

Vulnerability of persons with Disabilities...

Running Head: VULNERABILITY OF PERSONS WITH DISABILITIES TO HIV  
INFECTION

Vulnerability of Persons with Disabilities to HIV Infection: The Case of the Blind, the  
Deaf and the Physically Disabled in Gullele Sub City of Addis Ababa.

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Graduate School of Social work  
Addis Ababa University

August 2007

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**SCHOOL OF GRADUATE STUDIES**

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CITY OF ADDIS ABABA**

**BY**

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**Thesis Submitted to the School of Graduate Studies of Addis Ababa  
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**ADDIS ABABA**

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**Declaration**

This thesis is my original work and has not been presented for a degree in any other university, and that all sources of materials used for the thesis have been dully acknowledged.

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## ACCRONYMS

AAHAPCO-Addis Ababa HIV/AIDS Prevention and control Office  
AMREF -African Medical and Research Foundation  
CAFOD -Central African Federation of Disabled Persons -  
CARDOS-Center for Applied Research Development Oriented Services  
CBM-Christofel the Blind Mission  
CSA-Central Statistical Authority  
DFID-UK Department for International Development  
EFPD- Ethiopian Federation of Persons with Disabilities  
ENAB- Ethiopian National Association of the Blind  
ENAD- Ethiopian National Association of the Deaf  
ENAPHD-Ethiopian National Association of Physically Disabled  
EOA-Equal Opportunity Association  
FDRE-Federal Democratic Republic of Ethiopia  
FHI-Family Health International  
GOs-Government Organization  
GTZ- German Development Cooperation  
HAPCO-HIV/AIDs Prevention and Control Office  
HBC-Home Based Care  
HHAPCSO-Hiot HIV/AIDS Prevention and Control Service Organization  
HPD-O -Help for Persons with Disabilities Organization  
IDPDA-Information Development for Persons with Disabilities Association  
ILO-International Labor Organization  
MDGs- Millennium Development Goals  
MMM-Medical Missionary for Mary  
NAWD-National Association of Women with disabilities  
NEPAD-New Africa Partnership for Development  
NGOs- Non-governmental Organizations  
OSSA-Organization for Social Service and AIDS  
PDLHAs-Persons with Disabilities Living with HIV/AIDS  
PDs-Persons with Disabilities  
PLHA-Persons Living with HIV/AIDS  
PRSP- Poverty Reduction Strategy Papers  
STIs-Sexually Transmitted Infections  
UK-United Kingdom  
UNAIDS- United Nations Programme on HIV/AIDS  
UNESCO-United Nations Education and Science for Development  
UN-United Nations  
USA- United States of America  
VCT-Voluntary Counseling and Testing  
VSO-Volunteers Service Organization  
WHO-World Health Organization

Abstract

HIV/AIDS has been one of the deadly diseases affecting the lives of millions of people particularly in developing countries like Ethiopia. To alleviate the plight of the disease, a lot of efforts have been made in the country. Particularly, some sections of society have been beneficiaries of special treatment because of their perceived vulnerability to HIV. However, persons with disabilities are neglected in the overall attempt to curb the spread of the virus. They are rather perceived to be sexually inactive and have less social interaction to contract HIV. Based on this, this paper attempts to answer the following underlying questions: what risk factors contribute for the vulnerability of disabled people to HIV infection? What services related to HIV are available for persons with disabilities in Gullele Sub-City? The paper discusses issues related to disability and poverty, disability and HIV/AIDS, and poverty and HIV/AIDS. The research was carried out by using qualitative method. Data collection was carried out through in-depth interviews, focus group discussion and key informants interview. The subjects of the study include PDs, PDLHAs, representatives from local kebele administrators, and churches. Besides, organizations working on HIV/AIDS and disability were participants in the interview. Moreover, this research reviewed secondary data sources like National HIV policy documents and strategic plans. The finding of the study shows that persons with disabilities are at high risk of HIV infection due to the various factors like poverty, disability, lack of information, inaccessibility of HIV educational materials and social exclusion, and stigma. This implies urgent need to incorporate disability issues in HIV/AIDS and poverty reduction policies of the country.

Key Words: HIV/AIDS, Disability, Vulnerability, Risk, Persons with Disabilities

## **Chapter One**

### **Introduction**

#### **1.1 Background of the Study**

This study focuses on persons with disabilities in relation to HIV/AIDS. The study is about how disabled persons are exposed to HIV virus and the risk factors that makes them vulnerable. To begin with, it is found essential to look at the status and prevalence rate of HIV and AIDS from the global to local context, where the study was carried out. Therefore, this section presents some details on the historical perspectives of disability and the situation of HIV and AIDS in the World, Africa, and Ethiopia.

##### **1.1.1 Historical Perspectives**

Throughout history, people with various disabilities have together been marginalized. They have had a history of 'silence' and have been socially constructed as 'others'. In earlier times, disabled persons were not considered equal to the other 'non-disabled people. Indeed, in ancient times, a child born disabled was either thrown away or infanticide was practised by the mother because the disabled child as believed to have 'demons' or 'evil spirits'. The practice of infanticide was aimed to destroy the so- called 'demons' or 'evil spirit' in the disabled child (Gearheart &Weishehn, 1992).

This trend continued until the end of 16<sup>th</sup> century. There had been continuous marginalization and isolation of disabled people in social context of the time. However, changes had been observed since then and philosophers and churches began to teach groups of deaf people. This led to the establishment of schools especially for the deaf and the blind. The growing change of attitudes and knowledge on disability created the expansion of

institutional reform in most parts of Europe and United States of America (Gearheart & Weishehn, 1992).

Since 17<sup>th</sup> century, however, the approach to understanding or helping disabled people began to change in the West. Gradually, more progressive developments were observed and different models were adopted to address disability. This development resulted in the formation of three major models of disability. These include religious, medical and rights- based models of welfare for disability (Clapton&Fitzgerald, 1996).

According to the religious model, the root of understanding the bodily difference on disabled persons was grounded in the 'Biblical References'. Clapton and Fitzgerald (1996) argued that disability has been seen as a result of 'evil spirits', 'the devil', 'witchcraft' or 'God's displeasure'. During the pre-industrial period, those people with bodily limitations were required to stay at home and often ostracized by the able people. This threatened their survival and thereby some became homeless, dislocated and victims of poverty and shame. The central argument of this model lies on the perception that "disability was punishment from divine power for the wrong doing of either the disabled or their parents. The 'able bodied' people appear to carry out the punishment by ignoring, rejecting or putting aside those with disabilities" (Mackelplang&Salgiv, 1996:19).

Nevertheless, the religious model is later challenged by the enlightenment era of 18<sup>th</sup> century, which was based on reason. This era produced a medical model of disability, which came up with scientific knowledge in Europe and America. The model replaced the 'priest custodial' system for disabled people with the medical professionals. According to this model, disabled people are expected to access some support from the 'medical intuitions'. It

was argued by the then medical professionals that it is essential to help the disabled people to enable them compensate their deficiencies (Daniel, 2000).

On the other hand, the rights –based model of disability gives more emphasis to the socio-political construct within society. It was contended that there was transfer of disabled people from ‘dependency’ in the medical model to ‘independency’ and self responsibility. Emphasis was given to participation of disabled people in the social, political and civil rights movement. Disabled people were entitled to participate in social service activities such as employment, education and recreations (Clapton and Fitzgerald (1996).

In contrast to the traditional approach to disability, ‘social model’ of disability was also supported by the UK Department for International Development (DFID, 2000). This model is against the traditional way of categorizing persons with disabilities as ‘special’ or ‘different’ people from the non-disabled people. In the conventional approach to disability, people with disability need help from others to meet their social needs. But it was criticized for its medical approach, which promotes dependency and difference among disabled people (DFID, 2000).

The social model of disability emphasizes the promotion of social change to incorporate persons with disabilities in the larger social context. The model affirms that disability is not only the medical issue but the social restrictions emerging from discrimination. According to this model, therefore, active participation of disabled people is essential to address disability problems. For them, it is not the impairment but the social response that has much more influence on the lives of disabled people. According to this model, people with disability face three different types of discriminations in their life, namely ‘institutional, environmental and attitudinal’ (DFID, 2000, 7-8).

The aforementioned literature implies that disability is a 'social construction' in the human history. It shows that disability has been negatively connotated in the long history of society. These facts are still prevailing in most part of the world particularly in Africa. The pre-existing perceptions seem to have influence on the disabled peoples' access to social services. Recently, however, this service gap is manifested in relation to HIV/AIDS, which has close linkage with social interaction and communication. Therefore, this study follows the social model of disability in which PDs are victims of different social perception and directly or indirectly affected by the prevailing societal construction.

#### 1.1.2 **The Situation of HIV/AIDS**

AIDS is unique in human history in its rapid spread, its extent and the depth of its impact. We used to think of HIV/AIDS as a health crisis. Today, HIV/AIDS can no longer be confined to the health or any particular social group. In the world, AIDS is a health and economic crisis, and a threat to political stability. Since the advent of the first AIDS case in 1981, people newly infected with HIV in 1999 were 5.6 million. On the other hand, a joint report by UNAIDS (United Nations Programme on HIV/AIDS) and world health organization (WHO) shows that a total of 39.5 million people are living with HIV in the world. The report also specifically indicates the number of sub groups of population as adults to be 37.2 million and about 17.7 million as women. Children under the age of 15 are also among the widely affected groups and estimated to be 2.3 million (UNAIDS & WHO, 2006).

The magnitude of reported incidence and prevalence rates of HIV infection in Sub-Saharan African countries had a profound impact on the health sector as well as in the socio-economic development of the region in general. Sub-Saharan Africa, which has just over 10% of the world's population, is the most affected part of the world, where more than

two thirds of all people with HIV/AIDS are living. According to the WHO report, the Sub-Saharan countries are ranking first in HIV prevalence rate in the world. The report indicates that 63 per cent of adults and children affected by HIV epidemic are living in Sub-Saharan countries. According to the report, about 72 per cent of adult and child deaths in 2006 were evident in Sub-Saharan regions (WHO, 2006).

Ethiopia being part of Sub-Saharan Africa is facing similar challenges of HIV epidemic. The prevalence has risen gradually over the last 10 years. In the year 2003, about 4.4 per cent of its population had been infected by HIV (Ethiopian Ministry of Health, 2005).

According to *AIDS in Ethiopia Sixth report* launched in 2006, a total of 1,320,000(590,000 male and 730,000 female) were living with HIV in 2005. The report further indicates that the national prevalence rate is estimated to be 3.5 percent among which 10.5 percent and 1.9 percent are urban and rural dwellers respectively. Accordingly, AIDS deaths have also been escalating in the country each year.

There have been a lot of efforts made to curb the spread of the virus in Ethiopia. HIV/AIDS policies and programs have been formulated to address the problem. For instance, the national strategic plan designed for 2004 to 2008 includes the various care and support services for the persons living with HIV/AIDS in the country. Prevention and control mechanisms were outlined by the national and regional HIV/AIDS prevention and control offices. Moreover, HIV related information and education dissemination activities have been carried out by government and non-government organizations (NGOS) (National Strategic Plan, 2004-2008).

According to the Ethiopian Ministry of Health Report (2004), some segments of the Ethiopian society are more vulnerable to disease than others. The report indicates that



young adults, children, women, commercial sex workers, truck drivers, soldiers and adolescents are the most affected groups. Most of the policies and programs designed concerning HIV have been giving special attention and services to these groups. These are the segments of the society who are entitled to receive special care and support services in general (MOH, 2004).

Moreover, the groups are given various awareness raising education and information through radio, television, news papers, brochures and films. These risk population groups have been given special attention in alleviating the spread of the virus. In addition, a number of researches have been carried out in the area of HIV/AIDS concerning the above segments of society. However, persons with disabilities (PDs) have never been identified as high risk groups in the national HIV/AIDS prevention and protection policies and programs. Thus, the following section presents the details of problems faced by PDs in relation to HIV/AIDS (MOH, 2004).

### **1.1.3 Statement of the Problem**

Disability is an age old phenomenon in the history of human societies. It is often associated with various misconceptions and attitudes in different societies. Globally, persons with disabilities have been attached to loaded terms like 'evil spirit', 'witch craft', 'ill' and 'unfortunate' (Daniel,2000). However, such attitudes of the general population toward disabled population have gradually been declining (Clapton& Fitzgerald, 1996).

It has been estimated that about 10 percent of the world population is with disability (Global survey on Disability and HIV/AIDS, 2004). According to this estimate, there are about 600 million persons with different types of disabilities in the world. Together with this prevalence, the nature of problems and challenges encountered by disabled persons

## Vulnerability of persons with Disabilities...

makes disability a global concern. For instance, in the USA and UK more than 60 per cent of persons with disabilities live below the poverty line (Harknet ,1994).

Nevertheless, the situation is often worse in developing countries. Among the aforementioned global estimate, 80 per cent of disabled persons are living in developing countries particularly in Africa. This huge prevalence is associated with the prevailing poverty, illiteracy, ignorance and superstitions in Sub-Saharan countries. Besides these, lack of immunizations, accidents, and malnutrition often aggravates the incidence of disability in the sub region (World Bank/Yale University, 2004).

On the other hand, The African Campaign on Disability and HIV and AIDS report indicates that there are about 80 million people with disability in Africa. “These make up 15 to 20 per cent of people in the poorest communities, which are also severely affected by HIV and AIDS” (The African Campaign on Disability and HIV and AIDS Report, 2006:4).

However, the distribution of disabled persons varies across the different regions of the country. At the same time, statistics concerning the disabled persons are often misleading. This is because of the prevailing invisible disabilities, which are excluded in most statistical reports in the country. But an attempt was made to show the prevalence of PDs in eleven regions of Ethiopia (Tirusew, (2005).

## Vulnerability of persons with Disabilities...

Table A : Distribution of PDs in different Regions of Ethiopia

Region	Population(disability)in percent
Addis Ababa	17.7%
Southern Peoples	16.8%
Harare	14.4%
Amhara	14.0%
Tigray	13.3%
Oromo	12.7%
Benishangul	9.0%
Dire-Dawa	8.9%
Gambella	4.4%

Source: Adopted from Tirussew Tefera *et al* (1995:59),*Base Line Survey on Disabilities*  
In Ethiopia. IER: Addis Ababa University Printing Press

Table Two : Distribution of PDs in different Regions of Ethiopia

<b>Region</b>	<b>Population</b>
Oromia	333,653
Amhara	281,291
SNNP	174,941
Tigray	90,742
Addis Ababa	45,936
Somali	31,686
Afar	13,546
Benishangul	7,341
Dira Dawa	4,226
Harari	2,909
Gambela	

Source: Adopted from Country Profile on Disability: Federal Democratic  
Republic of Ethiopia, 2002.

## Vulnerability of persons with Disabilities...

The table shows the distribution of PDs in the country according to the proportion of population in the perspective regions. However, the country profile focused much on common disabilities like the blind, the deaf and physically disabled. Besides, it is possible to observe huge statistical variations in the above distribution of persons with disabilities at different time frame. This may indicate how data on the prevalence of disability can not be reliable in Ethiopia.

