

**SOCIAL INCLUSION OF PERSONS LIVING WITH HIV/AIDS IN MIZORAM**

**K.LALREMPUII**

**Department of Social Work**

**Mizoram University, Aizawl**

## **CHAPTER I**

### **INTRODUCTION**

The present study attempts to probe into the patterns and levels of social inclusion of persons living with HIV/AIDS (PLHAS) in Mizoram.

HIV/AIDS is a worldwide epidemic which has an alarming increase in incidence over the recent years. It has an impact on the individual, family and society (The Henry J. Kaiser Family 2006; Lyons 2008; Donahue and Williamson 1999; Nelson Mandela Foundation 2010).

The HIV virus that causes AIDS has become one of the world's most serious health and development challenges. There are 33.4 million people living with HIV/AIDS till 2012 and more than 25 million people have died of AIDS worldwide since the first cases were reported in 1981. In 2008, 2 million people died due to HIV/AIDS, and another 2.7 million were newly infected. While cases have been reported in all regions of the world, almost all those living with HIV (97%) reside in low and middle-income countries, particularly in sub-Saharan Africa. According to the World Health Organization (WHO), most people living with HIV or at risk for HIV do not have access to prevention, care and treatment, and there is still no cure.

The HIV epidemic not only affects the health of individuals, it impacts households, communities and the development and economic growth of nations. Many of the countries hardest hit by HIV suffer from other infectious diseases, food insecurity, and other serious problems. Despite these challenges, there have been successes and promising signs. New global efforts have been mounted to address the epidemic, particularly in the last decade. The statistics indicated that prevention has helped to reduce HIV prevalence rates in a small but

growing number of countries and new HIV infections are believed to be on the decline. In addition, the number of persons living with HIV receiving treatment in resource poor countries has increased 10-fold since 2002, reaching an estimated 4 million by 2008.

The adult HIV prevalence in India is 0.27 percent, as of 2011. Whilst this figure is small relative to other middle-income countries, the large population of 1.2 billion inhabitants means there are still around 2.1 million persons living with HIV in India. Overall, India's HIV epidemic is slowing down, with a 57 percent decline in new infections between 2000 and 2011, and a 29 percent decline in AIDS-related deaths between 2007 and 2011. India's HIV epidemic varies across its 28 states. The four states with the highest number of persons living with HIV (Andhra Pradesh, Karnataka, Maharashtra and Tamil Nadu) are all in the south, and account for 53 percent of all HIV infections in India. Despite this, the adult HIV prevalence is falling in these high prevalence states. However, in a few states in the north and northeast, HIV infections are rising. Of all persons living with HIV in India, 39 percent are women and 7 percent are children. In many low- and middle- income countries, women are disproportionately affected by HIV, but men are more affected in India. This is because HIV transmission here is concentrated among high-risk groups that are predominantly male, such as truck drivers, migrants and clients of sex workers. The vast majority of infections occur through heterosexual sex.

According to National AIDS Control Organization of India, the prevalence of AIDS in India in 2013 was 0.27, which is down from 0.41 in 2002. While the National AIDS Control Organization estimated that 2.39 million people live with HIV/AIDS in India in 2008 – 2009, a more recent investigation by the Million Death Study Collaborators in the British Medical Journal (2010) estimates the population to be between 1.4 – 1.6 million people. The

last decade has seen a 50% decline in the number of new HIV infections. According to more recent NACO data, India has demonstrated an overall reduction of 57 per cent in estimated annual new HIV infections (among adult population) from 0.274 million in 2000 to 0.116 million in 2011, and the estimated number of persons living with HIV was 2.08 million in 2011.

HIV/AIDS is a serious epidemic which does not have any cure. Persons Living with HIV/AIDS are physically and psychologically affected. They are always under stress and strain because of shame, ill health and terminal condition (Gatchel and Turk 1999; Reidpath and Chan 2010). Persons Living with HIV/AIDS are being stigmatized and discriminated by the people at large and they face many problems in their lives. A diagnosis of HIV infection is always profoundly shocking. Feeling of fear, anger, despair and thoughts of suicide are common among the HIV infected people. Stigma is also one of the major challenges that Persons living with HIV/AIDS face. Stigma, silence, discrimination and denial undermine prevention and care strategies and increase the exclusion of the epidemic on an individual (Mahajan and Coates 2008; Skinner and Mfecane 2004).

It is now a common knowledge that in HIV/AIDS, it is not the condition itself that hurts the most (because many other diseases and conditions lead to serious suffering and death), but the stigma and the possibility of rejection and discrimination, misunderstanding and loss of trust that HIV positive people have to deal with. Many people have done research on HIV/AIDS considering stigmatization and discrimination as the number one reason why HIV/AIDS cannot be curbed.

Persons living with HIV/AIDS may be excluded from family and community events and experience a loss of power and respect in the community. The effects may be akin to

social death. In a stigmatized environment, opportunity for HIV test is rejected for fear of being identified, leading to a delay in diagnosis and access to supportive counseling, treatment and care and as a result, both the individual and public suffer (Reidpath and Chan 2010).

The fear of negative impact prevents disclosure of status within the family and community which may lead to resentment, deterioration of interpersonal relations which interfere with social integration process of the Persons living with HIV/AIDS and the outcome can be self-isolation and exclusion from family and the community. Not only is HIV-related discrimination a human rights violation, but it is also necessary to address such discrimination and stigma in order to achieve public health goals and overcome the epidemic (Laewenson 2004).

Many organizations and institutions offer a broad range of services from emotional support to referrals for community resources. They may provide counseling services, advocate for a patient, or work with community groups that will aid the patients and other constituencies. A social inclusion perspective on HIV prevention and AIDS-related care implies the adoption of strategies to understand and confront social vulnerability (Panda; Chattarjee and Quader 2002).

