HIV and AIDS : related stigma and discrimination in Nepal

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DEDICATION

Dedicated to those who are deprived of rights, recognition and dignity due to HIV and AIDS–Related Stigma and Discrimination.

ABSTRACT

This thesis highlights the result of a review of available international and Nepalese literature to a) explore the contributing factors and manifestations of HIV and AIDS-related stigma and discrimination and b) explore the evidence of relevance and effectiveness of interventions in reducing stigma and discrimination.

HIV and AIDS-related stigma and discrimination exist in all level of Nepalese society. Rejection, isolation, avoidance, denial, participation restrictions are common manifestations. PLHIV are not only stigmatised by others but they also stigmatise themselves due to perceived stigma or experience of discrimination, which can have serious consequences, such as low self esteem, depression and self isolation.

The study shows that fear of contagion, negative attitudes towards PLHIV, and lack of anti discriminatory laws are major contributing factors to stigma and discrimination. Lack of or inadequate knowledge escalates the fear. HIV is associated with behaviours that are considered illegal or forbidden in most societies such as extra-marital sex, sex work, drug use and sex between men. This adds to the disease-specific stigma and, due to these reasons, PLHIV are often rejected or denied of their fundamental rights.

The impact of HIV and AIDS-related stigma and discrimination is not limited to lowering the quality of life of PLHIV, but it also is a barrier in responding to HIV epidemic effectively. Fear of discrimination prevents people from utilising HIV prevention services such as BCC, VCT, STI services and prevents people from seeking treatment for AIDS or disclosing their status openly. This increases further HIV transmission and exacerbates impacts of HIV and AIDS. Stigma is one of the serious obstacles towards achieving the goal of universal access of HIV prevention and care.

Reviewed interventions in the international literature highlight the need of multidimensional strategies to address HIV and AIDS-related stigma and discrimination through three main approaches; reducing and preventing stigma, challenging discrimination at institutional level and protecting and promoting human rights. Nepal is responding to stigma by implementing interventions such as service provision, media campaigns, empowering and mobilising PLHIV etc. However, there is a still big gap in the current interventions. It is recommended that Nepal should respond to stigma and discrimination in integrated approaches by empowering PLHIV, working with and mobilising family and community, health care settings, reforming laws and legislation, developing workplace polices, and imparting knowledge through IEC and media.

Key words used: HIV, AIDS, Stigma, Discrimination, Nepal

LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Treatment
BCC	Behaviour Change Communication
BBC	British Broadcasting Channel
CBO	Community Based Organisation
CBS	Central Bureau of Statistic
CPN	Communist Party of Nepal
CVD	Cardio Vascular Disease
DALY	Disability Adjusted Life Years
DOHS	Department of Health Service
FHI	Family Health International
FSW	Female Sex Worker
GDP	Gross Domestic Product
CHBC	Community and Home Based Care
HIV	Human Immunodeficiency Virus
ICRW	International Centre for Research on Women
IDU	Injecting Drug User
IEC	Information Education and Communication
ILO	International Labour Organisation
IMR	Infant Mortality Rate
INF	International Nepal Fellowship
KIT	Royal Tropical Institute
LGBTI	Lesbian, Gay, Bisexuals, Transgender and Intersexes
MOHP	Ministry of Health and Population
MSM	Male who have Sex with Male
NAPN	National Association of PLHIV in Nepal
NCASC	National Centre for AIDS and STD Control
NDHS	Nepal Demographic and Health survey
NGO	Non Governmental Organisation
NHP	National Health Policy

NLR	Netherlands Leprosy Relief
NPC	National Planning Commission
NSP	National Strategic Plan
OI	Opportunistic Infection
PLHIV	People Living with HIV
PEP	Post Exposure Prophylaxis
PMTCT	Prevention of Mother to Child Transmission
S&D	Stigma and Discrimination
SHP	Sub Health Post
STI	Sexually Transmitted Infection
TBCA	Thailand Business Coalition on AIDS
UNAIDS	United Nations Joint Program on AIDS
UNDOC	United Nations Office on Drug and Crime
UNDP	United Nations Development Program
UNFPA	United Nations Population Fund
UNGASS	United Nations General Assembly Special Session on AIDS
UNICEF	United Nations Children's Fund
USAID	United States of Agency for International Development
VCT	Voluntary Counselling and Testing
VDC	Village Development Committee
WHO	World Health Organization

INTRODUCTION

HIV continues to spread, globally 3.3 million people were living with HIV and AIDS by the end of year 2007 (UNAIDS, 2007a). Stigma and discrimination (S&D) associated with HIV and AIDS have been the greatest barrier to preventing further transmission, providing adequate treatment, care, and support and alleviating the impact (UNAIDS, 2002). Considering this, UNAIDS organised a World AIDS Campaign in 2002 and 2003 aiming at preventing, reducing and eliminating HIV and AIDS-related stigma and discrimination. Despite of being one of the major obstacles in the response to the HIV epidemic, S&D has been neglected in most national AIDS programme (UNAIDS, 2007b). Peter Piot, the executive director of UNAIDS has said "Since the beginning of the epidemic, stigma, discrimination, and gender inequality have been identified… as major obstacles to effective responses to HIV. Yet there has never been serious political and programmatic commitment to doing anything about them" (Piot P., 2006). Ban ki-moon, the UN General Secretary has recently stressed on the need for action against S&D as this remains the single most important barrier to combat HIV and AIDS (Ki-moon B, 2008).

If people know or fear that they will encounter S&D, they will be less motivated to seek counselling and testing service to know their status, they may be reluctant to disclose their status to their sex partners and not come forward for treatment and care. These reactions not only fuel HIV epidemic but also increase its impacts. Being globally pervasive S&D will create serious obstacles towards achieving the goal of universal access to HIV prevention, treatment care and support which will ultimately affect the Millennium Development Goal of halting and reversing HIV by 2015.

HIV and AIDS is a major public health challenge in Nepal as well. HIV has been spreading rapidly and Nepal has moved from Low HIV Epidemic Country to Concentrated Epidemic. WHO predicts that without effective interventions, AIDS will become the leading cause of adult death in Nepal over the next 10 years (FHI, 2007). Stigma poses a serious obstacle in effective response to HIV epidemic in Nepal and stigma reduction is one of the major strategies in the current national HIV/AIDS strategic planning (National Centre for AIDS and STD Control – NCASC, 2007).

I have been working in a Non-Governmental Organisation (NGO) in INF[1] in Paluwa HIV/AIDS Section in Pokhara Nepal. While working at INF

[1] **INF** (www.inf.org) is a NGO working in western Nepal in collaboration with Nepal Government since 1952 in the field of health and community development. **Paluwa** is one section of INF which aims to provide a continuum of care to people infected and affected by HIV and AIDS providing treatment, care and support such as, VCT, treatment of STIs and OIs, socio-economic support and home based care etc.

Paluwa with people infected and affected by HIV and AIDS, I have seen and experienced HIV and AIDS-related S&D very close-by. S&D is one of the key challenges of INF AIDS programme.

Reducing S&D is a critical part of local and national AIDS programmes. There is not much research and literature about this issue in Nepal. Thus, I would like to explore the nature, contributing factors and determinants of this problem and apply what I have learned in this course and from the literature to make recommendations for successful interventions to reduce HIV and AIDS-related S&D in Nepal.

This thesis is primarily intended for organisations working in the field of HIV and AIDS in Nepal, such NCASC and other government organisations (GOs), International and national non-governmental organisations (I/NGOs), network of vulnerable population and People Living with HIV (PLHIV) including my organisation INF Nepal.

CHAPTER 1. BACKGROUND INFORMATION OF NEPAL

1.1 General background

1.1.1 Geographical

Nepal is a landlocked mountainous country located in Southern Asia, between China and India. The country's total land area is 147, 181 sq km with 800 kilometres long boundary. Nepal's terrain is made up of Terai or flat river plains of the Ganges in the south and hills, like the rugged Himalayas in north (CBS, 2007).

1.1.2 Population

The population of Nepal is estimated to be 28.2 millions in 2007. The annual growth rate is 2% and total fertility rate is 4.22 per woman (UNFPA, 2007). Seventeen percentage of the population are living in urban area and 83 % are living in rural area. Life expectancy at birth for men is 62.9 and for women is 63.7 years (UNFPA, 2007).

1.1.3 Education

The adult literacy rate for men is 78.7% and for women is 54.5% (Nepal Demographic and Health Survey - NDHS, 2006). Net primary school enrolment ratio for male is 90% and 83% for female in 2006 (UNICEF, 2006).

1.1.4 Socio-cultural Situation

Nepal has a diverse landscape which makes diverse socio-cultural aspects such as religion, culture, ethnicity/caste, and language. The majority of the people follow Hindu religion. Nepali is official language and 92 different languages are spoken across the country. There are over 103 different caste/ethnic groups throughout the country (CBS, 2002). There is a deep-rooted caste system in Nepal which defines the social stratification by race or ethnicity. Although the caste system is officially abolished in Nepal, there is still high level of S&D related to caste and ethnicity. Lower caste people are often stigmatised and discriminated.

Nepal has a strong patriarchal social cultural structure and gender inequality is very high in the society. Nepalese women have very limited involvement in decision making in the household level to high level legislative and bureaucratic positions.

1.1.5 Political Situation

There have been rapid political changes in Nepal during the last 10 years. The 10 years long armed conflict ended in 2005 after Nepal Communist Party Maoist (CPNM) has signed a piece agreement with the government. The constituency assembly election successfully held on 10th April 2008 making CPNM, the single largest party. The first historic Constituent Assembly meeting on 28 May 2008 has voted Nepal to be "an independent, indivisible, sovereign, secular and an inclusive democratic republic nation" (BBC News, 2008). This motion has abolished the 240 year long monarchy in Nepal. Nepal is in a transition phase now.

1.1.6 Economic Situation

Nepal is one of the poorest countries with annual per capita income of US$ 320 in 2006 and about 31% people are living below the poverty line (World Bank, 2008). Nepal is in the 136th position in the human development index among 177 countries of the world in 2005 (UNDP, 2005a). The long political conflict has hindered the development and the economic growth in the country. The economic growth of Gross Domestic Product (GDP) in 2006/07 was only 2.5% (NPC, 2007).

1.2 Nepal's Health System

1.2.1 Health Situation

Nepal has made some progress over the years in raising the health status, particularly through expansion of immunization for vaccine-preventable diseases and priority disease interventions (WHO, 2006a). The trend in infant mortality rate (IMR) shows a decline from 103 per 1000 live births in 1986 to 51 per 1000 live births in 2006 (NDHS, 2006). The life expectancy at birth increased from 55 years for males and 53.5 years for females in 1991 (WHO, 2006a) to 63.3 years for males and 64.1 year for females in 2007 respectively (CBS, 2007).

However, there are still lots of challenges. Disability Adjusted Life Years lost due to ill health in Nepal remains the highest in the Region and are second to sub-Saharan Africa (WHO, 2006a). Major communicable diseases still persist and they are a major public health problem. At the same time, non communicable disease which are related to life-style and risk factors (e.g. diabetes, hypertension, CVD, cancer etc.) are increasing. Skin diseases, diarrhoeal disease, intestine worms, acute respiratory infections, and gastritis are top five causes of morbidity (DoHS, 2006). Children under five and reproductive age women are at highest risk of morbidity and mortality in Nepal.

Population growth remains high compared to the other countries in the Region. About two-thirds of the population are under 15 years of age, and the number of people 60 years and above is also increasing. Thus, the country is going through demographic and epidemiological transitions.

The national health policy emphasises on equity and social justice. Underserved and marginalized people have been priority in health services. However, there is high health disparity between the rich and poor and urban areas and rural areas in terms of access, utilization and health status (WHO, 2006a). The deeply rooted discriminatory practice based on class, caste and gender affects every area of the society including the utilisation of health services.

1.2.2 Information on Health Sector

Health service is largely provided by public sector in Nepal. The Department of Health Services (DoHS) which is one the three departments under the Ministry of Health and Population (MOPH) is responsible for delivering preventive, promotive and curative health services all over the country. All primary health care services are provided at various levels of public sector under DoHS. There are few Ayurvedic health centres under the Department of Ayurvidec Medicine. Some other private sector, NGOs/INGO are also providing health services in Nepal.

A National Health Policy (NHP) was adopted in 1991 to improve the health conditions of Nepalese people through the extension of primary health care system to the rural populations (MOPH, 1991). On the foundation of the NHP 1991, a second long term health plan (1997-2017) was developed (WHO, 2007). The major features of the health plan are development of integrated and essential qualitative health care services at the district level and below with active participation and mobilisation of private sector.

It is recommended that a country should spend at least 15% of its GDP on health but Nepal is spending around 5% only (WHO, 2006b). Out of the total expenditure on health, 72% was from private sector and only 8 % was from public sector in 2003 and 92% was out of pocket expenditure (WHO, 2006b). More funds are needed in rural and distant areas for primary health care and the government's plans also prioritise this, however, in reality, urban areas still gets get more funding for health where there is already better infrastructure available (WHO, 2007).

1.3 HIV and AIDS situation in Nepal

The first case of AIDS was reported in 1988. The NCASC has reported a total of 11,501 HIV positive cases by the mid May 2008 (NCASC, 2008a). It is estimated that a total of 70, 254 adult people are living with HIV and AIDS in Nepal by the end of 2007 (UNAIDS 2006b). After the detection of first HIV case in Nepal in 1998, Nepal has moved from Low HIV Epidemic Country to Concentrated Epidemic in most at risk populations such as female sex workers (FSW), injecting drug users (IDUs) and seasonal labour migrants who return after working abroad (FHI, 2007). WHO predicts that without effective interventions, AIDS will become the leading cause of adult death in Nepal over the next 10 years (FHI, 2007).