According to the 1984 population census in Ethiopia, 42.2 percent of all the disabled population are the blind (1.5% of the total population), 7.8 percent are the deaf (0.28% of the total population), 6.5 percent are the leprosy (0.23% of the total population), 2 percent are the epilepsy (0.07% of the total population), and 24 percent are persons with other disabilities (0.87% of the total population) (CSA, 1984).

Similarly, the 1994 population and housing census of the country shows that out of the total population of 53,477,265, about 988,849 are persons with different types of disabilities. According to the source, the census did not include homeless disabled persons ( Population and Housing Census, 1994).

Subsequently, a baseline survey was conducted in 1995 on the prevalence of disabled persons in the country. This data shows the distribution based on the types of disability in the country. According to this survey, 30.8 per cent are physically impaired; 30.4 per cent are visually impaired; 14.9 per cent are the deaf; 10.3 percent are chronically ill; 6.5 per cent are mentally retarded and 7.1% are persons with other kinds of disabilities (Tirusaw, 1995). This variation of specific disability percentage distributions from both reports indicates the drawbacks to determine the prevalence rate of PDs in Ethiopia.

Moreover, a particular Housing and Population Survey conducted in Addis Ababa indicates that there are about 54,030 disability cases among 1,423,111 people. According to the survey, about 988,853(1.86%) of disability cases were reported in the 1994 population census of the country (Daniel, 2000:6). Though it might be difficult to take these evidences for granted, they could be used as basis to trace the magnitude of persons with disabilities in Ethiopia in general and Addis Ababa in particular.

Despite their huge numerical existence in the country, PDs are made to appear and feel incapable and suffering from the outcomes of non-inclusive and ill-designed infrastructural facilities and other forms of organized activities or services of society. This is predominantly manifested in HIV related support services. Disabled persons are not seen as high risk groups in HIV/AIDS programs in the country (World Bank and Yale University, 2003).

It has often been assumed that persons with disabilities (PDs) are less likely to be affected by HIV/AIDS than the non-disabled people. The assumption is that they are sexually inactive and have less exposure to unsafe sex and sexual violence. According to this claim, individuals with physical, sensory and mental disabilities are unlikely to use drugs, and are less likely to be victims of violence or rape than their non-disabled peers (World Bank, 2004).

In contrast, HIV/AIDS-associated needs and problems of PDs in general deserve to be treated as a core issue. According to the Global survey on HIV/AIDS and Disability (2004), such needs and problems could be justified on at least three major counts. First, by virtue of citizenship, PDs need to be legally entitled to be incorporated into interventions designed to safeguard the well-being of the population against the short and long-term threats

of HIV. Second, the physical limitations and socio-economic impact of disability necessitate that PDs be targeted for focused and specialized attention in the course of the mainstream undertaking. This may help guarantee that they will not risk being left out or neglected in the design and implementation of anti-AIDS programs that are normally formulated within the context of the interests and concerns of the public. Moreover, Non Governmental Organizations (NGOs) sponsored or government-run social rehabilitation and integration of PDs can hardly begin to make any impact without adequately filling out existing disability-related HIV/AIDS policy and service delivery gaps.

Third, it would not be an overstatement of the facts to say that the success of the national HIV/AIDS policy and program implementation depends on how comprehensive the practice is with regard to PDs. In view of the size of the PDs community, relative to the total population, they should be treated as an important category rather than peripheral, which currently seems to be the case ( Groce, 2003).

In a country like Ethiopia, where an estimated 10 percent of the total population of 77 million lives with some kind of permanent disability, failure to accord this vast community in connection with the issue of HIV/AIDS has negative impact on the process and intended outcomes of the mainstream prevention and control undertakings.

A survey conducted by Handicap International (2004) on some 200 deaf individuals indicates that the welfare services provided for PDLHA are insignificant. The nature of HIV/AIDS education among members of the disability community is very poor. The survey shows that most respondents are ignorant about the ways in which HIV/AIDS could be spread (HIV/AIDS and Disability Presentation of Handicap International Activities, 2004). To this end, it is not difficult to imagine that the marginalization of PDs can have grave

implications when it comes to HIV/AIDS, given that it is a serious national public health concern.

#### **1.1.4 Significance of the Study**

Persons with disabilities are one of the social categories that are usually neglected in HIV/AIDS prevention, management and care. Many HIV/AIDS programs and projects do not target the disabled persons. However, it is evident that the disabled like other groups are also at the risk of contracting HIV/AIDS and therefore should be targeted ( Groce, 2004). Involving the disabled adds value to the programs, as they not only become beneficiaries but also participants.

A number of researches have been done on the HIV/AIDS related issues. These researches, however, have overwhelmingly focused on people in general and the youth and women in particular. To the knowledge of the researcher, no full-fledged research has so far been done on persons with disabilities and HIV/ AIDS related issues. But the fact that this segment of the society is the most marginalized and triple- burdened (HIV/AIDS, disability and poverty), there is a need to conduct practical research to fill up this huge gap.

This would create a greater impact especially when disabled persons are seen in the forefront in the fight against HIV/AIDS. Many programs do not seem to recognize the role that disabled persons can play in the fight against HIV/AIDS ( Ngnwa, 2002)

Moreover, since the issue of disability is associated with the prevailing societal myths and stereotypes in relation to HIV/AIDS, it demands creation of awareness for the public. This should be supported by a relevant research. There fore, these factors call for an urgent empirical research like the current one.

Above all, this research would be useful for policy and program designers in the area of HIV/AIDS. The findings could facilitate them to reconsider their previous policies. It could also function as a foot step for further research.

### **1.1.5 Objectives of the Study**

The general objective of this research is to assess the extent to which persons with disabilities (the deaf, the blind and the physically handicapped) are vulnerable to HIV/AIDS.

This will be accomplished through the following specific objectives:

1. Identify the risk factors of persons with disabilities to HIV infection.
2. Identify if PDs are included in HIV/AIDS mainstreaming programs?
3. Review existing policy framework on HIV/AIDS in relation to disability issues.
4. Identify the HIV/AIDS related services available for persons with Disabilities.
5. Provide implication for practice

### **1.1.6 Definition of Terms**

**Impairment:** There is no one definition for the term impairment. Jonson (1993:2) describes impairment as a disease caused by defective genes or injuries during or after birth, which often leads to disability. Impairment could also be ‘permanent or transitory in nature’ (UN, 1994:9). However, for the purpose of this research, impairment refers to “physical or mental disease, loss, abnormality or injury. It includes lack of part or all limbs; partial or total defects of eyes, ears; brain damage and failure to develop to maturity in any organ or body mechanism (Daniel, 2000: 7).

**Disability:** Definition of disability often depends on the national social legislation and cultural standards. This makes the concept difficult to understand in global context.

However, attempts were made to give basic concept of the term. According to UN General



Assembly, disability is defined as “a permanent physical or mental impairment that limits one or more major life activities. People are said to have disability if they find it difficult to move, see, hear, feel, think, control themselves or do certain things” (UN General Assembly, 1993).

This research, however, uses the following definition as operational definition to disability:

*a state in which functional limitations and or impairments are causative factors of the existing difficulties in performing one or more activities which (in accordance with the subjects age, sex and normative social roles) are generally accepted as essential, basic components of daily living, such as self care, social relations and economic activity (ILO in FDRE Country Profile on Disability, 2002:9).*

**Handicap:** It is more related to lack of social interaction due to disability. Jonsson (1993:3) defines handicap as “a social consequence of disability and is a function of the relation between the individual and the environment”. Regards to this study, ‘handicap’ indicates a disadvantage for a given individual resulting from an impairment or disability that limits or prevents the fulfilment of a role that is normal ,depending on sex, social and cultural factors for the individual (UN, 1994).

**Deaf (Hard of Hearing):** Deafness is having difficulty in hearing sound. Hearing loss may be mild, severe or total. Children may bear with poor or no hearing. Most elderly people loose some hearing with their age. Hearing impairment is a full or partial decrease in the ability to detect or understand sounds caused by a wide range of biological and environmental factors, loss of hearing can happen to any organism that perceives sound (Beckles, 2004).

**Blind (Visual impairment):** Visual disability may be total blindness or partial. But for this paper, blind persons refer to those having difficulties in seeing or they may not be able to see at all (JICA, 2002).

**Physical Disability:** For the purpose of this study, physical disability refers to the damage to muscle nerves, skin bones or other body parts. This could be congenital (from birth) or accidental due to injury (Malindwa, 2003).

**Persons with Disabilities or Disabled Persons/People:** The use of these terminologies varies in different cultural and social background. However, they were used interchangeably in this paper for convenience. Thus, for the purpose of this study persons with disabilities include the blind, the deaf and the physically disabled.

**Vulnerability:** It is a complex and contested concept with a variety of definitions arising from different disciplines. It could be analyzed in different settings like poverty; health problems like HIV/AIDS and others related problems. In relation to this study, however, it encompasses the social, economic and physical factors which could increase the susceptibility of an individual or group (persons with disability) to the impact of HIV infection (The Lancet Journal of Infectious Disease, 2004:268).

**Poverty:** poverty is a multi-dimensional concept and thus no single way to define it concretely. However, for the purpose of this research focus is given to the 'basic needs approach' to define poverty. Therefore, according to Hagenars and Vos((1988:213), poverty "encompasses different dimensions of deprivation that relate to human capabilities including consumption and food security, health, education, rights, voice, security, dignity and decent work".

### **1.1.7 Limitation of the Study**

Despite all the efforts made to accomplish this study, some practical limitations had inevitably been part of it. The sensitive nature of both HIV and disability had created some challenges for the researcher during data collection. The first challenge is related to the deaf participants. In this regard, the researcher's inability to use sign language created problem to get complete message through interpreter. The use of the third person for sign language interpretation could also affect the confidentiality of the data. This resulted in the limitation of the data collected. Second, the high expectation of incentives from both PDs and PDLHAs for interview sessions challenged full access to the data. This problem is compounded with the under financed system by the department. But, the researcher exerted the utmost effort to minimize these sources of bias by employing all the possible mechanisms to contact the study subjects more than once and ensuring the necessary data needed with out compromising their interest and time.

## **Chapter Two**

### **Literature Review**

#### **2.1 Conceptual Framework**

##### **2.1.1 Disability and Poverty**

Research indicates that poverty and disability are much linked to each other. They usually reinforce each other and worsen the life of disabled people. It was argued that disabled persons' living situation affects their chances of working, enjoying their family life and daily activities. According to the UK Department for International Development (DFID), only 2 % of disabled persons living in developing countries have probability to access basic services and rehabilitation (DFID, 2000).

In arguing the relationship between poverty and disability Elwan (1999) discusses how poverty causes impairment as : “ poor nutrition, limited access to vaccination programmes to health and maternity care, poor hygiene, bad sanitation, inadequate information about the causes of impairments, all cause disability” (Elwan,1999:21).

This may indicate that poverty in this term could have greater disabling impact on people. On the other hand, this causal relationship is often manifested when disability itself is resulting in poverty. It has been argued that disability exacerbates poverty by increasing the possible discrimination and lack of economic advantage in the disabled people. Disabled are denied access to education and thereby unable to get employed. As a result, it is often difficult to break the vicious circle of poverty and disability (DFID, 2000).

Choruma (2006) argues that disability has impact on the schooling, employment and equal participation in the larger society. This is compounded by the prevailing illiteracy

among the disabled people. Choruma states that they are in a situation where there is little possibility to earn income. The prevailing social isolation and discrimination prevent them from accessing social services. Besides, being disabled itself costs them considerable hardship in their daily life. The fact that they are considered incapable to run their own life often makes them dependent on their families. The non-disabled people often fail to consider them as productive as themselves. Poverty can also lead to secondary disability for the individuals with previous disability. It could be the poor living conditions, unemployment, poor nutrition, poor health care and lack of education. Thus, they may not have enough income to earn their living. This in turn could negatively affect their disability (Choruma, 2006).

It was also recognized that persons with disabilities are ‘among the poorest of the poor in all parts of the world’ ( Beckles ,2004:4-5). She argues that poverty for disabled people is not only monetary but it is also question of “voiceless ness” which accelerates the situation of further discrimination, powerlessness, and exclusion.

A report by DFID indicates that most people with disability find their schooling, working for living, enjoying family life and participating as equals in social life difficult. According to DFID estimate, only 2% of persons with disabilities have access to rehabilitation and basic services. The report clearly shows that about 98 per cent of children with disabilities are not in a position to attend school in developing countries. The same percent of disabled people in developing countries lack access to basic services. Thus, an estimated 80 per cent of disabled people are unemployed in the world (DFID, 2000).

According to a world report on disability and rehabilitation, the linkage between poverty and disability is further explained by WHO (2005:1) as follows:

## Vulnerability of persons with Disabilities...

Poverty is a root cause of many disabilities. About 80% of the world's 600 million people with disabilities live in low-income countries, often in poverty, isolation and despair. Poverty further limits access to basic health services, including rehabilitation and education. Most of the developmental initiatives often ignore the need of people with disabilities.

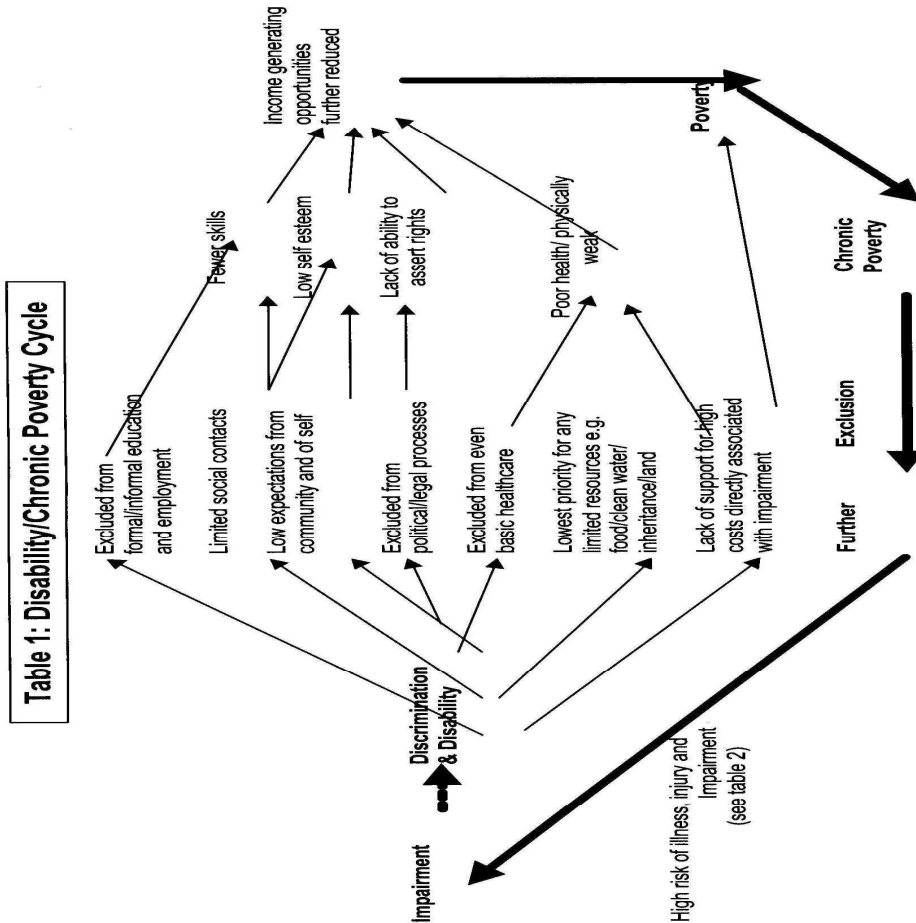
This indicates that poverty has a disabling effect on the life of people. As a result, the disabled people may not have ample access to basic human services due to their disability.