Social inclusion is the positive steps an organisation or institution can take to combat the risk of individuals or communities being excluded from mainstream society for reasons such as Unemployment, Low income, Poor housing and Family conflict/breakdown. It is basically the steps taken to avoid marginalization of particular people in the society. According to Rebecca Fraser (2011), "With regard to relationships and human behavior,

social inclusion means accepting someone into interpersonal interactions and social networks.’’

Social exclusion is defined in the bewildering diversity of ways. European foundation (1995) defines social exclusion as the process through which individuals or groups wholly or partially excluded from full participation in the society in which they live. This definition focuses on the process nature of social exclusion. Others lay greater stress on multiple deprivations as a defining feature of social exclusion; low income and insecure job, poor housing, family stress and social alienation (Paugam 1995). Some definitions integrate both of the features. For instance, Paul Appasamy et al (1995) defined social exclusion as ‘‘a process which restricts the access of certain social groups to valued resources and entitlements, relegating them to the status of social outsiders. It is a multidimensional concept, conceived to capture different forms of social disadvantage – economic social political and cultural – that persist, in multiple variants and with different intensity, across nations.’’

### **1.1 Overview of Literature**

A review of literature helps to understand and support more of the present study. The social exclusion of Persons Living with HIV/AIDS exists worldwide, although they manifest themselves across countries, communities, individuals and religious groups.

As HIV/AIDS is a socio economic problem of global scale, there are numerous policy initiatives at international, national and state levels to combat it. There are state and civil society actors playing active role in prevention, treatment and care of persons living with HIV/AIDS. As part of these initiatives, there were a number of research projects undertaken

to understand the multiple dimensions of the problem. This has contributed to rapid growth of literature on HIV/AIDS over the past three decades.

A significant portion of this literature includes studies on persons living with HIV/AIDS (PLHAS). This section of the literature mainly focuses on interrelated aspects of the life of the PLHAS viz., the social and economic characteristics (see Mahmud 2004; Moatli and Ventelou 2007; Debnarayan 2011), psycho social aspects (see Gatchel and Turk 1999; Reidpath and Chan 2010), care and support (see Barnett, Koning and Francis 1995; Duer 2004; Khondom 2009), quality of life (see Narain 2004; Shippy and Karpiak 2010), stigma and discrimination (see Miriam, Peter and Richard 2002; Skinner and Mfecane 2004; Anish, Jennifer and Thomas 2008) as well as social inclusion (see Laewenson 2004; Caceres, Aggleton and Galea 2008; Oxoby 2009; Allman 2013; Catherine 2013) and exclusion (see Wiseman 2002; Carvel 2001; Daniel 2001; Peirson 2010; Sian 2012). In fact application of the theoretical frame work of social exclusion in understanding the social life of people would enhances the effectiveness of policy making and social work practices.

The social exclusion framework has become very popular in development studies all over the world though it emerged in the North as a social policy discourse. The SEF is lauded for its ability to understand the multiple dimensions of institutional well-being of people viz. social, economic and political. It helps to comprehend the situations of those who are hitherto excluded (like ethnic minorities, SC/ST) and those who are excluded due to the operation of the forces of globalization (unemployed, PLHAS). Its ability to promote comprehensive understanding of the dynamics of the process of exclusion/inclusion as well agencies and mechanisms of exclusion are appreciated by the social scientists from the South (see Kabeer 2000).

## **1.2 Statement of the Problem**

The prevalence rate of HIV/AIDS is very high in Mizoram. Mizoram stands second in prevalence of AIDS/HIV amongst the North Eastern states and was only next to Manipur. Between 1990 and February 2011 there were 54349 cases declared as positive out of 137248 cases blood tested. During this period there were 543 cases found to be suffering from AIDS and 177 AIDS deaths were also reported. According to MSACS the predominant mode of transmission of HIV during this period was sexual contact (64%) while injecting drug use (24%) was reported as another significant mode of transmission (NAACCO) Many organizations like Mizoram State AIDS Control Society (MSACS), Grace Society, MCHP, Chhawmdawlina In, Disciple AIDS Intervention Ministry, Jericho Inn, Protective Home, Samaritan Society of Mizoram etc have taken up the initiatives to control the alarming spread of HIV/AIDS and to fight against HIV/AIDS in Mizoram. They do offer a wide range of services like Syringe and Needles Exchange Programme (SNEP), Condom Promotion, Awareness Programme, Counseling, Free regular Medical Check-up (RMC), Oral Substitution Therapy (OST) for Injecting Drug Users etc.

In this context, the present study attempts to probe into the patterns of social inclusion of persons living with HIV/AIDS (PLHAS). It tries to locate the patterns and levels of social inclusion of PLHAS in the broader socio economic structural context and developmental disparities in the state. It attempts to understand the role played by state and civil society actors in the process of inclusion of PLHAS. Further, it will throw light on the mechanisms adopted in inclusion and exclusion of PLHAS. In the light it will offer suggestions for policy making and social work practice towards promoting social inclusion of PLHAS.



The results of the present study will be useful to policy makers, planners, and social workers interested as well as committed to the cause of promotion of social inclusion and well-being of PLHAS and prevention of the AIDS pandemic. They will find adequate information for developing interventions with general public as well as PLHAS.

### **1.3 Objectives**

The specific objectives of the present study are as follows.

1. To probe into the socio-economic characteristics of Persons living with HIV/AIDS (PLHAS).
2. To probe into the pattern of social inclusion of PLHAS
3. To assess extent of social inclusion of PLHAS and identify its determinants.
4. To understand the process of social inclusion and exclusion of PLHAS.
5. To identify the agencies and mechanisms of the inclusion and exclusion of Persons living with HIV/AIDS.

### **1.4 Hypotheses**

To provide focus to the following hypotheses are formulated which will be tested for their empirical veracity.

1. Men with HIV/AIDS are more included than their women counterparts.
2. There is direct relationship between socio economic status and social inclusion of PLHAS.
3. There is inter-district variation in social inclusion of PLHAS.

