## MULTIPLICITY OF DISCRIMINATION:

## A CASE STUDY OF DEAF WOMEN'S ACCESS TO HIV/AIDS COUNSELLING SERVICES IN SELECTED INSTITUTIONS

 $\mathbf{BY}$ 

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A Dissertation Submitted in Partial Fulfillment of the Requirements for the Award of the Masters of Arts (Gender Studies) of Makerere University, Kampala

**OCTOBER 2010** 

## **DECLARATION**

I, NANTUMBWE MIRIAM SEBULIBA FAITH, hereby declare that this study is original and has not been published and/or submitted for any other degree award to any other University before.
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SignedDate
This is to certify that this dissertation was carried out under supervision and approved as
the candidate's original work.
Signed: Date
Dr
Supervisor

## **DEDICATION**

This dissertation is dedicated to two families; my parental family whose sweat and sacrifice formed the foundation of my education career and my matrimonial family whose motivation, encouragement and support have given me thrust to always aspire for more.

#### **ACKNOWLEDGEMENT**

This dissertation would not have seen the light without the persistent support of some distinguished personalities. First and foremost, I give all praise and glory to the Lord for the immeasurable grace that overwhelms me everyday.

My special regards are due to the entire staff of the Department of Gender and Women Studies of Makerere University for the enormous support given to me when pursuing this course. My profound gratitude goes to my diligent and caring supervisor, Dr. Sengendo May, for the constructive advice that shaped the general structure of this dissertation. In the same way, gratitude is due to Mrs. Nancy Muwangala who tirelessly made my identification of and communication with Deaf communities possible. Worthy noting also are my brothers Michael, Mephibosheth and Simon, my in-laws Suudi and Damalie, whose conviction for studying observes no boundaries and sufficed to challenge me the more. I am also deeply indebted to all the study participants, who generously agreed to participate in the study, openly sharing their experiences, ideas, insights and energy and all other people who contributed to make this study a success. My final heart felt gratitude goes to my soul mate Mr. Kiwanuka Godfrey who accepted to undertake my economic drain towards this study unconditionally. In summary, you all supported me in diverse ways and thus contributed to make my study remarkable.

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#### ABBREVIATIONS AND ACRONYMS

AIC AIDS Information Centre

AIDS Acquired Immune Deficiency Syndrome
EUD European Union against Discrimination

FGDs Focus Group Discussion

HIV Human Immune Deficiency

NGO Non-Governmental Organisation

PWDs Persons with Disabilities
SLI Sign Language Interpreter

SSA Sub-Saharan Africa

TASO The AIDS Support Organisation

TIHC Teenage Information and Health Centre

UK United Kingdom

UN United Nations

UNAIDS Joint United Nations Program on HIV/AIDS

USA United States of America

USD Uganda Society for the Deaf

VCT Voluntary Counselling and Testing

WHO World Health Organization

WWD Women with Disabilities

#### **ABSTRACT**

This study investigated the different ways through which discrimination was constructed as deaf women seek to access HIV/AIDS counselling services in Kampala District. Multiplicity of discrimination was investigated through three different ways. First, it was through analyzing the extent to which institutional rules and norms within legislation policies and practices, construct discrimination of deaf women as they seek to access HIV/AIDS counselling services. Secondly it was through examining how society constructs deaf women and demonstrates impacts on their access to HIV/AIDS counselling services. Thirdly, it was through analyzing the extent to which interaction between deaf women and HIV/AIDS counselling service providers could create and reinforce multiple discrimination in access to and control over resources.

The study examined the extent to which social structures that provide authoritative guidelines for social behaviour, could construct discrimination, as claimed by the sociological Institutional theory. This argument was applied in order to establish the extent to which institutional rules, norms, and routines could construct discrimination for deaf women. Further, the study examined the extent to which structural relationships create and reproduce systemic differences in the positioning of different groups of people in society as argued in Social Relations Framework. This explanation of the research problem therefore, led the study to apply the major concepts of access to HIV/AIDS counselling services; multiplicity of discrimination in terms of (i) disability (ii) gender (iii) poverty.

A cross-sectional study design was used for collection of data. The study was conducted in seven selected institutions. Five (5) of them, namely: National Union of Disabled Persons in Uganda (NUDIPU) in Kisaasi, Straight Talk Foundation at Kamwokya, Naguru Teenage Information and Health Centre at Naguru, The AIDS Support Organisation (TASO) at Mulago and Aids Information Centre (AIC) at Kisenyi were including deaf and those who are not. Two (2), namely Uganda Society for the Deaf (USD) Vocational Training Centre at Namirembe and Uganda National Association of the Deaf (UNAD) at Kamwokya were specifically for the deaf. The study used both qualitative and quantitative methods, observation and case studies. The findings of the study were based on a sample population of sixty-seven (67) respondents from seven selected institutions, who included deaf women, service providers including Sign Language Interpreters and women infected with HIV/AIDS.

The results of the study revealed that policies, rules, norms and practices used by institutions were discriminatory to deaf women who are perceived to be irrational and less intelligent. In this case, multiple discrimination was revealed through the following power related actions: (i) isolation, (ii) neglect (iii) exclusion and restriction from recognition. It was also established that the position of deaf women was considered homogeneous with that of able-bodied women. Further findings revealed that communication barrier was an immense challenge followed by deaf women being inaccessible, with high illiteracy levels and inadequate financial resources. In addition, inability to use sign language and distrust by individuals within the deaf community were considered as prime hindering factors for deaf women's access to services. Further more, findings revealed that service providers dictated methods and channels used for delivering information to deaf women.

The study recommended that in order to empower deaf women, there was need to create and maintain situations that would change negative stereotypes among institutional personnel, families and communities. Deaf women and PWDs should be provided with appropriate, equal and similar services and information to ensure observation of their rights. In order to overcome communication barrier, the study recommended that deaf women and girls should be provided with SLI or trained in the use of sign language so as to competently communicate with talking communities. Similarly, the study recommended that Institutional personnel/ service providers should be trained in sign language so that they communicate directly with deaf women to ensure confidentiality. Organizations should mainstream programmes targeting deaf women to eliminate discrimination. To avoid economic dependence, deaf women should be trained in employable skills to earn incomes and make sole decisions while utilizing HIV/AIDS Counselling services.

#### **CHAPTER ONE**

#### **BACKGROUND TO THE STUDY**

#### 1.1. Introduction

In many communities, deaf women and other Persons with Disabilities (PWDs) experience situations of discrimination. Yet, if the various kinds and levels of discrimination continue being experienced by PWDs, they harm and increase stigma among those affected. Further more, international level studies have shown that, people in need cannot access services, yet organizations cannot deliver appropriate services needed by affected individuals (WHO, 1999). Earlier studies had shown that institutions deliver services and resources in an unequal way (NUDIPU, 2003). However, the extent to which deaf women access Human Immuno Deficiency Virus/ Acquired Immune Deficiency Syndrome (HIV/AIDS) counselling services is questionable, yet they are highly predisposed to HIV/AIDS infection. Most of them may be subject to what is known as the "Triple Burden" of disability, poverty and HIV/ AIDS, which could expose them to experience alarming levels of discrimination and stigmatization (Link & Phelan, 2001). This study aimed at examining how discrimination is constructed through multiple actions as deaf women try to access HIV/AIDS counselling services in selected institutions in Kampala district.

#### 1.2. Background to the Study

Service and resource provision interventions in society can easily assume that women have similarities of inequalities and common needs. Yet women are heterogeneous and have categories (Barnet, 1992) including the deaf who form part of PWDs. Service and resource provisions currently delivered by dedicated Non-governmental (NGO), government and private agencies (WHO, 1999) were established for over ten years. They include those dealing with counselling, testing, care and support for women and men infected and affected by HIV/ AIDS.

HIV/AIDS counselling services had been accessed by few persons including AIDS patients due to stigmatization and socio-cultural aspects of society (UNAIDS 2001). Worldwide, women and men, infected and non-infected alike, currently access the pervasive and popular HIV/AIDS counselling services and treatment. Despite this being the expectation, it is highly

probable that deaf women experience multiplicity of discrimination while accessing such services.

Feminist theorists argue that PWDs are socially excluded and handicapism is constructed (Begum 1992). Disabled persons<sup>1</sup> form the most marginalized group in society. Uganda AIDS Commission (UAC) (2005) pointed out that PWDs had been forgotten consciously and unconsciously in the fight against HIV/AIDS. Further, in a paper presented by Mwesigwa (2007), he stipulates that PWDs consist of the deaf, blind, the deaf-blind, physically disabled, mentally retarded, epileptic, and a host of many other affiliate groups. Deaf persons therefore are part of disabled persons since they experience deafness<sup>2</sup>.

Within the year 2010, major planned HIV/AIDS campaigns and interventions have been implemented to address information, awareness, prevention for the general population, followed by care and support for the affected and infected. However, majority of HIV /AIDS service providers have not assessed how HIV/AIDS affects PWDs and the unique deaf women community with distinctive issues and needs that require exclusive interventions (Banda 2005). This could be attributed to assumptions that policy makers, implementers or majority of service providers have excluded deaf women from their mainstream programs, HIV/AIDS programs inclusive.

The 2002 Uganda National Census Report indicated that PWDs make 10% of whom 30% or 750,000 persons are deaf women and men. Effort is yet to be made to adjust the Ugandan Health System and AIDS communication approaches into languages that can improve access by deaf women and men. Lack of deaf counsellors implies that deaf women and men lack privacy during counselling with the assistance of an interpreter (Janssen, 2003), thus a breach of privacy in Voluntary Counselling and Testing (VCT) ethics rules (Murangira, 2004). Further, sign language interpreters (SLI) are inadequate in numbers (Mboya 2005) and rarely participate in counselling efforts because they feel the signs used are too sexually explicit (Janssen, 2003). This may consequently lead to the deaf being discriminated from counselling and thus hampering prevention efforts against HIV/AIDS.

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<sup>&</sup>lt;sup>1</sup> In this research, disability is regarded as any restriction or lack of ability by a person to perform an activity in a manner or within a range considered normal for a human being, as exemplified by deafness.

<sup>&</sup>lt;sup>2</sup> Deafness refers to inability to receive spoken messages, thus a loss of sense of hearing which can be complete or partial(Ndlovu, 2000)

HIV/AIDS disease affects patients physically, economically, socially, emotionally and spiritually. HIV/AIDS Counselling services were initiated to respond to the threatening HIV/AIDS epidemic which proved to be a global socio-economic challenge, defying all efforts to contain it (WHO, 1998). HIV/AIDS counselling is a confidential process enabling a person to assess his/her relative risk of acquiring or transmitting HIV (UNAIDS, 2004). Fatal and stigmatizing incidents of HIV/AIDS disease outcome (Banda 2005) necessitated worldwide establishment of treatment and counselling centres (WHO 1998). In response, HIV/AIDS counselling services established were initially extended to Gay men who formed the majority of those infected in the United Kingdom (UK) and United States of America (USA) (Marge, 1993). These services however proved to be masculine in nature, thus extended to men only.

The African situation revealed that HIV/AIDS pandemic was spreading in heterosexual intercourse, while propagated by cultural practices such as marriage and polygamy. HIV/AIDS counselling services and treatment were few and unaffordable and therefore available to only those who were economically empowered (Barnet, 1992). In Uganda, the extreme fatality of HIV/AIDS deserved emergency establishment of counselling and treatment centres which began in 1983, with the Ministry of Health spearheading the process in hospitals and health centres (Kaleeba, Kadowe, Kalinaki, and Glen, 2000). NGOs like The Aids Support Organization (TASO) and the Aids Information Centre (AIC) followed suit, making HIV/AIDS counselling services accessible to both men and women, (UNAIDS, 2001).

Worldwide, VCT is now recognized as an important element of HIV/AIDS prevention, care and support programmes and services, and indeed an entry point for the control of HIV transmission (Republic of Eritrea, 2005). HIV/AIDS counselling services presently offered include Free standing counselling and testing services, Integrated counselling and testing services, and Post-test counselling services (WHO, 2002).

Subsequent to feminization of the HIV/AIDS pandemic<sup>3</sup> which is more apparent in Sub-Saharan Africa, attention is extended to policy makers and other stakeholders to establish

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<sup>&</sup>lt;sup>3</sup> HIV/AIDS is currently considered to be typical of women

whether they contribute towards discrimination of deaf women while accessing HIV/AIDS services, counselling services inclusive (Wider 2003).<sup>4</sup> This study specifically is directed to deaf women as they form part of people occupying vulnerable positions, and experiencing sub-inequalities within inequalities. It is intended to analyze the construction of multiplicity of discrimination of deaf women while accessing HIV/AIDS counselling services in selected institutions in Kampala District.

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<sup>&</sup>lt;sup>4</sup> Jennifer Wider, MD Society for Women's Health Research in News Alert, 2003

#### 1.3. Problem Statement

It has been indicated at international level that organizations cannot deliver appropriate services needed by affected people and individuals who continue to be stigmatized and rejected (WHO, 1999). The research gap identified in this study is embedded in the fact that though earlier studies had shown that institutions deliver services and resources in an unequal way (NUDIPU, 2003), the extent to which deaf women access HIV/AIDS counselling services is unknown. Yet they are highly predisposed to HIV/AIDS infection. Most of them may be subject to what is known as the "Triple Burden" of disability, poverty and HIV/ AIDS, which could expose them to experience alarming levels of discrimination and stigmatization (Link and Phelan, 2001).

Discrimination occurs in complex and countless ways (EUD, 2006). Considering discrimination in terms of exclusion and/or restriction from recognition, this study illustrated how deaf women, face "double invisibility" both as women and disabled while accessing HIV/AIDS counselling services. This study examined two ways through which multiplicity of discrimination could be constructed and demonstrated as deaf women seek to access HIV/AIDS counselling services. First, the study argued that discrimination of deaf women might be embedded in the institutional rules and norms within policies and practices as argued by Institutional theorists (Mudrick, 1988). Secondly, the study examined the extent to which structural relationships create and reproduce systemic differences in the positioning of different groups of women in society as argued in Social Relations Framework. Deaf women form part of people occupying vulnerable positions, and experiencing subinequalities within inequalities.

#### 1.4. Objectives of the Study

#### 1.4.1 General Objective

To examine how gender based discrimination is constructed through multiple actions as deaf women seek to access HIV/AIDS counselling services in selected institutions in Kampala District.

#### 1.4.2. Specific Objectives

The study objectives were to:

- Examine the extent to which institutional rules and norms through policies and practices, construct discrimination of deaf women while accessing HIV/AIDS counselling services.
- 2. Examine the extent to which the structural positioning of deaf women in society affects their access to HIV/AIDS counselling services.
- Analyse the extent to which interaction between deaf women and HIV/AIDS
  counselling service providers create and reinforce multiple discrimination in access to
  and control over HIV/AIDS counseling services and resources.

#### 1.4. 3. Research Questions

In order to examine the construction of multiplicity of discrimination, below are six research questions addressing the three objectives above:

Objective One: Construction of discrimination of deaf women through Institutional rules and norms that deal with access to HIV/AIDS counselling services.

#### **Research Questions**

- i) How do institutional rules and norms construct discrimination of deaf women while accessing HIV/AIDS counselling services?
- ii) How have institutions and their personnel contributed to the delivery of HIV/AIDS services and information to deaf Women?

Objective Two (2): The structural positioning of deaf women in society and how it affects their access to HIV/AIDS counselling services.

#### **Research Questions:**

iii) To what extent does the structural positioning of deaf women in society affect their access to HIV/AIDS counselling services?

iv) What are the general attitudes of both HIV/AIDS counselling service providers and deaf women towards each other as deaf women try to access HIV/AIDS counseling services?

Objective Three (3): <u>Creation and reinforcement of multiple discrimination during interaction</u> between deaf women and HIV/AIDS counselling service providers in access to and control over HIV/AIDS counseling services and resources

#### **Research Questions**

- v) To what extent does the interaction between deaf women and HIV/AIDS counselling service providers create and reinforce multiple discrimination in access to and control over HIV/AIDS counseling services and resources?
- vi) What problems do Institutional personnel/service providers encounter while delivering HIV/AIDS counselling services to deaf women and what challenges do deaf women meet while seeking to access HIV/AIDS counselling Centres?

#### 1.5. Scope of the Study

The study entailed examining the construction and demonstration of multiplicity of discriminatory forms used on deaf women, both infected and non-infected, while accessing HIV/AIDS counselling services in selected institutions in Kampala District. Specifically, it had to examine the extent to which discrimination of deaf women might be embedded in the institutional rules and norms due to inequalities in the policies and practices for delivery of services. Similarly, the study the extent to which the structural positioning of deaf women in society affects their access to HIV/AIDS counselling services. It further analysed the extent to which interaction between deaf women and HIV/AIDS counselling service providers create and reinforce multiple discrimination in access to and control over HIV/AIDS counseling services and resources.