For instance, the Biwako Millennium Goals of Asian and the Pacific report on persons with disabilities estimated that over 400 million people are disabled and 40% of them live in poverty. The prevailing disability and poverty prohibited them from accessing services like health, education and employment. They are not often participants in the community decision making processes. In the same report, it was mentioned that approximately 50 million persons in the Latin America and the Caribbean are with disability (Beckles, 2004:5).

Nevertheless, international and national development initiatives have not yet given special attention to alleviate poverty of disabled people. For instance, Poverty Reduction Strategy Papers (PRSPs), Millennium Development Goals (MDGs), The New Partnership for Africa (NEPAD), African charters and United Nations (UN) conventions have no mention on disabled persons' concern in relation to economic development. The failure in these global economic development initiatives to address the vulnerable groups like persons with disabilities may not make the development effort comprehensive and inclusive. This exacerbates the possibility of forming a vicious circle between disability and poverty

(Choruma, 2006). The diagram below shows a conceptual framework diagram on how poverty and disability make a vicious circle.

11



SOURCE: Adopted from Rebecca Yeo (2001, 11), Chronic Poverty and Disability: Action on Disability and Development. Chronic Poverty Research Center.

This vicious cycle has resulted in making persons with disabilities the poorest among the poor in developing countries. It is shown that they also experience lower literacy than the non disabled segments.

## **2.2 Disability and HIV/AIDS**

In the discourse of HIV/AIDS, no significant attempt has been made to prevent the vulnerability of disabled persons to HIV/AIDS. However, research indicates that the virus has a profound effect on disabled persons' ability to protect them from HIV. Research indicates that two major factors have been found to contribute to their vulnerability to HIV. First, people with disability have poor access to resources. This inaccessibility to resources is related to the prevailing poverty factors affecting the disabled. They are among the unemployed and illiterate in a society. This is because disabled children are not often sent to schools and thereby are forced into adult unemployment (Abrahams (2007).

Abrahams also states that absence of education prevents them from accessing written materials about HIV transmission and prevention. Especially, most of the written and visual materials about HIV do not consider the disabled, the blind and the deaf. Second, disabled persons are often given low social role and thus are neglected from services. This perceived low status towards disabled people affects their marriage choice. Particularly, disabled women are not given opportunity for partner choice. This may lead to transient relationships which often happen violently (Abrahams, 2007).

The author goes on to say that disabled persons do not take part in the educational, social, political and economic activities of a society. As a result, they are either forgotten or unconsidered in most of the HIV related programs. This in turn contributes for their susceptibility to HIV infection (Abarahams, 2007).



## Vulnerability of persons with Disabilities...

This clearly indicates that disabled persons' access to information and education relevant to HIV/AIDS is determined by the prevailing perception from their non-disabled sections of the larger society. It is predetermined first by their family and then by the society at large. This view thus strengthens the argument posed by the social model as disability is socially constructed problem rather than disease by itself (DFID, 2000).

The issue of equal access to the reproductive health and sexuality information is further initiated by the standard rules on the equalization of opportunities for persons with disabilities. According to UN convention (1994), the standard rule 9.2 indicates:

Persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood. Taking into account that persons with disabilities may experience difficulties in getting married and setting up family, states should encourage the availability of appropriate counselling. Persons with disabilities must have the same access to family planning methods, as well as to information in accessible form on the sexual functioning of their bodies (UN, 1994; Rule 9.2).

The above quote seems to urge the concerned bodies to incorporate disabled people in the reproductive health services. It could be inferred that HIV/AIDS is part of the reproductive health issue that needs to be addressed according to the UN convention. But this is often criticized for its lack of practicality.

Furthermore, the scarcity of empirical research on HIV/AIDS and disability has made access to data on prevalence of PDLHAs difficult. However, few research attempts have been carried out in the developed countries. A small survey conducted in USA in 1994 found that HIV infection rate in the State of Maryland among the deaf community doubled

those of the hearing community. Accordingly, some studies conducted in USA estimated that 7,000 to 26,000 deaf people are found HIV positive. It was also shown that about 700 deaf people died of AIDS case (World Bank, 1995).

This huge figure may indicate that disabled persons particularly the deaf are extremely exposed to HIV epidemic. But this is not the only statistics that could be trusted upon. The study might exclude the invisible disabilities including the deaf in the Maryland State. Besides, the data does not mention the prevalence in developing continents like Africa, in which it could be worse. Thus, this data can not be taken as a ground for arguing the vulnerability of PDs to HIV infection. However, it could have implication for the prevalence rate in developing countries, which may be worse than the developed nations.

In relation to this, scientific literature indicates that there is a huge research gap in developing countries concerning vulnerability of persons with disabilities to HIV. Nevertheless, a research attempt was made in Zambia on physically disabled women and reproductive health services. The finding shows that women with physical disability are relegated from AIDS information and education programs. They are not in a position to get reproductive health care services like the non-disabled women. Sexuality issues are rarely discussed among the disabled women and they are not encouraged to talk about it in the public. This has resulted in their infection to the virus (Smith et al, 2004 in Yousafi and Edwards, 2004).

In addition to this, a research conducted by Nganwa et al (2000) indicates that the prevailing physical, social and mental barriers limit disabled people from having interaction and participation in public meetings. As HIV/AIDS is often associated with 'interaction and participation' of individuals with others, it requires them to take part in the interaction

process. However, PDs have very limited interaction horizon which hinders their access to HIV related information, services, prevention and treatment. This in turn effected on their vulnerability to the virus.

### **2.3 Poverty and HIV/AIDS**

HIV infection rate is not the same at all levels of income in a society. Kedir (2005, 14) notes, “HIV/AIDS is not exclusively a problem of the poor. However, the risk of infection is highest among the poor given their lack of information about the disease and their general hopelessness about their welfare.” He added that HIV risk behaviors are closely related to the level of income of individuals. The prevailing poverty, ignorance and fear among the poor results in stigma and discrimination towards HIV patients. Kedir (2005) further argues that shortage of food for eating could have risk of exposure to HIV/AIDS. This could happen when the poor opt for sexual practice to get income for their daily livelihood. He concludes that poverty contributes a lot for the exposure to risk behaviors, which may lead to infection. This linkage between poverty and HIV/AIDS has an implication on the disabled people, who are often at the heart of poverty. The disability compounded with poverty might increase the risk behavior to HIV infection.

### **2.4 HIV Risk Factors**

Exposure of Persons with disabilities to HIV has been linked to various risk factors. A community-based research conducted in 2002 indicates that the lives of disabled persons are often determined by the ‘decisions and outcomes of the social environment in which the disability was born’ (Nganwa et al, 20002). It was argued that the prevailing physical, mental and social barriers often relegate disabled persons from accessing HIV related services.

The fact that AIDS as a disease related to social interaction and participation limits the chance of having the exposure to interact with their neighbourhoods, peers and other social groups. The weaker the integrations and communication for information on HIV, the more the disabled are ignorant of the transmission, prevention and control methods. It was underlined that it is the 'societal response rather than the 'biological' impairment that makes the disabled vulnerable to the disease (Nganwa, et al, 2002). Some of the risk factors are presented below:

#### **2.4.1 Family Situation**

It was also pointed out that PDs vulnerability to HIV is attached to their living situation at home. In supporting this, Ngawa et al (2002) argue that family plays an important role in shaping the life experience of disabled children. According to their view, disabled children are often over protected at home and do not experience social environment. They are not encouraged to discuss issues related to sexual relationship with their friends. This has been associated to protection of disabled girls from unwanted pregnancy and thus limiting the number of disabled children at the family level. This inhibits them from participating in sexuality related information.

It also results in disabled adolescents' absence from HIV related education, which is believed to provide them skills and knowledge on the disease prevention mechanisms. On the other hand, the situation that PDs live with their parents as adult with out fully experiencing the external environment and social interaction greatly influences their sexual life.

### **2.4.2 Sexual Abuse**

According to Nganwa et al (2002), a study conducted by African Medical and Research Foundation (AMREF) in Kenya in 2000 indicates that the sexual abuse experienced by disabled children and adolescents at home is often unconsidered by their family. It was found that such abuses are usually from their family member. There is no possibility to report the rape case of disabled girl either at home or out of home. Although there are some attempts to protect the disabled children from the sexual abuses, it was aimed to protect pregnancy but not from HIV infection. Above all, the study asserted that women with disabilities were made to have low self esteem, which reduces their potential to report the abuse cases to the law enforcing bodies.

As mentioned earlier, poverty is one of the most determinant factors that fuels disabled persons' vulnerability to HIV virus. It was stated that disabled people are required to develop coping mechanisms to bear the negative impact of HIV/AIDS. This coping mechanism is closely related to the income they are able to afford. However, this capability is intimidated by the persistent household poverty they suffer from. Nganwa (2002) argued that poverty stricken people with disabilities strive to fulfil their economic need and this is often done by using sex as a 'means'. Thus, Poverty influences their decision on their sex matters i.e. they are forced to have more than one partner. This may expose them to further sexual abuse and thereby contract the virus.

### **2.4.3 Poor Access to Health Education**

Health education is an important tool in transferring knowledge and skills of prevention from HIV/AIDS. Any strategy for the prevention of the disease is directly or indirectly correlated to information obtained through education. However, the amount of

knowledge acquired is determined by the socio-economic context, educational status and the available health services for the people (Ngawana et al, 2002:19).

It is very unlikely that disabled persons get these opportunities accordingly. The high illiteracy level they are in has great influence in hampering their access to relevant HIV knowledge. The available sex educations in the schools and community may not reach PDS in accessible form. In other words, PDs in special schools do not get the same sex education as those in 'normal' schools. Likewise, there is no health education related to reproductive health addressing PDs in particular. Above all, the dramas and theoretical practices designed for knowledge promotion on HIV/AIDS systematically exclude PDs (UNESCO, 2000).

#### **2.4.4 Gender and Sexual Abuse**

It has been argued that women with disability have less opportunity to get married than their non-disabled counter parts in Sub-Saharan countries. In this region, marriage is traditionally associated with the roles a woman could play at her husband's home. Men consider disabled women as those with out roles at home and thus do not make any permanent marriage with them. In this regard, Ngwana, et al (2002) argues as follows:

In agrarian societies, survival depends on physical capabilities. Women are married because they are a source of labour. Disabled women are, therefore, viewed as liabilities and have less opportunity for marriage. In addition, beauty in Africa is largely physical and the beauty of the soul rarely comes into play when choosing a spouse. The low social status makes women with disabilities less likely than men with disabilities to find a spouse. Thus, such difficulty in finding a partner, coupled with the need to have children makes

women with disability especially vulnerable to HIV (Nganwa et al, 2002:191-192).

This indicates that women with disability have little chance to be married and thus opted to make unsafe sexual practice, which is likely to expose them to HIV infection. Their desire to have children is also hampered by their family and this likely makes them prone to extramarital sex, which could fuel their potential to contract the virus.

Worst, they are often raped by the men, who are already married. This is because these women are believed to be free of HIV virus and targeted by some men. Particularly they are victims of forced sex and they could not protect themselves due to their impairment (Yousafzi & Edwards, 2004).

#### **2.4.5 Poor Access to Legislation**

Legal provision is one of the most important services provided to protect people from HIV/AIDS related stigma and discrimination. Persons with disabilities often need support from the legal bodies to protect them from sexual abuses and neglect like the other segments of society. However Choruma (2006) argues that disabled people are not given emphasis by legal entities, such as police and court. He claims that the rape cases of disabled people, for example, are not reported in time to the legal bodies. Most sexual violence cases fail to reach police and media. This is often associated with the public perception that women with disability are labelled to a subordinate social status and thus underestimated by the court and the police. In addition to this, disabled women and girls lack knowledge and information about their rights to have appropriate legal services by the law enforcement body (Choruma, 2006).

## **2.5 Global Efforts to Help Persons with Disabilities**

Many attempts have been made to include PDs in social service sectors. A handful of international and national organizations have included PDs in their development policies and programs. The world health organization (WHO) is one of the international institutions, which has designed specific programs to address some of the poverty related problems of PDs. According to the WHO (2006) report, the organization has been involved in rehabilitation, prevention and management programs. The plan was designed for five years (2006-2011).

Another most important international attempt made to help PDs was on the occasion of International Day of Persons with Disabilities declared by UN in 1992. The document calls for understanding of disability and the role of disabled persons in social context. It focuses on the creation of awareness for the public about PDs in general.

In addition to these, the German Development Cooperation (GTZ) has developed a program to address the exclusion of PDs in development plans. According the 2006 policy report, disability has been discussed from the development perspectives. It was shown that any development efforts need to address the poverty of disabled persons in order to achieve its goals. The report indicates that it is essential to meet the interests and needs of PDs in order to accomplish the millennium development goals in 2015. The document suggests the inclusion of PDs in the poverty reduction strategies of different countries. However, the policy document criticizes that the Millennium development Goals (MDGs) fail to explicitly include the vulnerable groups of persons with disabilities (GFMECD, 2006).

Moreover, the United Nations (UN) has declared standard rules on the equalization of opportunities for persons with disabilities. According to the Department for International



Development (DFID), the standard rules have given special attention on the promotion of equal participation for disable persons. These were aimed to be met through medical care, rehabilitation, accessibility, education, employment and other related service provision mechanisms (DFID, 2000).

Although the above international efforts to enable PDs to be integrated to the larger society and thus become beneficiaries of opportunities for social services is a constructive step, all the documents have no mention of services related to HIV/AIDS. None of the above documents has incorporated the service provisions addressing the impact of HIV on this disadvantaged people.

However, the World Bank has made a survey on HIV/AIDS and disability in 2004. The organization, together with Yale University, has conducted a baseline survey concerning the vulnerability of PDs to HIV infection. The survey shows the prevailing societal perceptions on disability and HIV/ AIDS have made greater influence on PDs social life. It also presents the counter argument that PDs are at high risk of HIV due to various risk factors associated to them. Nevertheless, the organization's attempt is merely a research based rather than intervention on HIV/AIDS. It was a survey aimed at disseminating information on HIV and persons with disability to different stakeholders across the world.