These hypotheses were drawn intuitively in the context of Mizoram. The first hypothesis relates social inclusion to gender in the context where the patriarchy prevails as a principle of social organization. On the other hand, the second hypothesis relates the same

with emerging social class structure due to occupational differentiation in the wake of its integration in the wider national and global economy. The third hypothesis is proposed to see the effect of development on inclusion. Testing of these hypotheses will provide the direction and target of intervention for social inclusion of PLHAS in Mizoram.

### **1.5 Chapter Scheme**

The study is organised into the following five chapters.

1. Introduction
2. Review of Literature
3. Methodology
4. Results and Discussion
5. Conclusion

## **CHAPTER II**

### **REVIEW OF LITERATURE**

A review of literature helps to understand and support more of the present study. The social exclusion of Persons Living with HIV/AIDS exists worldwide, although they manifest themselves . This chapter attempts to present the review of literature on HIV/AIDS, social inclusion and social exclusion of PLHAS. This chapter has been organized into four major sections viz., Studies on HIV/AIDS in abroad, studies on HIV/AIDS in India, studies on HIV/AIDS in northeast India and studies on social inclusion and social exclusion of PLHAS.

#### **2.1 Studies on HIV/AIDS in Abroad**

Jean-Paul Moatli and Bruno Ventelou (2007) presented that public health experts and economists share a common dissatisfaction towards previous economic analyses of the impacts of HIV/AIDS. According to them, a growing body of evidence not allows a better understanding of the full economic and societal dimensions of the epidemic. It is no certain that poverty contributes to poverty, although we still do not know enough about the complex pathways of this relationship. Moatli and Ventelou mentioned that to illustrate this idea, an “endogenous” growth model which takes into account the evolution of society’s human capital is used in order to re-assess the macroeconomic impact of HIV/AIDS. A fairly wide range of epidemic effects modify the economy’s long term growth regime, creating the risk of what we might call an epidemic or “regressive trap” of rapidly falling GDP. Government action should be designed in view of this risk, with health and educational interventions.

Leslie B, Wolf and Bernard LO (2008) examined ethical issues related to HIV/AIDS testing, treatment and research. Key issues analyzed include confidentiality, informed consent, end of life, research design, conflict of interest, vulnerable populations and various vaccine research. Major United States and international legal statutes, regulation and guidance documents provide the consent for analyses and recommendations.

Jessica Ogden (2010) highlighted the specific issues that cluster around the provision of 'care' in the context of the global HIV/AIDS pandemic. She argued that the economic concept of the 'care economy' provides a useful lens through which to view the HIV/AIDS pandemic, as it illuminates the increased labour, time and other demands placed upon households and shows that the assumptions on which norms and expectations of care provision are increasingly being challenged. While some studies are being made in policy and programming around HIV and AIDS-related care, much more needs to be known and done to enable individuals, families and households to survive in a world shaken by AIDS. Care provides fundamental public goods. According to her, a strategy of simply downloading responsibility for care onto women, families and communities can no longer be a viable, appropriate or sustainable response and this is no less true in this current area of expanding treatment options for Persons Living with HIV/AIDS. The analyses suggests that there are two distinct but inter-related areas for policy intervention and development. The first concerns international health policy and there is an argument that the international 'care agenda' needs to incorporate an understanding of the care economy into its frameworks and strategies for action, giving particular focus to the caregiver. The second area encompasses a broad national healthcare policy agenda, where a range of public, private and non-

governmental sector actors come together with common purpose to ensure that households affected by HIV/AIDS are protected and enabled to survive.

E.Barnett, K.de Koning and V.Francis (1995) in their report sets out to describe current policy and practice related to health and AIDS education in primary and secondary schools in Africa and Asia. It focuses on health and educational context, and the priority attached HIV/AIDS, curriculum context, teaching methods, teacher preparation and the concerns of young people with regards to health generally and AIDS specifically. The report also draws on published and unpublished literature as well as empirical work in four countries: Pakistan, India, Uganda and Ghana. The empirical work combines key informant and documentary analysis of stated policy and practice, with detailed work carried out in selected schools in each of the country. The school data pays particular attention to the worries and concerns of young people. As such, it may provide a useful starting point for discussion on developing 'student centred' health education curricula.

Rajan Gupta(2008) provides a comprehensive and unifying view of a number of health issues confronting India and how, overtime, they could impact the stability and security of the nation. New pandemics like HIV have confounded attempts at containment because their spread highlights vulnerabilities in social and political norms and of communicable diseases for which risky individual lifestyles and behaviors, societal norms and beliefs, poverty and lack of empowerment and stigma and discrimination are major factor which are necessary to examine the system as a whole and to develop new paradigms and tools. Sexually Transmitted Infections and addictions to drugs have emerged as a major interconnected global threat.

Lather P Smithies (2001) witnessed the womens' courage and struggle. The book aimed to provide support and information to women with HIV/AIDS and their friends, families and loved ones, to encourage women with HIV/AIDS to advocate for themselves, one another, and their communities, and to promote public awareness of womens' HIV/AIDS issues to a compassionate for all Persons Living with HIV/AIDS.