#### 1.6. Significance of the Study

The results of this study revealed that multiplicity of discrimination of deaf women could lead to stigmatization due to their gender, disability, HIV and AIDS status. Principally, the study revealed that deaf women are at a higher risk to HIV/AIDS due to their exclusion from mainstream HIV/AIDS services interventions. The study will draw attention to policy makers, implementers and other service providers on issues related to deaf women and HIV/AIDS counselling services since there is lack of policy framework on disability and HIV and AIDS. Hence, the study will enhance awareness to the future researchers, Ministry of Health, NGOs, and community, about the multiplicity of discrimination of deaf women in accessing HIV/AIDS Counselling services.

#### 1.7. Lay out of the Dissertation

This first chapter provided a highlight of the background to the study, research problem and purpose of the study, objectives, research questions, scope and the significance of the study. The second chapter described the theoretical framework and conceptualization of the study. The third chapter provided a review of related literature, and the fourth chapter outlined how the study was carried out, indicating the research design, the methods that were employed in the study, how the selection of study population, sample size and sampling procedures, data collection methods, data analysis, presentation and ethical consideration were applied. The fifth chapter provided for presentation and analysis of the results and the sixth chapter outlined the summary, conclusions drawn from the study and gave recommendations for further research.

#### **CHAPTER TWO**

#### THEORETICAL FRAMEWORK AND CONCEPTUALISATION OF THE STUDY

#### 2.1. Introduction

This chapter presents a review of the theory and framework that provided points of departure for addressing the problem statement of this study. The theory and framework which informed this study are explained in details and the conceptualization shows the relationship between the variables including ways in which they affect one another. The chapter also includes gaps in theoretical and conceptual perspectives.

#### 2.2. Theoretical Review

The study was guided by Institutional theory and the Social relations framework.

Institutions are frameworks for socially constructed rules and norms which function to limit choice or structures that humans impose on human interaction (North 1999)<sup>5</sup>. Institutional theory involves processes of establishing social structures, including rules, norms, and routines as authoritative guidelines for social behaviour (Scott, 2004). Institutional sites for gender relations are the family, community, market and state (Goetz, 1997). Institutional rules and norms exist at community or societal level and are not determined and/or chosen by individual (Kabeer, 1999).

An analysis of the main institutions in society shows that they are all patriarchal in nature and, the well-knit and deep-rooted system makes patriarchy seem natural (Bhasin, 1994). The basic building blocks of many institutions are quite invisibly gendered outwardly leading to the assumption that institutions are egalitarian and therefore deliver services equally. In this respect, institutions can be analysed to assess gender inequalities by looking at the rules, activities, people, resources and power. It can then be possible to establish how discrimination of deaf women is constructed especially when accessing services like HIV/AIDS counselling services.

Gender norms, values and rights form part of the moral order of family and indirectly permeate other institutions of community, market and state (Goetz, 1997). The family is largely identified as the primary institution in which women's entitlements and capabilities

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<sup>&</sup>lt;sup>5</sup> Douglas North, Public Lecture at the World Bank, September 16, 1999

are distorted to the extent of undermining women's capacity to manage transactions, social, economic or otherwise. Thus, deaf women usually experience family neglect, low self esteem, abuse and stigmatization and as such socialized into incapable beings.

The community as an institutional site takes form in health and school organizations, political factions, NGOs, religious institutions and media. The design of program delivery for example health care centres, can facilitate or inhibit equitable access for females and males. The state is a main factor in perpetuating domination of men and subordination of women through its "discriminatory laws, administrative procedures and control mechanisms favouring and giving men more resources and opportunities" (Badri, 2001). Governments design policies for social equity to guide service delivery practice and to facilitate equal access as an appropriate strategy for social transformation. On the contrary, women's freedom, dignity and equality are persistently compromised by law and custom in ways that men's are not. Changing people's values and behaviour as well as entrenched institutional cultures is not easy.

The field of disability has not yet recognized that women with disabilities (WWD) experience combined discrimination based on gender and disability; policies and practices in the field have not been designed to address the specific needs of women with disabilities (Kutza, 1985). In many settings, discrimination and social inequalities result from entire social groups having little voice and neglect which translates into lower access to services like HIV/AIDS counselling. Such is likely to be the case for deaf women who lack voice and eventually face triple disadvantage while trying to access resources as women, deaf and poor. Using the institutional theory, the study explored how social institutions could determine deaf women's access to available opportunities and resources they need to advance their interests.

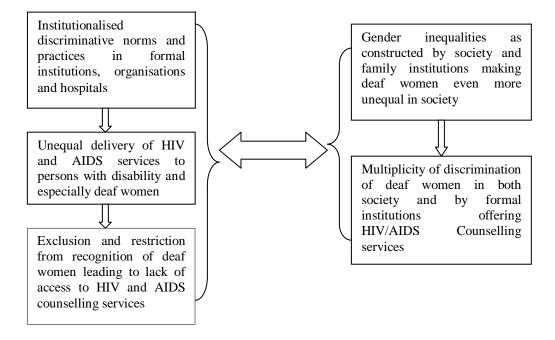
Under the social relations framework, Kabeer (1994) uses the term "social relations" to describe the structural relationships that create and reproduce systemic differences in the positioning of different groups of people in society. Gender relations as one type of social relations produce and dictate cross cutting inequalities that determine what tangible and intangible resources, claims and responsibilities are available to groups and individuals. The social relations continuum positions "not as having a physical handicap but as having impairment to reasoning and basic intelligence" (Corker, 2002).

The study relied on Institutional theory and Social relations framework which generally argue that individuals and social groups, for example PWDs, can be excluded by unnecessary societal barriers. Discrimination of deaf women might reduce their opportunities to access HIV/AIDS counselling services and create a difference in their treatment regardless of individual merit. Using Kabeer's application of the Social relations to highlight formation and reproduction of gender inequality in individual institutions, the study examined inequality experienced by deaf women while accessing HIV/AIDS counselling services and support in various institutions.

#### 2.3. Conceptual Framework

The conceptual framework below is showing multiplicity of discrimination of deaf women while accessing HIV/AIDS Counselling Services.

Figure 2.1: Conceptualising the Avenues for Multiplicity of Discrimination of Deaf Women



The conceptual framework above is examining how multiplicity of discrimination of deaf women is constructed. Institutionalised discriminative norms and practice as well as unequal delivery of HIV/AIDS services to PWD lead to their exclusion from access to HIV/AIDS counseling services. On the other hand, society and family institutions construct gender inequality among deaf women. The outcome is discriminatory access to and utilization of HIV/AIDS counselling services by deaf women resulting into ultimate multiplicity of discrimination of deaf women while accessing HIV/AIDS counselling services.

#### **CHAPTER THREE**

#### LITERATURE REVIEW

#### 3.1. Introduction

This chapter presents an analysis of existing literature on multiplicity of discrimination of deaf women. The aim of this analysis is to reveal contributions made by scholars who have written before this study and also to highlight gaps and weaknesses in existing knowledge. This literature review focuses on themes of the study which include multiplicity of discrimination, Institutionalised discriminative norms and practices, Gender inequalities as constructed by society and family, institutions/ organisations, Rules and Norms, unequal delivery of HIV/AIDS of Counselling services and exclusion and restriction from recognition. In reviewing the literature, this chapter includes global, regional and local dimensions of the key aspects of the problem which this study addresses.

#### 3.2. Multiplicity of discrimination:

Sociologists understand discrimination as a complex of social relations that produces intergroup inequities in social outcomes but not as isolated individual acts. All inequality is seen as a legacy of discrimination and a social injustice to be remedied (Encyclopaedia, 2001 - 2006). Multiplicity of discrimination explores the complexity and various forms of discrimination and how these are experienced by victims.

History shows that there are many forms of discrimination occurring universally in all demographic and socio-economic strata of society (Arrow, 1973) – based on for example race, religion or socio-cultural. Discrimination occurs when group boundaries impede individuals' freedom to participate in social exchanges; it is not merely a subjective attitude but is a conduct outwardly manifested. To discriminate socially is to make a distinction between people on the basis of class or category disregarding individual merit, basing among others on social identities, resource allocation, power relations, cultural and structural norms of societies that perpetuate inequality (EUD, 2006). Discrimination may not be officially endorsed yet remain an actuality in practice. It entails impairments of one's full and equal participation in society, often targeting certain groups of people, such as women, PWDs or people living with HIV/AIDS, and ethnic minorities. In this study, discrimination is understood as treating a

particular group of people less favourably than others basing on among others, social identities, power differences, resource allocation, cultural and structural norms of societies. Specifically, it highlighted the multiplicity of discrimination of deaf women during their access to HIV/AIDS counselling services.

The standing committee on Social Policy in Queen's Park Toronto Ontario in 2004 noted that the issue of multiplicity of discrimination is quite new for PWDs and is hard to tackle (Cross and Anello, 2003). PWDs and deaf women experience discrimination on the basis of gender, poverty, and education, which is increased by lack of support and services, attitudinal and communication issues as well as economic equality, all in relation to disability (Kutza,1985) hence, multiple obstacles to equality of access. Deaf women lack good role models, promotion and empowerment and access in general. Deaf women have historically been denied public acceptance and recognition as equals for social, educational, and economic resources (Munoz-Bell and Ruiz, 2000).

#### 3.2.1. Manifestation of Multiplicity of Discrimination of Deaf Women

HIV/AIDS is no longer an issue for scientists alone. During the 8<sup>th</sup> Commonwealth Women's meeting (8WAMM) which took place in Uganda in 2007, delegate ministers from 32 countries (Africa, Asia, Europe and Caribbean) declared that gender equalities lie at the heart of the HIV/AIDS epidemic. Most experts agree that gender inequality and violations of women's rights are important factors in HIV transmission that critically place women in vulnerable positions in the face of HIV/AIDS<sup>6</sup>, and recommend adoption of a more programmatic approach towards gender equality when implementing national plans.

There is ample evidence that deaf women like other PWDs experience major psycho-social problems resulting largely from being discriminated or neglected and these include depression, stress and social isolation (Nosek and Hughes, 2003). They are more likely to experience public spaces as intimidating and dangerous through sexual violence in relationships and in institutions. Social attitudes and distorted media images make it hard to accept that PWDs have the same needs, desires and problems as able-bodied persons (Nganwa, Batesaki, Balaba,

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<sup>&</sup>lt;sup>6</sup> UNAIDS (2005) Facing the Future Together: Report of the Secretary General's Task Force on Women, Girls and HIV/AIDS in Southern Africa, which contains many findings and recommendations applicable beyond Southern Africa.

Serunkuma, Yousafzai, 2002) and this has resulted into social exclusion<sup>7</sup> of PWDs and specifically deaf women. Social exclusion emphasizes that discrimination and its attached stigma is due to disability, gender or ill health (Francis, 2002) and translates into 'PWDs being refused participation in social affairs' (World Bank, 2003). With regard to deaf women, this is likely to deter their access to HIV/AIDS counselling services provided in the communities, hence no utilization<sup>8</sup>.

WWD, are conceptualized as a group with multiple minority status. Like other PWDs, they are typically seen as helpless, childlike, dependent, needy, passive, failures and victimized (Menz, Hansen, Smith, Brown, Ford, & McCrowey, 1989), and corrupted masculinity for men generated by enforced dependency (AIDS action, 1997). In their own writings, twenty-three (23) WWDs described their lives and experiences of being female and having a disability, with anger and bitterness about their isolation, despair, powerlessness and poverty (Campling, 1981). WWDs face discrimination as women, hence gender based discrimination whose root causes can be traced to culture of every society. They are "constructed as the other" (Wendell, 1999), "basing on power differences manifested in control over resources which has cultural roots in the patriarchal nature of society" (Republic of Uganda, 2006).

The United Nations aspire that women often experience a "glass ceiling" and that there are no societies in which women enjoy the same opportunities as men. This thus extends to WWD who are more likely than men with disabilities to identify themselves as disabled. Gender discrimination may combine with other forms of discrimination and present particular obstacles for deaf women (Batten, 2006). Gender differences often confirm and justify social inequalities where the gender relation is a relation of power, expressed both in the public and personal sphere, for example, 'denial of WWD their right to reproductive health and HIV/AIDS services and treatments' (Mukasa, 2005).

Though WWD face disabling factors based on their impairments, their position is considered homogeneous with that of non-disabled women on gender grounds. Generally, the social, economic and legal inequities that increase the vulnerability of women and girls to HIV

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<sup>&</sup>lt;sup>7</sup> Social exclusion is defined as the process through which individuals or groups are wholly or partially prevented from full participation in the society within which they live

<sup>&</sup>lt;sup>8</sup> Utilisation is dependent on affordability, physical accessibility and acceptability of services and not merely adequacy of supply

<sup>&</sup>lt;sup>9</sup> The term 'glass ceiling' describes the process by which women are barred from promotion by means of an invisible barrier.

infection are more pronounced for WWD (Groce, 2003). WWD and deaf women are more likely to suffer from a low social status, gender stereotypes, and gender-based violence and reduced access to information, education and economic opportunities, and therefore double burdened. They are discriminated against on more than one ground: gender and disability (Traustadottir, 1990) and they often have less access to essential services.

Traditionally, society believes that WWD are sex-neutral beings without a sexual identity as confirmed by a dominant societal myth that they do not have a sex life (AIDS Action, 1996) and are therefore free from or immune to HIV/AIDS (Nganzi and Matonhodze, 2004). This misbelief fuelled by another myth, namely that having sex with a virgin can cure HIV/AIDS, often result in the rape of disabled women and girls (Lwanga-Ntale, 2003). WWDs are rarely married due to the belief that they are unfit to fill the traditional roles of a mother, wife, homemaker, nurturer, or lover, hence often end up as poor, single mothers (Asch and Fine). These attitudinal misconceptions seem to be shared by HIV/AIDS counsellors and are outstandingly strange given the fact that many deaf women and men have born children of their own (Janssen, 2003). Unfortunately, PWDs who acquire HIV/AIDS may be unaware of the existence of VCT services.

There are also cases where staff in VCT centres deny PWDs access under the guise that they "cannot get AIDS" or that PWDs "do not engage in sexual activities and therefore are not at risk of acquiring HIV" (Yousafzi & Edwards, 2004), hence fall prey to HIV/AIDS. However, since the study was conducted in 2003, with the ongoing sensitization about HIV/AIDS there could be a difference in belief, so it only requires further investigation to prove its validity.

The severe level of disability also defines the basis for discrimination of deaf women from accessing and utilization of counselling services. People with different impairments need different types of information, counselling or practical support. The deaf, blind and those with multiple disabilities are common victims in this regard. Many people who have been trained to help PWDs are specialists in specific fields but lack knowledge in other fields, for example, a trainee for deaf, would not be knowledgeable about the mental disability of that individual, (Nosek and Hughes, 2003).

Recent widespread efforts to educate people about the dangers of HIV/AIDS may leave out majority of individuals in deaf communities since there are just a few individuals trained to handle deaf people and the interpreters are very expensive to hire (NUDIPU, 2003). Society is organized as though everyone can hear, therefore, communication barriers persist between the hearing and the deaf (Wendell, 1999). Education and special curricula in the schools have been insensitive and therefore not accommodated the communication skills of deaf or hard of hearing persons. However, currently Kyambogo University has introduced courses in which willing individuals are trained in communication skills for the deaf. The increase in number of interpreters as well as dissemination of information about HIV/AIDS to deaf persons is yet to be established.

Another discriminative factor identified is illiteracy. Many PWDs are unable to read and write (de Vries 2004) hence, they cannot access the abundant literature on various aspects of HIV/AIDS, including reproductive health and other critical areas of development which, unfortunately is in English and normal print. Sign language is not based on English but has its own grammatical structure, vocabulary and idioms (Golden & Ulrich, 1978). This increases their vulnerability to discrimination, because they cannot know when counselling is needed, where to get it from, how and why counselling, all explained in print literature (Nganzi and Matonhodze, 2004). Furthermore, resources are scarce and limit sign language translation for the deaf but able to read. Some young deaf persons are in the school system and receive HIV/AIDS training. However, most PWDs and deaf individuals have neither been in a learning environment, nor included in social or recreational activities. In Uganda, this highlights the extent to which PWDs are discriminated in terms of their general access to services and participation in community activities; it becomes all the more urgent when the service to which they are denied access is HIV/AIDS education and information.

#### 3.2.2. Delivery of HIV/AIDS Counselling Services to Deaf Women

HIV & AIDS is a serious issue in the world today that is threatening to reverse the development gains of the century. According to UNAIDS (2002), over 40 million people world over are living with the virus, out of which 28million people are in Sub-Saharan Africa(SSA), Uganda inclusive. Unfortunately, PWDs are not targeted by most programmes on HIV/AIDS (Republic of Uganda, 2006), and many African countries have not focused deaf women and HIV/AIDS pandemic. For example in Zimbabwe, the government, NGOs

and the private sector have led major interventions around HIV & AIDS prevention, care, support and mitigation, but little or none has targeted the disabled people and parents of disabled children (Nganzi et al, 2004).

