Results further revealed that PWDs are exposed to HIV/AIDS because they are socially excluded and this social exclusion is a key cause of their inaccessibility to appropriate HIV/AIDS education and contributing factors to their sexual exploitation.

## **5.7 Objective 2**

The second objective was to assess the impact of competence of health providers on the delivery of comprehensive HIV/AIDS services to PWDs in Masindi district. The results showed that there was a positive significant relationship between competence of service providers and delivery of comprehensive HIV/AIDS services among PWDs in Masindi District.

### **5.7.1 Skills of service providers**

Research findings confirmed that health practitioners often lack the necessary skills for dealing with disabled persons. Further findings confirmed that many health providers have a common belief that PWDs are not sexually active and therefore they are in little or no need of HIV/AIDS education. The deaf persons in particular face more barriers specific to their impairment since deafness sometimes is viewed as an invisible disability which often provokes even less attention.

Yet the results highlight just how acute the need is for appropriate HIV/AIDS information, education and crucially, communication.

### **5.7.2 Attitude of service providers**

Research findings as confirmed by the majority of the respondents that the attitude of society towards persons with disabilities in believing, among other things that disabled persons are not sexually active is a form of social exclusion, which does not fit into the able-bodied norms established by a society. The attitudinal discrimination is a significant factor in preventing disabled persons from accessing health facilities where they would get information about HIV/AIDS prevention and care or know their HIV status. Research findings further showed that PWDs were very much aware of these attitudes, and some felt that their only choice was to depend on general information, despite it being inappropriate to their needs. This was observed at health units where service providers were giving general information to all clients despite of their different disability needs like the deaf/dumb who would not get the message that was conveyed.

### **5.8 Objective 3**

The third objective was to establish the relationship between modes of service delivery and the delivery of comprehensive HIV/AIDS services to PWDs in Masindi district. Results showed a weak but positive relationship between modes of service delivery and delivery of comprehensive HIV/AIDS services to PWDs in Masindi district.

### **5.8.1 Partnerships and Networking and delivery of comprehensive HIV/AIDS services**

The goal of a partnership building strategy in responding to the challenge of HIV/AIDS is to scale up solidarity for HIV/AIDS responses for PWDs in Africa and beyond. It was noted during interviews that there were some community based organizations working in response to that call in Masindi district. These include TASO and JCRC which came into a partnership under Masindi NGO forum to help PWDs come out and access HIV/AIDS services. Basing on research findings therefore, it was concluded that a sound HIV/AIDS programme must embrace community action in setting priorities, making decisions, planning and implementing strategies to achieve better health services for PWDs.

### **5.8.2 Participatory service delivery**

The majority of the respondents confirmed that the existing policies ensure inclusion of PWDs needs and that PWDs were represented during policy formulation and participated in community development issues. Related research findings confirmed that in Africa, the African Campaign on HIV/AIDS and disability has been established to advocate for the inclusion of disabled persons in health related matters. During the key interviews, the district health inspector confirmed that the existing policies were structured to ensure inclusion of PWDs needs. Therefore, it was concluded that inclusion of PWDs in development strategies is very important so that their needs are put into consideration during the policy formulation and decision making process.

## **Recommendations**

The issues that limit inclusion of PWDs are the very factors that make them vulnerable to HIV infection. Strategies to ensure that available interventions reach PWDs and their families need to be formulated. For HIV/AIDS service organizations more particularly in Masindi district, the following should be put into consideration following objective by objective.

### **5.9 Objective 1**

The first objective was to assess the effect of socio-cultural factors in the delivery of comprehensive HIV/AIDS services to PWDs in Masindi district. The following recommendations were suggested in response to poverty, stigma and discrimination.

#### **5.9.1 Poverty and delivery of comprehensive HIV/AIDS services to PWDs.**

*“The Millennium Development Goal of having poverty cannot be addressed without responding to the needs of persons with disabilities across sub-Saharan Africa”* as cited by Health link Worldwide, (2004).