'Social Aspects of HIV/AIDS and Health (SAHA)- A Research to inform HIV/AIDS prevention, care and impact mitigation' stated that the SAHA research programme has specialized in research on the social determinants of health, not only with regard to HIV/AIDS, but also for public health in general. This research goes beyond medical interventions and strives to address health problems at their source, namely, at both the social and population levels. The programme has two primary goals: first, to conduct research that is policy relevant and responds to current challenges facing South Africa and secondly, to conduct intervention research programme assessments that aim to improve the lives of South Africans. SAHA conducted research in three main areas. These are as follows. Behavioral and Social Aspects of HIV/AIDS: This research aims to understand both social (i.e., interpersonal) and behavioural (i.e., personal) factors that drive the HIV/AIDS epidemic. The knowledge that is acquired is used to develop and test theory-based HIV behavioural prevention interventions to reduce HIV infections both among the general public and among persons living with HIV/AIDS (PLHA). Other research focuses on understanding and reducing stigma and discrimination among PLHAS; risk behaviour among men who have sex with men; and efforts to mitigate the impact of the disease among orphaned and vulnerable children (OVC). Epidemiology, Strategic Research and Health Policy: This section provides epidemiological support and expertise, undertakes applied epidemiological research that is

policy-relevant and conducts strategic research that address the needs and challenges facing South Africa and other African partner countries. The section encompasses four research areas: (1) Infectious Disease Epidemiology with a focus on HIV/AIDS survey methodology and epidemiological modeling; (2) Biostatistics, data management and analysis; (3) HIV/AIDS intervention research aimed at the development of synergistic prevention and care programmes; and (4) Monitoring and Evaluation including national programme impact assessment. Health Systems and Social Determinants of Health: This section focuses on research on developing and evaluating interventions which promote evidence-based health care provision. The issues dealt with include, among others, health services disparities, health promotion, transformation of health systems and operations research. With a specific emphasis on strengthening health equity, research is undertaken to investigate the fundamental structures of social hierarchy, and the socially determined conditions these structures create in which people grow, live, work and age. SAHA undertakes population-based HIV/AIDS surveys, employing the second-generation surveillance approach at national, provincial, and local community levels. These surveys provide essential information for informing policy and programmes in response to the HIV/AIDS epidemic in South Africa and neighbouring SADC countries. They serve as the primary data source for the National Strategic Plan for HIV & AIDS and STI for 2007-2011.

K Opong Asante (2011) sought to investigate the association between age, gender, social support and the psychological wellbeing of people living with HIV/AIDS in Ghana. The study has a method of Cross-sectional data containing information on demographics, social support and psychological well-being (stress, depression and anxiety) were collected from 107 men and women living with HIV/AIDS. Correlation analysis

revealed that social support was negatively associated with depression, stress and anxiety. Compared with males living with HIV. Women reported higher levels of negatively associated with depression, stress and anxiety. Female gender and low social support were significant predictors of depression and stress after controlling for selected independent variables. Older participants experienced higher levels of stress than their younger counterparts. The study has come to a conclusion that public health personnel and AIDS professionals may consider further interventions to promote psychological health in HIV/AIDS-positive individuals. More attention should be paid to the social environment of individuals diagnosed with HIV as the quality of social relationships may be particularly important for successful psychological adaptation to HIV.

Catherine Campbell and Andrew Gibbs (2009) examined the complex relationship between gender and stigma, and to consider the implications of this relationship for HIV/AIDS programmes. Their focus on HIV/AIDS, gender and stigma lies at the interface of two related interests. First, they believe that an understanding of stigma is required to deepen the analysis of facilitators and barriers for effective participatory HIV/AIDS programmes. Participation in HIV/AIDS prevention, treatment and care programmes has become somewhat of a mantra. HIV-related stigma serves to deprive people with AIDS of the confidence and agency they need to access treatment, participate in programmes and increase self-efficacy, all of which have positive health outcomes. Currently, much research into HIV-related stigma remains at the descriptive level, emphasising the impact of stigma on agency, rather than exploring the complex psycho-social roots of stigma. Their second interest in the relationship between HIV/AIDS, gender and stigma relates to the way in which the HIV/AIDS pandemic is driven by gender inequality and exacerbates gender inequality



(UNIFEM, 2004). They recognise gender as a socially constructed relationship that limits women's access to material and symbolic resources compared to men's access to these. The role of HIV-related stigma in supporting gender inequality is under theorised – but as they hope to make clear, they mentioned that this needs to be at the centre of any understanding of HIV-related stigma. Understanding the relationships between stigma, gender inequality and the continuing HIV/AIDS pandemic is crucial if this cycle is to be broken. In this chapter, case workers develop a social psychological reading of HIV-related stigma, which focuses on the relationship between the individual and society. The aim of social psychology is to understand how social imperatives become sedimented in the individual psyche (Joffe, 1999) and how this might best be resisted (Howarth, 2006). In relation to the social dimension of the individual-society interface, they are particularly interested in the inter-relationship between the symbolic and material dimensions of human life in shaping peoples' experiences of HIV/AIDS (Campbell, *et al.*, 2005a; Cornish, 2006). In relation to the individual psychological dimension of this interface, they are concerned with the way in which this social world shapes and sets the context for the construction of social identities and agency, which are central to the ways in which stigma is internalised or resisted. Stigmatised people often have highly marginalized social identities and limited agency, because of poverty and symbolic forms of chronic marginalization. Key to the process of resisting stigma is that people start to view themselves as competent social actors, capable of withstanding some of the impacts of marginalisation, if not actually able to change the underlying causes. In order to illustrate the argument, three interventions involving FSWs will be explored. Women engaged in sex work (visible and invisible) often have higher prevalence levels of HIV/AIDS than other population groups (UNAIDS, 2002; Cote *et al.*, 2004; Dunkle *et al.*, 2004; Chen *et*

*al.*, 2007). A focus on female sex workers is particularly illustrative of our argument, because this group of women sit at the intersection of multiple forms of symbolic marginalisation or stigmatisation – HIV/AIDS, gender, occupation – and material marginalisation – poverty, limited access to health care and so on. All these shape the contexts in which sex workers construct their social identities and their ability to assert agency in ways that protect their health. Case workers define stigma as any negative thoughts, feelings or actions against people infected with or affected by HIV/AIDS (Campbell *et al.*, 2007) HIV/AIDS stigma is increasingly described as a major driver of the HIV/AIDS pandemic through limiting peoples' access to prevention, formal and informal care and more recently anti-retroviral treatment (Deacon *et al.*, 2005; Ogden and Nyblade, 2005; Rankin *et al.*, 2005). Stigma inhibits many women from learning their HIV status, for fear of abandonment or violence by their partners (Gaillard *et al.*, 2002; Medley *et al.*, 2004). Men – who associate their ability to conceive children as a central and prized dimension of their masculinity – may also deny or hide their status, for fear that this will hinder the likelihood of them conceiving children, leaving them to die without having fulfilled their masculine life destiny of 'leaving behind people who bear their names' (Steinberg, 2007). It is important however, to move away from the common tendency to describe the effects of stigma, and to seek to *explain* its underlying drivers in order to inform stigma reduction interventions (Campbell and Deacon, 2006). In the following section a theoretical model of stigma will be outlined, leading on to a discussion of the possibility of effective interventions.