National departments provide services in form of policy developments and formulation as established by researchers in the department of health in South Africa<sup>10</sup>. They further indicated that, a number of departments do not have specific programmmes and therefore do not render services directly to PWDs. According to the findings, it has been proven that policy makers, implementers and major actors on HIV/AIDS have failed to appreciate disabled people as a unique community with distinctive issues and specific needs that require special or specific interventions.

Though Uganda has been cited as the most successful country in SSA in combating HIV/AIDS pandemic, its multisectoral response has continued to be silent on issues and needs of disability and PWDs (UNAD, 1996). As a consequence, society is not well informed of the fatal implications of this deadly disease and the remarkable number of PWDs who have died in silence (NUDIPU, 2003). Basing on information derived from those working and interacting with PWDs, the incidence of HIV/AIDS among this section of the population is high, yet little has been done to restrain its prevalence (Murangira, 2004). Therefore there is need to examine the different forms of HIV/AIDS services and support delivered to this disadvantaged group.

#### 3.2.3. Challenges in reaching and responding to PWD needs and preferences

PWDs may be difficult to target because of the marginalization, isolation and discrimination they face, but nonetheless critical to include in HIV/AIDS programmes. They are likely to be inaccessible particularly those residing deep in rural areas where service providers rarely reach. Even service providers confirm that PWDs are generally geographically scattered in urban and rural areas, (Murangira, 2004) and so not easy to reach and group for sensitisation and service provision purposes.

<sup>&</sup>lt;sup>10</sup> Case Research for the Department of Health on Service Provision for People with Disabilities, South Africa. (Directorate: Chronic Diseases, Disability and Geriatrics)

In Uganda, many PWDs are isolated in their home environment or reside under institutional care. Many deaf persons are confined in enclosed places where they are cared for by relatives who are least conversant with HIV/AIDS counselling, thus making it a problem too. Facilities and services from which rural-based PWDs might otherwise benefit are located mainly in urban centres requiring transport which is often prohibitive for those who live in villages (Nganzi and Matonhodze, 2004). People often live miles away from the nearest TV, radio or billboard, for sensitising on HIV/AIDS. Worse still, educators combine media campaigns with other interventions like counselling, peer educators and travelling theatre groups. All these cannot be accessed by the deaf since they cannot even be mobilised.

Uganda is one of the least urbanised countries in Africa, with over 80% of the population living in rural areas. The rural-based population and those living in urban areas still have strong belief in witchcraft. Research conducted in the rural districts of Rukungiri and Kaberamaido revealed that most PWDs perceive HIV/AIDS to be caused by witchcraft and therefore visit witch doctors first when they fall sick (NUDIPU, 2003). This is self discrimination from the arena of accessing HIV/AIDS counselling service and subsequent treatment, and a big constraint to efforts meant to sensitize PWDs on the nature and threat of HIV/AIDS.

Communication is an integral part of HIV/AIDS counselling services among all health care services. However, communication barriers persist between the able-bodied and PWDs (Nemon, 1980). HIV/AIDS Information especially through public campaigns contributes towards HIV/AIDS prevention efforts used around the world to relay messages that encourage people to modify their behaviours or address some stigma surrounding HIV/AIDS<sup>11</sup>. Media campaigns using posters, billboards, and popularly radio among others, are employed to provide the general public with much needed facts that can help dispel myths and misconceptions about HIV/AIDS and empower people to take control over their lives (Nkulazizi, 2005). While such effective communication is routinely availed to hearing communities, it is not availed to deaf persons who use sign language interpretation and this bears a discriminatory impact on deaf persons.

The nature/ mode of information dissemination on HIV/AIDS is not user-friendly to PWDs, particularly deaf and blind who lack access to HIV/AIDS-related information (Mwesigwa,

<sup>&</sup>lt;sup>11</sup> UVRI-IAVI HIV Vaccine programme newsletter, 2007.

2005). Currently available services and resources as well as channels of disseminating critical HIV/AIDS information are inappropriate and leave certain categories of PWDs (deaf) isolated and excluded. The deaf for example, cannot grasp verbally disseminated HIV/AIDS messages and as such remain ignorant about the available services and opportunities. They are unaware of their sexual status and have inadequate knowledge and information about distribution centres of condoms and their use as a preventive measure. They are also unaware that condoms are freely distributed in designated health units, and the few that secure access use them improperly or just keep them without using them (Nganzi and Matonhodze, 2004). Similarly, HIV/AIDS information centres are not readily accessible to deaf women yet, access to care and information is a human right, as stipulated in the Universal Declaration of Human Rights (UDHR). Consequently, deaf women's exposure to the virus is increased when they indulge in unprotected sex.

Denial of deaf women access to mainstream HIV/AIDS services worsens the situation. For example, VCT services neither provide information, education and communication materials on HIV and AIDS nor offer counselling using sign language, which positions deaf women in vulnerable situations to infection (Mukasa, 2005). This reveals that there is a wide gap between WWDs and able-bodied women when providing HIV/AIDS counselling services possibly resulting from inadequate skilled personnel (NUDIPU and NUWODU, 2004). However, it is important to note that VCT is a necessity for the diagnosis and access to treatment which is currently available and often life-saving, though not a complete cure (Republic of Eritrea, 2005). Studies in Nairobi focused on the deaf women's access to HIV/AIDS Counselling Centre for the Deaf that was staffed with people who could communicate using sign language (Muganda, 2004). The study revealed that, many of those who went to the centre had no knowledge of HIV/AIDS whatsoever. So they had to educate them first before embarking on pre-test counselling.

Many PWDs in the developing world are unaware of their reproductive health rights (DFID, 2004a) another factor that exposes them at risk of HIV infection and sexual exploitation. Consequently, the marginalized deaf become less equipped with information regarding the fatal disease, making a tremendous increase in the numbers of those who die of the disease (NUDIPU, 2003). However, it has been observed that able-bodied women are given such

services free at Mulago Referral hospital, yet it is a right that would apply to all regardless of their ability.

Dependency of PWDs and deaf women on carers who accompany them to HIV/AIDS counselling centres denies them confidentiality and an obvious rejection of Article 17 of the International Covenant on Civil and Political Rights (UNHCR, 1976). Lack of privacy is real and reveals discrimination of deaf persons while able-bodied persons are accorded high levels of confidentiality. In addition, negative attitudes of certain professionals that PWDs are asexual leave some PWDs and their caregivers reluctant to access services.

Formal health establishments, discourage disabled and deaf women from accessing such services to avoid any humiliation.<sup>12</sup> Although it is vital to have enough knowledge and background about deaf culture and sign language among others, evidently a few deaf professionals work within the health care. In France they have tested how a deaf person can be provided with information and established the best way would be by using deaf professionals in sign language<sup>13</sup>. The Ugandan situation seems to be different since most hospitals, referrals inclusive are ill-equipped with doctors and counsellors who can effectively communicate with deaf women using sign language.

The poverty situation in the family has a negative implication on the livelihood of growing PWDs. Young PWDS particularly girls from very poor families are more vulnerable and some are lured into sex in the name of gaining material needs (Yousafzi et al, 2004). Ignorantly, many deaf women have contracted AIDS but do not seek for any medical and counselling services, hence "Triple Burden" of disability, poverty and HIV/AIDS (Banda, 2005).

Poverty has complicated access to information. in that most PWDs cannot even afford radios and televisions (Nkulazizi, 2005), leave alone newspapers where most information on HIV/AIDS is disseminated. Even when such sources would be accessible, they are of less

<sup>13</sup> Statement by Mr. Verstraete, Standing Committee on Social Policy, Queen's Park, Toronto, Ontario, February 8, 2004

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<sup>&</sup>lt;sup>12</sup> F. Nsubuga-Muyonja & Meldah Tumukunde (2004): Report of a Desk Study on the Level of Knowledge and Access to HIV/AIDS Information and Services by People with Disabilities in Uganda, Kampala.

value to deaf persons who would not hear anything on a radio, and cannot get anything from news papers since the majority are illiterate, (DFID, 2004a).

PWDs are among the poorest, least educated, and most marginalised of all the world's peoples. They are at serious risk of HIV/AIDS and attention needs to be focused on them (Groce, 2003). According to World Bank estimates, 17 percent of PWDs belong to the poor and illiterate sections of society in developing countries (de Vries, 2004). The HIV/AIDS scourge, most deeply affects those least able to enjoy their rights, the poorest, the weakest, the least educated and the most sidelined and marginalized (Gitonga, 2004).

#### 3.3. Definition of Key concepts

Access to

- Opportunity or ability to obtain and use available HIV/AIDS

Counselling Services and treatment which are within the vicinity of

a potential user

Discrimination - making a distinction between people and treating them in a

different, usually bad, manner because of their class or category,

race, disability, gender, resource allocation, power relations, cultural

and structural norms instead of who they are as individuals.

Service provision - A state of providing the public with the use of a service, such as

health, counselling, transportation.

Utilisation - The actual acceptance and use of HIV/AIDS Counselling Services

offered

Gender-based discrimination - is any action that grants or denies opportunities,

privileges, or rewards to a person just on the basis of their sex

#### **CHAPTER FOUR**

#### RESEARCH METHODOLOGY

#### 4.1. Introduction

This chapter presents an explanation of the methodology used in this study; the research design, the study population, sample size and sampling procedures, data collection methods, data analysis, ethical consideration and study limitations.

#### 4. 2. Research Design

This study adopted a cross sectional study design<sup>14</sup> using qualitative and quantitative methods to collect detailed required information so as to come up with recommendations that would address the research problem. It was cross-sectional because it set out to investigate construction of multiple discrimination as deaf women seek to access HIV/AIDS counselling services at this point in time in selected institutions in Kampala District.

#### 4.3. Study Area

Institutions selected for the study are found in Kampala district. The criteria for selection of these institutions were based on ability to deliver HIV/AIDS services and/or serve deaf persons. Institutions where the study was conducted included the following:

i) Uganda Society for the Deaf (USD) Vocational Training Centre at Namirembe. This is a vocational institution specifically providing training to both mature deaf girls and boys in carpentry, building tailoring, home economics, art and craft, Computer Science, Sign Language, Mathematics, English and Religious education. At the same time USD is a convergence area for deaf women and men who meet and exchange socio-economic ideas. The researcher tried to find out whether the female students of age were being guided on matters concerning sex and HIV/AIDS.

 $<sup>^{14}</sup>$  A Cross sectional study design is one which collects data about various variables of the sample at one point of time in order to uncover relationships existing among those variables

- ii) Uganda National Association of the Deaf (UNAD) at Kamwokya: This is a strong National Association for the Deaf that brings together all different categories of deaf women and men in Uganda. It acts as their own voice and is involved in advocacy, awareness raising, training (including adult literacy), information, research and dissemination. The researcher wanted to establish whether their institution was providing members opportunity to access HIV/AIDS counselling services and social identity as deaf was not constructing their discrimination in the process.
- iii) National Union of Disabled Persons in Uganda (NUDIPU) in Kisaasi: This is a dynamic and internationally recognized civil rights movement and an indigenous umbrella NGO for PWDs in Uganda. Its main purpose is to influence provision of services in favour of PWDs in Uganda. It advocates for equalisation of opportunities, involvement and participation in policy planning and implementation of disability programmes in close co-operation with government, NGO's and the public. The researcher wanted to establish whether HIV/AIDS programme was among those being implemented by the institution and whether equality of rights was being observed.
- iv) Straight Talk Foundation at Kamwokya: Services offered by this institution include counselling in various aspects HIV/AIDS inclusive, life-skills training and behavioural change, health communication and out-reach programmes. Since they had an outreach program, the research wanted to find out whether deaf women were part of their clients.
- v) Naguru Teenage Information and Health Centre at Naguru (TIHC): offers counselling, HIV/AIDS testing and treatment services. The researcher wanted to establish whether deaf women were visiting this centre to receive counselling services and also to compare their access to that of able-bodied and infected with HIV/AIDS.
- vi) The AIDS Support Organisation (TASO) at Mulago. This is specifically concerned with counselling, medication and social support to needy clients including training deaf women on awareness about HIV/AIDS. The researcher wanted to find out how deaf women and ablebodied women were handled while accessing HIV/AIDS counselling services so that it could become known whether the deaf women were being discriminated while acquiring similar services.
- vii) Aids Information Centre (AIC) at Kisenyi: provides services ranging form Training counsellors, VCT, TB screening, Family Planning, STD/STI management, Medical social

support, and treatment of common diseases. The researcher's interest to this institution laid in identifying whether deaf women were part of their clients.

The selected institutions were those deemed knowledgeable and also expected to be offering HIV/AIDS counselling services to the communities where PWDs live and some of them are specifically for deaf women and men.

#### 4.4. Study Population

The study population was from seven selected institutions in Kampala district. They included deaf women, SLIs, HIV/AIDS service providers, counsellors and HIV-positive women. They were targeted because they were deemed knowledgeable and expected to provide relevant information concerning construction of discrimination while deaf women access HIV/AIDS counselling services. Deaf women population in Kampala district is estimated to be seven hundred (700) while service providers in the selected institutions are about ninety (90)

#### 4.5. Sampling Strategies

In this study, participants were selected basing upon Maxwell's (1996) definition of purposeful sampling when desired population have typical characteristics necessary to provide information but rare and very difficult to locate and recruit for a study. The sampling was done from deaf women, HIV/AIDS service providers and women infected with HIV/AIDS in the seven selected institutions. Participants were recruited with a snowballing effect from contacts established by the researcher. The precondition for selecting deaf women respondents was that they would competently communicate using sign language. A total of 67 respondents were interviewed; twenty (20) were service providers two of whom were deaf, thirty seven (37) were deaf women and ten (10) HIV-positive women. The hearing HIV-positive women were interviewed to compare their accessibility to HIV/AIDS counselling services with that of deaf women.

#### 4.6. Research Methods

This section provides the research methods or data collection tools that were used to collect data during the study. The research methods for this study were selected basing on their appropriateness to the study, the degree of success on the field and ethical considerations. Quantitative data was collected using questionnaires as the main data collection instrument because it allows flexibility, which enables the tapping of rich data. The questionnaire consisted of close-ended questions and open-ended questions which were framed with the aim of soliciting deeper information which would otherwise be difficult to obtain. Questionnaires were administered to both administrators and other employees in the institutions visited.

Qualitative methods of data collection were used because they give more information as it is more investigative and allows room for probing and getting a deeper insight of the respondents' views. Summarily, the techniques of interview, focus group discussions, observation and case study were utilized. In this study, SLIs were employed to relay messages between the researcher and the deaf respondents. Interview guides were used for in-depth interviews held with hearing HIV-positive women respondents to get deeper understanding of the deaf women's access to and utilization of HIV/AIDS counselling services.

Focus group discussions were conducted to capture information that individuals might not be able to release during the above approaches. Focus group discussions with between five to seven were held with deaf women respondents being aided by SLIs. In combination with participant observation, the method allowed access to unexpected issues. All FGDs were tape-recorded, the data was transcribed and translated. The discussion of deaf members in a group format was lively and energetic, which allowed members the comfort of being creative and thoughtful.

The researcher also used observation method in order to supplement on the FGDs and indepth interviews. An observation guide was used and emphasis was put on observable aspects like facilities in VCTs centres, equipment, and overt behaviors of the deaf women, HIV-Positive women and service providers. The researcher used the information gathered to offer descriptive and predictive information on multiplicity of discrimination of deaf women.

The researcher also used case study method to investigate two cases involving a deaf female student who is HIV-positive and another case involving deaf women's sex life in relation to HIV/AIDS counselling services.

Data gathered was later quantified for easy analysis.

#### 4.7. Data Analysis and Presentation.

Data collected was analyzed both quantitatively and qualitatively. Codes were attached to alternative answers given from the questionnaires and entered in a computer. Qualitative data in form of narrative views corresponding to objectives was quantified and tabulated basing on frequency distributions of emerging sub-themes using the Statistical Package for Social Sciences (computer software package).

#### 4.8. Study Procedure

Reliability of the instruments was ensured by a pre-test of the questionnaires and interview guides in one selected institution namely Wakiso Secondary School for the Deaf in Wakiso District. In order to ascertain the formality of this study, the researcher secured an introductory letter from the head of department Women and Gender Studies, Makerere University that was presented to the respondents from the selected institutions of PWDs and those offering HIV/AIDS counselling services. Following prior appointments with the organization leaders, the researcher visited the institutions and offices to meet with the respondents and explain the purpose of the study to them. After getting permission from the leaders of these organizations questionnaires were administered to the institutional personnel/service providers and then collected at a later date to allow sufficient time for complete response. It became evident that respondents did not experience difficulties while responding to the questionnaires.

The researcher was a hearing woman. Interaction with deaf women was aided by sign language interpreters who were professionally and socially active in the deaf community. FGDs were held with deaf women and those who were not deaf but infected with HIV/AIDS to obtain the required information being aided by tape-recording and taking photographs to capture reality on the ground. Case studies were also used to elicit for information from a deaf HIV infected female student and from an SLI to clarify on issues of sexuality for deaf girls. The researcher made follow up visits in case of ambiguities and where responses

required further clarification. Collected data was then subjected to editing, to eliminate irrelevant data and inconsistencies and ensure uniformity.