Nepal's HIV epidemic is mainly driven by injecting drug use, sex work and migration. Many sex workers are also IDU, migrants or both, increasing the HIV among risk groups and majority of clients of sex workers are married, who are potentially spreading HIV into general populations (USAID, 2008).

The deteriorating economic conditions, low socioeconomic status of women and high levels of labour migration are the major factors that provide potential for growth of Nepal's HIV epidemic (UNAIDS, 2007a). There is a special concern on rapid spread of HIV among seasonal labour migrants, 46% of estimated HIV infections are among them. See annex 1.

Nepal has initiated various efforts for HIV prevention and care. Nepal launched its first National AIDS programme in 1988. NCASC is the separate body under MOPH to implement, monitor, and evaluate HIV/AIDS related activities. With the representations of key ministries and non-governmental organisations, a National AIDS Coordination Committee was established in 1992. The major responsibility of the committee is to co-ordinate HIV/AIDS prevention and control programmes with various ministries at central level.

The NCASC has launched three five-year (1997-2001, 2002-2006, and 2006-2011) National Strategic Plans (NSP) for HIV and AIDS in Nepal. The current five-year plans (2006-2011) focuses on universal access for HIV prevention, Treatment and care and support services for infected and affected people with HIV and AIDS (NCASC, 2007).

Recently, treatment, care and support services have been expanded. The service outlets and the usage of Voluntary Counselling and Testing (VCT), treatment of Sexually Transmitted Infections (STIs), Prevention of Mother to Child Transmission (PMTCT), treatment of Opportunistic Infections (OIs) and Antiretroviral Treatment (ART) have increased (UNGASS, 2008) and now over 1400 PLHIV are receiving free ART from 22 different sites

spread over the country (NCASC, 2008b). However, the coverage is still very low compared to the need. The coverage among MSM and migrants is only 23% and 14% respectively (UNGASS, 2008). The coverage of ART and PMTCT also remains low at 17% and 2% respectively. S&D against certain groups, including IDUs and FSWs are one of the major barriers for scaling up of the services in Nepal (UNAIDS, 2006a).

CHAPTER 2. PROBLEM STATEMENT, OBJECTIVES AND METHODOLOGY

2. 1. Problem Statement

HIV and AIDS-related S&D are the greatest obstacles to effective HIV prevention, care and treatment programmes all over the world (UNAIDS, 2002a). Stigma and its psychological consequences cause indescribable suffering to those who are stigmatised (Van Brakel WH., 2005). There is a significant level of stigma towards PLHIV at every level of Nepalese society (FHI, 2004a). People at risk and PLHIV are discriminated even by their family members. In most places, people reject those living with HIV socially and deprive them from the basic fundamental rights, including property rights etc. HIV/AIDS-related stigma and discrimination in health care settings exist in Nepal like in other places in the world.

HIV AND AIDS-related stigma is fuelled by assumptions about lack of moral integrity and values of a person; people tend to associate AIDS with moral impropriety (International Centre for Research on Women - ICRW, 2006a). In many countries, HIV infection is commonly perceived as the result of a personal choice – one chooses to engage in 'bad' or 'immoral behaviours'. IDUs, FSWs, and MSM suffer more S&D because of their illegal status or behaviour associated with social taboos. Because of stigma they do not have access to health care and appropriate information, education and communication, which makes them more vulnerable to the HIV infection. Women are more vulnerable to HIV-related stigma and they suffer more compared to a man (FHI, 2004a). They receive less support than their husbands when both are HIV-positive and they are also morally condemned and blamed more for their HIV status.

There are many reasons for HIV and AIDS-related stigma in Nepal. Firstly, lack of knowledge and understanding about HIV and AIDS. People have many misconceptions regarding HIV and AIDS, mainly about the modes of transmission (FHI, 2004a). Therefore fear of getting HIV keeps people away from infected persons. Secondly, HIV infection is directly linked with very sensitive topics such as sex and sexuality. It is also linked with perceived illegal and immoral behaviour such as drug use, sex work, sex between men etc. Many people think that HIV infection is the result of immoral and promiscuous behaviour. Thirdly, the information, education and communication [IEC] strategies used in this field have been inappropriate. For a long time, HIV has been portrayed as a killer disease for which there is no treatment. All these factors lead to S&D. Please see attached problem diagram in the Annex 2.

The effect of HIV AND AIDS-related stigma is not only limited to escalating emotional pain and suffering of PLHIV, but also has a profound effect on HIV prevention and care activities. S&D seriously affects HIV prevention, treatment and care services in Nepal (NCASC, 2007). This ranges from denial of services and support, to not accessing services, for the fear of being stigmatised and rejected. Because of self and perceived stigma and discriminatory behaviour of service providers, PLHIV often do not come forward to access services. This creates a complex problem in many ways. Firstly, the service that is most essential for health and for minimising the impact of the disease is not fully utilised. Secondly, the participation and views of infected and affected individuals, essential for designing appropriate policy and services, are often lacking. Thirdly, the magnitude of the impact on individuals, families and society is not known, thus it is difficult to undertake immediate and effective action.

2.2 Study questions

- What is HIV and AIDS related stigma and discrimination?
- What are the contributing factors and manifestations of HIV and AIDS-related stigma and discrimination in Nepal?
- What are the consequences of HIV and AIDS-related stigma and discrimination in Nepal?
- How to reduce HIV and AIDS-related stigma and discrimination in Nepal?

2.3 Thesis objectives

2.3.1 General objective

To explore the context, the determinants and the consequences of HIV and AIDS related stigma in Nepal and to make evidence based recommendations to INF and to the governmental and nongovernmental authorities in Nepal on strategies and interventions to reduce stigma and its impact.

2.3.2 Specific Objectives

- To describe HIV and AIDS-related S&D in Nepal
- To analyse the determinants HIV and AIDS-related S&D in Nepal.
- To describe the consequences of HIV and AIDS-related S&D in Nepal.
- To describe the best practice interventions internationally and nationally to fight S&D towards PLHIV
- To use the findings to make recommendations to combat HIV and AIDS-related S&D in Nepal.

2.4 METHODOLOGY

2.4.1 Study Design

Descriptive study is the major study design of this thesis.

2.4.2 Study method

The following study methods are used in this thesis:

The thesis is mainly based on literature review. The KIT library, Netherlands Leprosy Relief (NLR) Library, VU library are used to search the published literature on the topic.

Key words used in the search included; HIV, AIDS, Stigma, Discrimination, Social exclusion, Rejection, Prejudice, Human Rights, Injecting Drug Use, Voluntary Counselling and Testing, best practice, mainstreaming, Nepal and some combination among this key words. Some search was done through the reference of articles identified in the first wave.

Websites: UNAIDS, WHO, FHI, ICRW, Pop council, ILO, Pubmed, Cochrane Library, KIT, NCASC, Policy Project, Science Direct are used to search literature.

Some unpublished reports of the author's organization i.e. INF Paluwa and other organizations were also collected and studied. The author's personal experience of working in INF has been also used.

Some information was collected by administering a questionnaire among the staff of counselling and community and home based care (CHBC) unit of INF Paluwa. See questionnaire in Annex 3. The questionnaire was sent to a total of 7 staff (4 VCT counsellors and 3 home based care workers) by email and the scanned copies of filled questionnaire were sent back by them. Two of them are themselves living with HIV. Some of them were called by the author to probe their views. This was done to identify HIV and AIDS-related stigma their clients come across everyday counselling.

2.4.1 Study Limitation

There are some limitations to this study. Firstly, his study is based on literature review. Although plenty of publications were found on the topic, very few published papers were available about Nepal. Some of the literature found to be useful was neither accessible online nor as hardcopy. Some information collected from Pokhara, Nepal e.g. the questionnaire to counsellors, might not be representative for Nepal as

whole, as there is a high diversity in culture and socio-economic condition in various places of Nepal.

Stigma is a complex social process which needs to be explored also from perspectives other than public health, using social science and psychology methods. Being a public health person, the capacity of the author may be limited to study this topic.

CHAPTER 3. HIV AND AIDS-RELATED S&D IN NEPAL

3.1. Literature Review

3.1.1 What is Stigma?

Stigma has an ancient root. The origin of the word stigma comes from ancient Greece where outcast groups were branded, or physically marked, as permanent measures of their status (UNAIDS, 2002a). In different cultures and times, slaves, criminals, adulters or those suspected, have been branded or physically marked.

The original definition of stigma has been described by US sociologist Erving Goffman (1963) in his research among individuals with mental illness, physical deformity or social deviant behaviours, who had experienced stigmatisation. He had argued that stigmatised individual is a person with a "spoiled identity" who is "rendered unworthy" in the eyes of others (UNAIDS, 2002a). He has defined stigma as "an undesirable or discrediting attribute that an individual possesses, thus reducing that individual's status in the eyes of society" (cited in Morrison K., 2006).

Weiss and Ramakrishna have described stigma as "a social process or related personal experience characterised by exclusion, rejection, blame or devaluation that results from experience or reasonable anticipation of an adverse social judgement about a person or group. In health related stigma, this judgment is based on an enduring feature of identity conferred by a health problem or health related condition" (cited in Van Brakel, W.H., 2005).

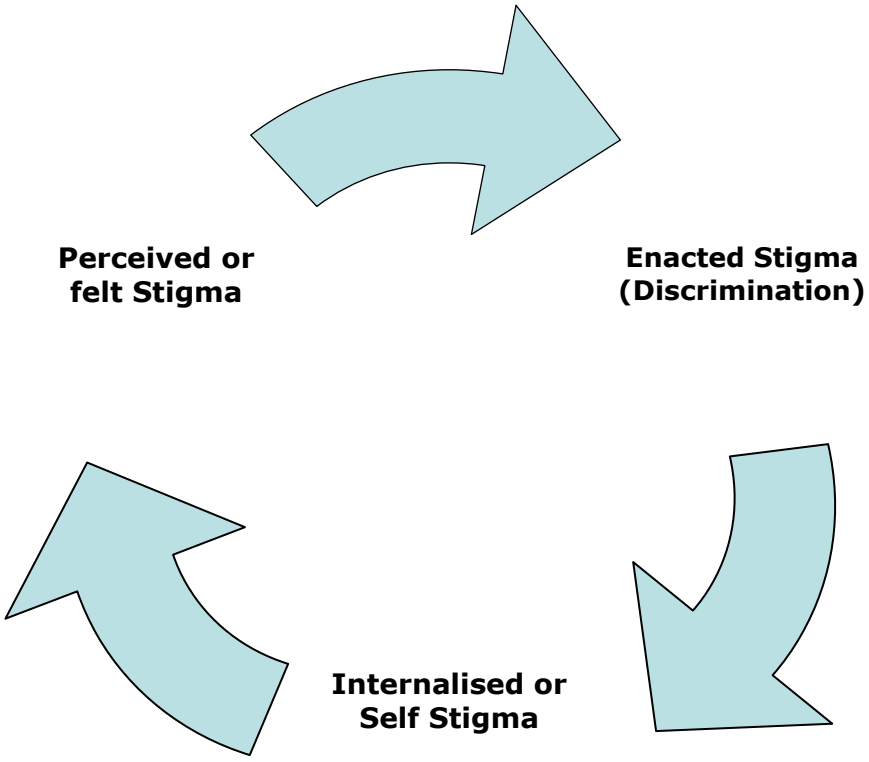
Stigma is universal and it is based on one or more factors, such as, caste, ethnicity class, colour, disease, religious beliefs, sex and sexuality (Foreman M., 2003). HIV is not only the stigmatised condition, stigma has been seen throughout the history in relation to other diseases including leprosy, tuberculosis, and syphilis which are considered to be happened as a result of misbehaviour or conduct against social norms (Brouard, 2006).

3.1.2 Conceptual framework of stigma

The conceptual framework for this study was adapted from Morrison K, 2006. There are three elements of stigma i.e. perceived or self stigma, enacted stigma and internalised stigma. These three elements of stigma interact to each others and work in a circle. Stigma primarily lies in the area of perceptions and attitudes, such as a negative attribution to a

group or individual. Perceived stigma comes from these negative attributions. It turns into enacted stigma or discrimination when somebody acts or behaves differently towards an affected person based on the negative attitudes. Such discrimination makes affected the person to feel or believe that they have done something wrong causing him/her to internalise stigma. However, some people may never experience discrimination but internalise stigma due to perceived stigma. Please see figure 1. The three types of stigma are described more below.

Figure 1: Conceptual framework of stigma and discrimination



Adapted from: Morrison K, 2006

Perceived or felt stigma refers to real or imagined fear of societal attitudes and potential discrimination (Brown et al., 2001). It is either the affected people's perception about how society views about their problem or disease such as fear, embarrassment, or disgust etc. or society's perception of that problem or disease. This can affect affected persons' views of themselves and of their surrounding community. The perception and the fear of discrimination (enacted stigma), can lead to avoidance behaviour. An example of perceived stigma is a sex worker not attending a VCT centre for counselling and testing, due fear of being stigmatised.

Enacted stigma refers to behaviour that is individually or collectively applied to people on the basis of their belonging or perceived belonging to

a particular group. Enacted stigma is real experience of discrimination (Brown et al., 2001). Enacted stigma describes a process that moves beyond perception and attitudes and into actions. For example, when disclosure of one's HIV status leads to loss of a job, isolation or rejection.