Mignone J (2007) stated that HIV/AIDS has developed under diverse conditions around the world with consequent variations in the mode of transmission and the rate of transmission. In the industrialized countries what began as an epidemic among men who

have sex with men and then sharing drug users, is now increasingly concentrated in poor and marginalized sectors of the population. In Eastern Europe, HIV is spreading rapidly among drug users. In Africa and South Asia, the AIDS epidemic is almost entirely among heterosexual non-drug users. Latin America represents a composite of the industrial and developing world both in its economic performance and its HIV epidemic. As a discussion paper of the Public Health Agency of Canada suggests "Social determinants of health influence a person's risk of HIV infection, the speed with which HIV infection will progress to AIDS and a person's ability to manage and live with HIV/AIDS." However, social determinants of health in general and of HIV/AIDS in particular, can be categorized in a number of ways. To be useful for research, programmatic and policy purposes, the categorizations should add explanatory power to the plausible pathways between factors and outcomes, and not simply be a laundry list of societal aspects.

A study investigating the relation between mental health and HIV/AIDS and problems related to accessibility and adequacy of mental health care and psychological and social support for the needs of people living with HIV/AIDS will have important theoretical and practical significance. This is a research project and the aim of the study is a preliminary assessment of the current system of mental health care for people living with HIV/AIDS and identification of the needs and barriers in this area. The research consists of the following parts: 1. Analysis of the current system of mental health care for PLHAS. 2. Epidemiological estimates. 3. Assessment of needs, barriers and relevant solutions in relation to mental health and HIV. The study has the following expected outcomes: 1. Research instruments. 2. National reports including legal and institutional analysis of the health care system for PLHAS, epidemiological estimates of mental disorders among PLHAS, their

needs in this area, barriers in satisfying these needs and recommendations. 3. International report. The estimated number of people living with HIV worldwide in 2007 ranges from 30 up to 36 million. The annual number of new HIV infections in 2007 was estimated at a level of 2.2 – 3.2 million. HIV infection still constitutes an important issue of public health in Europe. In some European countries, e.g. Estonia, Latvia, Luxembourg, Portugal and the United Kingdom, a substantial increase in the numbers of HIV cases were reported. The HIV epidemic has a heterogenous character in Europe, a significant diversity can be observed across the European regions and countries. In the Central European and Scandinavian countries it remains on the same level, new infections are mainly attributable to sexual contacts. On the other hand, in Eastern Europe, especially in The Russian Federation, Ukraine and in the Baltic countries, a significant increase in new HIV infections was observed. In those countries there was also an increase in mortalities caused by AIDS, especially among injection drug users. Research conducted in other countries shows that about  $\frac{3}{4}$  people living with HIV/AIDS experienced at least one mental disorder in their lifetime. The mental health of people living with HIV/AIDS is a complex issue. On the one hand, some mental disorders are seen as a factor increasing a risk of infection. On the other hand, mental and neurological disorders can occur in the course of HIV infection and its treatment. Information on being infected is a serious psychological burden. People living with HIV/AIDS experience in their every-day life many psychological and social problems, they meet with discrimination, rejection and social exclusion. The problem of HIV epidemic still arouse fear and lack of social acceptance for infected people. Providing them appropriate psychological and psychiatric care, psychological and social support and counseling can contribute to improvement of quality of life. It can also prevent further infections.

Psychological support helps infected persons to accept the diagnosis and learn to live with it. Thanks to this they can deal with everyday problems related to HIV, not only those of a psychological nature. This involves a change in life-style and taking more responsibility for their own health and the health of others. The important issues in health care of people living with HIV/AIDS are problems of psychiatric comorbidity and provision of adequate mental health care. In relation to people living with HIV/AIDS dual and triple diagnosis are established in cases in which apart from the HIV infection a mental disorder or a mental disorder together with dependence on psychoactive substances is diagnosed. Providing psychological and psychiatric care for people living with HIV/AIDS who also suffer from mental disorders is crucial for the effectiveness of antiretroviral therapy. Both the physical and psychological state related to mental disorders can significantly influence the continuation and compliance in antiretroviral therapy. Alcohol and other psychoactive substances can cause a weakening of the organism, the medicines taken can interact with each other, so it is important that care for people living with HIV/AIDS who suffer from mental disorders has an integrated character. Therefore, a study investigating the relation between mental health and HIV/AIDS and problems related to accessibility and adequacy of mental health care and psychological and social support for the needs of people living with HIV/AIDS will have important theoretical and practical significance. The aim of the study is a preliminary assessment of the current system of mental health care for people living with HIV/AIDS and identification of the needs and barriers in this area. The research consists of four parts: Analysis of the current system of mental health care for people living with HIV/AIDS:

- a) Analysis of legislation and policies.
- b) Institutional analysis of health care, including mental health care for people living with

HIV/AIDS; Epidemiological estimates; Assessment of needs, barriers and relevant solutions in:

a) Mental health care for people living with HIV/AIDS; b) HIV/AIDS prevention and treatment for people suffering from mental disorders. Assessment of needs, barriers and relevant solutions in mental health care for people living with HIV/AIDS – exploration of perspectives of people living with HIV/AIDS and personnel of the health care facilities for people living with HIV/AIDS (nurses and medical doctors).