The first recommendation is that there should be direct interventions concerning HIV/AIDS health promotion to PWDs by the Government with the help of other organizations. This strategy should focus on promoting participation of PWDs in community development programmes.

Secondary, the role of CBR should be put into consideration to open the door for PWDs and their families to access HIV/AIDS interventions through building networks that are wider than the traditional liaisons with disability related organizations.

The government with the help of other NGOs should partner to put up self-help projects for PWDs which would enable them have their own incomes that would help them access health centers and receive HIV/AIDS care and prevention.

The government should also ensure that health services are accessible to all by extending these services to the communities where most PWDs live.

### **5.9.2 Stigma and discrimination**

One way of responding to the consequences of social exclusion and re-conceptualizing disability is through promotion of the social model, “Rather than PWDs having to change to fit society. Society must make room for them and uphold their rights” (DFID, 2000:7). The perception of disability as a problem of the one with a disability continues to pervade societies because the alternative commands much effort a real shift in understanding

As evidenced by the research findings, PWDs are sexually active, therefore there is need for health providers to put this into consideration while they attend to clients who seek for HIV/AIDS services and they should give special attention to different PWDs needs.

The fact that disabled persons are subjected to humiliation while trying to access information about HIV/AIDS which leads to disillusionment, therefore, there is need for the Government and the communities through sensitization to empower disabled persons to act and step out to fight for their rights especially in regard to HIV/AIDS care and treatment.



## **5.10 Objective 2**

The second objective was to assess the impact of competence of health providers on the delivery of comprehensive HIV/AIDS services to PWDs in Masindi district. The following recommendations were put forward to respond to skills and attitudes of health providers.

### **5.10.1 Skills of Health providers**

Numerous studies identify lack of training of health professionals in dealing with disability as a factor contributing to the lack of attention to HIV/AIDS prevention for disabled persons, and the lack of awareness of the needs of disabled people.

Discussion of HIV/AIDS in sub-Saharan Africa is still a taboo in many areas. Therefore, service providers should be empowered with the skills to bridge the gap between these two subjects i.e. disability and HIV/AIDS with whom society is generally uncomfortable with.

The above should be extended to deal more effectively with HIV/AIDS through peer support and counseling. This would help in identifying and dealing with the needs of persons with varying disabilities.

Stake holders should work hand in hand to train their workers in skills that would enable them deal with different disabilities; such skills would include sign language and use of braille for the deaf/dumb and blind persons respectively.

In addition, Post-test clubs should be formed at all health units in order to help HIV PWDs share challenges and seek for solutions amongst themselves through peer counseling.

### **5.10.2 Attitude of Service providers**

Health practitioners often have negative attitudes towards the disabled persons as confirmed by the majority of the respondents. Some of them stigmatize and discriminate against PWDs due to negative perceptions towards them. Disability is still a matter that many people would rather not consider: it is uncomfortable, and calls into question many of our assumptions about what a 'normal' life is (*The Lancet*, 1999).

Therefore, mainstream development agencies should take on disability and at the same time, disability agencies should target disability and HIV/AIDS specifically. Particularly, initiatives should promote the needs of women with disabilities which is lacking according to the results.

Results showed that there was a distinct lack of rural-based initiatives given the number of disabled persons reported, therefore there is need for social marketing that focuses on disability and HIV/AIDS by health providers and the Government should take a lead in this matter.

There should be a formal monitoring and evaluation of disability and HIV/AIDS activities and projects by the government and other organizations offering these services. This would also help in putting checks and balances on the service providers and how they actually handle PWDs at the health units.

### **5.11 Objective 3**

The third objective was to establish the relationship between modes of service delivery and the delivery of comprehensive HIV/AIDS services to PWDs in Masindi district. The following

recommendations were put forward to respond to partnership and networking, and participatory service delivery

### **5.11.1 Partnership and Networking**

World Bank is increasingly focusing on disability and development with its Global Partnership for Disability and Development (GPDD). Many communities in Africa have responded to epidemics with community initiatives that take the sick with HIV.