#### 4.9. Ethical Considerations

HIV/AIDS is a condition that is dreaded and stigmatizing. These are issues which are difficult to address openly at societal and individual level. In that respect therefore, before respondents became subject to research, they had to be notified of the aims, methods, and anticipated benefits of the research. In addition no respondent became subject to this research unless he/she consented to participate. No pressure or inducement of any kind was applied to encourage an individual to become a subject of research. Furthermore, the researcher assured the respondents about the degree of anonymity and confidentiality in the information that they would provide.

# 4.10. Limitations of the Study

The major limitation of this study was that the research was conducted using SLIs during communication with deaf participants. To ensure realization of information, the sample population used was small but better educated, exposed, more social and possessed an opportunity of using sign language. However this limited generalizability of the findings of this study to the entire deaf women community. There was also likelihood of SLIs offering answers which might not have been as genuine as offered by deaf respondents.

In addition there were practical and socio-cultural difficulties in identifying, locating and reaching deaf women that would arise directly from the context and life circumstances of this population. Many PWDs were less likely to access mainstream services leading to few deaf women with ability to use Sign Language interacting with service providers. Similarly, most deaf respondents were expected to routinely rely on carers who might be protective and hostile regarding matters concerning provision of HIV/AIDS programs to PWDs. In order to overcome this, the researcher adopted the snowballing effect from existing contacts established when recruiting deaf participants.

Respondents expecting to be rewarded; during the data collection in the field, some respondents would expect money or any other kind of reward from the researcher. However, the researcher would show them introductory letter from MakerereUniversity showing that the data being collected was specifically academic.

# **CHAPTER FIVE**

### PRESENTATION AND DISCUSSION OF FINDINGS

#### 5.1. Introduction

This chapter provides the presentation and discussion of research findings collected in the study conducted during the period between July and September, 2008. The study set out to examine how discrimination was being constructed through multiple actions as deaf women try to access HIV/AIDS Counselling services in selected institutions in Kampala District. First, the study set out to examine the extent to which institutional rules and norms construct discrimination of deaf women as they seek to access HIV/AIDS counselling services. Secondly, the study set out to examine the extent to which the structural positioning of deaf women in society affects their access to HIV/AIDS counselling services. Thirdly, the study intended to analyse the extent to which the interaction between deaf women and HIV/AIDS counselling service providers create and reinforce multiple discrimination in access to and control over resources.

# 5.2. Socio-Demographic Characteristics of Respondents

The presentation and discussion of findings starts with description and analysis of demographic characteristics in this study in order to provide background information that was considered essential for purposes of making reliable interpretation and conclusions. The results of this section were derived from the instruments (questionnaires) that were administered to service providers, and responses obtained from deaf women respondents during the FGDs to provide background information about their occupation, age, sex, levels of education, in addition to their marital status. A total of 67 respondents were interviewed of whom twenty (20) were service providers (two of whom were deaf), thirty seven (37) were deaf women and ten HIV-positive women.

# **5.2.1.** Deaf Women Respondents from Deaf communities

Deaf women interviewed were part of Deaf communities in two Organisations for the deaf namely Uganda Society for the Deaf (USD) Vocational Training Institute and Uganda National Association of the Deaf (UNAD).

Table 5.1: Deaf Women Respondents from Deaf communities by age and education levels

	Uganda Society for the Deaf(USD)  Uganda National Association for the Deaf (UNAD)																	
Age	No. of respondents		Prima	ry	Second	lary	Vocatio	onal	No. o respo s	of ondent	Prima	ıry	Seco	ondary	Voca	ntional	Overa ll Fotal	%age
	freq	%	freq	%	freq	%	freq	%	Freq	%	freq	%	freq	%	freq	%	freq	%
5-20	5	20	4	20	-	-	5	20	1	8. 3	1	8. 3	-	-	-		6	16.2
1-25	8	32	7	28	1	4	8	32	2	16.7	2	16.7	-	-	-		10	27
6-30	6	24	6	24	1	4	6	24	3	25	2	16.7	-	-	1	8.3	9	24. 3
1-35	2	8	2	8	-	-	2	8	4	33. 3	4	33. 2	-	-	3	25	6	16. 2
6-40	3	12	3	12	3	12	3	12	1	8. 3	1	8. 3	1	8. 3	1	8.3	4	10.8
1-45	1	4	1	4	1	4	1	4	1	8. 3	1	8. 3	1	8. 3	1	8. 3	2	5.4
Total	25	100	24	96	6	24	5	100	12	100	11	91. 5	2	16.6	6	49.9	37	100

Source: Research Findings Aug - September, 2008

Findings as shown in Table 5.1. revealed that the selected sample of deaf women had received basic training in using sign language and tended to be educated, holding a privileged socio-economic status than the average deaf woman. This was gauged in accordance to the deaf community "yardstick" of being able to communicate in National Sign Language with talking communities, an indication that they had attended school, and ability to earn an income however meagre it could be. They reported through SLI that they had attained varying educational backgrounds ranging from Primary to vocational training. In this case therefore, since the deaf women respondents were able to communicate using National Sign language, it would be easier for them to access HIV/AIDS counselling services.

**Table 5.2: Occupation of Deaf Women Respondents** 

	US	SD	UNAD		Total	
Occupation/ Position	Freq	%	Freq	%	Freq	%
Student	20	80	-	_	20	54.0
Cleaner	-	-	4	33.3	4	10.8
Instructor at Vocational Institution	5	20	4	33.3	9	24.3
Knitting/ Tailoring	-	-	2	16.6	2	5.4
Housewife	-	-	2	16.6	2	5.4
Total	25	100	12	100	37	100

Source: Research Findings Aug - September, 2008

Table 5.2. shows the occupation status of deaf women respondents who were involved in this study. These included students, instructors at vocational institutions, cleaners, those engaged in tailoring and knitting. Selected respondent students from USD vocational institution formed 54% of the total deaf women in the study and had capacity to respond well to anticipated questions. Only 5% of the deaf women respondents were housewives without paid

employment. These findings reveal the contrary to what Asch and Fine (1988) highlighted that WWD are typically regarded as helpless, childlike, dependent, needy, victimized and passive. Apart from female students from USD, the rest of the selected deaf women showed capacity to sustain themselves. Through FGDs held with them using SLI, it was noted that deaf women basically have lower educational levels, and therefore accorded low-paying jobs or unemployed.

The results of the study may include a significant bias if considered to represent deaf women population in Kampala District. The sample size was non-randomized because the researcher experienced difficulties in identifying a homogeneous randomized sample. Further, the selected sample was expected to be conversant with the use of sign language for easier communication.

#### 5.2.2. Characteristics of Service Providers interviewed

The study was conducted in seven selected institutions in Kampala District two of which were specifically for the deaf. The remaining organisations were generally serving communities irrespective of category or social identity. The findings revealed that of all the organisations visited, TASO, AIC and Naguru TIHC are counselling centres supposed to offer counselling services to all categories of people including PWDs. The rest of the organizations including Straight Talk Foundation, NUDIPU and USD laboured to create awareness about HIV/AIDS among the communities they serve.

Service providers interviewed from the institutions where the research was conducted included counsellors, SLIs, co-ordinator HIV/AIDS programme, coordinator outreach program and editor. Counsellors constituted 65% of service providers interviewed of whom only 10% were counsellors as well as SLIs. 10% could use sign language but were not counsellors. This concurs with Nemon (1980) who stated that few professionals are fluent in sign language and, as a result, they cannot communicate directly with most deaf persons.

Further, service providers were requested to provide their educational background levels in order to establish their ability to handle deaf women as they seek to access HIV/AIDS counselling services. Below is Table 5.3. summarizing the sex, positions occupied and levels of education of the respondent service providers.

Table 5.3: Service Providers' Education levels by Sex and Position in the organization

		Education level						
Position in the organisation	Sex	Primary		Vocational		Diploma/Degree		
		freq	%	freq	%	freq	%	
Counsellor	Male					2	10	
Counsellor	Female					9	45	
Counsellor/sign language interpreter	Female					2	10	
Sign language interpreter	Female					2	10	
General Staff	Female	1	5			1	5	
Coordinator of program	Male			1	5			
Coordinator of program	Female					1	5	
Editor	Male					1	5	
TOTAL		1	5	1	5	18	100	

Source: Research Findings August - September, 2008

Results showed that service providers who attained either a diploma or degree constituted 90%. Findings further showed that most of the respondent service providers were female, well educated and understood the questions that were asked in the questionnaires. Their responses and information given was therefore considered reliable. Being female for the majority of these service providers was probably an extension of their female reproductive roles of nurturing from the private to public sphere.

#### 5.3. Institutional Policies/Rules and Norms in Relation to Deaf Women

Institutional rules and norms propel management of institutions (Scott, 2004). Discrimination of deaf women may be entrenched in the institutional rules and norms of organisations due to inequalities in the policies norms and practices for delivery of services, thus the need to examine them.

Five counsellors out of the thirteen defined institutional rules and norms generally as orders and instructions in place to follow while running their institutions and to restrict them from acting otherwise. However, this was different from the way earlier scholars had defined it as authoritative guidelines for social behaviour (Scott, 2004). Others had the view that institutional rules and norms exist at the level of community or society and not determined and/or chosen by individual as said by (Kabeer 1999).

From the findings, institutionalised discriminative policies, norms and practices existed in formal institutions and organisations examined in the study as they would not consider deaf

women as a special category. Through FGDs, deaf women and girls expressed their disappointment at being discriminated against at both family and community level. At family/household level, societal norms and practices were discriminative to deaf women and girls. Deaf women and girls defined discrimination at house hold level as being denied chance to participate in conversations or appear in public, overburdened with housework compared with siblings. They would be damped or neglected by own family members which would make them loiter in search for deaf colleagues and this would expose them to HIV/AIDS.

The deaf women and girls reported that family members would not offer emotional and moral support; family members were not able to use Sign language and regarded them as inhuman and discontented because of failure to provide them with basic needs. Hence, the family as an institution was providing a front for discrimination of deaf women using societal norms and practices. This is in line with research conducted by World Bank (2003) who found out that that the stigma attached to having a disability (deaf) means that PWDs are often refused participation in social affairs.

Below in Figure 5.1. is a caption showing the researcher (on the left) inquiring while observing what is transpiring between SLI and the students from USD.

Figure 5.1: Students at USD expressing their feelings of discrimination through SLI



Source: Research Findings Aug - September, 2008

At community level, organizations and formal institutions like HIV/AIDS counselling centres also had discriminative policies, norms and practices. Of the Institutions visited,

it was according to policy and practices that TASO, AIC, Naguru and Straight Talk Foundation are offering HIV/AIDS counselling and apart from Straight Talk Foundation, all others undertake testing and issuing of drugs. Apart from Uganda Society for the Deaf Vocational Training centre, there were no rules in other institutions set to prevent deaf women access HIV/AIDS counselling services. Similarly, there were no policies guiding deaf women access to HIV/AIDS counselling services and according to the norm, counselling centres would not be expecting deaf women to visit them and so had no resources in place for them, for example, availability of SLI. It became obvious that these institutions perceived HIV/AIDS to be a hearing person's disease. This concurs with Wendell (1989) who had the notion about society being organized as though everyone can hear, therefore, communication barriers persist between the hearing and the deaf. Under such circumstance therefore, it would be highly improbable to find in place rules or policies guiding deaf women's access to HIV/AIDS counselling services, hence denial of access and eventual discrimination of deaf women

### 5.3.1. HIV knowledge, awareness and Training among Deaf Women

FGDs held with the twenty female students at USD, revealed that they were all aware about HIV/AIDS and its fatal implications. They said that they came to learn about HIV/AIDS while at school as per institutional policy to create awareness, and impart knowledge on how people acquire it through especially sex and sharing sharp objects although some are born with the disease and others are raped by infected individuals. Some reported reading books to get the information while some friends could offer them advise about the disease or getting pregnant or both although they lacked knowledge on how to protect themselves from contracting the disease or how to have safe sex.

The deaf instructors interviewed at USD were mature women who might have engaged in sex because some reported having children of their own but had never gone for VCT. FGDs held with these women revealed that there were cases of deaf women who remarried when they were sure they had lost their partners to AIDS. UNAD respondents were aware that having sexual relations is the basic cause of spread but very few knew about other means of spread, for example, some of their colleagues were unaware that sharing sharp instruments like razor blades and nail cutters would expose them to the disease. The illiterate deaf women were reported to have a misconception like

transmission of HIV/AIDS through sharing utensils or staying close to an infected person. In addition the deaf women confessed that they lacked basic information on human sexuality and birth control. This is confirmed by research conducted by DFID (2004a), who held the same view that many disabled people in the developing world are not aware of their reproductive health rights. Deaf women showed concern and asked whether those taking ARVs (Anti-retro Viral Drugs) could test positive. They were dismayed by some deaf children being negatively influenced by media and condemned the act of men raping deaf girls who cannot shout for their rescue.

UNAD runs a program for its clients with policies on HIV/AIDS. UNAD deaf women respondents (32%) said they would occasionally receive training in the presence of SLI, and trainers were treating them like hearing persons. Although Uganda has been running aggressive sensitization activities on HIV/AIDS, UNAD respondents narrated about the plight of fellow illiterate deaf women especially the unmarrieds who were unaware of the existence of HIV/AIDS. The few who were aware just had imaginations on how the disease could be contracted. This is in agreement with Murangira (2004) who also reported that though Uganda has been cited as the most successful country in Sub-Saharan Africa (SSA) in combating HIV/AIDS pandemic, its multi-sectoral response has continued to be silent on issues and needs of disability and PWDs. It can therefore be concluded that policies in place are discriminatory and do not specifically address deaf women as a special category of persons.

The study also questioned how often the organisations provide training about HIV/AIDS to deaf women. The responses from the 85% of service providers are indicated in Table 5.4.

Table 5.4 Routine Trainings about HIV/AIDS

Training Intervals	frequency	percentage
monthly	15	88.2
Quarterly	4	23.5
Yearly	9	52.9
Adhoc	2	11.8

\*Multiple Responses

Source: Research Findings Aug - September, 2008

Respondents from NUDIPU said that their organization per se was not involved in training deaf women and men on awareness but boasted of networking with TASO whom they would invite to disseminate information on HIV/AIDS and train group members and interested deaf persons. The counsellors at Naguru TIHC and AIC said that their centre provided training on HIV/AIDS to Talking Communities but not deaf women and men because they lack trained personnel to handle deaf persons, hence discrimination of deaf women from trainings offered.

As for TASO, according to their working norms that include flexibility, speaking the same language and ensure effective communication, it became apparent that deaf women were principally being attended to by one specific counsellor who is also a PWD (Physical). She would provide training on awareness about HIV/AIDS to deaf women indicating that a policy exists that targets deaf women and men concerning HIV/AIDS.

# 5.3.2. HIV/AIDS Counselling Services, Counselling Centres and Personnel

In all the seven institutions visited, NUDIPU, USD and UNAD, TASO had trained personnel, to handle deaf persons while in others, their deaf clients would come with their own SLI. The service providers whose designation was counsellors had formal qualifications in HIV/AIDS counselling. The situation is analogous to the example identified by Nosek et al (2003) that, a trainee for deaf, would not be knowledgeable about the mental disability of that individual.

To be more specific, Straight Talk Foundation respondents said that the organization was lacking trained personnel to handle deaf persons and communication to this category of persons in outreach programmes is through a community member, hence an element of discrimination existed. During workshops within communities, respondents said that it would cost a person patience in order to understand messages from the deaf who rarely sought counselling services from their organization as they lacked SLI. This conforms to what NUDIPU (2003) also found that the baseline for this discrimination may be attributed to the fact that there are just a few individuals trained to handle deaf people and the interpreters are very expensive to hire. The inability to cater for the deaf women and men when publicly dealing with communities was discriminating them and denying them

necessary information as compared to able-bodied women due lack of trained personnel, hence their discrimination

NUDIPU respondents (10%) reported that being an NGO for PWDs, it possessed sign language interpreters as part of their staff to aid in communication with deaf women and men although faced with financial constraints. Respondents from AIC reported that they were not trained to handle deaf persons but managed to cope with the few deaf clients who visited the centre by communicating with them through sign language interpreters or holding written discussion. TASO respondent said that she was basically the only person handling deaf women and men since other counsellors with formal qualifications in HIV/AIDS counselling had a communication barrier with deaf women and men.

The study wanted to find out how often deaf persons seek HIV/AIDS counselling services in these organization. Of the Institutions engaged in HIV/AIDS counselling, the services were open to the general communities. Three-quarters of the service providers responded of which 7% said that deaf persons had never sought for HIV/AIDS counselling, the services. 73% are reported to rarely seek for HIV/AIDS counselling services, 7% do it weekly and the remaining 13% do so anytime.

TASO counsellor said that deaf persons seek counselling services from TASO depending on individuals' appointment since they have flexible appointment times. For the case of Naguru TIHC, the organisation was offering counselling, HIV/AIDS testing and treatment services to various clients twice a week although individual clients would be met regularly at various intervals in case they were HIV positive. Counsellors said that the deaf rarely reported to the centre. AIC Counsellors suggested that deaf women like other people were exposed to HIV/AIDS infection and therefore needed counselling except that they lacked appropriate communication.