Recently, African based initiative has also been launched to address HIV/ADS problems of disabled people. It is a campaign on disability and HIV/AIDS and has designed a strategy for the years 2007-2011. Basically, the campaign aims at improving HIV related services for disabled persons in Africa. In addition, it attempts to reduce the vulnerability of disabled persons to HIV infection. The campaign identified major goals to reach persons with disabilities in HIV information and services. It is involved in creating awareness on the

vulnerability of disabled people on the impact of HIV/ AIDS. Besides, it works to promote local level knowledge and skills of disabled people and to help them participate in HIV service provision. Above all, the campaign strives to maintain the mainstreaming of disability in HIV/AIDS policies, programs, legislative documents and guidelines both at national and international levels (The African Campaign on Disability and HIV/AIDS, 2006).

The campaign incorporates various regional stakeholders like the Central African Federation of Disabled Persons (CAFOD), Christoffel Blinden Mission (CBM), Voluntary Services Overseas (VSO), TASO (UGANDA) and Association *Burkinabee pour le Bien Etre des Personnes Handicapees (A.B.B.E.P.H)*.

## **2.6 Services Available to HIV Infected Persons in Ethiopia**

In dealing with disability and HIV/AIDS concern in Ethiopia, it is essential to see the policy roles in addressing the problem. The HIV/AIDS Policy in Ethiopia was primarily aimed at providing a favorable environment for a multi-sectoral approach for the prevention and control of the disease under the coordination of the National AIDS Prevention and Control Secretariat and Council, which was established in 2000 (FHI and Addis Ababa City administration health bureau, 2002).

The National Strategic Plan for Intensified Multi-sectoral Responses to HIV/AIDS (2004-2009) identified high risk groups in the society who are especially vulnerable to HIV infections for widely varying reasons, such as gender disparities, socio-cultural pressures, biological factors, psychological makeup, economic problems, and occupational characteristics. Accordingly, segments of the population mainly women, youths, sex workers, soldiers, heavy-duty truck and long-distance bus drivers, orphans and vulnerable children have been targeted as high risk groups requiring special attention vis-à-vis the threat of

HIV/AIDS. They have been provided with access to wide-ranging services that basically include information dissemination and support provisions. Practical attention to these particular groups of society would be in the interest of the overall national effort to combat the spread of the virus and thus to the well-being of the whole society which, after all, stands to ultimately benefit from the success of the endeavor ( National HIV/AIDS Strategic Plan, 2004-2009).

In order to reduce vulnerability among these special target groups, the strategy provides for different kinds of welfare services for HIV/AIDS cases within the framework of "major activities" and "method of implementation". Yet, there is no one major activity or method of implementation that aims at or mentions PDs, including orphans with disabilities.

Prior assessments made on the Strategic Framework (2000-2004) also indicates that PDs are either left out as a group of no concern or ignored in the implementation process of HIV/AIDS Policy and Strategic Framework. For instance, the care and support service assessment conducted by Family Health International (FHI) indicates that seven major welfare service areas are focused and provided by the various organizations and associations in Addis Ababa. One of these services is home based care (HBC) which includes the medical care, nursing care, counseling and material support for PLHA in different sub cities. The special target group beneficiaries of HBC programs included PLHA, bed-redden patients and AIDS orphan (FHI and Addis Ababa City Administration Health Bureau, 2002).

In addition to HBC, socioeconomic support services are delivered for PLHA. Included under such services are food support, follow up counseling, and legal support, and spiritual support, financial and medical support. Moreover, clinical care services are provided for the target groups mentioned above. This service encompasses HIV/AIDS testing service

in the laboratory, provision of essential drugs kept for the treatment of HIV/AIDS related illness, medical supplies and equipment (test kits), and referrals for further medical care ((FHI and Addis Ababa City administration health bureau, 2002).

Furthermore, Tuberculosis (TB) and sexually transmitted infections (STIs) treatments are made to the identified vulnerable groups to alleviate HIV/AIDS risk factors. Organizations and institutions engaged in the service provision deliver VCT service for these segments in need of knowing their HIV status. Yet, the assessment study made by Family Health International and Addis Ababa Health Bureau makes no mention of PDs or PDLHA in any way, thus indicating the general behavior of disregard of these people.

Similarly, in the domain of medical support, socioeconomic, physiological or emotional and human rights and legal supports, the PDLHA are not included in specific terms. Wisdom and foresight does not seem to have been exercised in Ethiopia in the area of disability contrary to the Abuja Declaration on the Framework for Action against AIDS and Tuberculosis (African Economic Commission, 2001). African governments, including the government in Ethiopia have identified PDs by this Declaration as a high-risk group in the African context due to the extreme discrimination, stigma and abject poverty. However, this declaration has not been supported by implementation in the country.

Although assessment reports have been made by some disability organizations, such as Information Development for Persons with Disabilities Association (IDPDA) and Center for Applied Research Development Oriented Services (CARDOS), their findings capitalize on the needs of PDs and PDLHA for education, information and communication in accessible formats. These include audiovisual equipments for the blind and the deaf, including sign language communication and interpretation.

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Another practical but, unfortunately, small attempt made so far in providing some welfare services related to HIV/AIDS for women and men with disabilities in Ethiopia was that of the National Association of Women with Disabilities (NAWD).

According to Lakech Haile Mariam (2005), the president of National Association of Woman with Disabilities, women with disabilities are highly vulnerable to rape due to the wrong conception that they are HIV/AIDS free simply due to their physical their inhibition. They do not have adequate information about the disease, as most parents do not send their disabled children to school.

## **Chapter Three**

### **Research Methodology**

#### **3.1 Research Design**

This study used both the case study and the views of other researchers on the area as part of its research methodology. In the former case, a cross sectional qualitative method by using instruments, such as in depth individual interviews, focus group discussion, and key informants interview was employed. Besides, secondary data sources were employed during the data collection period. A qualitative research design was selected for the fact that the study explores individual beliefs, attitudes and social interactions in relation to HIV/AIDS and persons with disabilities. In order to get views and opinions of individual PDs, individual PDLHAs and organizations, questions related to sexual behaviors, risk factors to HIV infection, access to HIV related services and the efforts made by HIV/AIDS policy makers were administered.

#### **3.2 Study Site and Population**

The study was conducted in Gullele sub city. The sub city is one of the ten sub cities of Addis Ababa. According to the 2007 population projection, its total population is estimated to be 346,023 out of which 169,155 are male and 176,868 are female. However, there is no well registered statistics showing the number of PDs in the sub city. But in 2007, the Social and Civil Affairs Department of Gullele sub city Administration has conducted an assessment study on PDs in general. According to this document, the total number of PDs in the Sub- City is estimated to be 2,890. This statistics is a crude amount and it does not identify the number PDs in terms of sex and disability types. On the other hand, the number

of PDLHAs in the sub- city is not identified due to absence of data and study done on similar issue.

This study targets persons with disabilities (PDs) and persons with disabilities living with HIV/AIDS ( PDLHAs).The selected members of the study subjects include the deaf, the blind and physically disabled. In addition to this, organizational level assessment was made in 15 different organizations and three associations in Addis Ababa.

### **3.3 Data Collection Techniques**

The primary data was collected by using semi-structured interview questions designed for selected individual persons with disabilities living with HIV/AIDS (PDLHAs) individual persons with disabilities (PDs). Besides, the interview was administered to organizations and associations working on HIV/AIDS. In this case, organizations refer to those engaged in HIV/AIDS related service provision in Addis Ababa, where as associations include Ethiopian National Association of the Deaf (ENAD), Ethiopian National Association of the Blind (ENAB), and Ethiopian National Association of the Physically Handicapped (ENAPH). These organizations were asked for their inclusion of HIV related service provision for individual PDLHAs and PDs.

Another semi-structured questionnaire was administered to selected disability associations and organizations, which have included disability programs in relation to HIV/AIDS. In addition, open-ended interview questions were administered to organizations engaged in the HIV/AIDS service provision. One programme personnel was selected from each of the organizations and associations for the interview purpose.

The interview questions designed for such associations and organizations basically included the types of services provided and communication and education systems

applied by these organizations for PDLHA. Besides, the interview questions addressed the issue of inclusion of PDs in HIV/AIDS programs of the organizations.

On the other hand, semi-structured interview was administered to individual PDLHAs for the risk factors which could accelerate their vulnerability to HIV infection. They were also interviewed about poverty related issues which may fuel the probability of contracting the virus. Moreover, questions on HIV related services were administered to 12 selected PDLHAs and 6 PDs. They were asked about the perception of society and culture related stereotypes related to disability.

The interviews with PDLHAs (the blind) were carried out by the help of their care takers, namely parents, siblings and peers of the selected PDLHAs in *Gullele* Sub City. This was done as an option for the challenge the researcher encountered in the attempt to interview these subjects. A volunteer sign language interpreter, who has studied masters in special needs education, was also involved during the interview with the selected deaf interviewees. The other PDLHAs (physically disabled ones) were personally interviewed by the principal researcher. In both cases, however, consent was maintained to keep the information confidential and respect the privacy of the interviewees. The researcher read the confidentiality statement to participants the Blind and physically disabled PDLHAs and PDs before the actual interview session. The deaf were also informed about the confidentiality statement through a sign language interpreter.

Moreover, focus group discussion was held with 2 selected members from two disability associations (ENAB and ENAD) and 2 representatives from Non governmental organizations (NGOs) working on disability and HIV/AIDS in the city. These organizations include Help for Persons with Disabilities Organization (HPD-O) and Information and



Development for Persons with Disabilities Association (IDPDA). Local administrative bodies (2kebele representatives) from the sub city also participated in the discussion. Totally 6 people were participated in the discussion session of two round.

Table C: The Details of Discussants

Discussants	Sessions	Number of participants	Total number of discussants per session (6)
ENAD representative	2	1	
ENAB representative	2	1	
IDPDA representatives	2	1	
HPD-O representatives	2	1	
Kebele representatives	2	2	

The discussion was facilitated by the researcher and a volunteer observer from Ethiopian National association of the Blind (NAB). The major points of discussion held with the participants were: provision of HIV related services to PLHA in general and the inclusion of PDLHA in particular in the available services, the net work established between the disability associations and HIV related service organizations in HIV prevention and control activities and the efforts made to address HIV related problems of PDs in the city. The discussion was held in Amharic, the local language spoken by all the participants.

On the other hand, key informants' interview was held with one selected *kebele* (05) administrator, one health professional from *Shero Meda* Health Center, one religious leader from the sub city, two parents of children with disability, and a teacher from *Tsehay Chora* primary school. The in-depth interview was conducted in two ways\_ telephone and

face –to- face methods. The telephone interview method was used to interview the *kebele* administrator and health professional, where as the latter method was used to interview the religious leader and selected parents. The telephone interview lasted for half an hour in the first contact and 15 minutes for the second interview session. It took a total of 45 minutes. The telephone interview is employed because of the difficulty to contact these two interviewees. Lastly, however, it was managed to re- contact the interviewees personally in order to finalize the interview questions and recapitulate the previous telephone interview. During the face- to-face interview, the researcher took notes immediately after the interview to minimize interruptions of the interview session.

Regarding the questions designed for the key informants, the health professional was interviewed questions related to VCT services provided by the health center. On the other hand, parents and a religious leader were asked questions related to cultural stereotypes associated with PDs.

Secondary data sources were also reviewed in the study. Policy documents, especially the national HIV/AIDS policy and HIV/AIDS strategic plan of Addis Ababa were reviewed to check the inclusion of PDs in their guidelines and national planning. In addition, annual reports of some organizations working on disability and HIV/AIDS were analyzed.

### 3.4 Sampling Procedures

Table D :Summary Study subjects, tools and purpose

Study Subjects	Tools Used	Sample	Purpose
Individual PDLHAs	Semi-structured interviews	Purposive	To explore opinions and views related to services, sexual behaviors, risk factors, policy interventions
Individual PDs	Semi-structured interviews	Purposive	To explore opinions and views related to services, sexual behaviors, risk factors, policy interventions
Organizations working on HIV/AIDS	Semi-structured interviews,FGDs	Purposive	To explore opinions and views related to services, sexual behaviors, risk factors, policy interventions
Organizations working on PDs and HIV/AIDS	Semi-structured interviews, FGDs, key informants interview	Purposive	To explore opinions and views related to services, sexual behaviors, risk factors, policy interventions
PDs associations	Semi-structured interviews, FGDs, key informants interview	Purposive	To explore opinions and views related to services, sexual behaviors, risk factors, policy interventions

The study employed a purposive sampling for the selection of both individual PDLHAs providing HIV/AIDS services in Addis Ababa. Among the different disability types, the blind, the deaf and the physically disabled were selected for the purpose of this study.

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Among these groups, 12 PDLHAs were selected for the individual interview. Within the selected PDLHAs, eight were females (four women at the age category of 25-49 and four girls at the age category of 15-25). Among the females, three were blind, three were deaf and the other two were physically disabled. The remaining four were men PDLHAs out of which two were blind and one was deaf and the other one was physically disabled. In addition, six PDs out of which three male and three female, were purposively selected. The selection includes two from each of the three selected disability types.

Second, the selection of organizations working on HIV/AIDS programs and those working on disability and HIV/AIDS programs was also purposive. This was because of the limited number of social service organizations engaged in provision of services to PDs in relation to HIV/AIDS. Among the 15 organizations selected, five were local NGOs working on Disability and HIV related activities, namely HPD-O, IDPDA, Medical Missionary of Mary (MMM), Christoffel the Blind Mission (CBM) and Center for Applied Research and Development oriented services (CARDOS). The other three organizations were Addis Ababa HIV/AIDS Prevention and Control Office (AAHAPCO), *Zewditu* Hospital and *Sheromeda* health Centers. The latter two organizations were from the VCT centers in the city.

The interviewees were also selected from three disability associations (ENAB, ENAD and ENAPH) in the city. The remaining four organizations were from NGOs (Mekdim Ethiopia, , Organization for Social Service and AIDS (OSSA), Hiot HIV/AIDS Prevention and Control Service Organization (HHAPCSO) and Dawn of Hope, working on HIV/AIDS service provision for PLHAs in the city.

### **3.5 Pilot Test**

Pilot test was carried out in two selected kebeles (03 and 04) of Gullele Sub City. This was done to ensure the feasibility and clarity of some of the interview questionnaires designed for the interviewees. Based on the pilot test, some necessary modifications were made on the questions. More over, to prevent the contamination of as a result of piloting the researcher excluded the two kebeles in the actual data collection process.

### **3.6 Ethical Considerations**

As disability and HIV/AIDS are highly sensitive issues, they need to be carefully considered in any research. In this regard, official ethical clearance was secured from the school of social work. On the other hand, the researcher first introduced the purpose of the study to the interviewees. Then, the privacy and confidentiality of PDLHAs were addressed before the interview was conducted. The interviewees were informed that all the information they provide would be kept secret. Besides, the anonymity (not exposing their personal issues to others or secrecy) of the participants was maintained during and after the interview. The interview was held after oral and written consent of the participants.