Community Based Rehabilitation (CBR) therefore should be an entry point for PWDs to access HIV prevention programmes. The CBR programmes need to ensure that PWDs who have AIDS, have access to the services provided by community based AIDS support Organizations. For example, CBR should challenge HIV projects to provide information packaged for different disability groups. The dissemination of this material should be done by HIV prevention Organizations with CBR programme playing a contact or facilitatory role

More difficult, but just as important, is the need for CBR to address the need for communities to protect PWDs from sexual exploitation. There is a need to awaken social consciousness to the plight of women with disabilities. Some of the more vulnerable disability groups such as the blind, deaf and mentally handicapped persons need special attention. Although, CBR should spearhead the protection of PWDs, care needs to be taken to avoid hindering the opportunities to have children. Where disabled orphans are concerned, the CBR workers need to ensure accessibility and integration of these children in their new homes.

More important also, District Probation Officers (DPOs), together with CBR programmes should network with the district, regional and National HIV organizations (government and NGOs), to ensure that PWDs and their families access and participate in HIV prevention and treatment interventions. In this case, the role of CBR may not be in conducting the actual research, but to bring the disability issue to the attention of researchers in HIV.

### **5.11.2 Participatory Service delivery**

Whilst some governments, NGOs, and donors action as described in this study appear to acknowledge the beginning of an inclusive approach concerning persons with disabilities, it is nonetheless under-developed, with policies more integrated in some places than others. Therefore there is need to assimilate these policies to cover all areas including the disability action.

More so, it is important to reflect on the extent to which the promises remain as rhetoric, having an action plan is one thing, but its implementing is a different issue altogether, therefore it is important that the plans are put into action rather than just mentioned and action is never done.

More still, emphasis should be put on the concept of social inclusion rather than social exclusion, the duality of inclusion and exclusion should not be over-simplified and is a case to be debated beyond the submission of this paper. One of the ways to do this could be integrating the social model of disability throughout disability debates, which would mean that physical solutions such as ramps would be automatically be constructed.

Finally, to counter all the above recommendations, the study recommends a re-conceptualization of disability via the social model. This model provides a rigorous and over-arching classification

for the concept of disability and its integration into the attitudes and the environment of sub-Saharan African societies regarding disability and HIV/AIDS more generally is very important. If combined with the socially inclusive approach, the model would provide a real departure from the discrimination endured by Persons with disabilities.

### **Contributions and suggestions for further Research.**

This study has contributed to the body of knowledge in the area of factors affecting the delivery of comprehensive HIV/AIDS services to persons with disabilities in Masindi district. Further efforts should be directed in conducting a study in the area of disability and social exclusion in relation to HIV/AIDS and women with disabilities in order to understand the issue of HIV/AIDS and social exclusion amongst women with disabilities in global terms. This is because this study has found out that women with disabilities in particular lacked information regarding HIV/AIDS and lack of statistical data on initiatives responding to HIV/AIDS and women with disabilities suggest that this is another area in need of greater study.

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## **Appendix i: Questionnaire for PWDs**

Dear participant,

My name is Kyohairwe Patience, a student of Uganda Management Institute undertaking a study on factors affecting the delivery of comprehensive HIV/AIDS services to People with Disabilities in Masindi district. This study will lead to an award of a Masters' degree on completion and recommendations shall be forwarded on how best HIV/AIDS service providers can better serve PWDs. I am kindly seeking for your participation in this study by filling the questionnaire below. The information generated from this study will be handled with utmost confidentiality and no identity is required while filling this questionnaire.