Frederik le R Booyesen and Tanza Amtz (2012) studied on the socio-economic impact of HIV/AIDS shows that diversity in methodological design, which often is a result of practical considerations and resource constraints rather than of poor design, is the norm. This limits the comparability of research findings. More detailed reporting on method, which is not the norm, can go some way towards facilitating such comparison. Furthermore, the review underlines the importance of exploring intervention issues in more detail. Booyesen and Tanza mentioned that researchers need to employ results in answering specific policy questions. Scope remains for more impact studies to be conducted in developing countries in general and in certain high prevalence countries in specific, i.e. Southern Africa. Studies that explore the urban/rural dynamics of and clients' perceptions and behavior in seeking care and support are necessary to better understand the epidemic. The role of community-based organizations, non-governmental organizations and other stakeholders in studies of this nature can be expanded. Larger studies generally have more statistical power, but smaller, in-depth studies can be equally valuable. A careful stratification of sample populations can enhance the quality of cross-sectional studies. Qualitative methods should be used to complement the current reliance on survey-based methods of data collection. More

longitudinal studies are required to explore the long-term impacts of HIV/AIDS. HIV/AIDS training for fieldworkers should be standard in studies of this nature, while cognizance should be taken of the dangers of employing local people as fieldworkers in studies of such sensitive nature. Scope remains for the further empirical analysis of data from impact studies, which requires these data sets being made accessible to more researchers. In the longer term, an attempt at standardizing core modules in impact studies can help to improve our understanding of the impact of HIV/AIDS in different settings.

‘The Socio-Economic Causes and Consequences of HIV/AIDS: A focus on South Asia’ states that HIV/AIDS is a major development challenge with implications beyond the health sector. Socio-economic factors such as gender inequality, poverty and livelihood issues, which are key causes of high mobility and migration of people and trafficking of women and children also contribute to the spread of HIV/AIDS, and are, in turn exacerbated by it. These factors operate within the legal and ethical environment, which also influences responses to the HIV-affected. The regional symposium discussed inter-related and complex issues pertaining to migration, trafficking, law and ethics and AIDS in South Asia. It promoted regional cooperation by emphasising trans-border challenges and responses. Representatives from countries in the region had the opportunity to learn, share information and develop mutually supportive policies and strategies.

Stefano Bertozzi, Nancy S. Padian, Jeny Wegbreit, Lisa M. DeMaria, Becca Feldman, Helene Gayle, Julian Gold, Robert Grant, and Michael T. Isbelle (2009) stated that although global commitment to control the HIV/AIDS pandemic has increased significantly in recent years, the virus continues to spread with alarming and increasing speed. Despite the rapid spread of HIV, several countries have achieved important success in curbing its

transmission. Enormous advances in HIV/AIDS treatment regimens have fundamentally altered the natural history of the disease and sharply reduced HIV-related morbidity and mortality in countries where such treatments are accessible. The advent of anti-retroviral drugs in the late 1980s began a revolution in the management of HIV, which can be seen as analogous to the use of penicillin for treating bacterial infections in the 1940s. The most notable advance on the treatment front is the use of combination antiretroviral therapy, which is far more effective than monotherapy (zidovudine or AZT), the standard of care when the first edition of this volume was published. Recent declines in the price of combination antiretroviral therapy in developing countries from US\$15,000 per year to less than US\$150 in some countries have prompted numerous developing countries to introduce antiretroviral therapy through the public sector. These declines also pose difficult questions regarding the optimal allocation of limited resources for HIV/AIDS, as well as the potential impact on already strained health care infrastructures. Even though the current deficit in evaluation research is glaring, the magnitude and seriousness of the global pandemic means that action is nevertheless required. Moreover, despite such gaps in knowledge, we can still improve control strategies by tailoring interventions to the nature and scope of the epidemic. HIV transmission predominantly occurs through three mechanisms: sexual transmission, exposure to infected blood or blood products, or perinatal transmission (including breast-feeding). The likelihood of transmission is heavily affected by social, cultural, and environmental factors that often differ markedly between and within regions and countries. There is also some indication that molecular, viral, immunological, or other host factors might influence the likelihood of HIV transmission.

## **2.2 Studies on HIV/AIDS in India**



A study on 'Social and economic implications of HIV/AIDS: evidence from West Bengal' was Conducted by Sarker and Debnarayan. Bases on household level's field survey in West Bengal state in Indian context, this study suggests that poverty and lower level of human capital provide the basic initiatives for both rural-urban migration and risky occupational choice for household's income, and thus contributes to the spread of HIV/AIDS. Also, the HIV/AIDS epiemic of those economically and socially disadvantaged households leads to the consequence of absolute economic and social poverty,the benefit of action by government or non-government organizations is insignificant for them.

Anish P.Mahajan, Jennifer N.Sayles and Thomas J.Coates (2008) highlighted that although stigma is considered major barrier to effective responses to the HIV/AIDS epidemic, stigma reduction efforts are neglected to the bottom of AIDS program priorities. The complexity of HIV/AIDS reated stigma is often cited as a primary reason for the limited response to this pervasive phenomenon. On this paper, we systematically review the scientific literature on HIV/AIDS related stigma to identify gaps in the available evidence and highlight promising strategies to address stigma. The study focusses on the following key challenges: defining, measuring, and reducing HIV/AIDS related stigma as well as assessing the impact of stigma on the effectiveness of HIV prevention and treatment programs. Based on the literature, the study concludes by offering a set of recommendations that may represent important next steps in a multifaceted response to stigma in the HIV/AIDS epidemic.

Rashmi Kandwal, P.K Garg, R.D garg (2008) emphasized on health perspective and state that GIS is a useful tool that aids and assists in health research, health education, planning, monitoring and evaluation of health programmes that are meant to control and

eradicate certain life threatening diseases and epidemics. HIV/AIDS is one such epidemic that poses a serious challenge and threatens the overall human welfare. This communication is an attempt to link and understand the health scenario in a GIS context with emphasis on HIV/AIDS. Various GIS based functionalities for health studies and their scope in analyzing and controlling epidemiological diseases are explored. Overall scenario of the spread of HIV/AIDS around the world is presented along with the Indian perspective. Finally, they conclude with the general management problems, issues and challenges related to HIV/AIDS prevailing in India.