### **3.7 Data Analysis**

The data from the different qualitative sources were thematically analyzed. Particularly interview results and quotes from the key informants and individual PDs and PDLHA were organized and coded for the analysis. Double translation was made for the interview results. First, the manuscript was translated into English and this was back translated into Amharic for validation. Some data sources were also tabulated for the numerical representation. Besides, the focus group discussion results were summarized. Finally, the secondary data sources were reviewed.

Though there had been subjectivity in the analysis of the qualitative data collected, great attempt was made by the researcher to minimize inevitability of the bias. For this purpose, cross checking of data from individual interviews, focus group discussion and key informants' interview was made to increase reliability of the findings.

## **Chapter Four**

### **Data Presentation, Analysis and Discussion**

Analysis of the data was divided into two major sections. The first section includes the interview results from individual persons with disabilities living with HIV/AIDS (PDLHA) and those disabled persons free of the virus (PDs). This section consists of answers to the following five sub-sections: risk factors, cultural perceptions, service related, psychosocial, sexual behavior and income level of the respondents. The second major section includes analysis and discussion of interview results from organizations working on HIV/AIDS and disability. This section focuses on analysis of answers from the respondents in relation to services and risk factors to HIV infection in disabled people.

#### **4.1 Characteristics of Respondents**

This study explores the socio-demographic characteristics of individual PDLHA and PDs. The individual interviewees were asked about their age, educational level, marital and employment status. Based on this, out of the total of 18 respondents, 14 of the respondents are at the age category between 20 and 35. Most of them fall under adult age category. Regards the sex compositions of the respondents, 11 are female and the remaining seven are male. The data collected on the educational background of the respondents shows that 14 out of 18 have primary education. Where as, only two have completed their secondary education.

The interview data also indicates the marital status of the respondents and it was found that only three of the female respondents, who are deaf, are staying with their husband. But two of the blind women respondents are widows. The remaining five women and girls with disability are unmarried so far. But they had casual sexual relationships. On the other hand,

five of male respondents are married but are divorced. Among them, the blind and physically disabled had been married to women with visual impairment and physical impairment respectively.

The data concerning the employment status of the respondents reveals that only one female respondent has been employed in one of the disability organizations, called Equal Opportunity Association (EOA). She is the manager of the association and working on advocacy and awareness raising programs in the country. She is blind and living with 'non-disabled' man as a cohabitant. All the others, 17, are engaged in informal work sectors in the sub city.

The next section presents the interview findings related to services to individual PDs and PDLHAs. It could be recalled that identifying the availability of HIV related services to PDs and PDLHA is one of the objectives this study is supposed to achieve. Based on this, therefore, 18 individuals (12 PDLHA and 6PDs) participated in the interview and the result is presented as follows.

#### **4.2 Data Presentation**

The tables below show that the different service related questions and the answers obtained from the interview questions.



Table 1: Questions addressing the access, knowledge, services, and opinions of the respondents

**Table 1.1 Access**

	Variables (Access)	Yes	No
1	<b>Getting VCT services</b>	3	15
2	<b>Taking ART services</b>	5	7
3	<b>Treatment for opportunistic infections</b>	0	15
4	<b>materials in accessible format for PDs (the deaf &amp;the blind)?</b>	2	4

**Table 1.2 Knowledge**

	Variable	Yes	No
1	<b>Do you have any knowledge about HIV/AIDS before you contracted the virus?</b>	18	0

**Table 1.3 Services**

	Variable	Yes	No
1	<b>Do HIV/AIDS Outreach campaigns services reach you (mobile campaigns)?</b>	2	16
2	<b>Do you get legal protection for your sexual abuse?(police and court support)</b>	1	17

**Table 1.4 Opinions**

	Variable	Yes	No
1	<b>Do you think the available health care facilities are physically accessible to you?</b>	0	4
2	<b>Do you think the government provides equitable and fair services for PDLHA?</b>	2	16

In the first question regarding VCT service, both PDs and PDLHA were asked for the response. The interview result indicates that 15 out of 18 respondents replied that they have no opportunity of getting voluntary counseling and testing (VCT) service. Only three of the

respondents are beneficiaries of the service. It appears to be a problem for most of the disabled persons to get such service in health service centers. One of the deaf respondents from the PDLHA group underlined VCT related problems of PDs as follows:

Though I know that voluntary counseling and testing is available in the nearby Shiromeda health Center I could not go to the center due to the fear that as a deaf person I am expected to have a sign language interpreter to get the counseling service. I could not tell directly to the health professional but through an interpreter that I could get the service. If I try to get the counseling in this way, then it is obvious that I will be further isolate myself from my friends and relatives. I could have benefited from the service if the counselor is able to understand me directly through sign language.

It could be recognized that both PDs and PDLHA have practical challenges with regard to HIV testing and counseling in different centers. As it was indicated in the quote, deaf people are in a serious problem getting the service. For one thing, the deaf are missing their confidentiality and trust on other people. The sensitivity of the disease itself needs respect for privacy. If these people are identified as HIV positive, it seems that it worsens their social and economic value as disabled. They are already victims of social isolation due to their disability. Thus, revealing their sero- status adds fuel to their further discrimination.

Moreover, the physically disabled ones can not reach the VCT center because of their disability. Those who are supposed to use wheel chair can not afford it easily. This seems to escalate the problem of getting VCT service accordingly like the non-disabled people in the sub-city. Above all, the respondents complain that there is only one government VCT center in the sub-city and some of them are not able to get the service because the health center is crowded by a number of non-disabled persons who need similar service.

The interviewees (PDLHAs) were also asked about if they use antiretroviral treatment (ART) since their infection. The data indicates that 7 of the respondents are not using ART service. Where as 5 of the respondents seem to be users of the service. The data

shows variation in the number of the users of ART and most of the respondents are not taking drug. However, some of the users of the drug said that they have stopped taking the drug due to lack of proper feeding habit prescribed by the physician. In this regard, one of the blind respondents with the virus reflected her view as follows:

Since I came to know that I am infected with HIV virus, I decide to take the drug. I used to take it for some time but I could not take it according to the prescribed time. At the same time I can not afford to have a good meal at daily basis. I was told by the physician to have enough food per day. But I can not help myself in that and quit taking the drug. I then stopped meeting the physician.

It could be realized from the responses that PDLHAs could not afford what they are required to do while taking the drug. Though they seem to have knowledge on the importance ART drug, its application became difficult for them as disabled. For one thing they could not afford the meals they are required to have every time. On the other hand, it seems that they do not have enough knowledge on how and when to use the drug. Thus it might be related to their poor income level, which affects their access to ART service. This is because taking the drug is correlated with taking sufficient meals and appropriate use of the drug.

The interviewees were also posed a question on the availability of treatment for opportunistic infections (like tuberculosis), which may increase the probability of getting HIV virus. The result shows that 18 of the respondents did not have any treatment on the infections so far. Some respondents seem to acknowledge that they know the impact of the opportunistic diseases on HIV infection. But they complain about lack of money to get such treatments. It may imply that these people are not familiar with treatment to other risky diseases which could lead to HIV infection.

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In response to access to HIV information in accessible format, 6 of the respondents (the blind and the deaf interviewees) said that they hardly get materials in accessible format. The blind could not easily access the materials like Braille and audiocassettes. Like wise, the deaf have no access to sign language interpretation programs. The deaf acknowledge that there is sign language program in Ethiopian television. But they found it difficult to attend simply because most of them do not have television service at their home. Though there are TV services in the public recreational centers in local kebeles, the sign language programs are not tolerated for long time and changed by other channels based on the interest of the non-disabled attendees.

On the other hand, two of the blind respondents replied that they had got two Braille formatted in HIV related information including its transmission, prevention and protection methods. They got it from their friends who have been served by the Mary Medical Missionary (MMM), a non-governmental organization (NGO) operating in Arada sub-city. The two blind respondents added that they have got a lot of HIV information and they decided to protect themselves from the infection since then.

One may understand from the above responses that the deaf and the blind are facing difficulties in getting HIV information at least in an appropriate format. A significant number of blind people and deaf people have very limited options for overwhelmingly increasing information materials related to HIV for those people who are able to see and hear. They have special needs with regards to HIV information.

Though it might be understood publicly that the blind and the deaf require communicating through these specially designed materials, it is not recognized by service sectors. Thus, if these people are not getting access to such formatted materials, it is likely

they may not have enough information about the virus. Let alone absence of information on HIV, even those non-disabled people are suffering seriously by the virus despite the recently booming information materials on HIV/AIDS. This shows that PDs like the blind and the deaf, in this case, are denied access to sufficient information on HIV which contributes for their exposure to the infection.

The research suggests that HIV/AIDS related need of PDs have not yet been clearly identified and thus no special programs are designed to help them.

Next, both the PDs and PDLHAs were asked question on their perception towards vulnerability of disabled persons to HIV infection in comparison to the non-disabled people. Among the respondents, nine replied that they do not have any idea about whether they are at high risk of getting HIV infection. However, seven of the respondents acknowledged that they are at greater risk of contracting the virus.

According to these respondents, two main points were given as reasons for their response. On one hand, they do not have information on the over all nature of the disease. On the other hand, they could not be beneficiaries of the available materials due to their illiteracy. These might put them at high risk to contract the virus in comparison to the non-disabled persons. However, the remaining two of the respondents did not give any comment on the question.

In relation to knowledge basis, the respondents were asked about their level of knowledge before they are infected with virus. It appears that all of the respondents have heard about the disease. But they regret that they do not have detail knowledge on the transmission and protection mechanisms to the virus. As it requires care before and after the infection, it is found difficult to know what necessary measures to protect and to care for one

self after infection. The result also shows that the respondents do not have any idea about the difference between HIV and AIDS.

Data was also obtained from questions posed to PDLHAs on whether their sero-positive status is known by service organizations in the sub-city. The result indicates that nine of the respondents' reacted that their HIV status is not known by service organizations. Only three of the respondents reported their sero-positive status to service organizations.

The result shows information gap between the PDLHAs and HIV service organizations in the sub-city. Unless PDLHAs inform their status to get the relevant services, it might be challenging to reach them easily. However, they fear that the service organizations are the same with the non-disabled persons and this could affect their participation. They worry that if they are identified by the non-disabled as HIV positive it fuels further discrimination with the already prevailing stigma and discrimination due to disability. In any case, the result shows that both parties, PDLHA and the service organizations, could have role to alleviate this service gap. Although both may be responsible to create link between the services and needs, PDLHA are missing the services intended to be used by all victims of the virus including non-disabled people. This service gap may worsen their quality of life and further deteriorates their attitude towards HIV/AIDS.

Like wise, question addressing the intervention of the government in provision of services related to HIV/AIDS was presented to the interviewees. Regards this, 16 of the respondents did not get direct services from the government. There is no special service provision for them as disabled. The following story was recalled from one of the blind respondents during the interview:

## Vulnerability of persons with Disabilities...

I heard that there are a lot of media campaigns particularly through radio, television and printed materials like posters. On one hand, I can not afford radio and television to listen to the information. On the other hand, I can not see the visually based information in the television. So, I can not deny that the government has made effort on disseminating HIV information. But the disabled like me use none of the information.

The result clearly depicts that the government has put in much effort in promoting awareness on the people by using various methods of information materials. Nevertheless, these materials are not disabled people friendly. They fail to consider PDs and PDLHA. On the other hand, a contextual factor like poverty further impedes PDs from getting the information sources. These people may not afford the costs of transportation, visual and reading materials like television and magazines and brochures respectively.

But they recognize that some of them have been visiting the service sectors in the nearby government organizations. It was mentioned that two of the respondents have made contact with Gullele Sub-city HIV/AIDS prevention and control office. But they could not access information designed to their needs. They simply take part in service provision programs designed for all people in general. However, the deaf and physically disabled people in the sub-city are still non beneficiaries of such services due to their disability. The physically handicapped are unable to reach the office to get reference because of lack of help from the non-disabled for long distance and inaccessibility of wheel chairs and other appliances. The deaf on the other hand, could not communicate effectively with people without sign language interpreters to get the service.

The data shows that government has no special program in relation to HIV service provision to PDs. They are given services together with the non-disabled people alike. It could indicate that the special needs of PDs are not yet recognized by the government HIV service sectors.

## Vulnerability of persons with Disabilities...

Subsequently, the physically handicapped members of PDS and PDLHA were asked for the accessibility of health facilities in the sub-city. All of the respondents said that both the buildings and the distance from the place of resident are inaccessible to them. It seems that there are no as such buildings designed considering disabled people even in the whole sub cities. No building in the country found to be disabled people friendly. Almost all building constructions target the needs of non-disabled people.

The next important question addressed to all the respondents was aimed to answer whether HIV outreach campaign programs are reaching PDs and PDLHA. In response, 16 of the respondents replied that they have never been part of the outreach program. They pointed out that the program is completely designed to non-disabled people. Most of the outreach programs have been conducted through drama, music, and literature and through distribution of posters and brochures. But the drama and music do not give sense to the deaf if they have attended. On the other hand, information through the reading materials like brochures and posters can not be accessed by the blind. This indicates that whether disabled people attended these out reach programs or not it does not bring difference unless the campaign incorporated the special needs of the blind, the deaf and physically disabled.

Lastly, all the respondents were asked a question related to legal services provided for them at the time of sexual abuses. The data indicates that 17 of the respondents have no legal service in general. They added that even though they want the abuse cases to be reported they can not afford the process of the court and they often fail to get support from the non-disabled because they also fear that the perpetrator may harm them. The remaining one of the respondents had once got police intervention when she was forcefully raped in her teens. That was the moment when the perpetrator no longer escapes from the police control.



## Vulnerability of persons with Disabilities...

The interview results appear to be sad for the disabled people who are unable to get appropriate legal provision. It shows that these people are not in a position to get legal protection as victims of sexual abuse. The problem is also correlated with social and economic consequences. Shortage of income may hamper their capacity to report the case. On the other hand, the report and follow up of the case could result in further discrimination from the non-disabled people in the community. It is, therefore, more likely that PDs could easily be exposed to persistent sexual abuse and this may increase their infection.

Table 2 : Access to information, service providing organization, and the use of ART

### Service

	Variables	No of respondents	
1	<b>Ggetting HIV information?</b>		
	<i>Television</i>	-	
	<i>Pictures</i>	5	
	<i>Brochures</i>	-	
	<i>Others</i>	13	
2	<b>Organization providing HIV related services?</b>		
	<i>Addis Ababa HAPCO</i>	-	
	<i>Federal HAPCO</i>	-	
	<i>Disability Associations</i>	4	
	<i>PLHA Associations</i>	6	
	<i>Others</i>	8	
3	<b>Use of ART service,</b>		
	<i>Government organizations</i>	3	
	<i>NGOs</i>	-	
	<i>Voluntary Associations</i>	-	
	<i>Others</i>	-	
4	<b>ART services?</b>		
	<i>Free of charge</i>	3	
	<i>Pay for it</i>	-	

The above table indicates the questions and responses related to services particularly HIV information sources, and the providers of such services to the PDLHAs. The data obtained from the questions show that 13 of the respondents for the first question said that they get most of HIV information through their family members. The family often participates in community discussion on HIV/AIDS. However, it is not uncommon that the family is not willing to talk about sexuality issues at home. It depends on the level of education of the family members. It was reflected in the interview that the family with low education seems to hide such sexuality information from the disabled sons and daughters. This is because they are hardly considered as victims of the disease.