Internalised stigma refers to a process in which a person with a stigmatised condition accepts the perceived exclusionary view of society and self-stigmatises himself or herself (Weiss, M.G. 2008).

3.1.3 HIV and AIDS related S&D

HIV and AIDS-related stigma is a process of devaluation of people either living with or associated with HIV and AIDS (UNAIDS, 2002a). Stigma is often aggravated by pre-existing stigmatised conditions such as illicit sex and intravenous drug use which are two primary routes of HIV transmission.

HIV-related discrimination is an action that results from stigma. It occurs when a person is being treated unfairly and unjustly on the basis of their actual or presumed HIV status of belonging, or being perceived to belong to a particular group e.g. for example, FSWs, MSM or IDUs etc. (UNAIDS, 2002b).

3.1.4 Pre-existing stigma and HIV and AIDS-related S&D

Parker and Aggleton described that HIV and AIDS-related stigma interacts with pre-existing stigma associated with sexuality, gender, race and poverty (Parker and Aggleton, 2002). These components interact with one another reinforcing stigma and prejudice among these groups. HIV and AIDS-related stigma is most closely related with sexual stigma. This is mainly because one of the major modes of transmission of HIV is sexual and the epidemic initially affected populations whose sexual practices or identities were different from what was considered the "norm". HIV and AIDS-related stigma therefore appropriated and reinforced pre-existing stigma associated with sexually transmitted diseases, promiscuity, prostitution and sexual deviation.

Stigma is also linked with gender. Women suffer more from stigma, because they are perceived as responsible for spreading the infection. In settings where the heterosexual transmission is common, the spread of HIV infection has been associated with female sexual behaviour that is not consistent with gender norms (Parker and Aggleton, 2002). Prostitution is widely perceived as non-normative female behaviour, and female sex workers are identified as the vector of infection placing their clients and their clients' sexual partners at risk. Women with HIV infection are viewed as "promiscuous" or "sex workers". Likewise, men who

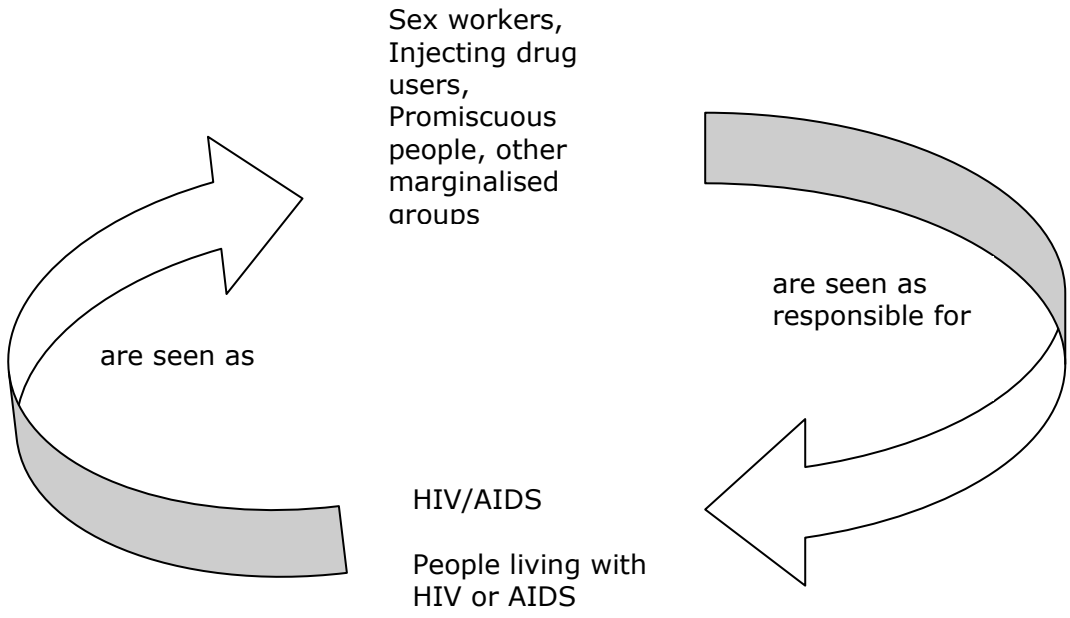
become infected may be seen as homosexual, bisexual, having had sex with a prostitute or having used illicit drug use (UNAIDS, 2002a).
Stigma related to race and ethnicity also interacts with HIV and AIDS-related stigma. There is a racist assumption about African sexuality being responsible for the infection and there are assumptions in developing countries that this is the result of "immoral behaviour" of Westerners. In the eyes of some African and Asian leaders, HIV/AIDS is a disease of the West, linked to weakness of family structures, liberal social value and moral decline (UNAIDS, 2002a).

HIV/AIDS-related S&D interacts with pre-existing stigma associated with social and economic class as well. Poverty increases vulnerability to HIV and HIV exacerbates poverty (Parker and Aggleton, 2002). Poor, homeless, landless and jobless people are more stigmatised. The diagram in the annex 4 shows the link between HIV and AIDS and pre-existing sources of stigma.

Stigma and marginalisation: a vicious circle

All individuals infected with HIV are believed to be from the marginalised groups since HIV/AIDS is associated with marginalised behaviours and groups (Parker and Aggleton, 2002). This creates a vicious circle of HIV/AIDS-related stigma. See the figure 2.

Figure 2: The vicious circle of stigma and marginalisation



(Source: Parker and Aggleton, 2002)

3.2 Manifestations, determinants and impact of HIV and AIDS-related S&D in Nepal

Literature of study conducted on HIV and AIDS-related stigma in Nepal is very limited. Therefore, in this part, I will mainly use the unpublished report of INF Paluwa. I have also put the reflections of INF Paluwa counsellors and CHBC workers experience on stigma by analysing answers of a questionnaire administered to them.

3.2.1 Manifestations

From the previous chapter, we have learnt that HIV and AIDS-related S&D are universal. Rejection, isolation, avoidance, denial are common manifestations of HIV and AIDS-related S&D. In Nepal People living with HIV are stigmatised and face discrimination in at all societal levels; in the community, at health facilities and most importantly, within the family (CARE Nepal, 2004). There are various forms of HIV and AIDS-related S&D among individuals and communities and their intensity varies enormously in intensity, partly depending on the level of knowledge and attitude.

3.2.1.1 Individual level

Stigma affects at mostly individual level. PLHIV are treated differently by friends, family members, and other individuals in one to one contact (UNDP, 2007). Much of the discrimination may occur due to self or internalized stigma which can lead to self-discrimination where an individual feels guilty or unworthy, leading to a low self esteem, depression and abnormal behaviours such as self isolation, avoidance and introversion (Baral SC et al., 2007)

INF Paluwa counsellors replied that majority of PLHIV suffer from felt and self stigma such as anxiety, guilt, fear and worthlessness after they are diagnosed as HIV positive. They replied that most of their clients have self-stigmatization. Majority of their clients have fear of disclosure and fear of losing honour and social standing.

3.2.1.2 Family and the community level

Families are primary source of care-giving and illness management in Nepal. They can play a significant role in providing care and support to PLHIV. However, they are important sources of HIV and AIDS S&D too (FHI, 2004a). The study conducted by FHI Nepal in 2004 revealed that PLHIV were told to stay away from the home, they were not introduced to guests and not invited in the ceremonies. They did this because they were

afraid that they would lose their "Ijjat" (honour, respect in Nepali) in the community (FHI, 2004a).

Family members do not want to invest on health care and education of PLHIV as they believe that this is the waste of money as they are going to die soon (Experience of Counsellors). Women suffer more from S&D. There are differences in support for men and women who are HIV positive. Women face a lack of acceptance and support from the family members more than their HIV positive husband (FHI, 2004a). They are also morally condemned for the infection and assumed to be responsible for the infection. Some PLHIV especially the women are forced to leave the house after getting HIV status.

> "My family members were not supportive towards me right from the beginning. It was clear that it was my husband who infected me. The same family members were good to my husband who was also HIV positive. When they came to know that I was also HIV positive at the time I gave birth to my son, they made sure I did not use the same toilet used by others in the family. By then my husband was dead. When I returned from my Maiti (parents' home), they kept telling me to go back…"
>
> - 21 years HIV positive female
>
> (Source: FHI, 2004a)

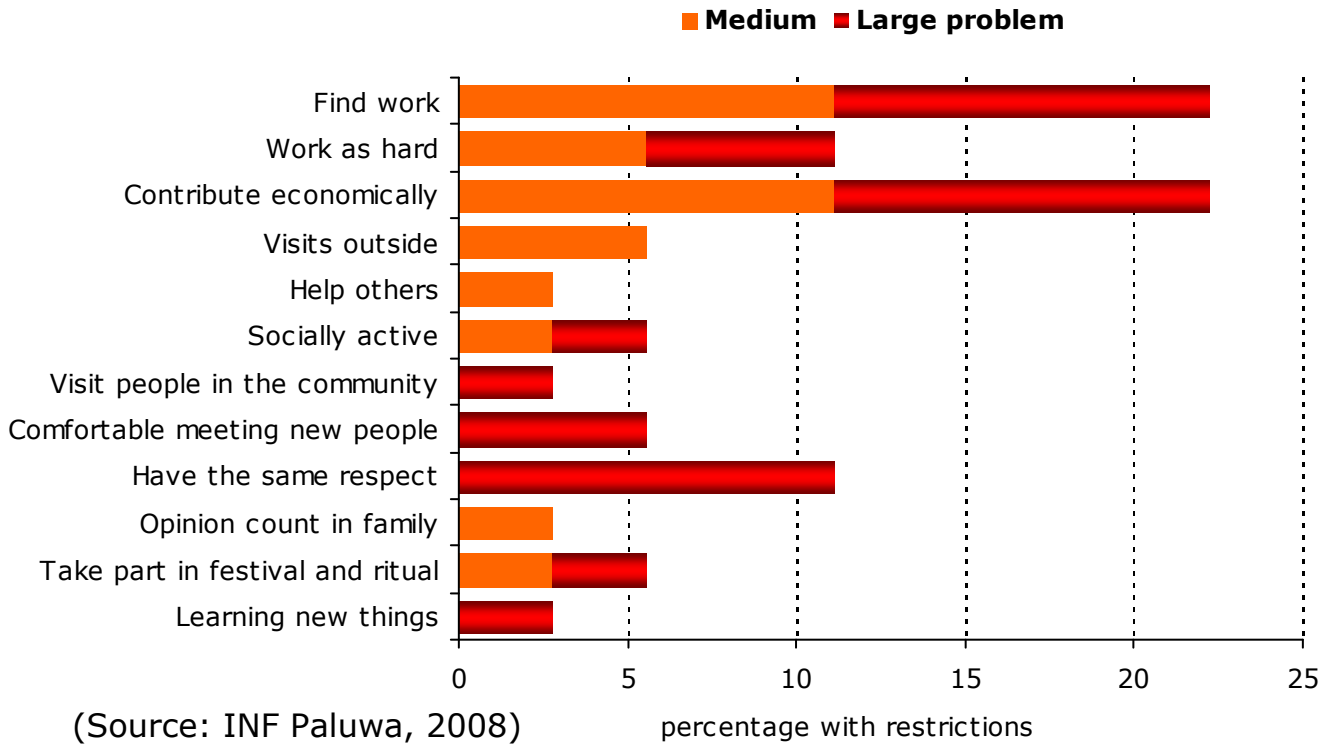
There is a problem in schooling of HIV infected children. In many schools of Pokhara are reluctant to admit the children if they find that s/he is HIV positive or born from HIV positive parents (experience of counsellors).

3.2.1.3 Participation restriction

A pilot study conducted in 2008 by INF Paluwa in Pokhara revealed that nearly 45% of the PLHIV (n=14) had participation restrictions in some form (INF Paluwa, 2008). Most of the participants had problems in finding work and contributing economically in the household. Another significant problem they had was less respect in the community compared to their peers. See figure 3. The study also revealed that it was difficult to find adequate number of respondents to interview. One of the criteria of inclusion was that PLHIV had to have disclosed his/her status at least to family members and or society. Otherwise, if other people do not know his/her status s/he may not face any stigma and social participation restrictions as they may be living like other non-infected persons. Most of the PLHIV had not disclosed their status because of fear of stigma. The

study was conducted by using the Participation Scale[2] (an internationally validated tool) to measure the social participation among people with disability, leprosy and PLHIV.

Figure 3: Profile of participation restrictions among PLHIV in Pokhara, Nepal (n=14)



(Source: INF Paluwa, 2008)

3.2.1.4 Workplace

A study conducted by UNAIDS in India reported little workplace related discrimination because most of the PLHIV had not disclosed their status (UNAIDS, 2001). Much is not known in Nepal's context about the S&D in the workplace but we can assume that the situation might be similar to India. A well known case of HIV-related discrimination in workplace was covered in the headlines one national magazine in 2005. A woman working in a school as a helper was expelled from the job because she was assumed to be HIV infected (Himal Magazine, 2005, cited in FHI, 2006a). Her husband used to be a migrant worker and died of AIDS few months before. She had tested twice for HIV and she was negative. Most of the clients of INF Paluwa have been hiding their HIV status because they fear losing job if they disclose their status to their employer.

[2] This scale was developed by Van Brakel et. al to measure social participation by conducting studies in Nepal, India and Brazil by using standard methods. The instruments were based on the participation domain of International Classifications of Functioning, Disability and Health (ICF). See Van Brakel W.H. et al., 2006.