#### 5.3.3. Methods for disseminating HIV/AIDS campaign messages to deaf women and men

A specific question was asked on channels or means used by the institution to disseminate HIV/AIDS information to deaf women and men. As for Straight Talk Foundation, 15% of the total respondents reported that in case deaf women visited the centre which was a rare incident, counsellors would use gestures with the hope that they were making meaningful

communication but deaf women would still fail to understand the meaning of some gestures used resulting into their rejecting to continue visiting the centre yet some of them might sincerely be infected with HIV/AIDS.

USD female students (54% of deaf women respondents) reported channels or means used by the institution to disseminate HIV/AIDS information to deaf women and men as Drama, charts, text books, few pictures, few Video tapes, and newspapers. FGDs held with them expounded further the kind of information disseminated to them and it revolved around how people contract AIDS – using unsterile injections, sharing sharp instruments like nail cutters, prostitution, sex with different partners, signs and symptoms of HIV/AIDS, how to guard one self against the disease. They reported that this had been going on for almost three years being part of sex education offered at school. On the whole all students had noted that persons communicating and disseminating HIV/AIDS information to them were not very competent in sign language thus, leading to deaf persons getting limited and scanty information.

UNAD respondents (32% of deaf women respondents) reported that they could not access HIV/AIDS information aired on radios. They said that information flow to them was very difficult but suggested that they could benefit from TV programmes or drama or through announcements made in their church congregation. This conformed to the view held by NUDIPU, (2003) that the marginalized deaf become less equipped with information regarding the fatal disease, making a tremendous increase in the numbers of those who die of the disease. FGDs also revealed that literate deaf women could opt for exchanging written notes with the counsellors as service providers as a way of communication but they lamented that counsellors' writing was often beyond the literacy skill of the deaf women. This is confirmed by de Vries (2004) who pointed out that many PWDs are unable to read and write. As such they expressed fear to visit counselling centres because they felt that this kind of communication was too slow to enable counsellors attend deaf clients.

From the standpoint of service providers, it was established that the currently available services and resources as well as channels of disseminating HIVAIDS information were not specifically taking into account deaf women and men. Service providers did not support TV programmes to be an appropriate method of disseminating HIV/AIDS campaign messages

for deaf women and men. 50% of them said that although deaf women could watch TV programmes, very few of them understood the messages due to their defect. It must be noted that there is a difference in communication by service providers with Talking communities and deaf women and men. Basing on this consideration Nkulazizi (2005) highlights that media campaigns using posters, billboards, and popularly radio among others, are employed to provide the general public with much needed facts that can help dispel myths and misconceptions about HIV/AIDS and empower people to take control over their lives. This is apparent evidence that these services and resources as well as channels for disseminating HIVAIDS information discriminate deaf women and men since they are not deaf-friendly.

Service providers as well suggested that provision of information, education/training and campaigning would be the most appropriate method. They added that even written materials, posters, billboards method could to a small extent be effective. In addition, they suggested that special seminars for deaf women and men could be organized as a way of trying to include them in Counselling programmes. Overall, all service providers opted for possibility to be trained in appropriate ways of designing suitable messages and disseminate critical information to the deaf to avoid isolating and excluding certain categories of PWDs.

# 5.3.4. Venues for reaching Deaf Women

Service providers were requested to suggest convenient places for reaching deaf women and train them about HIV/AIDS epidemic. Figure 5.2.below reveals the findings:

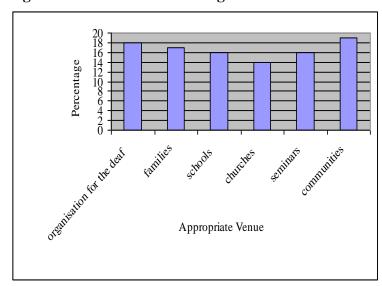


Figure 5. 2: Venues for reaching Deaf Women

Source: Research Findings Aug - September, 2008

The biggest number (19%) suggested that they should be met within the communities where they were residing, indicating that they were not sensitive to discrimination of deaf women. This is in conformity with the standing committee on Social Policy in Queen's Park Toronto Ontario in 2004 (Cross, 2003) that noted that the issue of multiplicity of discrimination is quite new for people with disabilities and is hard to tackle. Others suggested that deaf women should be met within organizations for the deaf (18%). Other suggestions included families, schools, seminars and churches. FGDs with UNAD women respondents revealed that churches for the deaf, specifically Emmanuel Church for the deaf at Ntinda would be the most convenient because of assured congregation after church service on a Sunday. Yet USD respondents preferred to be met at their vocational institute known by majority of the deaf as their embassy, and after all the mother organization of all institutions for the deaf. These suggestions indicated that these deaf women were appreciating the fact that they were being discriminated.

In order to establish whether there were any other organisations in locality reaching deaf persons with HIV/AIDS preventive messages/care & support, 42.5% of the service providers reported in the affirmative and the rest denied knowledge about this. Those who reported yes amazingly listed particular organizations within the study like TASO whom they described as having resources & experienced personnel to do the job, UNAD who was running youth programmes which try to reach the deaf and through NUDIPU partnership.

### 5.3.5. Key Elements in Institutional Rules and Norms showing discrimination of Deaf women

Discrimination of deaf women is constructed in various ways using institutional rules, norms and practice during delivery of HIV/ AIDS counselling services. Design of program policies is for social equity to guide practice in service delivery and facilitate equal access. On the contrary, discriminatory laws, administrative procedures and control mechanisms favour Talking communities and give them more resources and opportunities than deaf women, for example, at health centres they can either facilitate or inhibit equitable access for females and males. Deaf women as a social group has little voice and is neglected thus translating into lower access to services. Their social isolation is displayed in being denied chance to interact with others or societal refusal to accept them participate in social affairs basing on their social identity as deaf.

It was noted that sign language employs the use of English language meaning that deaf women who never attended school would not be conversant with it and therefore face discrimination during communication. Again, the rules followed when using sign language are far different from guiding principles applied in the use of English language, hence confirming what Golden & Ulrich (1978) said that sign language has its own grammatical structure, vocabulary and idioms.

Service providers inadequate in the use of sign language testified that they were unaware of the fact that delivery of HIV/AIDS messages to communities was done in a language beyond the understanding of deaf women. The counsellors at Naguru TIHC reported incidents where few deaf women who visited their centre deaf women would pay for their SLIs for HIV/AIDS counselling and testing. This practice could therefore be described as discrimination for deaf women to pay SLIs while receiving HIV/AIDS counselling services while talking communities were receiving the services free of charge. Service providers interviewed in Straight Talk Foundation reported that when they hold workshops within communities, it would require a person to be patient in order to understand messages from the deaf. Hence, when viewed from this standpoint, service providers' lack of direct interaction with deaf women would be considered as discrimination.

The turn-up of deaf clients at counselling centres like TASO was considered negligible as compared to talking communities. For example, TASO Counsellor confirmed that at the moment she would handle six deaf women clients who go for regular counselling compared

to over fifty HIV positive women visiting the centre every day although the numbers in need of counselling would be far higher than that. The few numbers of deaf women clients she attributed to lack of information and fear of stigmatisation by other clients who visit the centre, hence another element of discrimination.

Confidentiality would be inexistent while HIV/AIDS counselling was being offered to deaf women while using SLI, and in majority of cases, deaf women would be overlooked by service providers as they considered them to be sexually inactive. Due to all this, they would face discrimination as women, less literate, poor and deaf. UNAD women respondents said they would occasionally receive training in the presence of a sign language interpreter, and trainers would treat them like hearing persons which is another element of discrimination.

To enrich the findings, the researcher conducted a case study on one female student to establish whether deaf and HIV positive women face discrimination constructed by institutional norms as they access HIV/AIDS counselling services. This is female student at USD who was born deaf and HIV-positive, can access HIV/AIDS Counselling centre but does not access counselling services. Information was obtained from her being assisted by SLI.

#### Case Study 1: A female Deaf HIV-positive Student

This female student at the vocational institute is aged twenty years and an orphan. She was born deaf and HIV positive. This girl visits Mildmay clinic on a weekly basis where she is offered drugs after presenting her medical form. She said that she regularly undergoes testing and receives prescriptions without understanding why the action had been undertaken. No one communicates to her while at the clinic due to lack of SLI and as such she does not receive any counselling. She said that she knows about the disease but has not had the chance to see any other deaf woman seeking for treatment; she sees able-bodied women who are HIV-positive at the clinic.

In addition to the several kinds of policies or authoritatively publicized rules, there was to be found in almost every organization a number of practices which had not been established as orders or regulations and which would not be enforced by sanctions but which would nevertheless be observed in the organization by norm, custom or other reasons. Often, the line between policy and practice is not sharp unless the organization follows the practice or policy of policy documentation.

# 5.4. Structural positioning of Deaf women in Society and Demonstration of impacts

Another specific objective of the study was to examine the extent to which the structural positioning of deaf women in society affects their access to HIV/AIDS counselling services. In the context of this study, positioning is defined as placement in society of a homogeneous category of persons with similar defining characteristics, whether socially, culturally, economically or otherwise.

Being a small community, the deaf community is very tight knit, ably offering strong support and strong condemnation to its members at times. This dependence on and identification with the deaf community for information and assistance in any field is reinforced by their negative experiences in the hearing world. But even more critical, the closeness of the community can act as an incubator for sexually transmitted diseases. Deaf women are constructed by society as PWD who are poor, women and deaf. Deafness condition the manner in which deaf

women perceive themselves and their place in society as well as the manner in which society responds to them and makes its resources available to them.

From the findings, deaf respondents defined their structural positioning as being discriminated against by society that relegates them to irrational beings because of their disability and inability to communicate verbally. Deaf women complained that society constructed them as being less intelligent and positions them in the lowest social strata at the very extreme designated for stupid and non-intelligent people, "kasiru", basing on their unusual way of communication. This is not very different from the view held by (Corker, 2002) who described being deaf as having an impairment to reasoning and basic intelligence". Though deaf women were experiencing disabling factors based on their impairments, it was established that their position in society was considered homogeneous with that of able-bodied women on gender grounds. Thus, as confirmed by Wendell (1999), deaf women face discrimination as women, hence gender based discrimination, and as such constructed as the "other".

Deaf women further reported that their structural positioning in society was for poor docile beings who are sexually inactive and expected to neither get pregnant nor engage in sexual relationships and therefore not at risk of acquiring HIV/AIDS disease. Basing on that, deaf girls complained that their families do not provide them with sex education and would avoid discussing issues of sexuality including HIV/AIDS. This finding could be in agreement with the research done by AIDS Action (1996) who discovered a dominant societal myth surrounding their sexuality that they do not have a sex life. Deaf women reported that they were targeted by others as they were assumed t to be sexually inactive and therefore "safer" (95%). In addition, they reported that they were being discouraged from associating with peers of opposite sex.

In order to establish how these deaf women related to family, community as well as institutions offering services within communities, the study first established whom these deaf women stay with. Back home, respondent female students from USD replied that they were staying either with their parents, relatives like sisters or aunts while some were in custody of guardians like Catholic Sisters. Adult Deaf women instructors at the Vocational training centre clarified that they were heads of households and were in charge of their own families

caring for their socio-economic needs using the income they would get from the jobs they were engaged in.

UNAD respondents reported that some were staying with their families; others were married and staying with their husbands. Such a finding about married deaf women though few was disproving what Asch and Fine (1988) had pointed out that deaf women are rarely married since they are seen as unfit to fill the traditional roles of a mother, wife, homemaker, nurturer, or lover, hence often end up as poor, single mothers. Other deaf women reported that they were staying on their own depending on their meagre incomes which they would obtain from say, knitting, teaching deaf children or caring for children. It became apparent that deaf women heading households or staying on their own were the decision makers concerning different aspects including expenditures in their homes and so could decide on utilization of HIV/AIDS Counselling services. Those having husbands or staying with their families were dependants and could not make sole decisions. This therefore had a bearing on their utilization of SLI and access to HIV/AIDS Counselling services as they had to consult first before taking on their decisions.

#### 5.4.1. Deaf Women's Access to HIV/AIDS Information and Counselling Services and Resources

Respondents were asked to specify how deaf women access HIV/AIDS Counselling services in their organizations. All service providers said that the services were open to all people without specialist access, say depending on gender, status or social position. However, they did not specify whether currently available services and resources as well as channels for disseminating HIVAIDS information were taking into account deaf women and men. Only 35 % said that the services were being freely accessed and 25% said that their services could as well be accessed through institution/member organization. When analysed from this standpoint, the existing gap constituting the remaining number of service providers who never gave their views could be used to conclude that possibly they were not aware of any criteria followed by deaf women when trying to access HIV/AIDS Counselling services. Counsellors as a category had a view that the services they were providing improved on the information base and knowledge of their clients apart from deaf women and men whom they failed to communicate with effectively.

UNAD deaf women respondents (32%) said that in many instances, service providers would deny them opportunity to access services. They further added that whenever they accessed the services, they would be placed in positions rendering them to pay for their interpreters so to effectively communicate with service providers or else they would be isolated. Isolation is a situation resulting from discrimination and it is a fundamental problem as noted by Nosek and Hughes (2003) that deaf women like others with disabilities experience major psychosocial problems like social isolation, depression, stress or neglected resulting largely from being discriminated.

The deaf instructors (20%) interviewed at USD expressed their desperate need for accessing HIV/AIDS counselling services. However, like those from UNAD, they reported being afraid of going to AIC, Kisenyi nearby because they would have to move with an interpreter whom they could not fully entrust with their confidentiality. Deaf women from UNAD said that those who were able to receive HIV/AIDS counselling would be assisted by relatives, friends, spouses or SLI. They said that specifically NUDIPU and UNAD link them to TASO to get HIV/AIDS counselling services after being mobilized, indicating that institutions specifically for the deaf and PWDs are obliged to care for their members. On the other hand it cannot be ruled out that the role of the 'gatekeeper' (guardians and family members) and their level of knowledge of HIV/AIDS, could determine what information reaches these individuals, and their tendency to be protective might reinforce discrimination of deaf women.

With regard to amount of information on HIV/AIDS reaching deaf women, 90% of the service providers said that it was less than that reaching the general population and 5% said that it is equal to that reaching the general population. None said that it was more than that reaching the general population. It was appalling to learn from service providers themselves that negligible information on HIV/AIDS reach deaf women. This could be attributed to deaf women in society being neglected and therefore discriminated.

Responding to the question on whether they had been approached by deaf women and men seeking for information, advice or support on HIV/AIDS, 85% of the respondent service providers said yes. Table 5.5 below summarises the responses.

Table 5.5: Information/Advice/Support on HIV/AIDS sought by deaf women

Information/Advice/Support on HIV/AIDS sought by deaf women	Frequency	Percentage
Voluntary counselling and testing	13	76.5
Information on HIV and ways of protection	2	11.8
Medication care and support for positive clients	1	5.9
To obtain interpretation when going for VCT	1	5.9
Total	17	100.0

Source: Research Findings Aug - September, 2008

Findings revealed that 76.5% of the service providers had been approached by deaf women seeking for VCT and almost 12% wanted information on HIV and ways of protection; almost 6% wanted medication, care and support for HIV/AIDS positive clients and an equivalent number were seeking to obtain interpretation when going for VCT.

Specifically, at AIC, counsellors said that deaf women and men would visit the centre in order to seek for information, advice or support on HIV/AIDS or in preparation for marriage; at Straight Talk Foundation, the respondent counsellor reported having been approached by a deaf woman seeking for information on whether VCT services were paid for and how long it would take to get their tested results. Counsellors at Naguru testified that deaf women had approached them seeking to know their sero-status after being suspicious about their health. At TASO, HIV-positive deaf women and men would go there to seek medication, care and support.

Like is the case for Talking Communities, circumstances arise requiring deaf women to visit HIV/AIDS counselling centres. This could be supported by de Vries (2004) who suggested that it is important to note that VCT is a necessity for the diagnosis and access to treatment of HIV/AIDS which is currently available and often life-saving, though not a complete cure. However, service providers reported that few deaf women would test for HIV/AIDS.

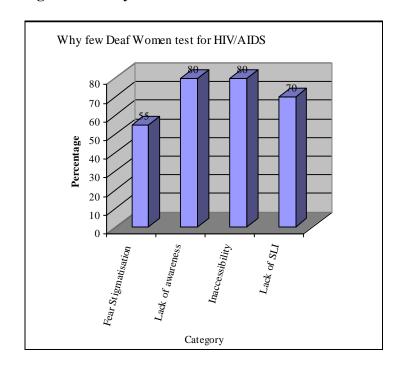


Figure 5.3. Why Deaf Women test for HIV/AIDS

Source: Research Findings Aug - September, 2008

Counsellors (80%) (Figure 5.3.) advanced their reasons and attributed this to either deaf women's lack of awareness on counselling and testing services or services were hard for them to access in terms of geographical location, communication or costs involved (80%). They further said that others feared to be tested because of suspected increased stigmatization. TASO counsellor added that deaf women were unwilling to go public about their sero-status, making it difficult to meet the deaf HIV-positive women. She said that at the moment, she was attending to five HIV-positive deaf women clients who were visiting the counselling centre but were not willing to share information concerning them. Interestingly she also highlighted on the plight of deaf women as follows:

"TASO has overcome communication barrier by mainstreaming disability in their programmes. Indeed, as the only counselor with disabilities that TASO Mulago is proud of, I have encouraged PWDs to access HIV/AIDS services. During outreach programs, like all other counsellors, I move with testing kits to use for testing my clients with disabilities especially members of families".