However, out of six physically handicapped persons, two of the respondents have got opportunity to get little information from pictures and HIV related posters on the notice boards and health centers in the nearby. But the remaining four of the participants do not have any way participation to get the information. It was pointed out by the respondents that mobility is a difficult matter for them to read and see the posters wherever they are located and at the same time they can not attend community meeting on reproductive health issues.

From the above results, it is possible to infer that disabled persons' opportunity to get HIV related information is highly determined by the nature of their disability, their family and accessibility of information materials. For instance, disability related to mobility may be challenged by physical accessibility of the information centers and distances from the users.

In addition to this, lack of prosthetic and orthotic appliances often inhibits accessing information from the service areas. Regarding the family related problems, education plays a key role in changing the attitude of the family members towards disabled

sons and daughters. On the other hand, lack of participation in community gatherings further relegates the disabled from getting information. In this regard, both PDs and PDLHA are missing such communication potential to alleviate problems related to information access.

It is the next question posed to the interviewees on the organization, which is actively involved in the provision of HIV services to PDs and PDLHA. The data shows that six of the respondents get services from associations of PLHA at different parts of the city. Especially they have been taking part in one of the associations in the sub city. Through this association, they are able to get little support from the concerned governmental and non-governmental organizations. However, the association currently changed its office from the sub city and they could not reach it as usual.

On the other hand, four of the respondents reacted that they some times get services like counseling by task forces organized by Ethiopian National Association of the Blind (ENAB).

But eight of the respondents are totally non-beneficiaries of any service available in the city. They could not get any reference to service organizations and associations simply because they are not registered or known by those service sectors. Even they do not know where these organizations are placed in the city.

Antiretroviral therapy (ART) is one of the services provided for people living with HIV. In this regard, PDLHAs were asked about the organization involved in such services. Thus, only three of the respondents started using ART drug but they stopped after a while. They had also been getting the drug free of charge. But recently, none of them are users of the drug. This is because they could not get enough nutrition at the right time. Health professionals told them that the drug has side effect if the user does not have access to

appropriate nutritional support. In a situation where they could not offer daily food, it is challenging for PDLHAs to think about balanced nutrition required while they are using the drug. Therefore, factors related to low income had a profound effect on the PDLHAs in the use of ART.

Table 3: Respondents' Sexual Behavior

	Varibales	No of respondents	
1	<b>How do you come to practice sexual intercourse?</b>		
	<i>Peer pressure</i>	-	
	<i>Own interest</i>	-	
	<i>Rape</i>	8	
	<i>Other (poor income,)</i>	10	
2	<b>What kind of person is your sexual partner?</b>		
	<i>PDs</i>	-	
	<i>'Non-disabled' person</i>	10	
	<i>Person with the same kind of disability like you</i>	8	
	<i>No sexual partner</i>	-	
3	<b>How often have you discussed about HIV with your partner?</b>		
	<i>Regularly</i>	-	
	<i>Occasionally</i>	-	
	<i>Not at all</i>	12	

In relation to the sexual behavior of the respondents, both the PDs and PDLHAs were participated in the interview. Based on the responses given, eight of the respondents had been victims of rape both by persons with disabilities and the non-disabled people. Mostly, however, they were raped by the non-disabled persons in their locality. The rape victims reacted that they can not protect themselves due to their disability. Especially, the blind complain that they are unable to identify their perpetrators. On the other hand, the physically disabled respondents desperately explain that their physical limitation to protect themselves exposes them to unwanted sexual practice.

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The above finding indicates that the sexual life or behavior of PDs is very risky in exposing them to HIV infection. On one hand, the rape practice by the perpetrators highly increases their infection rate to the virus. They have no knowledge about who actually raped them. It could be persons with HIV, who might wish to cleanse their sero- status. On the other hand, some PDs like the physically disabled fail to protect them selves from their perpetrators, thus, are easily become victims of the sexual abuse.

On the other hand, 10 of the respondents associated their sexual behavior to their low level of income. In this regard, ten of the respondents (the blind and the deaf girls) involved in sexual practice to get financial source. They reflect that they do not have permanent partner but they opt to have sexual relation with the non-disabled who could pay them some amount of money. However, this financial source is highly dependent on the will of their partner.

The result depicts that the income poverty has influenced the sexual choice of PDs particularly the young ones. Since their primary intention is supporting their daily subsistent life, they do not give attention to the risk of contracting HIV. This ignorance may escalate the likelihood of infection by the virus.

It is also important to know the sexual partner of PDs to identify their sexual behavior. The respondents have varying responses in this regard. Among the respondents, 10 replied that they have occasional partnership with the non-disabled persons. According to the respondents, it is the non-disabled who are often engaged in sexual relation with them. Though they are not consistent sexual partners, they are the ones who some times pay for them. Likewise, it is the non-disabled, who are engaged in raping the PDs.

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On the other hand, eight of the respondents have had sexual partner with persons with the same kind of disability. It was reflected that they do this because they often have social interaction within PDs and they have little chance to contact the non-disabled. Besides, they can maintain good relationship with those with the same kind of persons with disabilities. Nevertheless, they do not opt for PDs for sexual partner due to the disability and failure to get financial and other related support from the PDs. The need to help their daily subsistence limits their choice of making sexual partner.

It is evident from the above finding that PDs choice of sexual partner is associated with their need to get their daily subsistence. Sexual relationship is not just for reflection of actual sexual behavior but to fulfill their basic needs through financial resource. This indicates that failure to have a consistent sexual partner may lead to unsafe sex and thus expose them to HIV infection. In addition, PDs consider the sexual practice as source of income and this makes them to have sexual relation with some body whom they do not have any information about his or her sexual experience. This further escalates their infection rate.

Similarly, both PDs and PDLHAs were asked about their practice of discussing HIV related issues with their partner. The response indicates that 12 of the respondents have not had any discussion about HIV with their partners. They explain their fear that the discussion about HIV may lead to the idea of getting VCT and this could further reveals their HIV status to the non-disabled people. Particularly, the blind and the deaf are much worried about the confidentiality of the information during the VCT service in health centers. Thus, they opt not to talk about HIV and prefer continuing their sexual relationship with their partner without knowing their sero-status.

The finding might have indication that both PDs and PDLHAs have knowledge about HIV but the poverty related issues like absence of income for their daily life urges them to have sexual relation with people they do not know about their sero-status. Since the discussion on HIV is believed to reveal their HIV status to others, it is not encouraged among PDs and PDLHAs. Thus, they opt for silence about HIV. This ignorance may accelerate their level of infection with the virus. This is because they have no prior knowledge about their status and their partners' HIV status.

Table 4: Social Perception (PDLHAs)

	Variables	No of respondents(N=12)	
1	What is your family's perception towards your contract of HIV?		
	Negative	8	
	Positive	3	
	do not know	1	
2	What reaction do you observe from your peers and relatives?		
	Cooperative	4	
	stigmatizing	8	
	Others specify	-	

The data obtained from questions addressing the perception of people on PDLHAs presented as follows: It is evident from the data that eight of the respondents reacted that their families have negative attitude towards them. They complain that their infection fuels further relegation and marginalization from their family. Before their infection, they do not have any roles and responsibilities at home. They do not have active participation in the family discussions on common issues at home. This poor status is deteriorated after their status of HIV is identified by their family members. On the other hand, three of the respondents said that their families have positive attitude towards them. According to these respondents, their families are educated and they have been given roles and responsibilities to

play active role in their family matters. Though they are living with the virus, the health professionals and counselors in the sub city have given them HIV care and support, and counseling services. They are also regular users of ART drug.

The finding indicates that their families of PDs negatively perceive PDLHAs. In addition to their disability, their HIV status exposes them to further relegation by their family members. Such attitude towards PDLHAs discourages them not to reveal their sero-status in their family. It could be evaluated that if PDLHAs get positive attitude from their families they may take responsibility to further protect themselves and others. However, if this condition is reversed, it increases the probability that the PDLHAs could transmit the virus to both PDs and non-disabled people.

Apart from their families, PDLHAs also face some difficulties with their peers and relatives. The data in the above table indicates that eight of the respondents are found to be stigmatized by their peers and relatives. On the other hand, four of the respondents have got cooperative relationship with their peers and relatives.

This result implies that PDLHAs are not in a position to interact with their social environment and this may contribute in limiting their access to information related to HIV. If these people are denied access to information from their close families and relatives, it is not difficult to estimate that they have little opportunity to get enough information on the risk of HIV. Lack of relevant information, on the other hand, inhibits the knowledge about the virus and thereby increases the risk of disseminating the virus.

The next important section of the interview was administered for organizations and associations engaged in the provision of HIV related services for persons with disabilities living with HIV/AIDS and those PDs free of the virus in the sub-city. According to the data,



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among 15 organizations working on HIV related services in the city, only five organizations namely, Help for Persons with Disabilities Organization (HPD-O), Information Development for Persons with Disabilities Associations (IDPDA), Medical Missionary of Mary (MMM), Center for Applied Research Oriented Services (CARDOS) and Equal Opportunity Association (EOA) are directly involved in the provision of HIV relevant services for both PDs and PDLHAs in Gullelle the sub city and other sub cities.

Table 5A: Interview Results from Organizations and services provided

No	Variables	Number of Respondents	
1	Types of services are provided by your org.		
	Legal protection for the victims	-	
	Educational support	5	
	Nutritional assistance	1	
	Others specify( psychosocial, loans, medical, nursing, referral , research care &support,)	5	
2	Disability group served in the organization		
	The blind	-	
	The deaf	-	
	Physically disabled	-	
	All of the above disability groups	-	
	All disability groups	5	
3	Teaching of PDs about HIV		
	HIV information	4	
	Drug usage	4	
	Condom use	4	
	Safer sex	4	
	Others specify	-	
4	Home based services provided by the organization		
	counseling	4	
	nutritional	1	
	psychosocial	4	
	medical	2	
	Others(advocacy, awareness,)	3	
5	Getting ART service?		
	Free of charge	2	
	For payment	-	

Table5B: Organizational interview results ( YES or NO Questions)

No	Variables	Yes	No
1	Disability specific service provider?	5	
2	Provision of ART service for PDLHA?	2	3
3	Availability of policies & programs to include PDLH?	4	1
4	Provision home-based care & support service for PDLHA?	2	3

The interview result from the organizations shows that all of them are involved in the provision of educational support for both PDs and PDLHAs. The educational services include behavioral change communication (BCC), information communication change (ICC), and awareness raising. The organizations also provide educational materials such as Braille scripts which incorporate awareness raising information, pictorial teaching and VCT information.

In addition to the educational support, some organizations particularly IDPDA, HPD-O, EOA, and MMM have been giving psychosocial support for both PDs and PDLHAs. This support has been carried out through home-based counseling by the volunteer counselors in the locality. On the other hand, MMM as social service organization has been actively involved in providing medical and nursing care and referral services for PDLHAs in particular. This is the only organization providing nutritional support for both PDs and PDLHAs, who can not earn independent living.

Some organizations, however, are involved in indirect services like research activities in the area of disability and HIV/AIDS. Although, there has not been a full-fledged research done so far, assessment reports have been carried out to identify the statistics and problems of PDs in general. In relation to this, CARDOS and IDPDA have been disseminating relevant

assessment reports to organizations and associations working on HIV/AIDS in the city. In this regard, CARDOS is actively engaged in research related tasks in Addis Ababa in general and in Gullele sub-city in particular. This organization specially provides advocacy and awareness raising service for PDs and PDLHAs through drama and sign language for the deaf.

However, none of the above organizations are involved in legal provision for PDs and PDLHAs, who are victims of rape and sexual abuses by the non-disabled people. This often creates challenge for victimized PDs. This problem could be evaluated in two directions. On one hand, PDs who are victims of sexual abuses may not report the abuse cases due to security related reasons and ignorance of the service. If the cases are reported, it could expose them to further physical and verbal abuses by their perpetrators. On the other hand, there might be absence of appropriate legal provision for victimized PDs in particular.

All the above organizations are involved in giving the aforementioned services for all disability groups in Gullele sub city and other sub cities. The organizations are also involved in teaching condom use, HIV information (prevention and protection mechanisms), how to use drug effectively, and safer sex methods to PDs and PDLHAs.

Particularly, however, MMMM and HPD-O have been giving home based care and support for PDLHAs incorporated in their programme. In addition to these, these organizations facilitate network for PDLHAs to get ART services free of charge.

More over, organizations such as MMM, HPD-O, CARDOS and IDPDA have special programmes addressing HIV related problems of PDs and PDLHAs. Particularly, IDPDA play a partnership role in coordinating donor organizations with disability specific organizations and associations in Addis Ababa.

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It is evident from the findings that very few organizations are engaged in provision of HIV related services for PDs and PDLHAs in the sub-city. These organizations are not only operating in Gullele sub-city but also in other adjacent sub cities. However, even the services under provision are dependent on the good will of donor organizations. According to the representatives of the interviewed organizations, most donor organizations are not willing to give fund for disability organizations for the reason that they give priority for development projects and prevention oriented HIV/AIDS programmes. They are not much interested in provision of nutritional and medical services.

On the other hand, the donor organizations often refer to the absence of PDs in particular in national HIV/AIDS policy. They argue that they provide financial support for programmes already included in the government policies. There fore, absence of PDs in National HIV/AIDS policies has negative impact on getting appropriate fund for HIV programmes for PDs.

More over, absence of statistics of PDs and PDLHAs in Addis Ababa and in Gullele sub-city in particular inhibits the effort of the above service organizations.

In general terms, however, though the efforts made by the above organizations are encouraging to alleviate the risks of PDs to HIV, their dependence on donor institutions makes the over all attempt fragile. If there is no continuity for such services, it is still challenge for PDs to be protected from HIV risks. On the other hand, services provided by the above organizations could not be taken for granted to high number of PDs population in the sub city.

Table 5C: Problems Related to Services

	<b>Variables</b>	<b>No of respondents (N=5)</b>	
1	What troubles do you think PDs encounter to get VCT service?		
	Inaccessible VCT centers	5	
	Lack of sign language interpreters for the deaf	5	
	Lack of confidentiality from the centers	5	
	Other reason, specify ( absence of formatted materials)	3	
2	Who often refers to your organization to help PDLHA in HIV services?		
	Local government bodies	-	
	Local voluntary agencies	2	
	Disability associations	2	
	Traditional associations (edirs, equibs, etc.)	-	
	Others specify( self reported)	1	

Table 5C depicts that the major problems PDs encountered in relation to VCT service. According to the data, all the five service organizations' representatives gave similar response that PDs do not access VCT center. Besides, they do not have trained sign language interpreters and this spoils confidentiality of the information communicated with the concerned health professional or counselor. However, three of the respondents commented that PDs could not access appropriately formatted materials such as, Braille and visual materials to know about the importance of the VCT service.