### **SECTION A:**

#### **1. SOCAIL-DEMOGRAPHIC CHARACTERISTICS**

**Choose the appropriate answer by ticking in one of the options below.**

1a. Sex (1) M, (2) F,

1b. Age: (1) Below 20 yrs, (2) 21-30yrs, (3) 31-40y, (4) Above 40yrs

1c. Education level. (1) None, (2) Primary, (3) Secondary, (4) Vocational, (5) University,

(6) Post Graduate

1d Monthly income in shillings (1) 1,000-10,000, (2) 11,000-30,000, (3) 31,000-50,000,

(4) >50,000

1e Residence (1) Urban, (2) Peri-urban, (3) Rural

2. What type of disability do you have? *(Please tick all that apply)*

a. Physical

b. Hearing

c. Learning difficulty

- d. Mental or emotional health
- e. Speech / Communication
- f. Visual
- g. Other.....

3. Which of the following services have you received? *(Please tick all that apply).*

- a. V CT
- b. Guidance and counseling
- c. PMTCT
- d. Family planning services
- e. Treatment including ART
- f. Diagnosis and treatment of opportunistic illnesses
- g. None
- h. Other (specify).....

**SECTION B: INDEPENDENT VARIABLE**

For the following statements, please indicate the extent of your agreement or disagreement by ticking in the column that matches your opinion where **5 is strongly Agree, 4 Agree, 3 Not sure, 2 Disagree and 1 strongly disagree.**

<b>SECTION B1: Poverty</b>	<b>5</b>	<b>4</b>	<b>3</b>	<b>2</b>	<b>1</b>
4. Poverty predisposes PWDs to HIV infection.					
5. Poverty can cause disability.					
6. PWDs not access education because of poverty.					
7. Poverty increases risky sexual behaviors amongst PWDs.					

<b>SECTION B2. Stigma and Discrimination</b>	<b>5</b>	<b>4</b>	<b>3</b>	<b>2</b>	<b>1</b>
8. Society looks at PWDs as objects of pity and hopeless.					
9. PWDs are hidden in their homes by parents and care takers.					
10. Society believes that PWDs are less human due to their disabilities.					
11. Society blames PWDs when they test HIV positive.					
12. PWDs are prohibited from seeking for HIV/AIDS care and treatment by their care givers.					
13. PWDs are not involved in society activities due to their disabilities.					
14. PWDs are denied equal chances in accessing health care and treatment.					
15. PWDs deliberately resist seeking for treatment in formal health institutions in preference to self-medication at home.					
16. PWDs are treated unfairly by society due to their inability to do certain things themselves.					
17. PWDs are given priority by health providers when they seek for HIV/Aids care and treatment.					
18. PWDs are excluded from certain cultural rituals such as circumcision since they are believed to be sexually inactive.					
19. PWDs are given information regarding condoms use and reproductive health.					

Rate the statements on **competence of health providers** in the table below using 5-1 where **5 is strongly Agree, 4 is Agree, 3 is not sure, 2 is Disagree, and 1 is strongly Disagree**

<b>SECTION C1: Skills of Health providers</b>	<b>5</b>	<b>4</b>	<b>3</b>	<b>2</b>	<b>1</b>
20. Service providers have the skills for caring for PWDs in a friendly way including the deaf/dumb.					
21. Health providers put into consideration the needs of PWDs when providing HIV/AIDS Education, care and treatment.					
22. Service providers have enough knowledge and skills in HIV/Aids care and treatment.					
23. Service providers are able to communicate with deaf/dumb persons through use of sign language.					
24. Service providers have the competence to provide HIV/AIDS information and psycho-social support to PWDs through health talks and sensitizations.					
<b>SECTION C2:Perceptions of service providers</b>					
25. The attitudes of service providers are a hindrance for PWDs to seek for HIV/AIDS services.					
26. HIV positive PWDs fear to approach service providers because they may blame and treat them with less respect					
	<b>5</b>	<b>4</b>	<b>3</b>	<b>2</b>	<b>1</b>
27. Service providers willingly assist HIV/Aids PWDs by giving them priority to pass through					



the care path way.					
28. Service providers are willing to give out condoms to PWDs without questioning their capability of using them.					