The International Bank for Reconstruction and Development/The World Bank-Disclaimer (2009) stated that in the current scenario of social, economic and demographic change in India, there is increasing concern about the impact of the HIV/AIDS epidemic, and the future of India's next generation of economic and social stakeholders. There is also a growing understanding that the effective response to HIV/AIDS requires the partnership of all sectors. In this context, the private sector and other stakeholders have become critical partners in the effort to curb HIV/AIDS, as well as to reduce related stigma and discrimination. The IT sector, being a leading force of change and innovation and a channel to reach the country's youth, can play a unique role in addressing HIV/AIDS challenges. However, there is a need to increase the contribution of this key sector to India's response efforts. IT companies can make significant contribution such as leadership skills and resources to national, community and workplace programs. The issue of HIV/AIDS is an important entry point concern for IT companies in addressing the health of the sector's young workforce, responding inclusively to development challenges and building good will and relationships with communities.

### **2.3 Studies on Social Exclusion and Social Inclusion of Persons Living with HIV/AIDS in North East India**

Martha Morrow, MC ArunKumar, Emme Pearce and Heather E Dawson (2007) stated that Manipur and Nagaland in NorthEast India are among the Indian states with the highest prevalence of HIV. Most prevention and care programs focus on identified 'high risk' groups, but recent data suggest the epidemic is increasing among the general population, primarily through heterosexual sex. People with disability in India are more likely than the general population to be illiterate, unemployed and impoverished, but little is known of their HIV risk. This project aimed to enable HIV programs in Manipur and Nagaland to be more disability-inclusive. The objectives were to explore HIV risk and risk perception in relation to people with disability among HIV and disability programmers, and people with disability themselves identify HIV-related education and services, needs and preferences of persons with disability, and utilize findings and stakeholder consultation to draft practical guidelines for inclusion of disability into HIV programming. The findings revealed that participants believe persons with disability in these states are potentially vulnerable to HIV transmission due to social exclusion and poverty, lack of knowledge, gender norms and obstacles to accessing HIV programs.

Das, N.K. (2009) analysed on how identity politics have served to marginalise and exclude different groups in North-East India. These exclusions often assume a binary form, with oppositions including majority-minority, 'sons of the soil'-immigrants, locals-outsiders, tribal-non-tribal, hills-plains, inter-tribal and intra-tribal. Local people's anxiety for autonomy and the preservation of their language and culture should be viewed as a prerequisite for distributive justice, rather than dysfunctional to a healthy civil society.

## **2.4 Studies on Social Exclusion and Social Inclusion.**

A study on 'Social Inclusion and Economic Development in Latin America' Edited by Marya Buvinic and Jacqueline Mazza with Ruthanne Deutsch emphasizes on the economic development and social inclusion, the case for combating racial and ethnic exclusion, social inclusion and indigenous people's rights, disability and inclusion and anti-discrimination legislation and policies in Mexico.

A study on 'Promoting Social Inclusion and Respect for Diversity in Terms of HIV and AIDS' conducted by Brighton Gwezera, Noreen M Huni reviews on the strategic objectives of psychosocial care and support. The first objective is triple crisis which deals with HIV and AIDS, poverty and conflict. The second objective is responding where social inclusion and respect for diversity and rights based programming are studied. The third objective aims to enhance local capacity to support caregivers and communities practical experience in psychosocial support and give benefits to the children.

'Social Exclusion Hindering Treatment and Spread of HIV' by John Carvel states that a report by the trust warns of a vicious circle whereby people who are marginalized from society are more likely to become infected with HIV and less likely to seek prompt diagnosis and treatment. Those openly living with it face further social exclusion, leading to a cycle of desire and decline. In 2010, the number of new infections rose 14% to a record 3,125. More than 20,000 people know they are infected and the trust forecasts this will rise to 29,000 by 2003. The trust says those seeking medical help when their HIV infection is well advanced make up a large proportion of 500 a year who go on to die from AIDS. The report of social exclusion and HIV/AIDS mentioned that many of them

may know they have been at risk of HIV, yet their fear of the consequences of being found to have HIV has outweighed the prospect of untreated illness and death.

Daniel Reeders (2001) explores the link between discrimination, exclusion and sexual risk-taking, and asks how we can respond to the needs of culturally diverse men who have sex with men (MSM).

A study on 'Reducing Poverty by Tackling Social Exclusion' was published by Department for International Development in September 2005. The study mentioned that there are groups of people in all societies who are systematically disadvantaged because they are discriminated against. Discrimination occurs in public institutions, such as the legal system or men, women and children who are discriminated against often end up excluded from the society, the economic and political participation. They are more likely to be denied access to income, assets and services and suffer from social exclusion and poverty reduction is harder as a result.

An article on 'Dealing with the pain of Social Exclusion' was written by Sian Beilock. This article states that social exclusion is a common part of life and states that at some point, we have all felt ostracized at work, by our partner, or even snubbed by friends. On the surface, the pain of being excluded seems pretty different from physical pain, but it turns out that their experiences share a common biological basis in the brain.