HIV/AIDS co-coordinator at UNAD said that he knew six deaf HIV/AIDS positive women whom he had encouraged to seek for treatment and few others who died of the disease.

Deaf women themselves said that as a deaf community, they were exposed to very little information about sex in general and AIDS in particular. This confirmed that information on HIV/AIDS reaching deaf people was extremely less than that reaching the general population and the major cause was grounded in failure to attain meaningful communication. In addition, they admitted never having heard of any deaf woman benefiting from HIV/AIDS programmes aimed at the general population within their communities.

Deaf women further reported that very few of them would get tested for HIV/AIDS. UNAD respondents lamented about their colleagues who had dared to undertake testing but were struggling very secretly to go back for their results for fear of word circulating around their community. Their narration through SLI clarified that those who became aware of their HIV-positive sero-status would stealthily seek counselling and treatment from TASO or Naguru. Again, following the finding, although discrimination amongst deaf women and men was not indicated by service providers, the study established that discrimination of deaf women by fellow deaf colleagues existed especially when infected by HIV/AIDS.

Additionally, service providers reported that poverty and the generally low levels of literacy among PWDs were equally crippling factors for deaf women's access to HIV /AIDS counselling services. On the other hand, deaf women met in the FGDs pointed out that not only deaf women but most PWDs were poverty stricken due to unemployment. UNAD respondents pointed out that majority of deaf women were unemployed because of lack of employable skills. They attributed this to either their lack or low levels of formal education.

Deaf women instructors from USD noted that when deaf girls mature, their perception was to look for a marriage partner who could sustain them, hence their dependence status and exposure to HIV/AIDS. They further clarified that, transport funds to counselling centres proved to be a hindrance to deaf women's access to HIV/AIDS counselling services because of their high dependency levels and strict protection.

# 5.4.2. Factors enabling deaf women to access HIV/AIDS counselling services

Situations arise that would enable deaf women access HIV/AIDS counselling services. Respondent service providers cited the following in Table 5.6. below as circumstances paving way for deaf women to access HIV/AIDS counselling services

Table 5.6: Factors enabling deaf women access HIV/AIDS counselling services

Identified Factor	Frequency	Percentage
Support from relatives/family	6	30
Organised groups that fight for rights of PWDs	4	20
Mobilisation & community sensitization	4	20
Mandatory testing at Antenatal clinics for	2	10
pregnant women		
Those intending to marry	2	10
Increased awareness among service	1	10
providers/counsellors)		
Persistent long sickness	1	5
Sign language skills	1	5

\*Multiple Responses

Source: Research Findings Aug - September, 2008

The most recurring factor that enabled deaf women access HIV/AIDS counselling services was support from relatives/family with 30%. This was followed by organised groups that fight for their rights as indicated by 20% of the respondents and, mobilisation and community sensitization as shown by 20%. Probably this would have acted as a follow-up to the findings by Gitonga (2004) who established that HIV/AIDS scourge, most deeply affects those least able to enjoy their rights. Respondents added that generally, there was increased awareness among service providers like TASO who then included a cause for disability in their programmes. It can thus be understood that levels of discrimination differ whereby it could be higher outside family level as highlighted by factors compelling deaf women access HIV/AIDS counselling services.

As to whether the sex of the service provider was influencing deaf women's access to HIV/AIDS counselling services, only 20% of the service providers confirmed so, adding that their identity as well was determining the attitude and nature of services offered while 55% did not accept. One counsellor doubling as SLI added that communities would use the identity of deaf women to discourage them from accessing HIV/AIDS counselling services under the pretext that they would not understand the messages. Similarly, while 45% of

service providers reported that the gender or identity of deaf women would not be a hindrance, an equivalent number contradicted saying that both the gender and identity of an individual would affect their access to HIV/AIDS counselling services.

Counsellors supplemented this by declaring that while high ranking citizens feared to visit public HIV counselling centres, PWDs were least expected to go there, let alone contract HIV/AIDS. Otherwise, compared to men, these respondents predicted that women would be more likely to access HIV/AIDS counselling because of their reproductive health requirements and for some, their need to change marital status.

Deaf women themselves confirmed that their gender was influencing their access to the HIV/AIDS counselling services. They were saddened by the community's view that if a deaf woman contracted HIV/AIDS, then she was conceived as promiscuous. When asked whether culture would in any way restrain them from utilizing HIV/AIDS counselling services, deaf women respondents considered culture as "old-fashioned" and as such could not influence their access to HIV/AIDS counselling services.

#### 5.4.3. Diagnosis of HIV/AIDS among Deaf Women

Sometimes PWDs would be diagnosed with HIV/AIDS much later than non-disabled. Specifically, deaf women and men would be diagnosed with HIV/AIDS much later than talking communities. In order to clarify on this issue, service providers advanced various reasons and their responses were summarized in Figure 5.4. as follows:

Figure 5.4. Diagnosis of HIV/AIDS among Deaf Women

\*Multiple Responses

Source: Research Findings Aug - September, 2008

From their viewpoint, the ultimate majority of service providers (90%) said that deaf women were afraid and did not know much about HIV/AIDS and so they would be diagnosed with HIV/AIDS much later. Lack of knowledge about HIV/AIDS is an indication of discrimination because families and communities where these deaf women stay are aware and would at least labour to inform them had it not been the construction by society.

#### 5.5. Attitudes of HIV/AIDS service providers and deaf women towards each other

Findings showed that service providers were positive towards deaf women as they sympathized with them (28.6%) and equally, others had a view that deaf women were vulnerable because they lacked information (28.6%). Almost a quarter of the service providers said that they were at times negative towards deaf women due to the communication gap. These expressed fear and disgust that they would least expect deaf women visit HIV/AIDS counselling centres. Others said that deaf women also needed services like talking communities (7%), yet others wished they could be trained to handle them (7%), and still the rest emphasized that deaf women are difficult to handle (7%).

Table 5.7. Highlights a summary regarding the general attitude that the counsellors have about deaf persons:

Table 5.7: Counsellors' attitudes towards Deaf Women

General attitude of counsellors	Frequency	Percentage
Positive because they sympathise with them	4	28.6
Deaf women are vulnerable due to lack of	4	28.6
information		
Negative at times due to the communication gap	3	21.4
They wish to be trained to handle them	1	7.1
Need services like any other persons	1	7.1
Difficult to handle	1	7.1
Total	14	100.0

Source: Research Findings Aug - September, 2008

Deaf women respondents (32%) noted that counsellors who had been sensitized had a positive attitude although communication barrier and their high levels of illiteracy restricted them to receive information on counselling services. Majority (68%) said that they generally did not access good services including HIV/AIDS Counselling services, for example in hospitals, they would sit for long without being attended to or service providers would send them away because they referred to them as "kasiru" the stupid ones.

Deaf women further reported that some of the service providers like health counsellors were hostile and would intimidate them by rudely asking many funny questions unlike in case of talking communities. The finding compares well with that of Save the Children (2004) who cited examples of PWDs being denied access to VCT centres, whose staff tell them that disabled people "cannot get AIDS" or that disabled persons "do not engage in sexual activities and therefore are not at risk of acquiring HIV." With such attitude of service providers, deaf women expressed fear of visiting counselling centres to get useful information about HIV/AIDS and counselling with the anticipation that they would receive similar treatment. On the whole, Deaf girls and women interviewed expressed their dismay that such attitude would create in them attitudinal problem of both stigma and discrimination because of limited knowledge of rights of PWDs, thereby contributing to their low self esteem and a feeling of rejection.

# 5.5.1. Improving Deaf Women's access to HIV/AIDS Counselling Services

In order to make the Counselling centres of greater use to deaf persons, 85% of the service providers' views were tabulated in Table 5.8.

Table 5.8: Making HIV/AIDS Counselling centres deaf –communicative

Service Providers' View	Frequency	Percentage
Offering sign language services	7	41.2
Training Counsellors & medical workers in sign language	5	29.4
Community sensitization on deaf client service availability	3	17.6
UNAD mobilise members for HIV/AIDS counselling at	1	5.9
different levels		
Sufficient funding	1	5.9
Total	17	100.0

Source: Research Findings Aug - September, 2008

Of those who gave their views, the highest number (41%) opted for offering sign language services at the counselling centres, followed by training of their staff (Counsellors and medical workers) in sign language (29%). Specifically, AIC respondents expounded that deaf women would be attracted to visit the centre, if deaf-friendly services are integrated like the use of sign language or training literate deaf persons as counsellors. 17.6% suggested that the communities where deaf women live need to be sensitized on availability of deaf client services. The rest were of the view that funding need to be sufficient and that the apex organization for the deaf persons should mobilize their members for HIV/AIDS counselling at different levels.

The respondents were asked about what should be done to promote information, education and communication among deaf persons. Service providers generally suggested that there was need to integrate deaf-friendly in all service centres. Their views were summarized in Table 5.9. as follows:

Table 5.9: Promoting information, education and communication among deaf persons.

Suggestion by HIV/AIDS service providers	Frequency	Percentage
Publicize service centres that have deaf-friendly	6	30
services e.g. SLI		
Design deaf friendly education materials like flash	6	30
cards		
Train people in sign language both deaf & talking	5	25
communities		
Educate deaf women in reading/writing	3	15
Total	20	100.0

Source: Research Findings Aug - September, 2008

30% of the service providers suggested that communication, information and education on AIDS among deaf women and men could be promoted by using drama, posters coupled with designing deaf friendly education materials like flash cards. Another alternative equivalent was (30%) opted for publicizing HIV/AIDS Counselling while stationing there SLIs. Another suggestion (25%) was to train service providers, the deaf and talking communities in sign language in order to overcome the language barrier. In addition, professional counselling skills could be imparted to literate deaf to ensure confidentiality and meaningful communication, and the remaining 15% said that deaf women should receive education in reading and writing.

Deaf women also added that to make their access to HIV/AIDS counselling services better and easier, there would be need to have "talking compounds" (Visual aids) where they could see and interpret for themselves in addition to stationing SLIs at the counselling centres. They also added that if possible, they would prefer to directly communicate with service providers meaning that they would expect them to be trained both in counselling and sign language. Below is a caption of SLI communicating with Deaf women from UNAD (Figure 5.5.).



Figure 5.5: Communication between Respondents and SLI

Source: Research Findings Aug - September, 2008

The study also established that use of brochures and books when disseminating information would be a good communication strategy. Students from USD made this suggestion and further added that the use of media like TV was critical in communicating and training deaf persons.

# 5.5.2. Demonstration of impacts of Structural positioning of Deaf women in Society

Society positions deaf women in the lowest social strata of society for stupid and non-intelligent people, "kasiru", basing on their unusual way of communication. Service providers reported that their inability to use sign language, deterred them to reach deaf women directly or freely. Counsellors lamented about deaf teenage girls who lacked basic information about human sexuality, hence discrimination depicted. They felt that such gaps would make deaf youths more vulnerable to abuse while positioning them at increased risk of HIV/AIDS and unwanted pregnancies.

Deaf girls and women interviewed expressed their dismay towards Talking Communities who disrespected and hold wrong imagination about them, thus such acts manifested themselves as discrimination. Deaf female students at USD during FGDs bitterly expressed that instead of providing sex education, parents would avoid discussing issues of sexuality including HIV/AIDS with their deaf daughters and sons. Consequently, adolescents could miss getting correct, appropriate and reliable information. Through their SLI, one of them complained saying:

"Instead of making us aware so that we understand the dangers of HIV/AIDS epidemic, they tend to be timid and shy away from this responsibility and only instruct us not to be in company of peer members of opposite sex'.

With the exception of few, parents fail to communicate and/or talk to deaf children because of inability to use sign language an element of discrimination whereby deaf children are denied proper parental guidance. Merely discouraging them from associating with peer members was also condemning them to discrimination as reported by Deaf female students at USD.

Through FGD, deaf women instructors from USD reported that no specially trained service providers had been positioned at counselling centres to help them access services like HIV/AIDS Counseling services. One of the deaf women said that their fear and worry were compounded by the fact that if they were to go without an interpreter, they were likely to encounter miscommunication and misunderstanding.

Deaf women were dissatisfied by lack of special programmes from Government and the private sector targeting PWDs on HIV/AIDS related issues, hence insensitive programmes to

specific needs of deaf women. This is in accordance with Save the Children, (2004) who quoted examples of disabled persons being denied access to VCT centres, whose staff tell them that disabled people "cannot get AIDS" or that disabled persons "do not engage in sexual activities and therefore are not at risk of acquiring HIV". This indicated that deaf women were categorically as PWDs discriminated basing on communication and being denied access to HIV/AIDS counseling and thus overall there was lack of involvement of PWDs in mainstream development issues.

To compliment more on the findings, a case study was held with one of the respondents who doubles as HIV/AIDS counsellor and SLI.

# Case study 2: Deaf Women's sex life and HIV/AIDS Counselling Services

She wondered about who could advise young deaf girls and women about their right to accept or refuse having sex without force when confronted with men who them for their own pleasure. She narrated a story about her deaf niece who confided in her about her boyfriend intending to marry her but refused to go for VCT and insisting on having sex before marriage to ensure her fertility. Like any other person, she emphasized that deaf women and men are sexually active. Their caretakers wish to see them married formally following their cultural values of bringing pride to their families. She recommended the same for deaf men to be guided in sexual matters. She identified the problem of lack of counselling extended to deaf women and men. She cited incidents where workshops are organized for deaf women and men but with limited time schedule whileincompetent interpreters in sign language. Consequently, communication becomes difficult resulting into very little being gained from the workshop. She further said that she had noted that many organizations do not want to integrated programmes for the deaf into theirs due lack of communication.

Source: Research Findings Aug - September, 2008

The case above involved the SLI/Counsellor unveiling the risks that deaf women would face and the grounds used by communities and individuals to discriminate the deaf women. It can be concluded that deaf women are human beings in special category belonging to a particular community with unique kind of communication and exceptionally positioned within society.

# 5.6. Power Differences between HIV/AIDS counselling service provider and Deaf Women

The central issue in this sub-section was to investigate the extent to which power differences through the interaction between deaf women and HIV/AIDS counselling service providers create and reinforce multiple discrimination in access to and control over resources.

Power is displayed in a relational structure and those who are powerful subject their victims to submissive/ secondary positions when those occupying higher positions have more power than persons in low-power positions. Service providers described power differences as oppression and domination exercised by those in possession of resources, appealing personality, social skills, or social connections over those without. Deaf respondents on the other hand defined power differences as a tool for excluding them from societal activities and development work.

During HIV/AIDS counselling sessions, the study wanted to examine whether the interaction between deaf women and HIV/AIDS counselling service providers created and reinforced discrimination. Deaf women respondents reported that service providers would use their powers to ignore or send them away when they visited HIV/AIDS counselling centres without SLI. Thus, although the services were provided freely, deaf women would be overburdened with payment for their SLI during HIV/AIDS counselling and testing. It can be concluded that only literate deaf women who could use sign language, with ability to meet SLI charges could visit and access HIV/AIDS counselling services. This in itself is discrimination of deaf women evidenced by lack of economic power.

In addition to inappropriate communication, service providers on the other hand testified that they feared SLIs would not exhaust explaining the needed information using the peculiar method of communication during counselling sessions. 70% said that majority of deaf women detested the presence of interpreters in the counselling sessions because they were considered to be shy. They anticipated that the situation for deaf women in relation to HIV/AIDS would be worse because they "would not understand their situation much." One counsellor from Naguru TIHC had this to say:

".....these deaf women do not honour the pre-requisite of the centre where clients go with their spouses, instead they just sit in pre-test counseling sessions without understanding what had been imparted to the attendees."

Service providers were asked to clarify whether their clients pay for HIV/AIDS counselling services offered. Of the 55% who responded to the question, 18% only reported that their services were being paid for while the rest said that their services were freely offered to all people of various categories. At AIC, the counsellors reported that services offered were free for clients below twenty four years of age but those above had to pay.

During HIV/AIDS counselling sessions, UNAD respondents suggested that they would feel contented if only service providers like counsellors or doctors/ health workers would communicate directly to them using sign language, without SLI, which would ensure them confidentiality. Some added that they were reluctant to ask or disclose their concerns about HIV/AIDS for fear of "word getting around" that, fears to be talked about.

Further, deaf women reported that service providers dictate the methods and channels to use without consultation while delivering HIV/AIDS information to deaf women and men.