3.2.1.5 Health Care Settings

Health Care settings are the first sources of information of HIV status and health status for majority of the PLHIV. A study conducted by UNAIDS in India has shown that health care setting was the major source of S&D in India (UNAIDS, 2001). A study conducted in China revealed that health professionals had negative biases against AIDS patients and reported much less willingness to interact with AIDS patients than patient with hepatitis B (Li L. et al, 2006). The study conducted by FHI Nepal revealed that although some hospitals in Nepal treated PLHIV with proper care, however, many PLHIV had humiliating and embarrassing experience in health care settings (FHI, 2004a). S&D towards PLHIV in health care seetings exists in Pokhara too. Not maintaining confidentiality, rejecting or providing poor quality of treatment are examples of major types of discrimination existing in health care settings (Experience of Counsellors).

> *"I am very scared of getting sick. I do not want the doctors to tell me that gradually my AIDS is developing. And I do not want the doctors to behave badly with me. I have seen how they treat HIV patients and I do not want face that."*
>
> *- A 37 year male HIV positive*
>
> *(Source: FHI, 2004a)*

3.2.1.6 Policies and laws

In many countries, there are discriminatory polices and laws are enforced to vulnerable group and PLHIV. There are restrictions on entry and residence on the basis of HIV status (UNAIDS, 2002c). Mandatory HIV testing is required to receive work permit (UNDP, 2007). Some donor countries have policy of not funding needle exchange and condom promotion programme despite of their clear effectiveness in reducing HIV transmission (Herek, G.M. et al. 1996)

In conclusion we can say of HIV and AIDS-related stigma manifests in various level of the society from family to public places like health sector and workplaces. See effects of HIV and AIDS-related S&D at various levels in annex 5.

3.2.2 Determinants

3.2.2.1 Knowledge and Attitude

Stigma stems in part from the misconception. HIV is often known to be a contagious disease. Therefore, people often suspect that an individual with HIV and AIDS poses a threat to the community at a large (ICRW,

2006a). Knowledge and attitudes are important determinants of HIV and AIDS-related S&D in Nepal.

The recent Nepal Demographic and Health Survey reports that majority of people have heard about HIV/AIDS (73% women, n = 10,793 and 92% males, n = 4,397), however, they lack comprehensive knowledge[3] on modes of transmission. It was revealed that only 29% of women and 49 % of men know that HIV can not be transmitted by mosquito bites. Similarly, 13% men and 42% women believed that HIV can be transmitted by touching someone who has HIV/AIDS (NDHS, 2006). The same report shows that a majority of the people expressed a supportive and positive attitude towards PLHIV. However, a significant percentage of respondents had negative attitudes. The negative attitude is stronger among respondents from rural area, less educated people.

> *" I think HIV and AIDS are same. There is no cure…."*
>
> *- A 29 year old FSW in Pokhara*
>
> *(Source: Karki, 2004)*

Although general awareness of HIV and AIDS is generally high, comprehensive knowledge on HIV and AIDS, remains comparatively low among populations groups, especially among most-at-risk populations such as migrants and FSWs (UNGASS, 2008). A study conducted among migrant workers in Western and Far-Western region of Nepal revealed that they lack complete awareness about the modes of transmission of HIV (FHI, 2006b). Many have misconceptions like "a healthy looking person cannot have HIV infection", "mosquito bite can transmit HIV virus" and "sharing food with HIV infected person will transmit the virus". Such misconceptions will help to build fear of contagion and negative attitudes towards PLHIV which will fuel S&D.

Media can play important role in imparting knowledge on HIV and AIDS. Radios and television are key sources of information on HIV and AIDS. A media review conducted by NCASC in 2004 revealed that although Nepali media were covering lots of HIV-related issues, however, the information they were providing were not complete and fully understandable. Some term used with HIV and AIDS-related messages were considered to be contributing to increase the stigma and misconception (NCASC, 2004b).

3.2.2.2 Social and cultural factors

Stigma can be observed in every society, across time and culture. Despite of cultural and social diversity, the manifestations and effects of stigma are remarkably similar all over the world (Van Brakel W.H., 2005).

[3] Comprehensive knowledge means knowing that consistent use of condom during sexual intercourse, having just one uninfected faithful partner can reduce the chance of getting HIV, knowing that a healthy looking person can have the HIV virus, and rejecting two most common local misconceptions about HIV transmission and prevention such as HIV cannot be transmitted by mosquito bites, a person cannot get HIV by casual contacts etc., Source: NHDS, 2006.

HIV/AIDS-related S&D is fuelled by the inappropriate social and cultural beliefs and assumptions. Socially and personally, people tend to associate HIV with moral integrity (ICRW, 2006a). These stereotype beliefs are common in Nepal. A majority of the people (70%, n=54) responded that HIV/AIDS is a punishment for immoral behaviour, such as improper sexual relations and promiscuity (FHI, 2004a). The perception of routes of HIV transmission influenced by cultural ideas and practices related to HIV/AIDS and its assumed relation with disapproved social behaviour and association with marginalised groups. Such attitudes and realisation within particular social contexts create S&D in Nepali (FHI, 2004a). People assume that all PLHIV engage in particular behaviour such as sex work, injecting drug use or sex between male which are against social norm.

Moral Judgement: People who get AIDS did something to deserve it.

Values, Norms and Moral Judgement play an important role in fuelling stigma.

(Source: ICRW, 2006)

Gender is another important determinant for HIV and AIDS-related S&D in Nepal. There is high level of gender inequality in Nepal. Women are underpowered and cannot protect themselves against HIV infection. HIV positive women do suffer more than HIV positive men from being HIV positive. They are more stigmatised because of their low status in the society, resulting in lack of occupational skills, education and access to economic resources such as property (FHI, 2004a).

Nepalese society is complex in terms of caste and ethnic groups. The majority of the Nepalese people follow the Hindu religion and there is a strong hierarchy system based on caste and ethnicity in Hindu religion. The hierarchies also exist between individuals, families, and communities according to their class and economic and political status. The social relationships are influenced by religious or ritual norms and values. A study conducted by Heijnders on views of people with Leprosy in Nepal revealed that the hierarchy had an impact on the effect of stigma and the coping strategies people employed. Especially people with higher caste or class could cope with the stigma better and/or were less stigmatised (Heijnders ML, 2004). This was because people with higher status were more likely to receive information and support from the health worker and even from the community compared to those

"I would like to play with my sister's children but my family is afraid. People who are HIV-positive are dying of stigma and cannot lead a normal life."

- Anjan Amatya, HIV positive activist in Nepal

(Source: Bell T., 2003)

having lower status. Stigma therefore enforces already existing inequalities in social class, gender, and age.

3.2.2.3 Legislations and regulations

Legislation and regulation is important in promoting and protecting human rights of vulnerable people and PLHIV. HIV vulnerability and HIV and AIDS-related S&D both can be reduced by creating enabling environment which respects the human rights of PLHIV and affected people.

A legislative audit conducted by Ministry of Health with the support of Policy Project in 2004 revealed that there is no specific law to address HIV epidemic in Nepal and to protect the rights of people at risk of HIV infection and PLHIV (NCASC, 2004a). There is no prohibition of compulsory or mandatory HIV testing, and no requirement to obtain informed consent with pre- and post test counselling by those performing HIV tests. Also, there is no prohibition of HIV screening for general employment purposes and there is no legal requirement to implement universal precautions in the workplace. Furthermore, there is no law that provides employment security for HIV-positive people.

CHAPTER 4. PUBLIC HEALTH CONSEQUENCES OF HIV AND AIDS-RELATED STIGMA AND DISCRIMINATION

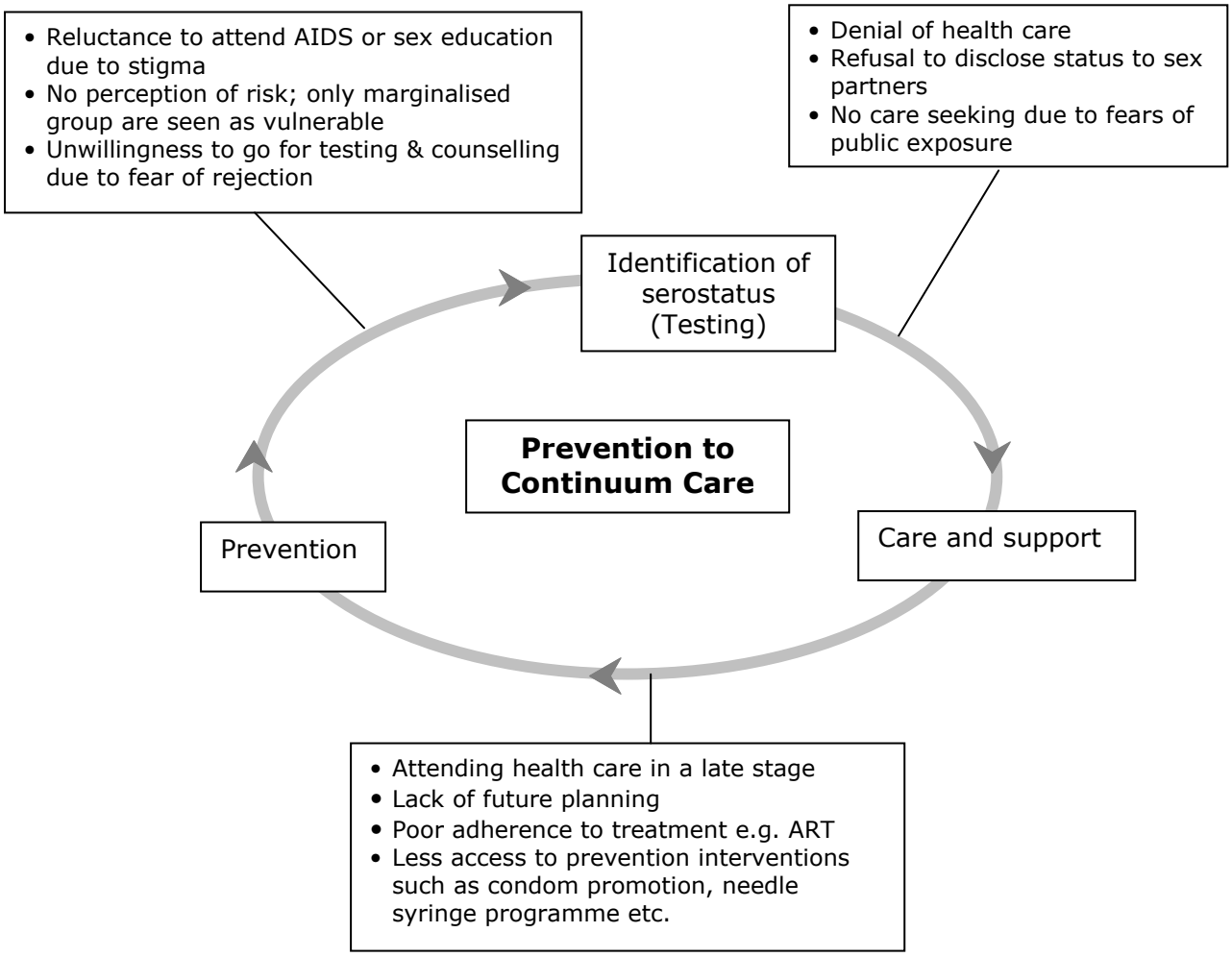
Since the beginning of the HIV/AIDS epidemic, S&D have fuelled the transmission of HIV and have greatly increased the negative impacts associated with the epidemic (UNAIDS, 2005b). The effect of the widespread S&D is not only limited to lowering the quality of life of PLHIV but it is also creating barrier in responding HIV effectively.

HIV and AIDS related S&D affects HIV prevention and care programmes in many ways. Firstly, this creates barriers by discouraging people from being tested and preventing people from recognising that they or family members are HIV positive. This also hinders access to HIV prevention services such as condom and needle exchange etc. Secondly, it prevents quality care, treatment. Thirdly, it increases the social inequalities by hindering access of PLHIV to housing, education, employment and mobility. Ultimately these all negatively affect the quality of life of PLHIV and their families leading to increased transmission, morbidity and mortality (Morrison K, 2006).

The "Prevention-to-Care continuum" is a widely-used model to respond to the HIV epidemic in the world (MacNeil and Anderson 1998 cited in Busza, 1999). While preventive interventions reduce the need for future care at the same time care and support activities also helps HIV prevention by normalising disease through creating awareness of the disease and its transmission routes. Care and support also empowers PLHIV to be in the forefront of HIV prevention in the community. They can convince others that they could be at risk also and encourage them to seek counselling and testing and adopt safer behaviours. This cycle works only in a supportive environment where people can feel they will receive care and support if they are found to be HIV positive and where behavioural

change is viewed positively. HIV and AIDS-related S&D hinder the creation of such a supportive environment at all stages of the cycle. The figure 4 illustrates how S&D create barriers to an appropriate response to HIV prevention and care.

Figure 4: Impact of stigma on HIV prevention and care



(Adapted from Busza, 1999)

4.1. Impacts on prevention

Globally, S&D are associated with lower uptake of HIV prevention activities including non participation in HIV informative meeting and counselling and reduced participation in programmes to prevent mother to child transmission (UNAIDS, 2007b). Most of the people and

communities do not consider that they are at risk of HIV and may acquire the infection through their own risk behaviours because they link HIV only with some marginalised groups (Busza, 1999). People are less likely to seek for testing services to find out their serostatus as they are afraid of being associated with those marginalised groups.