Representatives of the organizations also reacted on the referral service. The data shows that four of the representatives responded that it is the local voluntary and disability associations that are actively participated in the referral service to PDs and PDLHAs in the sub city. Only one of the respondents explained that PDs use self-referral to inform their HIV related service needs to the organizations.

Table 6: Income Related Questions (for both PDs &PDLHAs)

	Variables	No of respondents(N=18)	
1	<b>What support do you need to overcome the problem of HIV/AIDS?</b>		
	Medication(ART)	18	-
	Educational(training)	18	-
	nutritional	18	-
	financial	18	-
	Others specify( regular income )	18	-
2	<b>How do you earn your income?</b>		
	Office work(employment)	3	
	Small business(income generating activities)	2	
	Informal work	2	
	Assistance from others(friends, family, organizational)	6	
	No income at all	5	
3	<b>What alternatives do you use for your regular income?</b>		
	Family support	-	
	Community support	3	
	Direct financial support from NGOs,GOs	3	
	Financial support to generate their own income	11	

As mentioned in the literature section of this paper, income level poverty is also found to be a factor that inhibits PDs and PDLHAs from accessing HIV related educational materials. Besides, it contributes in exposing them to unsafe sexual practice. Based on this background, the data in table 6 shows that all of the respondents need medical, nutritional and educational support to protect themselves from the infection. More over, they require consistent and regular financial income.

The data also indicates that six out of the total 18 respondents replied that they are dependent on their friends and relatives for their income. On the other hand, five of the respondents do not have any income at all. Only three of them are engaged in office work.

The remaining four are involved in informal work sectors like petty trade and small business activities in their locality.

The respondents also reflected on the possible alternatives that could enable them to support themselves financially. According to their response, 11 out of 18 respondents prefer financial support from concerned organizations to generate their own income. They seem to opt for helping themselves by their own effort so that they are no more dependent on their families, relatives and friends in the future. They commented that this could help them to access HIV related educational materials and to protect themselves from unsafe sexual practices which they used to experience for income.

#### **4.2.1 Focus Group Discussion Results**

##### **4.2.1.1 Discussion on Services**

Participants of focus group discussion were interviewed for the services they provide for PDs and PDLHAs. All the discussants commented that they do not have as such dependable service packages for the disabled people. They have never developed HIV programmes for the disabled. However, some of the participants revealed that they have some initiatives to help the disabled in HIV related services. Particularly two organizations namely, HPD-O and IDPDA are active participants in the service provision. Both organizations have significant role in involving PDs and PDLHAs in HIV related services. However, the services are very occasional and thus few beneficiaries are participating in the programme. Although ENAB and ENAD are involved in rehabilitation services, the services packages exclude HIV related services. But ENAB has recently established a task force which might organize the blind to get HIV related services from relevant disability organizations.

However, although the efforts made by the two organizations are encouraging they can not address all the PDs and PDLHAs in the sub city. This is because they are giving service for PDs in other sub cities too. This creates resource competition and the services in Gullele sub city could be insignificant.

#### **4.2.1.2 Networking**

It was also underlined that the availability of network among the disability associations and organizations is insignificant. However, IDPDA is the only disability organization engaged in networking disability organizations and associations with HIV services organizations in Addis Ababa. It shows gap in the network activities to alleviate HIV related problems of PDs and PDLHAs.

#### **4.2.2 Key Informants' Interview Results**

On top of these, the key informants namely, a health professional, a religious leader and parents of PDs v HIV. According to the informants' views, PDs do not have regular social interaction and they are not susceptible to unsafe sexual practice with other people. Generally, the informants commented that HIV related problems of PDs are not often taken seriously by the local people.

On the other hand, a health professional from *Sheromeda* health Center in Gullele Sub city reacted that though she was trained sign language to give counseling service for the deaf she could not get the deaf who are willing to get the service. In addition, there is no clear statistics showing the number of PDs who have been given VCT service in the health center.



#### **4.2.3 Review of Secondary Documents**

In this regard, HIV/AIDS strategic plan of Addis Ababa has been assessed in order to check the inclusion of PDs. Both the strategic plans of 2004-2009 and National HIV/AIDS policy of 2006/07 were reviewed to know the available services for PDs in relation to HIV/AIDS. More over, the National Programme of Action for Rehabilitation of Persons with Disabilities developed by Ministry of Labor and Social Affairs (MOLSA) was assessed for inclusion of HIV related service provision. It was found from both the policy and strategic plan documents that they fail to include PDs in their programmes. This absence in the national policy could negatively affect the inclusion of PDs in HIV/AIDS programmes of social service organizations in the sub city. This complicates the situation when the donors refer to the presence of the beneficiaries in the existing national HIV/AIDS policy to help PDs.

More over, disability related programmes run by MOLSA have no mention on HIV services to PDs. This programme particularly focused on rehabilitation services such as, vocational skills development and marketable skills training for the disabled in general.

#### **4.2.4 Organizational Interview**

As part of the data source, five social service organizations namely, OSSA, HHAPSCO, HHAPSCO, Mekdim Ethiopia and Dawn of Hope, working on HIV related programmes were interviewed for special attempt made to provide services to PDs and PDLHAs. According to the response of the representatives of the organizations, their organizations provide HIV related services (nutritional, ART, psychosocial, BCC, ICC) to all segments of society who are reported to be infected with the virus and those bed ridden patients of AIDS. They are also involved in outreach campaigns to teach the community

about the transmission and prevention mechanisms of the Virus. But all these services are not specially designed for the disabled people in particular. In other words, the special needs of PDs are not considered in the services provided by the organizations.

#### 4.2.5 Risk Related Factors

In response to their experience on social interaction, both PDs and PDLHAs reacted that they have limited communication with the non-disabled population. They prefer dual communication with persons with the same kind of disability. This is because the non-disabled do not often tolerate to spend time communicating with them. Worst, sex related issues have not been point of discussion between the non-disabled and the disabled. They are encouraged to talk about their sexual behaviours in front of the non-disabled peers.

With regard to question addressed to PDs and PDLHAs in relation to their families' control, they replied that their family prefers to restrict them at home rather than moving out like the non-disabled people. According to the respondents view, their families are not willing to give them responsibility at home. They are often ordered by the non-disabled members of their family.

This could limit PDs exposure to HIV related education, conferences and participation in the community. Even if they are victims of the virus, they may not be reported to service sectors in the locality. This inevitably escalates their vulnerability to secondary infection.

The respondents were also asked for the influence of their income level poverty to their sexual behaviour. They explained that their low level household income limits their choice of safe sex. Especially the young female PDs (the blind and the deaf) opt for sexual intercourse to get money for their survival. Simultaneously, it is their sexual partners who make decision

either to use condom or not. Thus, use of condom is not a big deal but the only thing essential at the time is getting paid for the sexual practice. This could increase PDs probability of getting infected with the virus.

On the other hand, women with disability responded that they aspire to have children from the non-disabled men and they can not be sure of HIV status of the men. They rather rush towards sex to have child. They prefer it because they want to be like the non-disabled mothers who have their own children to be assisted. Here, the purpose is only to have child and the issue of sexually transmitted diseases is underestimated. This unsafe sexual practice could increase the likelihood of contracting HIV.

In connection with the challenges to PDs to access HIV/AIDS messages, care and support services, the respondents admitted that their low literacy intimidated their understanding of the messages. They added that the inaccessibility of messages for the blind and the deaf (Braille and sign language skills), and the inaccessibility of health service facilities for the physically disabled persons further complicate access to HIV related messages. Above all, the failure of HIV prevention and control services to include disabled persons in their programme makes the situation worst.

This information gap highly contributes for the vulnerability of PDs to HIV infection. It is likely that the spread of the virus escalates with increasing availability of information for the non-disabled people. In this regard, complete absence of information for PDs worsens the spread of the virus among the disabled.

### **4.3 Research Findings and Discussion**

This section of the paper presents findings and discussion. Based on the above data analysis, the major findings and its discussion of the study are as follows:

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It is evident from the data presented above that a number of factors contribute for vulnerability of PDs to HIV infection. One of the most dominant reasons is related to lack of access to information. In this regard, HIV related materials are not in an accessible format for PDs. For instance, there are no sufficient Braille materials for the blind which could help them to access the information easily.

In terms of the availability of HIV information in accessible format, a report by the South African National AIDs Council in 2002 depicts that the prevailing disability related stereotypes often undermine the campaign programmes to exclude PDs in the HIV/AIDS message. The Peoples' perception shows that disabled persons have poor sexual relation with other people and thus are less likely to be victims of the virus. This prejudice makes the inclusion of PDs in any HIV related message campaigns challenging. In addition to this, the information often does not consider the different disability groups. AIDS educators are not trained to be sign language interpreters.

More over, the materials like Braille are not considered and distributed to the blind during the campaign. This indicates the huge gap in access to HIV information for PDs in accessible format. This results in PDs susceptibility to HIV infection only because they do not have appropriate information on how to use condom, how to get counselling services and how to get HIV related care and support from HIV related service organizations in the sub city.

Like wise, the deaf can not access trained or professional sign language interpreters for HIV information. On the other hand, the physically handicapped often fail to reach the information centres in the sub city. Besides, their physical limitation inhibits them to access relevant HIV services in the sub city. As a result, the physically disabled may not have

sufficient HIV information and services. This gap inevitably escalates their exposure to the virus.

More over, the issue of confidentiality at the VCT centres fuels the problem. It is found that both the deaf and the blind are much worried about the confidentiality of their private information during counselling session. Further more, shortage of VCT centres in the sub city has its own impediment for PDs to access the service.

In relation to VCT related problems, a study on HIV counseling and testing for disabled people in Rwanda and Uganda supports that it is often difficult for the deaf to carry out effective communication with the third party, an interpreter. They are inhibited by the communication between the counselor and the interpreter. At the same time, they may not deliver exact message required of them to the counselor. Moreover, the deaf in particular may not get positive attitude from the counseling professionals. In other wards, in most cases the counseling professionals may not get training on sign language and thus the problem prevails for a long time (Yousafzi, & Edwards (2004).

The finding shows that the deaf people in particular are not in a position to access VCT service due to the aforementioned factors. In other wards, if these people do not know their HIV status, they might hide themselves and continue making unsafe sex even with the people who are with the virus. This may increase the probability to contract the virus due to ignorance of their status. If they came to know their status as positive, they could contribute in preventing the transmission of the virus to others and protect themselves in the future. On the other hand, if they are found HIV negative they could have revealed their infection to the care and support service sectors in the society. This is possible through provision of VCT

center, where the professional counselors are trained in sign language in particular and general awareness on the special needs of PDs and PDLHAs.

As indicated in literature section of the paper, legal provision is one of the important services for the disabled who experience sexual abuse due to their physical limitation. The finding shows that none of the organizations are involved in the referral service to the legal bodies. No such practice has been observed by both disability and general HIV service organizations. In this regard, both PDs and PDLHAs are victims of stigma and discrimination related to HIV/AIDs. In addition, PDs who are suffering from sexual abuse due to their inability to protect themselves as result of their physical limitation often fail to get legal protection from the police and the court. Even the attempt made by the disabled to report the abuse cases could be further risky for their security.

In connection to the legal service to the disabled, who are suffering from HIV related stigma and discrimination, Choruma (2006) argues that it is essential for the disabled to get appropriate protection from the police and court whenever they are victims of the perceived discrimination and sexual abuse. It is their right to access such provision. But this right to access the service is often inhibited by perception of the police and the court that the disabled are considered as subordinate in social relations and are less likely to be exposed to sexual abuse. On the other hand, the disabled often fail to know their right to have legal protection from the concerned parties.

Thus, though it is found to be important for the disabled to get legal services, HIV related service organizations and disability organizations failed to incorporate this service in their programmes. This could inevitably create a gap in addressing both the sexual abuse and perceived HIV related discrimination of the disabled in the sub city.

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The national HIV/AIDS policy documents reviewed to assess the inclusion of PDs indicate that both PDs and PDLHAs in particular are non-existent. Both the policy and the strategic plans of HIV/AIDS exclude PDs from the perceived risk groups such as the youth, women, truck drivers and commercial sex workers. It is clearly evident from this finding that this segment of society is neglected from HIV policy arena.

Despite the presence of policies and programmes, HIV/AIDS has been killing thousands of non-disabled people. Whereas people with special needs without related policy could seriously be forgotten and thus be victims of the virus.

Worst of all, absence of HIV services in disability specific programmes further deteriorates the situation of disabled people in Addis Ababa and in Gullele sub city in particular. There has not been any action plans developed to address HIV related special needs of PDs in the selected associations. This could inevitably contribute for reluctance of HIV related policy and programmes to include PDs.

Though there is a handful of HIV service organizations in Addis Ababa, most of them fail to include PDs in their programmes. The finding indicates that these organizations complain that the problem is associated with the national HIV/AIDS policy. The absence at the national policy affects the effort at the service sectors in the city.

However, few attempts have been made by some social service organizations and disability specific organizations in the sub city. As shown in the finding, only five organizations have been involved in the provision of HIV related services. These organizations are particularly providing major services including educational, nutritional, medical, advocacy and awareness raising. Some of these organizations are engaged in material production (like Braille) in accessible format.

Nevertheless, compared to the needs of PDs and PDLHAs, these services are insignificant. Besides, these services do not exhaustively address the clients in Gullele sub city. This is because PDs in adjacent sub cities are simultaneously competing for the same service delivered by the organizations. On the other hand, the amount of the services is dependent on the interest of the donor organizations at local and international level. All these factors intimidate the access of care and support services for HIV related needs of PDs and PDLHAs.

The finding on the risk factors that expose PDs to HIV infection depicts that the limited social interaction of PDS affects their level of interaction with others and thus fail to get HIV related messages. As pointed out by Nganwa (2002), PDs isolation and confinement based on culture and traditions, attitudes and prejudices often affect disabled persons' access to information obtained from communication. This isolation leads to low self-esteem and negative feelings. As a result, they become away from HIV related information. In other words, missing the opportunity to get relevant information expands their ignorance on HIV prevention and control mechanism. This indicates the contribution of poor social interaction in exposing PDs to lack of knowledge on the disease.

Similarly, the result shows that disabled persons are too much restricted by their families to stay at home. They are not allowed to practice and acquire knowledge on sex related matters. The parents argue that in making control of their disabled children, they are protecting them from pregnancy, which is not advisable for the disabled female at home. Many disabled people, lead isolated lives - unable to go out of their own homes. This directly affects their decision making on their sexual needs.



The results on the risk factor related to poverty indicate that PDs are much more exposed to unsafe sexual practice due to their poor living condition. The fact that disabled people are more likely to have received little or no education and to be out of employment, places them among the world's poorest, most stigmatized and most marginalized (Choruma, 2006). According to this study, most disabled people accept financial promises from the opposite sex due to ignorance about the consequences of unwanted pregnancies and HIV/AIDS. This is related to their desire to get financial resource for their survival. In the attempt to earn their living, PDs are increasing the likelihood of doing sexual intercourse with the non-disabled, whose HIV status is not known.