In addition, from the study, it became evident that service providers are hesitant to reach remote and rural areas where some deaf women live. Therefore, the deaf women were obliged to seek for information, support, care, treatment and counselling in HIV/AIDS.

# 5.6.1 Challenges encountered while including the Deaf persons in HIV/AIDS programmes

Respondents were then requested to outline the challenges they may have faced in trying to include the Deaf persons in their programmes. Service providers' responses were summarized as follows in Figure 5.6:

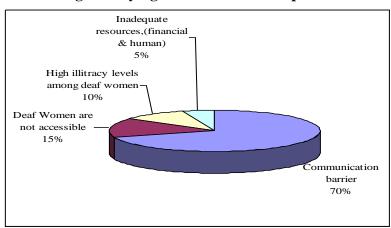


Figure 5.6: Challenges in trying to include the Deaf persons in HIV/AIDS programmes

Source: Research Findings Aug - September, 2008

The biggest challenge advanced was communication barrier (70%) followed by deaf women not being accessible (15%). Others cited high illiteracy levels among deaf women (10%) and inadequate financial and human resources (5%). One counsellor said:

"Deaf women are inaccessible and majority have low literacy skills that severely restrict their access to HIV/AIDS information materials. It becomes a problem to get them understand what is being discussed or getting feedback from them immediately without messages being distorted in case there is no sign language interpreter."

The low literacy levels can hinder access to information for this category of women since they cannot use sign language to communicate and this unique language is learnt while at school. This in itself is base for discrimination because these women would not volunteer to go and join other categories of persons when they do not share the same perception of situations. Otherwise counsellors believed that they were failing to include deaf women and men in their programmes because of the process of communication used. They reported that especially using written messages would be lengthy, yet they might fail to open up fully and most of them were perceived to neither read nor write. Generally, the major problem cited while offering HIV/AIDS counselling services to deaf women and men was dependence on SLIs.

Deaf women not being accessible was also cited as a challenge constituting 15%. This could be interpreted in various ways including to mean distance from their residential location to HIV/AIDS counselling centres being long. Service providers had a view that distance from the counselling centre could be a contributing factor hindering deaf women's access to the counselling centres. When asked about the challenges they faced in trying to include the Deaf women and men in their programmes, one of the counsellors from AIC said that such category of persons were generally geographically positioned in urban and rural areas in minute concentrations. She concluded by saying that deaf women are generally inaccessible especially those residing in rural areas or remote villages where service providers are hesitant to reach.

From yet another standpoint, deaf women being inaccessible could be attributed to a great extent to their being economically dependent. Another counsellor added that few of them were able to raise transport funds so that they would go to areas and places where the rest of the communities would access HIV/AIDS Information and counseling services. This would affect their level of awareness in matters pertaining to HIV/AIDS. The finding could be complimented by Nganzi and Matonhodze (2004) who hold the view those facilities and services from which rural-based PWDs might otherwise benefit are located mainly in urban centres; transport costs to such places are often prohibitive for those who live in villages.

Service providers were also requested to point out difficulties they would expect deaf women to encounter while trying to access HIV/AIDS counselling services. Majority reported that they would expect communication barrier to be the outstanding problem (66.7%). Other service providers said that deaf women would always be discriminated but did not expound on this (16.7%) and the rest said that deaf women did not know what to expect (16.7%).

Structural positioning of individual deaf women and girls would affect their access to HIV/AIDS counselling services. In order to confirm this view, the respondent SLI at USD highlighted:

"When in public, the girls reach the extent of declining to use sign language during communication so that they are not identified as deaf".

The deaf women expressed that their biggest challenge was communication. They reported that even if they were competent in use of Sign Language, most counsellors/service providers are incompetent and this robs them of confidentiality while using SLIs and much frustration would result there from. The co-coordinator HIV/AIDS programme for UNAD also reported through an SLI as follows:

"It will be very difficult to get information from these deaf women infected with HIV/AIDS unless conversant with sign language use as they have distrust for talking communities......"

They further reported that they would ask questions about HIV/AIDS but could not grasp meaning of gestures used by counsellors when answering them leading to deaf persons getting limited and scanty information. Research by Nemon (1980) indicates that this barrier to communication is the "single most critical factor affecting health care delivery" for deaf persons and thus backs up the finding, exposing more deaf women to HIV/AIDS disease.

FGDs held with deaf girls at USD revealed that they do not get adequate sex education since those who provide it were inadequate in sign language and therefore could not communicate well with them. In addition, their SLI insisted that:

"Deaf girls over-trust one another to the extent that they share boyfriends and do not resist sex, yet they hate condom-use expressing that "sex with condoms is not sweet".

Findings also revealed that deaf women instructors at USD complained about men who would pretend to love them but later deserted them after impregnating them. They said that they would be willing to undertake VCT to establish their sero-status before engaging in a sex relationship but when they lure their men to do so, their partners refuse or when they accept, they connive with the service providers to change their test results in favour of the men. At the same time, they testified through SLI that both deaf women and men were not

ready to use condoms because they would insist on "Sweet pa" meaning that sex using condoms was not sweet.

In other cases, they reported men deceiving them that they were going to use condoms but when time comes for sexual relations, men would switch off lights. However the reason advanced by the deaf women on condom-use is in contrast to Nganzi and Matonhodze (2004) who held the view that the few deaf men that manage to access the condoms do not use them but just keep them or use them improperly. Drawing from this finding, deaf women and men were unaware of protecting themselves against especially HIV/AIDS using condoms in addition to deaf women's failure to negotiate safe sex. It could therefore be described as discrimination of deaf men from accessing condoms which are otherwise availed or distributed to Talking communities.

UNAD women respondents said that that many have not been able to develop the social skills to avoid vulnerable situations like sexual abuse. They further acknowledged that deaf women were at greater risk of contracting HIV/AIDS than able-bodied persons, attributing this to varying factors that included being raped or engaging in sex in exchange for money, mistrust of partners and spouses having multiple partners.

The other challenge they cited was the services of SLI they had to pay for when visiting HIV/AIDS counselling centre. UNAD respondents had a view that due to lack of guidance and support from family members, deaf women would continue distancing themselves even from service providers when they acquire the disease. Again, they perceived family members to be playing the role of the 'gatekeeper' to them and this could determine what information reaches them because they are protective, and their own level of knowledge of HIV, and awareness of the vulnerability of those under their care is insufficient.

### 5.7. Talking Communities' Access to HIV/AIDS Counselling Services and Resources

As part of the methodology, the researcher made arrangements to interview a group of "women who were not deaf" to compare their accessibility to HIV/AIDS counselling services with that of deaf women. A meeting was arranged by one of the counsellors at Naguru TIHC with ten able-bodied HIV/AIDS positive women to establish whether they were being discriminated like deaf women while accessing HIV/AIDS counselling services. These were regular attendees of the counselling services 20% of whom were pregnant while 40% had

young babies and the rest had decided to access counselling services after experiencing ailing conditions. Their age ranged from twenty two to forty five years; 40% were married and 20% had permanent partners. These women attendees who exchanged their views with the researcher through FGD said that the counselling unit was locally being referred to as family clinic because it required women to come with their spouses/ partners when they visited the centre although their men were reluctant to undertake HIV/AIDS tests. They said that it was mandatory for pregnant women visiting the health centre for antenatal services to undertake HIV/AIDS counseling and testing. Those who tested positive would be advised to continue visiting the centre at intervals ranging from one to three months for continued counseling in addition to receiving treatment.

When asked whether they had ever come across deaf women attending counselling services, women attendees of counselling services reported having neither seen deaf women visiting the centre nor having met any within their communities receiving information on HIV/AIDS. From observation, they expressed surprise at the question and went further to condemn the men who would make such less intelligent women pregnant let alone spread the deadly disease to them. In case the deaf women contracted HIV/AIDS, women attendees expressed their disgust and later said that the deaf women would experience extreme suffering because they would not know what the problem would be.

Concerning the general attitude of counsellors towards their clients, the women respondents infected with HIV/AIDS reported that they were receiving good reception at the centre where they were well-attended to while receiving counselling services and advised to be firm on top of being provided with condoms for conjugal use. They said that they were proud of the centre as it was comforting them, further providing them with mosquito nets, sanitary water equipment and advising them on proper dieting, hence they did not want to miss such sessions which were held regularly. As such, it became apparent to the researcher that hearing women were at an advantage while accessing HIV/AIDS counseling and treatment because they got to know and understand issues surrounding the disease without encountering much difficulty. At the same time, it became apparent that nothing was inevitable about HIV/AIDS positive women discriminating deaf women whether free from the fatal disease or not.

#### 5.8. Exclusion and Restriction from Recognition, Enjoyment or Exercise of Human Rights

Neglecting the threat of HIV/AIDS to deaf women is one of the most dramatic forms of exclusion they can face. Exclusion is defined as the process through which individuals or groups are wholly or partially prevented from full participation in the society within which they live. Deaf respondents defined exclusion as an act of trying to eliminate them from community activities basing on their disability.

One of the acts of exclusion that deaf Student respondents at USD identified was their parents' failure to advise their own deaf children about the dangers of contracting HIV/AIDS. They said that parents were not providing deaf girls with all basic demands and would desert them while at school thus leaving room for deaf girls themselves befriending deaf men with the belief that these men would meet their material needs through exchange with sexual pleasure.

Deaf women respondents from UNAD reported that deaf women were receiving significantly less support and guidance from their mothers and other female relatives. While at home deaf girls through SLI similarly detailed lack of guidance, self esteem and role models and that due to loneliness, they would loiter a lot while looking for colleagues to communicate with. This unusual treatment of girls has an implication of exposing them to STDs, HIV and unwanted pregnancies and so demonstration of discrimination. Thus, this situation is analogous to that which Menz et al, (1989) found that PWDs are discriminated because of their disability, resulting in their intensified passivity, helplessness, dependence and failure.

#### 5.8.1. Promotion of Disability Equality in Organisations

In order to promote disability equality, 40% of the service providers suggested that staff like counselors and other medical personnel at HIV/AIDS counseling centres should be trained in use of in sign language and how to design messages suitable for the deaf.

Table 5.10: Promotion of Disability Equality in organisations

Category (Suggestions)	Frequency	Percentage
Training staff in sign language and on how to	8	40
design messages suitable for the deaf		
Sensitization and mass mobilization among deaf	3	15
women		
Working in partnership with deaf service provider	2	10
organisations		
Give equal services to PWDs	2	10
Utilise sign language as a second official	1	5
language in Uganda		
Employed specialised staff to manage specific	1	5
disabilities		
Train literate deaf in counseling skills	1	5

\*Multiple Responses

Source: Research Findings Aug - September, 2008

Table 5.10 shows that 15% said that there was need to mobilize and sensitize deaf women about HIV/AIDS and 10% emphasized the need to collaborate with organizations dealing with PWDS and working in partnership with deaf communities. Equally, 10% of the respondents were of the view that PWDs should be given equal services while 5% suggested that literate deaf women should be trained in counselling skills to ensure confidentiality during counselling.

Deaf women on the other hand reported that changing the attitude of talking communities that they were not stupid was yet to be achieved. They however suggested that in order to promote disability equality, talking communities should appreciate their disability and regard them as intelligent human beings. Further, they added that it would be of utmost co-operation if all categories of service providers would learn to use sign language so as to interact with them directly, let alone training deaf personnel in relevant skills. Concerning their access to HIV/AIDS counselling services, they held the view that they would appreciate if they were handled, supported, given care and treatment like talking communities.

#### **CHAPTER SIX**

## SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

#### 6.1. Introduction

This chapter presents summary, conclusions derived from the study and subsequent recommendations. In addition, the chapter points out future research implications.

#### 6.2. Summary

The general objective of the study was to examine how discrimination was constructed through multiple actions as deaf women try to access HIV/AIDS counselling services as indicated in Chapter 1 section 1.3. The specific objectives were: to examine the extent to which institutional rules and norms through policies and practices, construct discrimination of deaf women as they seek to have access to HIV/AIDS counselling services; to examine the extent to which the structural positioning of deaf women in society affects their access to HIV/AIDS counselling services; and to analyse the extent to which power differences through interaction between deaf women and HIV/AIDS counseling service providers create and reinforce multiple discrimination in access to and control over resources.

The study was conducted in Kampala District in seven selected institutions, two of which were specifically for the deaf while the rest were generally serving communities irrespective of category or social identity as indicated in the findings. The study employed the use of both quantitative and qualitative methods, observation and case studies to enrich the findings. A cross section of the population for the study was composed of deaf women and SLI, women infected with HIV/AIDS, and HIV/AIDS service providers from the seven selected institutions. The findings of the study were based on a sample population of sixty-seven (67) respondents. The study relied on Institutional theory and Social relations Framework which generally argue that individuals and social groups, for example PWDs, can be excluded by unnecessary societal barriers.

The first objective set out to establish whether and how outstanding institutional rules, norms, policies and practices guiding HIV/AIDS Counselling services construct discrimination while deaf women try to access HIV/AIDS Counselling services. The findings revealed that

policies, rules, norms and even practices used by institutions were considered discriminatory to deaf women for failure to consider them as a special category with specific needs. The discriminatory actions in this case were revealed as institutionalised discriminative norms and practices in the family, formal institutions, organisations and hospitals as well as unequal delivery of HIV/AIDS services to PWDs and especially deaf women

The second objective was to examine the extent to which the structural positioning of deaf women in society affects their access to HIV/AIDS counselling services. Deaf women are constructed by society as poor, dependent, docile sexually inactive and non intelligent WWDs. Thus, discrimination in this case manifested itself as isolation of deaf women if they would be in positions rendering them to pay for their interpreters while accessing the services. Generally, discriminatory actins revealed as gender inequalities as constructed by society and family institutions making deaf women even more unequal in society. Despite their disability, the position of deaf women was considered homogeneous with that of ablebodied women on gender grounds.

The third objective was to analyse the extent to which power differences through the interaction between deaf women and HIV/AIDS counselling service providers create and reinforce multiple discrimination in access to and control over resources. Findings revealed that communication barrier was advanced as an immense challenge followed by deaf women not being accessible. In addition the level of education and inability to use sign language was considered as the prime hindering factor for deaf women's access to HIV/AIDS counselling services. The discriminatory actions in this case were revealed as exclusion and restriction from recognition of deaf women leading to lack of access to HIV and AIDS counselling services, hence, multiplicity of discrimination of deaf women in both society and by formal institutions offering HIV/AIDS Counselling services.

#### 6.3. Conclusions

Selected organisations visited included National Union of Disabled Persons in Uganda (NUDIPU) in Kisaasi, Straight Talk Foundation at Kamwokya, Naguru Teenage Information and Health Centre at Naguru, The AIDS Support Organisation (TASO) at Mulago, Aids Information Centre (AIC) at Kisenyi, Uganda Society for the Deaf (USD) Vocational Training Centre at

Namirembe and Uganda National Association of the Deaf (UNAD) at Kamwokya. Apart from TASO, all other organisations lacked facilities for handling deaf women and men as well as extending HIV/AIDS counselling services to them due to lack of skilled personnel in Sign Language as revealed by the findings of this study. Construction and demonstration of discrimination would be displayed through multiple actions while deaf women try to access HIV/AIDS counselling services in selected institutions in Kampala District. However, when further assessed, the cause for discrimination would be grounded into communication barrier existing between deaf women, service providers and talking communities.

#### 6.3.1. Discrimination of deaf women by Institutional rules and Norms

Construction and demonstration of discrimination of deaf women by institutional rules and norms was examined. The findings revealed that policies, rules, norms and even practices used by institutions were discriminatory to deaf women as they would not consider them as a special category. This confirms what the Institutional theory points to processes of establishing social structures, including rules, norms, and routines as authoritative guidelines for social behaviour (Scott, 2004). Although there were no documented rules in these institutions to deny deaf women access to HIV/AIDS counselling services, even rules or policies guiding their access to HIV/AIDS counselling services were inexistent, hence manifestation of discrimination. Deaf women and girls complained about being discriminated against at family and community level by being. Discrimination manifested itself through deaf persons being denied participation in conversations and community activities, damped and denied to appear in public or neglected at home by own families. Thus, within institutions and organizations were institutionalized discriminative norms and practices in formal institutions, organisations and hospitals.

Basically, findings revealed that in addition to limited resources the institutions possessed, institutional personnel or service providers had formal qualifications with respect to their designation but were not trained to handle deaf persons as shown by the findings, therefore communication barrier became a fundamental problem. Hence, discrimination in this case was depicted through failure to provide SLIs to deaf women and men when publicly dealing with communities, resulting into unequal delivery of HIV and AIDS services to persons with disability and especially deaf women. Further, discrimination was displayed through denial of confidentiality to deaf women which is accorded to talking communities while

offering HIV/AIDS counselling services. Deaf women were dissatisfied by lack of special programmes from Government and the private sector targeting PWDs on HIV/AIDS related issues, hence insensitive programmes to specific needs of PWDs.