VCT is considered as the entry point for HIV prevention and care (UNAIDS, 2000). People who receive a negative result can change their life-style and behaviour to remain negative life-long and those who test positive can take measures to prevent further transmission. However, in many countries, or places where HIV is seen as a problem of marginalised groups, family and community may reject PLHIV. This fear of rejection or stigma is a common reason for low uptake of VCT (UNAIDS, 2000). A need assessment on VCT in Pokhara, Nepal revealed that one of the major barriers for low uptake of VCT service was stigma and fear of discrimination. A significant percentage of the respondents [40% FSWs, n=28 and 30% IDUs, n = 31] were worried about being positive and they also expressed the concern about confidentiality in the VCT centres (Karki, Y.B., 2004).

Some people might continue risk behaviour and fail to change it due to perceived stigma. They fear that such change would arouse suspicion and stigma. For example, HIV positive nursing mother may continue to breastfeed to her baby despite of her knowledge about the danger of transmission to the child, because she fears disclosure of her status by bottle feeding (Brouard, P. et al. 2006).

Stigma linked to HIV-associated behaviours such as drug use or certain sexual practices is also a barrier to successful HIV prevention. It hampers harm reduction interventions such as condom promotion and provision for FSWs, needle exchange among IDUs and sex education to adolescents since it is assumed that these activities would promote behaviours that are not in line with considered social "norm". Stigma enforces some donor countries to have no funding policy to needle exchange programme despite of their clear effectiveness in reducing HIV transmission (Herek, G.M. et al. 1996).

> *"I don't go anywhere because once the health workers know that I'm a drug addict they treat me differently. They don't try to understand me. They should treat us like normal sick persons."*
>
> - 19 year old unmarried boy in Pokhara
>
> (Source: Karki Y.B., 2004)

In Nepal, the coverage of needle exchange programme is reported to be just 8.6% (UNODC, 2008). Furthermore, Only 11,500 cases have been identified which is just 16% out of total HIV estimated cases. The coverage of ART and PMTCT is also low at 17% and 2% respectively. S&D

is considered to be one of the reasons for low coverage of prevention programme among various target groups in Nepal.

4.2. Impacts on treatment, care and support

Stigma not only fuels the spread of HIV infection but also affects the quality of life of PLHIV and their access to quality treatment and care. PLHIV are less likely to receive treatment, care and support as a result of S&D (UNAIDS 2005b). The shame associated with perceived and internalised stigma may prevent PLHIV from seeking treatment, care and support. The fear of S&D may influence PLHIV to reject or postpone care, prevent exercising other rights such as working, attending schools etc. (UNAIDS, 2007b). In Botswana, a survey of patients receiving antiretroviral therapy found 40 percent (n=112) delayed getting tested for HIV, mostly due to HIV-related stigma (UNAIDS, 2005b). In many ART programmes, stigma is one of the reasons of poor adherence.

After knowing his/her HIV status, an infected person can make planning for the future. Ideally, HIV positive individual notify their partners, family, and wider community, adopt safe behaviours to avoid further transmission, and receive care, understanding and support in return (Busza, 1999). However in reality, the fear of S&D discourages infected person from disclosing their serostatus to their sex partners, family members, friends, employers and even health care providers. A study conducted in South Africa revealed that non-disclosure is closely related to behaviours that supports the HIV transmission. Among the 903 sexually active HIV positive, 378 (42%) had sex with a person to whom they had not disclosed their status and they were more likely to have unprotected sex with the partners (Simbayi L.C. et. al, 2007)

4.3 Stigma and Discrimination: a barrier to universal access

In June 2006, the United Nations General Assembly made a new commitment to scale up toward the goal of universal access for HIV prevention, treatment, care, and support by 2010. The declaration commits UN member states to scale up their national responses to HIV and AIDS, with the involvement of affected communities, vulnerable groups, private sector, and PLHIV (UNAIDS, 2006b). To achieve this goal, countries will need to address the obstacles blocking provision and uptake of these services. From the beginning of the epidemic to the commitment to universal access, the experts and communities have consistently identified HIV-related S&D as critical barriers to effectively addressing HIV epidemic (cited in UNAIDS, 2007b). Despite of recognising this problem, no country has prioritised activities to reduce or eliminate S&D in their national AIDS plans. Without addressing HIV and AIDS-related S&D, the goal of Universal Access will not be achieved.

CHAPTER 5. REVIEW OF SELECTED INTERNATIONAL PUBLICATIONS ON INTERVENTIONS TO REDUCE STIGMA AND DISCRIMINATION

From previous chapters, we have learned that HIV and AIDS-related S&D is a complex phenomenon which is deeply linked to social norms and values. In recent years, a lot of progress has been made in tackling HIV and AIDS-related S&D around the world. A series of research studies have been conducted in some countries, such as India, Vietnam and Uganda etc. These studies were conducted mainly by UNAIDS and ICRW. Some interventions, strategies and frameworks have been developed according to the findings of their study results.

Not much has been done on HIV and AIDS-related S&D in Nepal and the documentation related to this issue also remains very rare. A literature review on interventions was done to identify successful actions that may be used to disentangle this issue in the country. A few selected publications that may be applicable to the situation in Nepal are reviewed here.

5.1 Review of interventions

HIV and AIDS-related S&D interacts within a broader social, cultural, political, and economic framework. It is not an individual action but it is a social process which creates and maintains social control and structural inequalities (Parker and Aggleton, 2002). Therefore, a single intervention or initiative such as individual psychological approach or legal reform does not have much impact on reducing S&D. The studies reviewed have shown that interventions should be multi-targeted and oriented at multiple levels (Heijnders and Meij 2006). They should aim at social, environmental and structural change to tackle various aspects of HIV and AIDS-related S&D simultaneously (Parker and Aggleton, 2002).

The best practices review follows three broad categories of strategies and interventions: 1) preventing and reduction of stigma, 2) challenging discrimination at the institution level and 3) promoting and protecting human rights (UNAIDS, 2007b). They are described separately in the following section.

5.1.1 Preventing and reducing stigma among different key audiences and communities

5.1.1.1 Working with people living with HIV and their families

In Belarus, with support from UNDP, Positive Movement, an NGO (PLHIV, their family members, doctors, psychologists and sociologists are the member of the NGO) implemented a project involving PLHIV in HIV prevention activities (UNDP, 2005b). PLHIV were provided psychological support and legal advice to cope with the internalised stigma. A range of activities were conducted. A self-help group for PLHIV was formed and they used to meet weekly. Individual and group therapy was provided by psychologists. A telephone hotline was run on HIV-related issues. This hotline was operated by trained counselors including PLHIV to provide information and emotional support to the callers. Legal advice was provided to PLHIV. PLHIV were involved in various HIV prevention activities such as recruiting new member in the self help group, providing education and emotional support to those who are tested positive. They also provided education and information to various groups such as PLHIV, young people, prisoners, university students etc.

Many positive outcomes were achieved as a result of this intervention (UNAIDS, 2005b). Firstly, there was increased access to information, individual and group psychological support, legal advice and medical care. Secondly, the number of PLHIV who were willing to disclosing their status increased. Two PLHIV gave interview openly in different TV channels and five articles containing life-stories of PLHIV were published in newspapers and magazines. These stories were used to discuss S&D faced by PLHIV. Thirdly, a small grants fund was established to support advocacy activities.

In Uganda, an approach 'counselling and support to HIV infected families, including their children' was used through "succession planning". HIV positive parents were supported for the future planning of their children and families. Key activities were, supporting HIV positive parents to disclose their status to their older children, helping them in designating "standby parents", assisting children in school fee, and motivating the community in taking care of orphans etc. It was reported that there was an increase number of HIV positive parents appointing guardians and disclosing their status to their children. This also improved the attitudes towards PLHIV and there was a prominent increase in the demand and uptake of VCT in the community (UNAIDS, 2005b).

5.1.1.2 Working with Religious leaders

Religious leaders are influential people in the community and can be a key stakeholder in stigma reduction interventions. A project called "The Sangha Meta (Compassionate Brethren) project" was implemented in Chiang Mai, northern Thailand in 1997 to mobilize Buddhist Monks and nuns. The project trained Buddhist monks, nuns and novices in HIV/AIDS prevention, care and support with participatory management skills and tools work with community in order to prevent infection and provide support fro affected people. An important part of the training was promoting positive attitudes among monks and nuns thorough close contact with PLHIV, for example eating food prepared by them. Buddhist religious ethics such as Five Precepts and Noble Eight fold paths were used as guideline to train and teach monks and local communities on how to reduce risk behaviours, raise awareness and how to prevent prejudice and discrimination. More than 3000 monks and nuns were trained by the project. Monks also conducted home visits and demonstrated care towards PLHIV, providing Buddhist based counselling and home based care. This project brought many positive changes in the community. After the implementation of the project, increased numbers of PLHIV are actively participating in community and religious activities. Community people are accepting PLHIV and their families, for example HIV positive children are now admitted in schools where previously they were rejected for admission. The Sangha Meta training model has been used successfully also with Christian, Hindu and Muslim religious leaders in neighbouring countries (Sangha Meta Project).

5.1.1.3 Working with Communities

ICRW implemented series of interventions in local communities to reduce the HIV/AIDS-related S&D in Viet Nam, Tanzania and India (ICRW, 2006a). In Vietnam, awareness raising workshops on stigma were conducted for communist party institutions and government agencies to use stigma toolkit to train local community leaders on stigma reduction. After attending the participatory action-plan workshop, the community leaders themselves developed their own plans and stigma reduction interventions. The ICRW team provided technical support and guidance in the implementation and evaluation of the programme.

> *"Skills Are Not Built Overnight, Stigma Reduction Takes Time"*
>
> *- Source: Hong K.T, 2006*

In Tanzania, ICRW worked with community-based organizations (CBOs) and supported them to integrate stigma reduction intervention in their activities. A community-based stigma reduction program was implemented by the CBOs. The staff members, local volunteers and peer educators were trained on stigma reduction issues. A stigma reduction toolkit (Understanding and Challenging Stigma: A Toolkit for action), designed

and developed based on the findings of research on stigma, was used in the training. This toolkit was especially used to address the gap in knowledge and understanding of stigma and equip participants with skills to carryout stigma reduction activities in the community. A trainers training was organised for 10 key influential leaders of the local community to improve their knowledge and understanding on HIV/AIDS and stigma and to develop action-plans to integrate stigma reduction activities in the ongoing activities of the local organizations. The CBOs integrated anti-S&D activities into existing activities such as integrating anti-stigma messages in community dramas etc. Stigma indicators were used to evaluate the community based stigma-reduction programme.

In Andra Pradesh, India, two local NGOs implemented interventions to reduce violence against women and reduce HIV/AIDS stigma (ICRW, 2006b). The NGO and the local community worked together to research design and implement the programme. An adapted stigma reduction toolkit was used to work with communities to address stigma and gender based violence. The toolkit was developed in collaboration with truckers and people who interacted with them such as FSWs, spouses and truckers' helpers etc. who are also at risk of HIV infection, violence and stigma. This intervention brought various groups together and helped them to understand the association between HIV/AIDS and stigma and gender-based violence and the need to address them in the community.

In all places there were promising outcomes of the community-based stigma reduction interventions. The community had more acceptable attitudes towards PLHIV. In Tanzania, programme staff effectively conducted the stigma reduction activities in the community. The attitude and behaviour of community leaders towards PLHIV was changed positively. Community members targeted by the intervention demonstrated less stigmatizing attitude compared to those who were not covered. In addition, the number of PLHIV attending the group counselling also increased. Condom use increased considerably among the truckers in India and awareness on HIV-related stigma and violence against women was increased among the local community. This created an enabling environment leading to more acceptance of PLHIV and eventually this led to their active participation in workshop seminar and other project activities.

5.1.1.4 Working with Media

Soul city is an NGO that established a national multi-media project in 1992 in South Africa. This project has been running various television series of edutainment dramas. Soul city aims to bring positive impact on peoples' life by imparting information on health and development issues impacting on social norms, attitudes and practice. Soul city has developed and aired 8 television series of about 13 episodes each and reached to

more than 16.2 million people (UNAIDS, 2005b). A variety of health related topics has been addressed in those broadcasts including HIV/AIDS. The TV series deal with HIV and AIDS-related issues such as living positively after being HIV positive and S&D. A radio series is developed to cover the rural audience in the same storyline and messages as TV series. Many positive impacts are being observed because of this project. An internal evaluation of the project has been carried out regularly. The evaluation findings revealed that this initiative has helped to create enabling environment for HIV prevention and care. First, it helped people to become more open about talking on sensitive issues related to HIV and AIDS such as sex, condom use etc. People were more willing to ask their partners to use condoms and practice safer sex. Second, this also helped to create awareness among the audience, such as PLHIV can live normal and healthy life etc. Third, people's attitude towards PLHIV was improved.

In Vietnam, the institute for social development studies (ISDS) mobilized journalists and media professionals in HIV and AIDS-related S&D (UNAIDS, 2007b). Training and workshops were conducted to discuss these issues. They were guided on how they can contribute to reducing or preventing stigma. For example, how to create enabling environment for HIV and AIDS and positive attitudes towards PLHIV through not portraying negative images of PLHIV, giving exact and accurate information, not providing sensational fear-inducing news coverage etc.