Sexual abuse has also been one of the major risk factors found to be increasing the probability of PDs to be infected by HIV. A research finding by Nganwa (2002) highly supports this finding. He states that “while the physically disabled women cannot run away from their abusers, the deaf, dumb and blind cannot shout or protect themselves from their abusers”. The study points out that they cannot even insist on having protected sex and faithfulness from their partners. In addition, high levels of poverty, rape and non-use of contraceptives are the most common factors, which predispose disabled women to HIV/AIDS.

According to the finding, the challenges to reach HIV messages, care and support services could also be taken as risk factor for the susceptibility of PDs to HIV infection. Similar research finding on HIV and Disability shows that due to the special needs of the disabled, making information available to them is often challenging for AIDS service organizations. It needs special commitment from the organizations to reach the disabled in HIV information. Thus, most organizations are reluctant to incorporate PDs in their

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HIV/AIDS service programmes to escape the preparation of formatted materials like Braille, Internet and 'talking computers' (EFPD, 2005). This has a profound effect on the access of educational materials in appropriate format.

## **Chapter Five**

### **Conclusion and Implication for Social Work**

#### **5.1 Conclusion**

This section of the paper presents the major findings and points of discussion presented in the previous sections.

Broadly speaking, this research has been dealing with the vulnerability of persons with disabilities particularly the deaf, the blind and the physically disabled to HIV infection. The study selected Gullele sub city as study area. The research finding mainly focused on HIV related service packages available for PDs, the efforts made by social service organizations, the efforts of disability associations, and risk factors for exposure of PDs to the virus, and the contribution of income level poverty in exposing PDs to the infection. The research outlined physical inaccessibility, material inaccessibility, sexual abuse, lack of confidentiality for VCT centers and PDs restricted relationship with others as the major areas of the finding. The entire points raised in the discussion and finding section reflect these major themes.

The finding of the study indicates that both PDs and PDLHAs are seriously suffering from the inaccessibility of materials to get HIV information. All HIV related information designed for the non-disabled people fail to address the needs of the disabled. Especially the absence of Braille scripts for the blind impedes the accessibility of information education communication (IEC) and behavioral change communication (BCC). Likewise, the deaf are non beneficiaries of such information due to the absence of trained sign language interpreters. On the other hand, the physically impaired have problems with the inaccessibility of buildings and structures used by service providers in the sub city. Besides,

these people do not have enough access to orthotic materials and wheelchairs to reach the service centers.

More over, most HIV prevention campaigns, which focus on public awareness raising through news papers, written materials, audio and visual materials, are inaccessible to the disabled people. Hardly, any HIV prevention messages are available for the blind or deaf people. This situation is further complicated due to their high level of illiteracy to access little available materials.

According to the finding, such inaccessibility of materials is compounded with the poverty the disabled people are suffering from and the frequently occurring sexual abuse perpetuated by the non-disabled people. The finding shows that lack of household income often makes the disabled to opt for sexual practice as a means of income. They are hardly ever decision makers on sexual intercourse. It is the one who has bargaining power could make choice on this matter. This condition inevitably exposes the disabled people to HIV infection.

In addition, these people are susceptible to be victims of sexual abuse by their non-disabled perpetrators. Whenever they are raped by the non-disabled, they can not get immediate protection from law enforcers such as the police and the court. Besides, attention is not given for the disabled victims from the police and the court. This is partly related to the societal perception that disabled people are hardly vulnerable to HIV infection. On the other hand, they can not protect themselves from the abuse due to their disability. Particularly the blind fail to identify their perpetrators. On the other hand, though the physically disabled could distinguish their sexual abusers they rarely protect themselves due to their physical limitation.

The research finding also depicts the influence some risk factors further that accelerates PDs vulnerability to HIV infection.

First, their dependency to get income for their survival leads them to opt for sexual intercourse as source of income. Second, families of the disabled children make serious control at home and the children could not access social interaction, which is believed to be one of the important social skills to get HIV related information through communication. Third, the challenges to reach the disabled in HIV messages make the situation of PDs risky. Fourth, the sexual abuse PDs experience and their failure to react on the abuse further increases the risk of contracting the virus.

Above all, the absence of disabled people in national HIV/ADS policy based on their special needs worsens the situation. Not only is the national policy but the disability associations in the sub city have no HIV related programmes designed to address HIV related needs of both PDs and PDLHAs. Nevertheless, little attempts have been made by few social service organizations in the city. But the services are not reliable and sufficient compared to the prevalence and needs of the disabled in the sub city.

## **5.2 Implication for Social Work Practice**

The research finding has a lot of implications for all relevant stakeholders to alleviate the vulnerability of PDs to HIV infection. First of all, the result calls for policy level intervention to address HIV related needs of the disabled people. Here it is the role of social worker to advocate and aware HIV policy makers to reconsider the inclusion of PDs in special package in all the relevant prevention and control programmes.

Another policy level intervention needs to be considered is the national Poverty Reduction Strategy Papers (PRSP). There is a need to incorporate PDs in this strategy to meet

their special needs. This could be achieved if the social worker is involved in lobbying and advocacy activities to persuade the policy makers.

In addition, social worker could do sensitization for disability associations and organizations in the city. Worker should also strive for making network among the national social welfare institution, national and regional HIV/AIDs policy makers and disability associations and non-governmental organizations in the sub- city. Moreover, it should be the task of social worker to follow up the implementation of policy plans at the grass root level. This, of course, could be done after the inclusion of PDs in HIV programmes of the concerned parties mentioned above.

Followed by policy intervention is developing special HIV related programmes for both PDs and PDLHAs. These programmes need to incorporate local community members, community social workers, traditional associations (*Edirs, Mahibers, and Equibs*), school teachers, church and traditional leaders. The networks within these local people enable the implementation of the programmes easily. This is because disability as shown in literature section is more of social construction rather than disease. If PDs and PDLHAs are understood by these people, provision of HIV related services will not be difficult.

In relation to social service sectors in the city, there is an urgent need to create awareness for the social service professionals such as health professionals, law enforcers (the police and the court). This could be done by the social workers to aware HIV/AIDS related needs of PDs and PDLHAs. The social worker should also be engaged in the provision of court services by presenting cases of the abused and stigmatized PDs and PDLHAs. He or she should defend the cases if needed.

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With regard to direct access to HIV related information, social worker should deal with GOs and NGOs in the production of materials in accessible formats. These include Braille scripts for the blind, wheel chairs and orthopedic materials for physically disabled and provision of professional training for sign language interpreters for the deaf.

More over, health professionals particularly those in the VCT centers should be given sign language training by special needs professionals.

On top of these, there need to be a comprehensive research on the prevalence of the infection rate at the national level. Social worker has to supplement the practical interventions with relevant applied research on the relation between HIV/AIDS and disability, and the accessibility of HIV services to disabled people.

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## Appendices

### *Appendix 1*

## Questionnaires

Addis Ababa University

Graduate school of social work

Vulnerability of Persons with disabilities to HIV Infection in Gullele Sub city of Addis  
Ababa

This Questionnaire is designed for individual persons with disabilities living with HIV/AIDS, namely the the blind, the deaf, and the physically handicapped. It is designed to organizations working on persons with disabilities and HIV/AIDS. In your attempt to answer the following questions, make sure that all your personal dealings will be kept secret and confidential. Besides, you need to know that the purpose of this research is purely for academic purpose. The answer that you provided here will have great benefit to the researcher and the target community.

**1 Put this(x) tick mark in front of your answer and write your answer on the  
Blank spaces given**

A. Questions to PDS and PDLHAs

I. Socio-demographic Characteristics of Respondents

Age-----

Sex-----

Religion-----

Ethnicity-----

Marital status-----

Educational level-----

II Integrated Questions

II

1. Have you ever got voluntary counseling and testing (VCT) services?  
 Yes  No
2. If your answer is No, how do you know your HIV+ serostatus?  
\_\_\_\_\_  
\_\_\_\_\_
3. If yes, where did you get the service?  
\_\_\_\_\_
4. For how many years you have been living with the virus?  
\_\_\_\_\_
5. Have you ever taken ARV treatment?  Yes  No
6. If yes, where did you receive ART? \_\_\_\_\_
7. If yes, where do you often go for treatment of opportunistic infection?  
\_\_\_\_\_
8. Where do you often get the AIDS educational materials?  
\_\_\_\_\_
9. Do you think the materials are in accessible format to you (braille for the blind, sign language interpretation for the deaf)? \_\_\_\_\_
10. Do you usually watch or listen for HIV/AIDS information?  
\_\_\_\_\_
11. Do you think disabled people like you are more vulnerable to HIV/AIDS?  
 Yes  No
12. If yes, why?  
\_\_\_\_\_
13. What specific action have you taken to protect the transmission of the infection to your friends, spouse and others?

14.. Do you have any information about the HIV prevention and protection before you contracted HIV? A/yes B/No

15. Do other people know that you are infected with the Virus?

- Yes  No

16. If they know your positive status, what is their perception towards you?

- discriminatory  
 stigmatizing  
 cooperative  
 do not care  
if other ,specify

17. How do you often get HIV information?

- A/television  
 B/pictures  
 C/brochures  
 D/others

5. What is your role in preventing other persons with disabilities from HIV infection?

- A/ teaching about the virus  
 B/ publicizing your self  
 C/involving in outreach campaigns

6. Which organization often provides you services related to HIV and Disability?

- A/Addis Ababa HAPCO  
 B/ Federal HAPCO  
 C/ disability association  
 D/ Association of people living with HIV  
 others

**III. Service Related questions**

1. Do you think the government provides equitable and fair services for HIV Positive disabled people?

Yes  No

2. If your response is No, explain any challenge that you encountered.

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3. Do you think the available health care facilities physically accessible to you as disabled and sero-positive person?  Yes  No

4. If  yes,  Why?

---

5. If  no,  why  not?

---

6. Is the health care affordable to you?  Yes  No

7. Do health professionals often give you health care services?

Yes  No

8. If  your response is no,  explain why.

---

---

9. Do any AIDS outreach campaigns service reach you?

Yes  No

10. If your answer is "yes", how? -----

11. Have you ever been abused by the non disabled people?

Yes  No

12. If yes, did you get any legal services?  Yes  No

13. If yes, what types of services are often provided to you? Explain.

---

14. Who often provides such legal services? \_\_\_\_\_

15. How do the law enforcers give protection to you?

---

---

16. Do you use Antiretroviral Therapy?

yes no

17. If you are the user of ART, who provides you the service?

government offices

NGOs

Voluntary associations

others

18. How do you get the ART service?

A/free of charge

B/pay for it

#### IV. Sexual Behavior of Persons with Disabilities

1. Have you ever had any sexual intercourse?  Yes  No

2. If yes, at what age you exactly had your first sexual intercourse?

---

3. What are the factors that contribute to your initiation to sex?

Due to peer pressure  by own interest

Raped or abused  others (specify) \_\_\_\_\_

4. What do you feel as being living with the virus?

---

---



5. Do you often expect that you are vulnerable to HIV infection as disabled person?

---

---

6. Could you explain the factors (psychological and cultural) that put you at a higher risk for HIV/AIDS infection?

---

---

5. Could you list at least the major reasons for the factors?

---

---

---

6. Do you have any partner?  Yes  No

7. What type of person is your partner?  person with disability  
 non disabled person  person with the same kind of disability like you

8. How often you have discussed the issue of HIV/AIDS with your partner?  
 regularly  sometimes  not at all

V. Cultural perspectives and risk factors

1. What your family's perception is towards your contract of HIV?

often negative  often positive  /not clear  do, not know

2. Are you often discriminated by your family because of your sero positive status?

Yes  No

3. If yes, explain the challenge you faced \_\_\_\_\_

4. Who is often involved in the discrimination of you?

Peers  family  neighborhood

## Vulnerability of persons with Disabilities...

- the community
5. With whom do you live?       Friends    family       relatives  
 other (specify)
6. Do you have any job?       Yes       No
7. Do you have regular income to earn your living?  
 Yes       No
8. If your answer is yes, how do you earn it?  
 Office work    Occasional work    small business    family /  
friend / relatives and organization assistance  
 others specify\_\_\_\_\_
9. Do you think that your low income contributes for your risky sexual health practice?  
 Yes       No
10. Does disability affect your sexual life behavior to become sexually passive?  
 agree    Disagree    strongly agree    strongly disagree  
 Not known

## Risk Factors

1. What is your experience of social interaction on sexual matters?
2. How does your family control you?
3. Does your low income contribute for your sexual behaviour?
4. What are the challenges to reach you HIV messages, care and support services?

***Thank You for your cooperation!***

*Appendix 2*

**Addis Ababa University**

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**B. Questions Designed to Organizations working on HIV/AIDS and Disability related Issues**

**Topic of the research: Vulnerability of Persons with disabilities to HIV Infection in Gullele Sub city of Addis Ababa**

The researcher is great full for your organization's willingness to answer the list of questions prepared below. Make sure that the purpose of this questionnaire is purely academic. You are kindly requested to answer all the questions freely.

**Background information**

Name of organization-----

Address-----

Phone no-----

Type of Organization:  Government

NGOs

Disability organization/Association

**Service related Questions**

1. Is your organization specifically disability service providing organization?

Yes

No

2. If your answer is yes, then what type of services are provided by your organization?

/legal protection  educational support  medical assistance

Nutritional assistance  care and support  others (specify)

3. What type of disabled persons does your organization serve?

VIII

- visually impaired    physically disabled    hard of hearing  
 intellectually disabled    all disability groups
4. How many individuals with disabilities have been served by your organization?
5. What does your organization often teach the persons with disabilities?  
 HIV/AIDS information?    Drug usage  
 Safe sex    condom usage
6. Does your organization provide home based care and support for PDs with HIV?  
 yes    no
7. If your answer is yes, what support do they get?  
 Counseling    nutritional    psychosocial    others
8. Does your organization provide ART service for PDLHA?  
 yes    no
9. If your answer is yes, how do they get it?  
 free of charge    pay for it
10. Does your organization have specific policies and programs that include PDLHAs ?  
 yes    no
11. If No, why do you think that is so?  
 They give focus to the non-disabled community  
 They design policy if and only if the policy is available at the governmental level  
 they could not often secure fund for the disability related projects

***Thank You for your cooperation!***

### ***Appendix 3***

#### ***Figure X: Physically Disabled Woman***

The picture below is taken by the oral consent agreed between the researcher and the subject of the study. Besides, privacy issues of the subject are respected in terms of keeping all the necessary secrets confidential. More over, the subject was explained the purpose of the research, which is believed to contribute for the disabled people by influencing policy makers and other relevant stakeholder in HIV/AIDS related problems. The figure below shows the situation of some of the physically disabled persons

Vulnerability of persons with Disabilities...