Rate statements on **Modes of delivery** using scale of 5-1; whereby **5 is strongly Agree, 4 is Agree, 3 is not sure, 2. Disagree, 1. Strongly Disagree**

<b>SECTION D1: Partnership and Networking</b>	<b>5</b>	<b>4</b>	<b>3</b>	<b>2</b>	<b>1</b>
29. Community based organizations help PWDs in building partnerships and networks that provide them with social support.					
30. Faith based Organizations help to raise awareness about HIV/Aids during worship days.					
31. Disability associations such as NUDIPU improve the bargaining power for resource mobilization and policy implementation in the treatment of HIV/AIDS amongst PWDs.					
32 Public-private partnerships make health care services accessible to PWDs through donation of supplies to health units.					
33. NGOs/FBOs contribute to creating awareness about the rights of PWDs through sensitizations.					

Rate your satisfaction regarding **Participatory service delivery** by ticking on the right hand side of the statements in the table below. **Strongly satisfied is 5, satisfied is 4, not sure is 3, dissatisfied is 2 and strongly dissatisfied is 1**

<b>SECTION D2: Participatory service delivery</b>	<b>5</b>	<b>4</b>	<b>3</b>	<b>2</b>	<b>1</b>
34. I am satisfied with the involvement of PWDs					

in mainstreaming development issues.					
35. PWDs needs are included in the existing institutional health settings.					
36. Involvement of HIV positive PWDs in HIV awareness and prevention strategies.					
37. Existing policies are structured to ensure inclusion of PWDs needs.					

**SECTION C: DEPENDENT VARIABLE**

Rate the **Delivery of comprehensive HIV/AIDS service** by ticking against the statement in the table below using the 5-1 scale where **5 is strongly Agree, 4 is Agree, 3- not sure, 2 Do not Agree, 1 is strongly do not Agree**

<b>SECTION E: Prevention care and treatment.</b>	<b>5</b>	<b>4</b>	<b>3</b>	<b>2</b>	<b>1</b>
38. I have ever been convinced that i need an HIV test.					
39. I have ever been counseled and there after tested for HIV.					
40. I have ever been tested for HIV without being counseled.					
41. Counseling has helped me understand living with HIV/AIDS.					
42. There are regular programs on the radio that sensitize the public about the rights of PWDs to access HIV/AIDS care and treatment					
	<b>5</b>	<b>4</b>	<b>3</b>	<b>2</b>	<b>1</b>
43. PWDs needs are always considered when providing HIV/AIDS education, care and treatment.					
44. My family is aware about my HIV status.					

45. I always make effort to get medication.					
46. I ensure all opportunistic infections are diagnosed and treated.					
47. I get treatment whenever I fall sick.					
48. I am registered in the HIV/ART clinic.					
49. Sometimes I fail to access the health unit and run out of drugs.					
50. All treatment prescribed by the doctor is provided including ART.					
51. Sometimes the drugs prescribed for me are expensive for me to afford.					
52. I follow the doctor's advice while taking drugs.					
53. Referrals of complicated cases are promptly done.					
54. I am always served septrin or dapson for prophylaxis.					
55. I have a medicine companion to remind me to take my drugs on time.					
56. My body reacts when I take septrin/dapson.					
57. I have started taking ARVS.					
58. My ART combination does not give me any side effects.					
59. I always use condoms to protect against opportunistic infections and un wanted pregnancies.					
60. I easily access condoms from the health units without any difficult.					

**THANK FOR YOUR PARTICIPATION**

**Appendix ii: INTERVIEW GUIDE FOR KEY INFORMANTS**

**SECTION ONE: Respondents personal Background**

- 1. Title of respondents.....
  
- 2. Age of respondent.....
  
- 3. Length of service in the health sector (in Months).....

**SECTION TWO: SOCIAL-CULTURAL FACTORS**

- 1. What are predisposing factors to HIV/AIDS and STIs infection amongst PWDs?  
.....  
.....
  