#### 6.3.2. Structural positioning of Deaf women in Society and Demonstration of impacts

Structural positioning of Deaf women in Society and Demonstration of impacts were examined. Findings revealed that society positions deaf women as poor, dependent, docile and non intelligent WWDs. On the other hand, service providers perceived deaf women to be sexually inactive, having impairment to reasoning and basic intelligence and so overlooked those who visited their organisations. In this case, discrimination was displayed as neglecting the threat of HIV/AIDS to deaf women. Deaf women respondents noted that sensitized counsellors had a positive attitude although communication barrier existed. However, the unsensitised counsellors were hostile and intimidating and would rudely deny them access HIV/AIDS counselling services or make them sit for long asking many funny. Generally, deaf female students and women had a feeling of rejection by Talking Communities who had a negative attitudinal problem resulting into both stigma and discrimination because of limited knowledge of rights of PWDs, hence, exclusion and restriction from recognition of deaf women leading to lack of access to HIV and AIDS counselling services. As such, discrimination was displayed emotionally as rejection and disgrace.

Considering their positioning in society to be homogeneus with able-bodied women irrespective of their disability signifies discrimination on gender grounds. This situation also supports the social relations theory, where Kabeer (1994) uses the term "social relations" to describe the structural relationships that create and reproduce systemic differences in the positioning of different groups of people in society. Being deaf could not protect deaf women from being subjected to gender inequalities as constructed by society and family institutions, making deaf women even more unequal in society.

Although HIV/AIDS counselling services were open to all people without specialist access, say depending on gender, status or social position, deaf women were placed in positions rendering them to pay for their interpreters in all cases where they accessed the services, or else they would be isolated and relegated to irrational beings. Thus their discrimination

manifested itself as isolation and neglect. Deaf women from UNAD said that they were exposed to very little information about sex in general and AIDS in particular. Those who were able to receive HIV/AIDS counselling would be assisted by relatives, friends, spouses or SLI. Few deaf women get tested for HIV/AIDS for fear of word circulating around their community. The study also discovered that discrimination of deaf women by fellow deaf colleagues was a reality especially when infected by HIV/AIDS, hence self discrimination in form of isolation and neglect. Sometimes the deaf would be diagnosed with HIV/AIDS much later than talking communities.

Inaccessibility by deaf women to HIV/AIDS counselling services was diagnosed as either being geographically positioned in urban and rural areas in minute concentrations, high illiteracy levels among deaf women or inadequate financial and human resources. Principally, service providers dealing with deaf women and men rarely consider them as a special category of human beings belonging to a particular community and having a unique kind of communication but exceptionally positioned in society.

#### 6.3.3. Power differences between deaf women and HIV/AIDS counselling service providers

Power is displayed in a relational structure where those who are powerful subject their victims to submissive/ secondary positions. During HIV/AIDS counselling sessions, the study wanted to examine whether power differences during the interaction between deaf women and HIV/AIDS counselling service providers created and reinforced discrimination. Service providers felt that deaf women were 'less intelligent and had low levels of education and this affected their access to and use of HIV/AIDS counselling services. Deaf women on the other hand considered inability to use sign language by service as the prime hindering factor followed by their identity as deaf women which communities would use to discourage them from accessing HIV/AIDS counselling services. Deaf women would feel discriminated when service providers like counsellors or doctors/ health workers communicated to them using sign language interpreter, which was compromising their confidentiality.

Only literate deaf women who had attended school, with ability to meet SLI charges could visit and access HIV/AIDS counselling services. They said that service providers dictated the method and channels to use while delivering information to deaf women. In addition, service providers feared that SLIs would not exhaust explaining the needed information using the

peculiar method of communication. Again, service providers are hesitant to offer services to clients residing deep in rural areas.

On the whole, the researcher identified the basic challenges traversed by deaf women rotating around communication challenges, SLI bias and distrust held by individuals within the deaf community which perpetuate inequality. Again, deaf women lack guidance and support from family and communities and receive scanty information on HIV/AIDS though they are at greater risk of contracting HIV/AIDS than able-bodied persons. Though the deaf community was classified as small and very tight knit, its closeness could act as an incubator for sexually transmitted disease including HIV/AIDS. It became evident that the most striking manifestations of discrimination were based on gender, poverty, geographical location, but overpowered by communication and unintended isolation and neglect in most of the institutions visited, hence, multiplicity of discrimination of deaf women in both society and by formal institutions offering HIV/AIDS Counselling services

#### **6.4. Recommendations**

Uganda's Article 21 of the constitution says that a person shall not be discriminated against on the ground of sex, race, colour, birth, creed or religion; and the PWDs Act, 2006 emphasizes to get rid of all kinds of discrimination against PWDs. Given our interdependence, any practice, policy, norm or rule that elevates any group of people over another will undoubtedly create discrimination.

Discrimination is not endorsed officially but remains a reality in practice and entails impairment of one's full and equal participation in society. Deaf women would like to experience an enabling situation where they would access HIV/AIDS counselling services freely to avoid discrimination.

The study examined the construction of multiple discrimination as deaf women try to access HIV/AIDS counselling services in selected institutions in Kampala District and in view of the findings and conclusions, the following recommendations are made:

For institutions to support and be guided by the interests of the poor and marginalized groups of people like PWDs, institutional cultures need to be transformed from those that were based on old vested interests.

Specific HIV/AIDS programmes sensitive to the needs of PWDs and deaf women should be designed and implemented by government as it its responsibility and that of the private sector.

Policies pertaining to deaf should be put in place. In addition, practice that strengthens discrimination should be avoided or accepted with utmost reluctance.

At family level, deaf women should be provided with chance to participate in household and community activities equitably being provided with SLI so as to competently communicate with talking communities. At institutional level service providers should be sensitised to become friendly to deaf women to gain trust and confidence from them. There is need to create and maintain situations that would change the negative stereotypes negative stereotypes among institutional personnel and families communities s that they appreciate disability. Similarly deaf women who discriminate fellow deaf colleagues as had been established need to be sensitized on HIV/AIDS.

In order to overcome communication barrier while aiding deaf women access HIV/AIDS counselling services, Institutional personnel/ service providers like counsellors or doctors need to be trained in the use of sign language, to avoid dependence on SLI and communicate directly with deaf women using. Another approach would be imparting deaf women themselves with professional counselling skills or training SLI to become counsellors and communicate directly with deaf women. Yet another approach would involve positioning competent and free services of SLI at all HIV/AIDS counseling centres to ensure confidentiality and meaningful communication and avoid hiring expensive SLIs. Service providers should be trained in designing deaf-friendly, appropriate, suitable and specially packaged messages and channels for disseminating critical HIVAIDS information without isolating and excluding them.

Trainings in Reproductive health should be extended to deaf women to impart knowledge about human sexuality and inevitably HIV/AIDS. In addition, special seminars for deaf women and men could be organized as a way of trying to include them in Counselling

programmes. In order to protect youth against HIV/AIDS, they should be advised to abstain from premarital sex until they complete their studies and get married.

With regard to inadequate financial and human resources and being economically dependent or poor, deaf women should be availed with employable skills so that they are able to earn incomes and make sole decisions on their utilization of HIV/AIDS Counseling services

#### 6.5. Areas for further Research

This study stimulates further assessment and need to reveal the multiplicity of discrimination in access to resources. Not all areas pertaining to deaf women were researched on in this study. The recommendations below constitute areas for further research. These include:

- 1. Mainstreaming deaf women concerns in Reproductive health research in Uganda with the view of scaling up their visibility and empowering them.
- Comparative study of deaf women and deaf men and their access to HIV/AIDS Service delivery systems with the idea of addressing stereotypes and negative attitudes.

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### **APPENDIX 1: QUESTIONNAIRES**

# QUESTIONNAIRE FOR COUNSELLOR/ ADMINISTRATOR/ SIGN LANGUAGE INTERPRETER ASSISTING IN DEAF WOMEN'S ACCESS TO HIV/AIDS COUNSELLING SERVICES

This research is intended to provide information that will be useful in examining how discrimination of deaf women is constructed through multiple actions as they try to access HIV/AIDS counselling services in selected institutions in Kampala District. This questionnaire is to facilitate the collection of data from Institutions for deaf women and men and those offering HIV/AIDS Counselling services. You are requested to provide information to necessitate the study. All the information you have given will be kept with utmost confidentiality.

Socio-demograghic characteristics
1. Name of your organization/ Institution:
2. Age of Respondent
5. Position in the organisation:
6. Educational level
7. Date of completing form
Section A: Discrimination of deaf women by institutional rules, norms as they access HIV/AIDS counselling Services
8. What type of services are offered in your organization? (Please specify)
9. Does your organization have any policy related to deaf persons and HIV/AIDS programs? Yes No
10. Is your organization/ Institution involved in training deaf women and men on awareness on HIV/AIDS and/or integrating them in care and support programme?  Yes

11. How often does the organisation provide training about HIV/AIDS? [please tick as appropriate]

Period	Response
monthly	
Quarterly	
Yearly	
Adhoc	

and men?
13. Do you have personnel trained to handle deaf persons?
YesNo
If not, please explain how your organization has been coping with the situation?
14. Do the organisation's service providers have any formal qualifications in HIV/AIDS counselling? Yes
15. How often do deaf persons seek counselling services in your organization?

#### Section B: Society construction of deaf women and demonstration of impacts

- 1. How does society construct deaf women?
- 2. How do people access your organisation's services? [Please tick as appropriate]

Service User	Response
specialist (eg men	
only)	
open to all people	
Free (Not paid for)	
Institution/	
organisation	
membership	

3. Are the services of	fered by your org	ganization of	importance to	the beneficiaries
1) Yes	. 2) No			

4. What are some of the factors that have enabled deaf women access HIV/AIDS counselling services?

	n materials, posters, billboards, fliers
	11 materials, posters, omodards, mers
Imorn	nation, education, training and campaign venues
	at is the general attitude that the counsellors have about deaf persons?
	ase suggest ways of how the above centre can be of greater use to deaf persons,
	ally deaf women
•	,
•••••	
•••••	
•••••	
7. Wh	nere do you think deaf women should be reached to be taught about HIV/2
	nere do you think deaf women should be reached to be taught about HIV/Anic?
	nere do you think deaf women should be reached to be taught about HIV/Amic?  In their organizations
	nere do you think deaf women should be reached to be taught about HIV/Amic?  In their organizations In their families
	lere do you think deaf women should be reached to be taught about HIV/Amic?  In their organizations In their families To their localities
	nere do you think deaf women should be reached to be taught about HIV/Anic?  In their organizations In their families
	In their organizations In their families To their localities Schools

HIV/AIDS?	ved on their information base and knowledge of
3. Does their level of education affect u	use of the services?
Yes No	
women?	while offering HIV/AIDS Counselling services to deaf
women? Yes	ou in your endeavor to offer these services to deaf
, ··· ( 5) ·······	
b). What kind of support does the abov	ve render to deaf women?
6. Do you think the amount of informa	ation on HIV/AIDS reaching deaf people is:
Less than the general Population	
Equal to that reaching the general	
population	
More than that reaching the population	general
7. Why is it that very few deaf peo appropriate)	ople get themselves tested for HIV? (Tick where
Fear of being more stigmatize	ed
Lack of awareness	
Inaccessibility	
No sign language translation	
Others (descr	·
8. Sometimes persons with d	isabilities like the deaf are diagnosed with HIV/AIDS
much later than non-disabled people be	ecause:
They do not recognize the symp	•
No one tells them the symptom	
No AIDS clinics welcomes dea	
They are afraid and do not know	w much
about HIV/AIDS	<u> </u>
They do not go to clinics because	se of
poverty	

	ine the challenges/or in your programme	opportunities you	may/nave faced in	trying to inc	iude tii
-					
					••••••
	we improve commu to HIV/AIDS counsel			leaf people	to mal
n D. Errebrei				:aa a <b>f h</b> a	la
n D: Exclusio	on and restriction fro			ise of huma	n righ
		m recognition, e	njoyment or exerc	ise of huma	n righ
1. Are deaf v	on and restriction fro	m recognition, or	njoyment or exerc	ise of huma	n righ
1. Are deaf v	on and restriction from	m recognition, e	njoyment or exercipeings?		
1. Are deaf v Yes	on and restriction from a ware of their	m recognition, or rights as human leads the way dear	enjoyment or exercipeings?	are being v	violated
1. Are deaf v Yes	on and restriction from and restriction from one aware of their would one describe	m recognition, or rights as human less the way dear	enjoyment or exercipeings?	are being v	violate
1. Are deaf v Yes	on and restriction from and restriction from a ware of their	m recognition, or rights as human learning the way dear	njoyment or exercipeings?  women's rights	are being v	violate
1. Are deaf v Yes	on and restriction from and restriction from aware of their No	m recognition, or rights as human less the way dealer to the control of disability	peings?  women's rights  requality in this org	are being v	violate

THANK YOU

# Appendix II: INTERVIEW GUIDE FOR DEAF WOMEN (HIV/AIDS POSITIVE/ UNAWARE OF SERO STATUS)/ ABLE-BODIED WOMEN AND INFECTED WITH HIV/AIDS

# Section A: Discrimination of deaf women constructed by institutional rules, norms as they access HIV/AIDS counselling Services

- 1. What is the name of your organization/Institution:?
- 2. What type of services are offered in your organization?
- 3. How old are you?
- 4. Have you ever been to school? What level of Education did you attain?
- 5. Are you married/ Single/ Separated?
- 6. Do you have children?
- 7. Are you aware of the different ways through which people become infected by HIV?
- 8. Is this organization/ Institution involved in training deaf women and men on awareness on HIV/AIDS and/or integrating them in care and support programme? How often?
- 9. What channels or means does the institution use to disseminate the information to deaf women and men?
- 10. How often do you seek HIV/AIDS Counselling services?
- 11. Please suggest ways of how the above centre can be of greater use to deaf persons, especially deaf women
- 12. What should be done to promote information, education and communication among deaf persons?

#### Section B: Society construction of deaf women and demonstration of impacts

- 13. What is the general attitude of the counsellors towards you?
- 14. How do deaf women access services in different organisations?
- 15. Where do you think deaf women should be reached to be taught about HIV/AIDS epidemic?
- 16. Are there organizations or institutions in your locality that are reaching Deaf persons with HIV/AIDS preventive messages or care and support?
- 17. What methods are appropriate to use in the dissemination of HIV/AIDS campaign messages to deaf women and men?
- 18. How can we improve communication and information needs for deaf women to make their access to HIV/AIDS counselling services better and easier?

### Section C: Power differences between HIV Counselling service providers and deaf women

- 19. Do you pay for HIV/AIDS counseling the services offered?
- 20. How have these services improved on your information base and knowledge of HIV/AIDS?
- 21. Does your level of education affect use of the services?
- 22. What problems do you encounter while accessing HIV/AIDS Counselling services?
- 24. Do you have anyone to assist you access HIV/AIDS counseling services?
- 23. How much information on HIV/AIDS reach deaf people as compared to other members of community?
- 24. What challenges have you experienced when trying to access HIV/AIDS counselling services?
- 25. Why is it that very few deaf people get themselves tested for HIV?
- 26. Why is it that disabled persons like the deaf are diagnosed with HIV/AIDS much later than able-bodied people.
- 27. What are some of the factors that have enabled deaf women access HIV/AIDS counselling services?

#### Section D: Exclusion and restriction from recognition, enjoyment or exercise of human rights

- 28. Are you aware of your rights as human beings?
- 29. How would one describe the way your rights are being violated?
- 30. How can we improve the promotion of disability equality in this organization?

### **APPENDIX III**

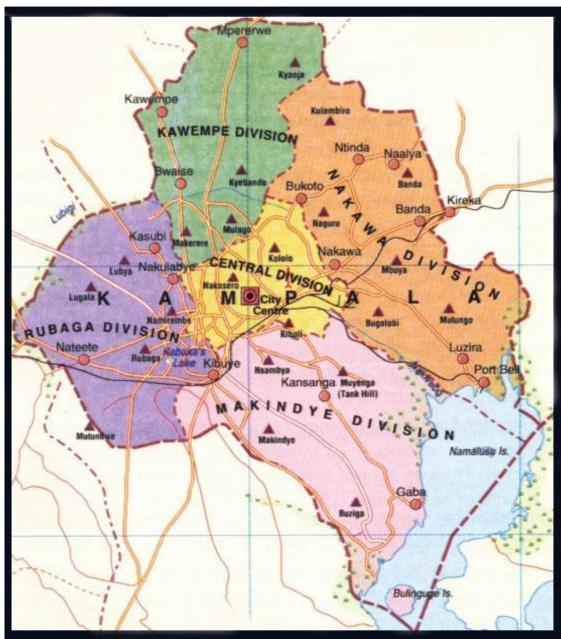
#### MAP OF UGANDA SHOWING THE LOCATION OF KAMPALA CITY



Source: Uganda Districts Information Handbook, Expanded Edition 2005-2006 Fountain Publishers 2005

## **APPENDIX 1V**

# MAP OF KAMPALA DISTRICT



Source: Uganda Districts Information Handbook, Expanded Edition 2005-2006 Fountain Publishers 2005