Media can publicize positive role models. Positive role models can play a critical role in the fight against HIV/AIDS-related S&D. A well-known example of this is Mr. Nelson Mandela, former president of South Africa, who is actively working to fight against stigma related to HIV and AIDS. On 6th January 2005, just after his son died, he announced that his son was died of AIDS. He was one of the few leaders in the region to break the silence over the disease (BBC News, 2005). Mr. Mandela decided to make public the cause of the death of his son to challenge the taboos surrounding HIV and AIDS in South Africa.

> *"Let us give publicity to HIV and AIDS and not hide it"*
>
> *- Nelson Mandela*
>
> *(Source: BBC news, 2005)*

5. 1.2. Challenging discrimination at institution level

5.1.2.1 Working with Health Care Providers

In Vietnam, an intervention research was implemented in four hospitals to challenge HIV-related S&D and to improve the quality of care in health care settings (Oanh K.T.H. at el, 2008). The study team conceptualised two basic causes of HIV-related stigma, the first is fear of causal transmission and the second is negative values/social judgments and

associations between HIV and certain behaviours. Six key components were implemented: establishment of a hospital steering committee, staff training focusing on universal precaution, hospital policy development, provision of material supplies to practice universal precautions, provision of educational materials, and monthly monitoring. Forty-three qualitative interviews were conducted among staff from the study hospitals both in the beginning and in the end of the research. At baseline, hospital staff reported high levels of fear and value based stigma. It was also reported that there was discriminatory behaviours and practices. The intervention was successful in reducing fear and value based stigma among all four hospital staff. Also, there was reduction in the practice of discriminatory behaviours towards PLHIV among the hospital worker. This study revealed that addressing S&D in health care setting can improve the quality of health care for PLHIV.

In India, the Horizons programme, with the support from the National AIDS Control Organisation, conducted an operational research project to develop and test hospital based S&D against PLHIV in three hospitals in New Delhi (Mahendra V.S. et al., 2006). A baseline assessment was conducted by interviewing health workers, PLHIV and NGO providers to identify the causes and manifestations of S&D in health care settings. The findings of the assessment helped to develop the "PLHIV Friendly Checklist" and a self assessment tool for hospital managers to identify institutional strengths and weaknesses in terms of service provision for PLHIV and hospitals' policies and procedures to prevent occupational exposure. The checklist covered the following areas: access to care services, HIV testing and counselling, confidentiality, infection control, and quality of care. Using this checklist a random sample of 884 health care workers was interviewed to identify their knowledge, attitudes and practice. The findings were discussed with the hospital managers. Based on this, the hospital managers, senior doctors, nurse and ward staff prepared a plan of action to improve the situation in the hospitals. The project team and local HIV NGO helped each hospital to implement their plan of action by providing training and disseminating policy guidelines and educational materials. This operational research has been reported to bring many positive changes in the hospitals. Firstly, the hospital management themselves internalised the existing problems and initiated their own stigma reduction approaches. Secondly, health care workers' knowledge of HIV transmission and universal precaution increased which ultimately help to improve their attitudes towards PLHIV.

5.1.2.2 Workplace interventions

In Thailand, the business and private sector has been mobilised to respond the problem posed by HIV and AIDS by the Thailand Business Coalition on AIDS (TBCA) which is a non-profit organisation, established in 1993 (UNAIDS, 2005b). TBCA was established with the support from

Thailand Ministry of Public Health, WHO, and the business sector. TBCA also helps to tackle the discrimination faced by employees living with HIV. TBCA carried out surveys among 403 and 125 Thai companies 1997 and in 2001 respectively, which discovered that there was widespread discrimination. Many companies were conducting randomly pre-employment on-the-job HIV testing, breeching employee's rights to confidentiality. No training programme was conducted for the employees to provide factual information on HIV and AIDS. Two major strategies were used by TBCA, building capacity of business partners and assisting them in preparing and implementing HIV workplace policy programmes. It provided six training curricula which aimed at preventing and controlling HIV in the workplace. Besides training/education and policy development, it also managed a community-based programme to assist former employees living with HIV and assisted them in legal issues. Some successes have been reported to be achieved by the programme, such as many business companies adopted HIV workplace policy, increased sense of acceptance and support for employees living with HIV in the workplace. The programme has become a model programme to be piloted in other countries across Asia.

RTI International has implemented a 4-year (2003–2007) Uganda workplace HIV/AIDS prevention Project, which aims to prevent HIV infection and mitigate the impact of HIV in informal-sector workplaces in Uganda (RTI international, 2007). The major target group of the project is informal sector workers such as market vendors, transport workers, transport workers etc. Faith Based Organisations and CBOs are the implementing partners for this project. The project provided support for approaches that include "ABC" (abstinence, being faithful, condom use) HIV prevention methods, prevention of mother-to-child transmission, reduction of HIV/AIDS-related S&D at the workplace, mitigation of the impact of HIV/AIDS among informal sector workers and their families. Testimonies from PLHIV are organised especially to reduce S&D. The project has reached nearly 530,000 people through various IEC activities. Over 400 peer educators have been trained and mobilized to educate their co-workers and over 800 education/awareness training sessions have been conducted. It is reported that this project has created enabling environment for HIV prevention and care including sensitizing community on S&D.

5.1.3 Promoting and protecting human rights

In India, the Lawyers Collective HIV/AIDS Unit, a non-profit NGO, was established by lawyers, law students and other law affiliates to provide legal aid to marginalized groups in public interest litigation, including the advocacy for PLHIV's rights. This NGO has initiated public interest litigation on the following health issues: access to treatment and service, HIV testing, privacy and confidentiality; protection of sex workers,

discrimination in employment and services etc. They also conducted public awareness campaigns through advocacy about legal and ethical implications of the AIDS epidemic, including dialogue on law reform for legal community, policy makers, activists, NGOs and other HIV-related organisations. The HIV/AIDS Unit has defended and won several cases for the workers who faced discrimination and lost their jobs from being HIV positive. They also petitioned government to provide access to ART for PLHIV. As a result of this, the government established 250 ART centres to provide treatment to 300,000 PLHIV under the National AIDS Programme (UNAIDS, 2007b).

The AIDS Law Unit in Namibia protects human rights of PLHIV and their families by providing free legal services, information and engaging in research and advocacy activities. This unit has handled several cases of HIV-related discrimination associated to employment and insurance sector. The unit conducted research on legal/policy responses to discrimination issues. Considerable positive outcomes have been reported. The unit facilitated development of AIDS workplace policies for several public private sector businesses. The unit also successfully challenged the Namibian Defence Force's policy of pre-employment testing and excluding people with HIV from employment. The labour court gave a verdict not to exclude people from the employment on the basis of HIV positive status (UNAIDS 2005b).

In four African countries (Kenya, Botswana, Namibia and Tanzania) parliamentarians themselves are working to improve women access to health services, especially HIV and AIDS care, treatment and prevention through a project called Parliamentarians for Women's Health (PWH). The project is working to increase the communication and links between parliamentarians and women PLHIV, raising awareness on women's health needs and socio-economic, cultural and political barriers that hinders women's access to health care. The project also provides technical assistance to parliamentarians in their day-to-day activities that enable formulating legislation to improve women access to health care. This project has been reported as being successful in raising awareness and understanding among parliamentarians on women's health needs and facilitating greater communication between parliamentarians, their constituents and women living with HIV (PWH, 2008).

Conclusion

The above mentioned case studies illustrate that stigma needs to be dealt through multi-faceted interventions and approaches. Dissemination of accurate and appropriate information is the foundation of such interventions and this should be accompanied by social mobilization and empowerment of vulnerable people and PLHIV. Provision of services such as VCT and ART are effective in reducing stigma as this help to improve

the quality of life of PLHIV. Beside these, law reform and policy formulation are very important aspects of the strategies to challenge the discrimination, which is common in health care settings and workplaces. Most of these successful programmes could be replicated in Nepal.

CHAPTER 6. CURRENT INTERVENTIONS IN NEPAL

In this chapter, I will be discussing the current interventions and activities implemented in Nepal to mitigate HIV and AIDS-related S&D. In Nepal, over 200 national NGOs and networks are working on HIV and AIDS prevention and care with the technical and financial support from the government of Nepal, UN agencies and external donor partners. A wide range of services is being provided to people most at risk of infection such as FSWs, IDUs, MSM and people infected and affected by HIV and AIDS. These services include behaviour change communication (BCC), STI diagnosis and treatment, harm reduction, VCT services, management and treatment of opportunistic infections, ART, home and community-based care, material and livelihood support, advocacy, community sensitization etc. Stigma reduction is a part of their activities (UNGASS, 2008).

6.1. Programme activities related to the reduction of S&D

6.1.1 VCT services

VCT service is an entry point to both HIV prevention and care and support services for people affected and infected by HIV (FHI, 2004b). It provides opportunities for people to reduce their risk of getting HIV. Counselling and testing also normalise HIV in the community as more people are tested, more will know their status and more will get the factual information on HIV and AIDS. This will help to reduce misconceptions which will facilitate to reduce the denial, S&D. In Nepal, various NGOs and public health sector provides VCT services. Recently, there has been a significant expansion of VCT services in Nepal (UNGASS, 2008). Currently, a total of 106 VCT centres are providing such services.

6.1.2 Treatment and care and support services

The government of Nepal started to provide free ART service in 2004. Currently, over 1500 people are taking ART from 22 different ART centres in Nepal (NCASC, 2008b). Management of OIs is also a part of services to be provided from these sites. PMTCT service is provided from 15 different hospitals in Nepal. NGOs and networks are providing other care and support services for PLHIV and their families such as, emotional and psychological support, income generation support, schooling support etc. Some organisations are providing these services through CHBC. CHBC service is considered to be helpful for reducing S&D. The CHBC workers and family members can help to decrease the fear of community by providing compassionate and open care.

6.1.3 Media Campaign

With the support from USAID and FHI Nepal, the National Centre for AIDS and STD control has launched many media campaigns.

A multimedia campaign "Let's start talking about AIDS today" implemented in 2002. The objectives of the campaign were to encourage Nepalese youth to protect themselves from HIV, generate political support among policy makers and sensitise people to reduce HIV-related stigma. The campaign showcased nine Nepalese celebrities, personalities and PLHIV on billboards, posters, television, and print media. It is estimated that the campaign reached to 85% of youth in Kathmandu. In the first three month only, the campaign reached to an audience of more than 3 million through TV, 2.5 million through print media and 3 million through radio. In the evaluation conducted in 2002, it was reported that those who exposed to campaign were more likely to know the correct modes of transmission of HIV than those who were not exposed. For example, 80% of the exposed audience knew that a person can not get HIV by sharing a meal with someone who is infected whereas only 34% of non-exposed audience knew this answer (FHI, 2007).

A Stigma Reduction Campaign called Ek Aapas ka Kura (Talking to Each Other) was implemented in the year 2005/2006 by FHI Nepal. This was a mass media campaign aimed at addressing the HIV and AIDS-related S&D existing in health care settings, families, and the wider community. PLHIV were mobilized to design and produce the radio program with the support from popular radio and television stars, and media experts. National radio and FM stations broadcasted this serial drama nationwide which dealt with various situations involving HIV and AIDS-related S&D (FHI, 2007). However, there is no evaluation conducted to measure the impact of this campaign.

Besides national level interventions, most of the HIV/AIDS-related organisations are organising media campaign at the local level in their working area to sensitise community people on HIV and AIDS aiming to reducing S&D.

6.1.4 Empowering and mobilising vulnerable group and PLHA

S&D can be mitigated through the mobilisation and empowerment of PLHIV. Especially, internalised and self stigma can be tacked by this approach. In Nepal many HIV/AIDS-related organisations are working in this area. National Association of People Living with HIV in Nepal (NAPN) has been working at the forefront of this. NAPN is a network of PLHIV and established in 2003. More than 120 PLHIV organisations have been affiliated to this network and they have more than 700 members (NAPN, 2008). One of the aims of NAPN is to empower PLHIV and build their

capacity to respond to the needs of PLHA in advocacy, counselling care, support and to improve access to healthcare and legal services. NAPN is implementing capacity building programmes in 40 PLHA organisations. NAPN and its network partners have initiated numbers of community awareness and stigma reduction activities through positive role models and anti-stigma messages.

In Nepal, a number of organisations are working on building and strengthening the leadership and advocacy skills of PLHIV and vulnerable groups. The Policy Project is conducting various activities to empower PLHIV and vulnerable groups such as MSM, IDUs, FSWs etc. The project helped them to form groups and build networks and organisations so that they can tackle the S&D in an organised way. They are also building their capacity through training, workshops, interaction and helping them to advocate for HIV/AIDS policies and programs, and their implementation. This has enabled their meaningful participation in policy, dialogue and advocacy (Policy Project, 2006).

> *"Through advocacy training, we now know that whether a person is big or small, everyone has equal rights. Now we are not scared to talk to people. Earlier, we used to feel very insecure."*
>
> *- A sex worker from Kathmandu*
>
> *(Source: Policy Project, 2006)*

6.1.5 Policy and legal response

HIV/AIDS has been a priority in the Three Year National Plan (2008 – 2010) in Nepal. Moreover, HIV/AIDS has been included as key component in the other important plans and frameworks such as the National Health Sector Programme Implementation Plan (2005), Poverty Reduction Strategy Paper and United National Development Frameworks (UNGASS, 2008). The country is currently implementing the third National HIV/AIDS Strategic plan (2006-2011) with S&D reduction as one of the core strategies (NCASC, 2007). There is a considerable improvement in the strategy nowadays as the strategy development process was done by involvement of multi-sector and non-health sectors as well.