- 2. Are there HIV/AIDS services specifically tailored for PWDs needs?  
.....  
.....
  
- 3. To what extent does poverty contribute to the high rates of HIV infections amongst PWDs?  
.....  
.....
  
- 4. What are major problems that have led PWDs not accessing education?  
.....  
.....
  
- 5. Does poverty increase risky sexual behaviors amongst PWDs?  
.....  
.....
  
- 6. How do PWDs access treatment whenever they are sick?  
.....  
.....

7. What are some of the reasons for health providers not providing comprehensive HIV/AIDS services to PWDs?

.....  
.....

8. Would you care for an HIV/Aids PWDs differently from other PLWHAs?

.....  
.....

9. What could be some of the reasons that health providers have for treating PWD different from other patients when they visit the health unit?

.....  
.....

10. How does society look/ treat PWDs who test HIV positive?

.....  
.....

11. Are PWDs given priorities when they seek for HIV/AIDS care and treatment?

.....  
.....

12. What kind of HIV/AIDS preventive measures that are provided to PWDs?

.....  
.....

**SECTION TWO: COMPETENCE OF HEALTH PROVIDERS**

1. What specific skills do service providers have for caring for PWDs?

.....  
.....

2. How do service providers put into consideration the needs of PWD when providing HIV/Aids, education, care and treatment?

.....  
.....

3. Are there service providers specifically trained in sign language to communicate with the deaf/dumb patients?

.....  
.....

4. How do service providers give HIV/AIDS information, psycho-social support to PWDs including deaf/dumb persons?

.....  
.....

5. Do you think that the attitude of health providers hinder PWDs from seeking for HIV/AIDS services?

.....  
.....

6. Do service providers give priority to HIV positive PWDs who visit the health unit to pass through the care path way with ease?

.....  
.....

7. What are some of the reasons for service providers not giving information on condom use as a preventive measure to PWDs?

.....  
.....

8. What are the major problems service providers have encountered while taking care of HIV/Aids PWDs patients?

.....  
.....

9. What recommendations do you suggest to overcome such problems?

.....  
.....

**SECTION THREE: MODES OF HIV DELIVERY**

1. Are there community based organizations that help PWDs to build partnerships and network for social support?

.....

.....  
2. Do Faith Based Organizations help to raise awareness about HIV/AIDS during worship days?  
.....  
.....

3. Are there PWDs associations that fight for the rights of PWDs in this area?  
.....  
.....

4. Are there disabled associations in this area that bargain for needs of PWDs to be included in the policy implementation?  
.....  
.....

5. How are deaf/dumb/blind persons helped to access HIV/AIDS care and treatment by the existing health institutions?  
.....  
.....

6. How do public-private partnerships make health care services accessible for PWDs?  
.....  
.....

7. How are PWDs involved in the mainstreaming development issues?  
.....  
.....

8. How are PWDs needs included in the existing institutional health settings?  
.....  
.....

9. How are HIV positive PWDs involved in HIV/AIDS awareness and prevention strategies?  
.....  
.....

10. How are existing policies structured to ensure inclusion of PWDs needs?  
.....

**SECTION FOUR: DEPENDENT VARIABLES**

1. How do you understand by the concept of comprehensive service delivery?

.....  
.....

2. What are some of the components of comprehensive service delivery?

.....  
.....

3. How do you understand the concept of positive living?

.....  
.....

4. What are some of the components of positive living?

.....  
.....

5. How does counseling help in understanding the importance of VCT?

.....  
.....

6. Are there regular programs that sensitize the public about HIV/AIDS care and treatment?

.....  
.....

7. Are HIV positive PWDs registered with this health unit exempted from paying user fee when they come for health services?

.....  
.....

8. How does the service providers assist PWDs to pass through the health care path way?

.....  
.....

9. Are there policies in place addressing the needs of PWDs regarding HIV/AIDS issues?

.....  
.....