Some initiatives have been started for the development of policies such as National Workplace policy, National Policy on Drug Control and HIV/AIDS and human right forum (UNGASS, 2008). Recently, there has been some progress in Nepal in terms of reform of laws related to HIV and AIDS. The Supreme Court has recognized Lesbian, Gay, Bisexuals, Transgender and Intersexes (LGBTI's) as natural person and has ordered the government to promulgate laws to ensure their rights to life and identity and amend all the discriminatory laws against PLHIV (UNGASS, 2008). In 2002, the Supreme Courte of Nepal has given a verdict recognizing sex work as a type of profession and everyone has the right to choose profession (Shrestha B., 2006).

6.1.6 Strengthening policy environment

There are 9 formal and informal networks of PLHIV, FSWs, MSM, IDUs and NGOs working in Nepal who are actively working to advocate their own issues related to HIV and AIDS and human rights, gender and S&D. They also work as pressure groups to improve their access to HIV prevention, care and treatment services. Representatives from these networks are also participating actively in the development of strategy and policy formulation such as National Strategic Plan, operational manual and guidelines (UNGASS, 2008).
Some achievements have been obtained in relation to mobilisation of the political commitment in the recent years. With the support from Policy Project, NCASC worked with policy makers from central to local level to create enabling policy to stop the spread of HIV and to reduce the S&D (Policy Project, 2006).

6.2 Gaps and challenges in Nepal

Nepal has made considerable achievements in the recent years in HIV prevention and care including stigma reduction activities. However, there are still many challenges and gaps which are hindering in the response to the epidemic. Major challenges are as below.

6.2.1 Political commitment

HIV and AIDS requires high level commitment and leadership. Currently, Nepal is in a political transition which poses political instability and it is believed that this is hampering all development work, including HIV and AIDS. This is apparently creating a barrier in the implementation of policies into practice and is an obstacle for programme harmonisation and co-ordination, leading to a weak system of co-ordination, monitoring and evaluation. The gap of implementation capacity of the government of Nepal is currently being filled by UNDP Nepal by providing management support to implement HIV/AIDS-related activities funded by Global fund, and DFID.

There has been a positive shift in some policies and legislation that which ensure the rights of marginalised group such as MSM, FSWs and IDUs etc. However, there are still big gaps between policies and realities. There is a lack of political commitment for the implementation and enforcement of these policies and laws. Vulnerable groups such as MSM, FSWs and IDUs are often harassed and abused by the police (FHI, 2001, Shrestha B., 2006, Peak MG et al., 2001).

6.2.2 Programme coverage

Although there has been expansion of HIV and AIDS-related services in recent years in Nepal, however, the programme coverage is still inadequate to address the epidemic including S&D. Most of the programmes focus in urban and cities whereas there are no services in rural and remote districts. VCT, STI, BCC and ART services are mostly located in the big cities. Seasonal migrants are one of the major risk groups to be affected by HIV and AIDS. Majority of the migrants are from rural villages. The current effort is not enough to increase coverage among this group.

6.2.3 Multi-sectoral response

HIV and AIDS can not be tackled by only the public health sector. We need a multisectoral response from all government units and the private sector to mitigate the impact of the epidemic. Despite of being one of the strategies of the national HIV/AIDS strategic plan, this has not been effectively initiated. The involvement of other sectors in HIV and AIDS is very limited.

6.2.4 Workplace polices

HIV affects labour and productivity and the workplace has a vital role to play in mitigating the impact of HIV infection (ILO, 2001). S&D is also an important issue in the workplace. In Nepal, there is hardly any sector which has developed and implemented the HIV workplace policy, including, ironically the organisations working in HIV and AIDS.

6.2.5 Health systems weaknesses and Human resources

Health system weaknesses such as poor infrastructure, staff turn-over and absenteeism and poor management of logistics and supplies have been major challenges in scaling up the treatment, care and support services in Nepal. There is a lack of adequately trained and skilled human resources to provide quality services.

CHAPTER 7. CONCLUSIONS AND RECOMMENDATIONS

The association between stigma and HIV and AIDS is as old as HIV epidemic itself. Stigma is a complex phenomenon that is deeply linked to social values and fear around sex and death and is associated with social inequalities related to gender, social class etc. Despite of cultural and social diversity, the manifestations and effects of stigma are remarkably similar all over the world. S&D related to HIV and AIDS has serious effects and implications for the life of individuals and also is an obstacle in the response to HIV epidemic.

Fear of contagion is a major contributing factor to HIV and AIDS-related stigma. Lack of or inadequate knowledge fuels this fear. HIV and AIDS are considered a death sentence having no treatment or cure. Many people in the community have misconceptions about the modes of transmission of HIV. Therefore they fear getting HIV and try to avoid PLHA, resulting S&D. Other important contributing factors are social norms and values. HIV is directly associated with behaviours that are considered illegal or forbidden in many societies, such as extra-marital sex, sex work, drug use and sex between men. People vulnerable to HIV or PLHIV are believed to be social evils or to deserve to have the disease as the result of their deeds.

Freedom from discrimination is a fundamental human right and this is also essential for the realisation of other rights (UNAIDS, 2002b). People at risk or PLHIV are often rejected or denied fundamental rights like equal rights of access to treatment, education, employment, movement etc. HIV-related S&D is widespread and this seriously hinders the efforts for HIV prevention and care. Fear of discrimination prevents people from utilising HIV prevention services such as BCC, VCT, STI services and prevents people seeking treatment for AIDS or disclosing their status openly. This increases the impact of the epidemic on individuals, families, communities and nations.

Nepal's current national HIV/AIDS strategic plan (2006-11) aims to scale up existing interventions to achieve universal access for HIV prevention, treatment and care services. The plan has identified S&D one of the barriers for this and the reduction of S&D has been one of the strategies. After reviewing the international best practices and experiences from Nepal, the following recommendations can be made to improve the S&D reduction interventions.

7.1 Family and Community

Family and community are primary sources of stigma related to HIV and AIDS. S&D is a social process that creates, maintains and legitimises social inequalities. This must therefore be challenged by promoting social and community changes through community mobilisation and social transformation. Various strategies need to be combined to reduce stigma prevailing at family and community such as counselling, IEC, community sensitisation and mobilisation, and involving family and community in HIV prevention and care. Community members need to realise that this is their own problem. Stigma cannot be addressed without encouraging local communities to talk openly about sex, sexuality Social inequalities such as; gender, class, caste etc. also need to be addressed.

Recommendations

- Provide family counselling to affected family members to cope with the psychosocial and economical problems raised by HIV infection.
- Provide factual information and understanding to family members on how HIV is transmitted and how we can prevent getting HIV. Provide some basic home based AIDS care skills to prepare them to provide care and support to PLHIV.
- Encourage and support PLHIV to disclose their HIV status to their family members so that they can provide emotional support and care at family level.
- Mobilise local youth clubs, CBOs, mothers groups, local leaders, community health volunteers/workers, religious leaders etc. to sensitise them regarding HIV and AIDS and initiate community based intervention to tackle S&D.
- The HIV and AIDS activities need to be coordinated and collaborated with local community and CBOs. A meaningful community involvement and participation is required in the design and implementation of programme. This will create an ownership feeling among the community which will lead to sustainability.
- Opinion makers such as religious leaders, celebrities and political leaders are influential people in the community. They should be mobilised in the stigma reduction programme.
- Encourage, advocate and support various religious groups to establish interfaith coalition to address HIV and AIDS related S&D jointly.
- A multisectoral approach is needed to address S&D. S&D interventions should also address social inequalities such as gender issues, caste system, poverty etc. Women empowerment and poverty alleviation programmes can be integrated together.

7.2 Empowering and mobilising people at risk and PLHIV

People at risk and people living with HIV can play a vital role in stigma reduction at any level of intervention and they can provide a strong foundation on which stigma reduction activities can be built. Being the stigmatised ones they have practical and real life experience and their knowledge needed to design stigma reduction interventions (Nyblade, L. et al. 2003). Interaction between the stigmatised and stigmatiser groups can be helpful in lowering stigma.

Recommendations

- Target people at risk people such as FSWs, IDUs, MSM and migrants and provide "life skills" for behaviour change regarding practicing safe sex, safe injecting etc.
- Build capacity their capacity by providing training on advocacy, communication and management.
- Motivate PLHIV and people at risk to form support and network groups so that they can advocate for their rights and challenge S&D collectively. For example, PLHIV self-help group can be formed to share feelings and take collective action against S&D.
- Advocate for Meaningful Involvement of People Living with HIV and AIDS (MIPA) in all HIV prevention and care interventions from planning to implementation.
- Encourage PLHIV and affected people to share their stories with communities. This will help the community to internalise the problem and also it will allow them to understand how HIV and AIDS disrupts people's lives. This will help to humanise the disease and allow them to realise why their society should respond the problem.

7.3 Media/IEC

Mass media can play a crucial role in informing and educating general people. In surveys around the world, radio and television are cited as key sources of information about HIV and AIDS by large numbers of people (UNAIDS, 2005a). The media can be an influential agent and advocate for social change. In Nepal also, radio, TV and print media are popular among their audiences and are the major source of the information. The media needs to play a positive role in preventing the spread of HIV and AIDS and in reducing its impact including S&D. The recent media campaign done in Nepal has demonstrated that media can create enabling environment for the reduction of S&D. The following activities can be recommended for this.

Recommendations

- Provide comprehensive knowledge and information to media people on HIV and AIDS by organising training, workshops and seminars. Discuss development issues related with HIV and AIDS such as socio-economic vulnerabilities of affected people including S&D.
- Build capacity of media people to effectively report on HIV and AIDS. Encourage them in holistic reporting by exploring and investigating in-depth insight of the HIV and AIDS-related issues and present an analytical perception.
- Encourage accurate, up-to-date and complete information in the media. Ensure that the coverage does not create misconceptions and stigmatisation and do not portray HIV and PLHIV in negative and stereotypical ways.
- Encourage and support the production of radio drama serials and TV telefilms to raise awareness among a wide range of audiences including the rural people, improving their understanding and acceptance of PLHIV.
- Build partnerships and ally with media people and form a working group to work together. Involve media people in designing and implementation of the stigma reduction interventions.

7.4 Health Care Settings

HIV and AIDS related S&D exists in health care settings worldwide. Research conducted in other countries reveals that major reasons for this are; lack of knowledge among health care providers and lack of institutional (hospital) policies protecting PLHIV and ensuring staff safety. Negative attitudes and discriminatory behaviour in health care settings have been reported in Nepal too. Lack of training and supervision, high workload, weak institutional management on infection control such as lack of supplies, protective materials and drugs for post exposure prophylaxis (PEP) are considered to be the major reasons that foster stigmatising attitudes and behaviours among health care workers.

Recommendations

- Work with hospital management and review the current policies and practices regarding the HIV and AIDS related treatment and care in the health care settings. Involve managers in identifying the gaps and develop plans of action improve the situation.
- Sensitize and train all levels of health workers (from cleaners to medical officers) on HIV and AIDS and related issues such as sex work,

injecting drug use, and sex between men etc. Focus on misconceptions regarding transmission, universal precaution, infection control and S&D.

- Encourage and support health care institutions to develop and implement HIV workplace policies including infection control policy, PEP policy etc.
- Ensure the availability and use of national policies and guidelines on HIV and AIDS such as guidelines on VCT, ART, PMTCT etc. in hospital and health care settings. Establish a monitoring and evaluation system to ensure if these guidelines are implemented.
- Ensure adequate supplies for infection control such as protective clothes, gloves, aprons etc. A designated doctor and medicines for PEP should be available 24 hours in the hospital as occupational exposure of HIV can happen anytime.
- Organise regular meetings with hospital staff, PLHIV groups and NGO workers to discuss strengths and weaknesses of existing HIV and AIDS related services in the health care settings.
- Establish networking and a two-way referral system between hospitals, NGOs and the PLHIV network to work collaboratively. For example, the PLHIV network can provide emotional support to the patients admitted in the hospital.
- Monitor workload and equity of distribution of staff in the health care system. Establish a system for staff burnout management in the health care settings.

7.5 Workplace and Employment

An HIV workplace policy is required to tackle S&D in the workplace as this is another environment where this problem is common. The International Labour Organisation (ILO) has produced a Code of practice on HIV/AIDS and the world of work which provides guidance to develop HIV workplace policies. The Code of Practice has recommended four key principles to be put in a workplace policy, they are, prevention of HIV in workplace settings, management and mitigation of impact of HIV and AIDS in the world of work, providing care and support to infected and affected workers and elimination of S&D on the basis of real or perceived HIV status (ILO, 2001). The ILO code of practice has helped many organisations, business entrepreneurships and private companies to develop workplace policy and programmes. As described in the previous chapter, there are very few organisations in Nepal having an HIV workplace policy. There is a need to advocate and support for the development and implementation of a workplace policy in Nepal.

Recommendations

- Based on the ILO Code of Practice on HIV and AIDS and the world of work, design and implement pilot workplace policies and programmes with the support from UNAIDS, ILO and NSASC.
- Encourage, motivate and support the private and business sector for the development and implementation of workplace policies. The government of Nepal can implement a policy for HIV and AIDS related organisations that they must have a HIV workplace policy.
- Lobby and advocate for the development of non-discriminatory policies in workplaces to ensure that an employee's contract can not be terminated on the basis of his/her HIV status. The policy must create enabling environment for HIV prevention and care in workplaces; an employee should have access to HIV prevention and care services.
- Encourage and support non-HIV GOs and NGOs to mainstream HIV and AIDS in their work. An HIV orientation programme should include care support and treatment, including rights of PLHIV and S&D. Organisations working on HIV and AIDS field must mainstream S&D intervention in all HIV and AIDS programme.

7.6 Human rights and legislation

One of the crucial approaches to address S&D is promoting laws and legal support to protect the rights of PLHIV and vulnerable populations. As discussed in the previous chapter, recently there has been some progress in Nepal in terms of reform of laws related to rights of vulnerable population and PLHIV. However, a lot has to be done in this area. Many people may not be aware of existing laws and policies that protect the rights of HIV infected people.

Recommendations

- Sensitize political leaders, policy makers, lawyers, human rights activists and judiciary officials on HIV and AIDS related S&D and challenge and encourage them to work for the protection of vulnerable groups and PLHIV.
- Advocate for review of the current laws and regulations that reinforce S&D and reform the law for the protection of the rights of PLHIV and vulnerable people.
- Establish an alliance of various networks such as network of vulnerable groups and PLHIV network to work collectively to fight S&D.
- Empower vulnerable groups and PLHIV by raising awareness on their rights and human rights in the light of existing laws and regulations.

- Advocate for the implementation and enforcement of existing laws and regulations towards the government.

7.7 Future research

S&D is a complex issue causing multidimensional consequences. There is a need of research on various aspects of HIV and AIDS-related S&D. As discussed above, not much has been done in Nepal in terms of research on this topic. There is a need to conduct research to explore determinants, manifestations and impacts of S&D in various levels, especially on women, vulnerable groups and health care settings.

Also, there is a need to adapt or develop practical tools and indicators to measure S&D. This is required mainly for the purpose of monitoring and evaluating interventions to address S&D.

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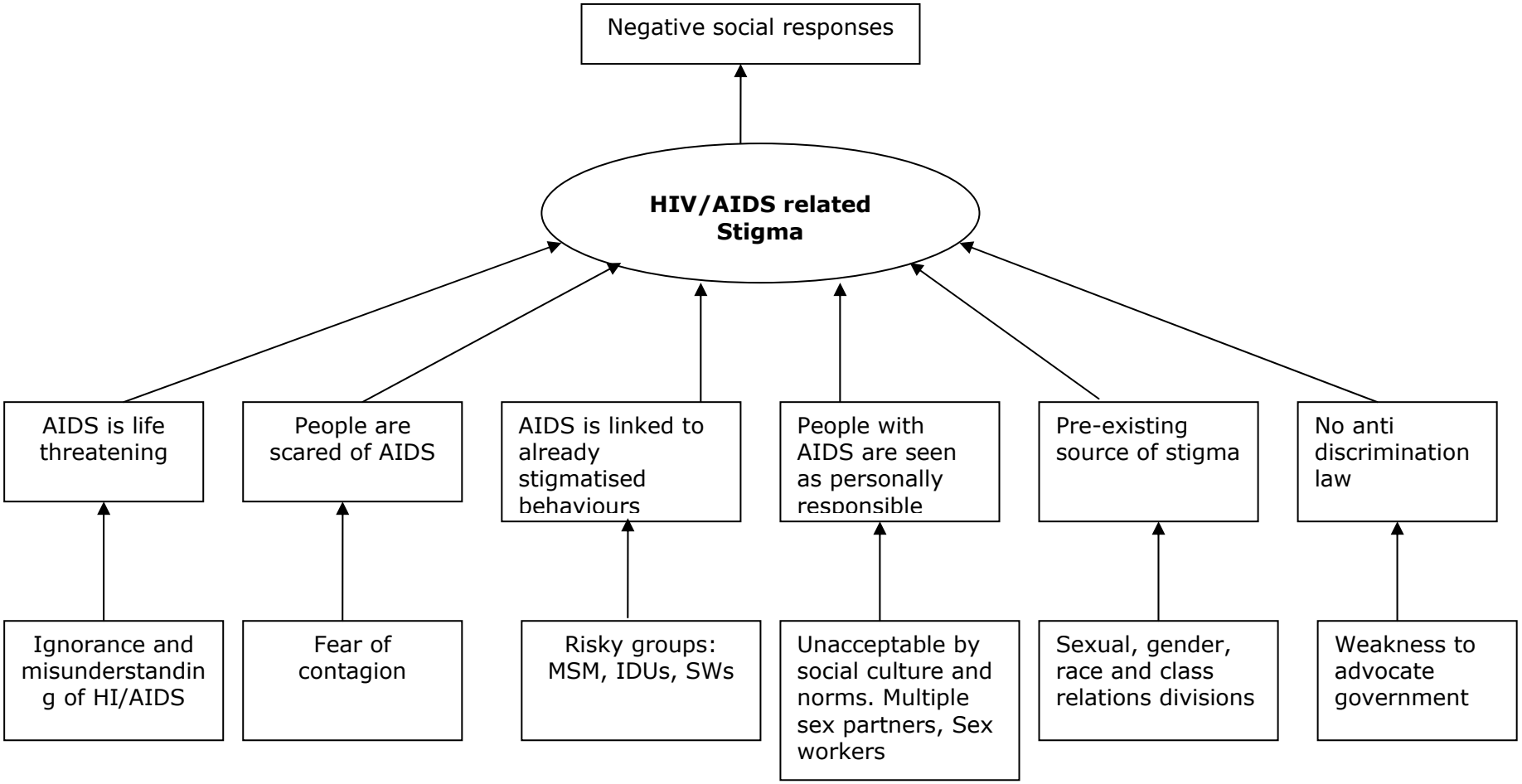
ANNEXES

Annex 1: Estimated distribution of HIV cases in Nepal

Population groups	Adult living with HIV	% of cases
Injecting Drug Users	6,493	9.24%
Men who have sex with Men	2,516	3.58%
Female Sex Workers	1,118	1.59%
Clients of Sex workers	13,594	19.35%
Seasonal labour migrants	32,341	46.03%
Sub-total at risk	**56,062**	**79.80%**
Urban female low risk	1,887	2.69%
Rural female low risk	12,305	17.52%
Sub-total low risk	**14,192**	**20.20%**
Grand total	**70,254**	

Source: UNAIDS, 2006

Annex 2: Conceptual framework of factors contributing to HIV and AIDS related stigma



The model adapted from Mawar et al, 2005, Parker et al, 2002 and Yan, H., 2005,

Annex 3: Questionnaire for VCT counsellors and CHBC workers

Please read the following questions and answer them:

1. **Haw long have you been working as a counsellor (**or in this field**)?**

   □ 0-1 year □ 1 -5 years □ 5 years and above

2. **To how many HIV positive clients you have provided counselling and support?**

   □ 0-50 □ 50 -100 □ 100 and above

3. **Do your HIV positive clients ever experience stigma and/or discrimination in their day to day life?**

   □ No, they do not experience □ only few experience □ Most

   □ All experience

4. **In your opinion, do they stigmatise themselves?**

   □ Yes □ No □ Do not know

   If yes how do they express this? (More than one option possible)

   □ Fear of disclosure
   □ Fear of losing honour & social standing
   □ Guilt
   □ Shame
   □ Loss of self-esteem
   □ Other …….. (please specify)
   □ All of above

5. **In your opinion, where and by whom do People Living with HIV (PLHIV) face discrimination?** (More than one option possible)

   □ Family & friends
   □ Society
   □ Health Care Settings
   □ Other …….. (please specify)

6. **What are the forms of discrimination at family level?** (More than one option possible)

   □ Isolation
   □ Separation and loss of contact with family
   □ Loss of respect
   □ Not involving in rituals
   □ Discrimination on ownership of property
   □ Other …….. (please specify)
   □ All of above

7. **What are the forms of discrimination at society level?** (More than one option possible)

   □ Physical and social restriction
   □ Loss of respect
   □ Not involving in rituals
   □ Other ……..... (please specify)
   □ All of above

8. **What are the forms of discrimination in Health Care Settings ?** (More than one option possible)

   □ Denying treatment
   □ Poor quality of services
   □ Testing HIV without consent
   □ Not maintaining confidentiality
   □ Other ……..... (please specify)
   □ All of above

9. **In your opinion, what are the common forms of HIV and AIDS related stigma and discriminations in your place?**

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10. **In your opinion, what steps should be taken to reduce HIV and AIDS stigma and discrimination?**

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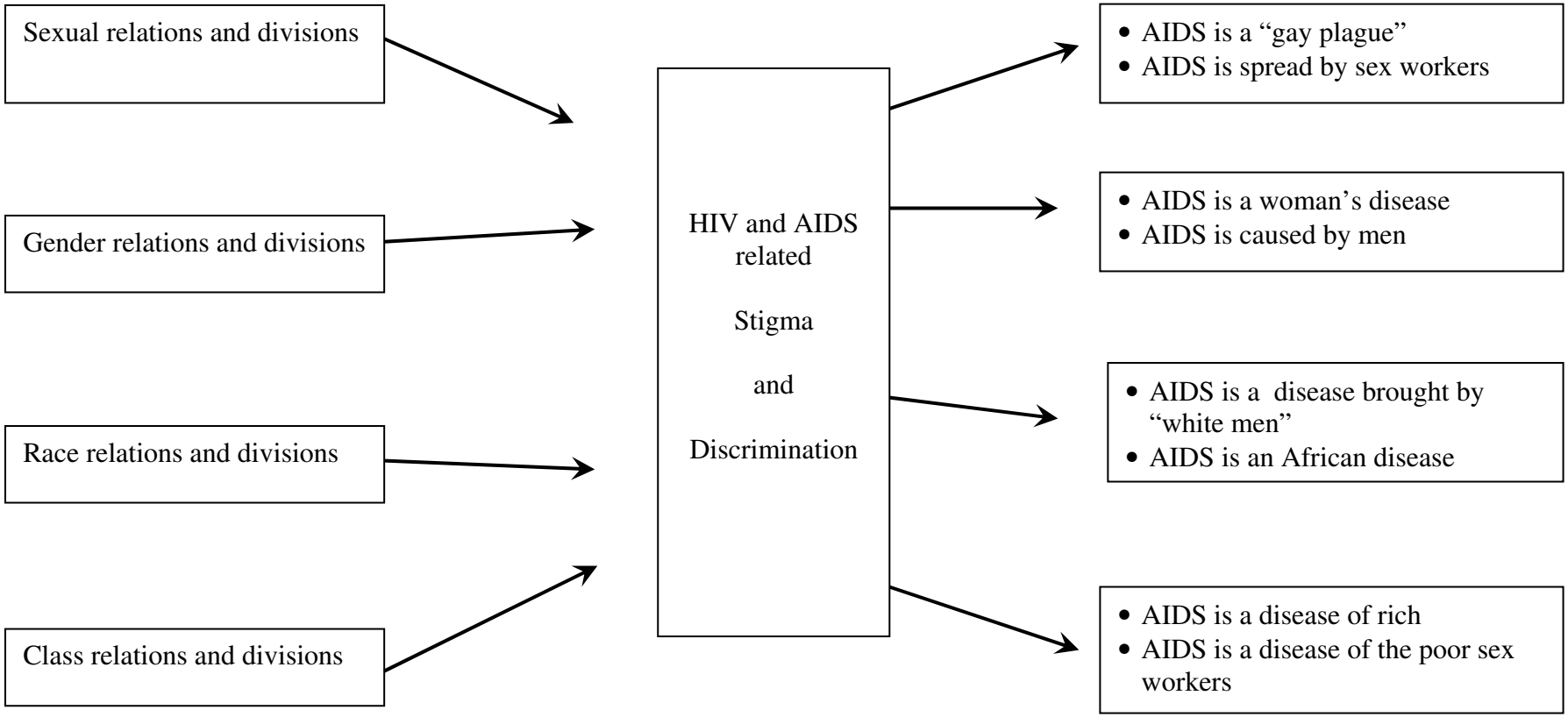
11. **Please provide a short case study of a client which illustrates HIV and AIDS related stigma and discrimination. (Please use a separate sheet if you need)**

Annex 4: The link between HIV/AIDS perceptions and pre-existing sources of stigma and discrimination



(Source: Parker and Angleton, 2002)

Annex 5: Effects of HIV/AIDS related stigma and discrimination at various levels

1. **Legislative / Governmental:** restrictions on entry and residence on the basis of HIV status, penal codes on homosexuality, restrictions on rights to anonymity and marriage.
2. **Marginalised groups:** Sex workers, MSM, transgender individuals, prisoners and migrant workers are all stigmatised by society already, making it even harder for them to gain access for support.
3. **People living with HIV:** low visibility of PLHIV fuels fear and ignorance and S&D make it difficult for PLHIV to form support groups.
4. **Individual, immediate family and community:** depression, punishment, physical harm and rejection by communities and families (especially affecting women), participation restrictions.
5. **Health services:** attitudes of Health Care Workers affect care seeking patterns of PLHIV, confidentiality breaches, refusal or delay for support and care, testing without consent.
6. **Women:** women living with HIV/AIDS are denied treatment and shelter, are rejected by families more frequently than men living with HIV/AIDS.
7. **Youth and education institutions:** children living with HIV/AIDS experience bullying and may be segregated from activities.
8. **Work place:** dismissal and recruitment on the basis of HIV status, denial of pension schemes or medical benefits on basis of HIV status.
9. **Media services**: may reinforce stereotypes and images of fear, guilt and immorality.
10. **Religious institutions*:*** exclusion from services and rites and segregation on basis of HIV status. Blame for sinful behaviour, without offer of forgiveness.

Modified from UNAIDS, 2002c