10. How are PWDs on ART/ septrin prophylaxis monitored to ensure good adherence?

.....  
.....

11. Are there measures in place that ensure HIV positive PWDs access HIV/AIDS care and treatment?

.....  
.....

12. Do PWDs access all the prescribed drugs for treatment of opportunistic infections without paying user fee?

**THANK FOR YOUR PARTICIPATION**

### Appendix iii: Questions and responses from key informants

Question	Response	Number (n)	% of response
<b>SOCIAL CULTURAL FACTORS</b>			
<b>HIV pre-disposing factors</b>	Poverty	14	54.5%
	Cultural rituals	3	13.6%
	Peer pressure	3	13.6%
	Lack of information	2	9.0 %
<b>Reasons for health providers not providing comprehensive HIV/AIDS services to PWDs</b>	Lack of knowledge and skills in special needs	4	18.2%
	Language barrier	8	36.4%
	Fear	6	27.2%
	Limited resources	4	18.2%
<b>COMPETENCE OF SERVICE PROVIDERS</b>			
<b>How do service providers give HIV/AIDS information and Psycho-social support to PWDs including the deaf/dumb</b>	Use of limited sign language with the help of care takers	8	36.4%
	Demonstration on flip charts	6	27.2%
	Referrals	2	9.0%

	PWDs workshops	6	27.2%
<b>What are some of the reasons for service providers not giving information on HIV preventive measures like condom use to PWDs?</b>	PWDs taken to be sexually inactive	12	54.5%
	Language barrier	6	27.2%
	Discrimination	2	9.0%
	Condoms not 100% correct	2	9.0%
<b>MODES OF DELIVERY</b>			
<b>Are there community based organizations that help PWDs build partnerships and networking in this area?</b>	Yes	7	31.8%
	No	13	59.1%
	Don't know	2	9.0%
<b>How do public-private partnerships make health care services accessible for PWDs</b>	Advocating for their rights	4	18.2%
	Building schools for special needs	8	36.4%
	Making accessibility easier , by putting ramps and donation of wheel chairs among others	7	31.8%
	Extending services to	3	13.6%

	communities		
<b>Are HIV positive PWDs involved in HIV/AIDS awareness and prevention strategies?</b>	Sensitization workshops	10	45.5%
	Community mobilization and awareness campaigns through drama	10	45.5%
	Aids community workers	2	9.0%
<b>DELIVERY OF COMPREHENSIVE HIV/AIDS SERVICES</b>			
<b>How does VCT help promote HIV prevention and care?</b>	Promotes HIV/AIDS awareness and prevention strategies	10	45.5%
	Promotes early HIV diagnosis and enrolment on Septrin/ART prophylaxis	6	27.2%
	Promotes positive living including adherence	4	18.2%
	Continuous information giving	2	9.0%
<b>What are the major problems service providers</b>	Lack of adherence	4	18.2%

<b>have encountered while caring for HIV PWDs patients?</b>	Communication skills	6	27.2%
	Limited resources	4	18.2%
	Accessibility	4	18.2%
	Cruelty of PWDs family members and care givers	4	18.2%
<b>What recommendations do you suggest to overcome them</b>	Continuous sensitizations on the rights of PWDs	4	18.2%
	Strengthening partnership and networking	4	18.2%
	Community/family involvement	3	13.6%
	Special units for PWDs	2	9.0%
	Training of Service providers in special skills	6	27.2%
	Government take initiative	3	13.6%

**THANK YOU FOR YOUR PARTICIPATION**

**Appendix 1V: OBSERVATION CHECK LIST**

<b>Facilities at Health unit</b>	<b>Very good</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Not available</b>
PWDs VCT Registers					
Registers of PWDs HIV positive clients					
Toilets					
Stair cases					
Access to the canteen					
Special unit					
Existence of ramps					
Sitting arrangement					

**THANK YOU FOR YOUR PARTICIPATION**