Carlos F Caceres, Peter Aggleton and Jerome T.Galea (2008) mentioned that despite a number of programmes to prevent HIV among men having sex with men, and more generally, sexually diverse populations, gay and other homosexually active men continue to be at heightened risk of HIV and its consequences. This paper analyses some of the reasons for this situation and offers policy and programmatic recommendations to contribute to a

solution. The social exclusion of MSM and transgender individuals is an overwhelming reality in the majority of countries worldwide. Although, progress has been achieved in some countries, in most of the world the situation remains problematic. Present challenges to equality and to the realization of health, include the memberships of groups or subcultures with high HIV prevalence, lower quality and coverage of services and programmes and the impact of higher level influences such as law, public policies, social norms and culture which together configure an environment that is hostile to the integration and needs of certain groups. A social inclusion perspective on HIV prevention and AIDS-related care implies the adoption of strategies to understand and confront social vulnerability. Social exclusion intensifies the burden of HIV transmission and morbidity. There is an urgent need to improve our understanding of the characteristics and HIV burden among sexually diverse populations, creatively confront legal, social and cultural factors enhancing social exclusion, ensure the provision of broad-based and effective HIV prevention, offer adequate care and treatment and confront special challenges that characterize work with these populations in lower and middle income countries.

‘Gender and Social Inclusion Strategy/ Indigenous Peoples Framework for the National AIDS Control Support Project (NACSP) 2012-2017.’ NACP III (2007-12) has shown considerable gains in halting and reversing the HIV epidemic. The numbers of new annual infections have decreased by 56% over the past decade and the epidemic has begun to stabilize. While there is a clear decline in HIV prevalence, estimates also indicate that the epidemic is concentrated among high risk groups in localized geographical locations. This highlights the importance of understanding infection trends and barriers to access HIV services among different social groups. The National AIDS Control Organization (NACO)

recognizes that larger contextual factors such as poverty, urbanisation, migration and social marginalization have a significant relationship with vulnerability to HIV/AIDS. In addition to this, lack of awareness, education and economic resources also result in creating barriers and limiting the access to HIV/AIDS services particularly for the high risk groups. The goal of ensuring universal access to HIV /AIDS information and services can only be achieved if the marginalized sections are mainstreamed through appropriate strategies. NACP aims to ensure that the target groups receive services in an equitable manner without any stigma and discrimination through an appropriate Gender and Social Inclusion (GESI) Strategy. NACO conducted a social assessment focusing on the implementation experience of NACP III (2007-2012) with the objective of assessing the equity, gender and social inclusion aspect of the programme in order to better address the social aspects through a Gender Equity and Social Inclusion (GESI) Strategy for the follow up NACSP funded by the World Bank. This assessment was done on the basis of desk review and field based interactions with the States AIDS Control Societies, policy makers, various development agencies, NGOs, the private sector and other concerned stakeholders. It highlights number of initiatives that NACP III has taken for infected and affected populations. NACP III launched many key initiatives to increase gender and social inclusion in the national Program. By ensuring that equity and respect for PLHIV formed an important component in both prevention and impact mitigation strategies as guiding principles, added emphasis was provided in addressing this important issue. National AIDS Control Organisation (NACO), set up in 1992, is working to slow down the spread of HIV/AIDS infection in the country. The apex body, through the National AIDS Control Programme or NACP, sets out objectives and guiding principles for a phased programmatic intervention. This phase is after completion of the Phase-III of NACP, which

has over the years focused on checking the spread of disease, expanded its horizons to include behaviour change, increased decentralization by setting up State AIDS Control Societies (SACS), NGO involvement, adopting national blood policy and ART treatment for both Adults and Paediatrics. The NACP-1 (1992-1999) was launched in 1992, and later extended from 1997 to 1999, was the first strategic plan for prevention and control of AIDS in the country. It was an effort to develop a national public health programme in HIV/AIDS prevention and control. NACP-II (1999 to 2007) aimed to reduce the spread of HIV infection in India through behaviour change and at the same time increase the ability to respond to the infection. NACP-II, moved away from a programme generating mass awareness on HIV prevention to a programme based on targeted intervention approach. NACP-III (2007-2012) sought to halt and reverse the epidemic by providing an integrated package of services for prevention, care support and treatment. The key thrust areas were: (a) prevention of new infections in high risk groups and general population through saturation of coverage of high risk groups with targeted interventions (TIs), (b) scaled up interventions in the general population, (c) providing greater care, support and treatment to a larger number of people living with HIV/AIDS, (d) strengthening the infrastructure, systems and human resources in prevention, care, support and treatment programmes at the district, state and national levels, and (e) strategic information management system for monitoring. A Social Assessment for NACP III was undertaken to assess the equity, gender and social inclusion aspect of NACPIII, so as to strengthen the existing programs and to take corrective measures in NACP-IV with special focus, if required. The methodology for the SA involved a review of the NACP documents and NACO publications and activities undertaken by various stakeholders during the period 2007-2012. The process included: (i) Desk Review; (ii) Field



based interactions with the States AIDS Control Society; (iii) stakeholder consultations. To understand the perspectives of the key stakeholders, field based interaction. NACP- III maintained a thrust on creating an enabling environment so that there is a greater acceptance of infected and affected people by the community. Enabling environment has a ripple effect on prevention, care and support of HIV, and most importantly, when the human rights i.e. to live a life of dignity, without stigma and discrimination are respected, it helps society in many ways. To reduce stigma and discrimination associated with the infected and affected persons and ensure that they have an access to prevention and quality treatment, care, and other supports like legal services, NACP – III took affirmative actions, which were aimed at •

Creating an Enabling Environment where NACP III recognized that effective prevention, care, support and treatment for HIV/AIDS is possible in an environment in which human rights are respected and where those infected with or affected by HIV live a life of dignity, without stigma and discrimination. It aimed to work in partnership with PLHA networks and other stakeholders towards creating an enabling environment by addressing issues of stigma, discrimination, legal and ethical concerns. The activities have focussed on creating an enabling environment to address the legal and socioeconomic barriers which are likely to adversely impact the outcomes of national HIV response. •

Addressing Stigma and Discrimination where NACP-III addressed the issue of stigma and discrimination through communication, research, advocacy, capacity development and partnership building. Stigma and discrimination is an obstacle to an effective response to HIV/AIDS at all levels. Stigma and discrimination is perceived in social settings including family, community, schools and workplace along with stigma and discrimination from service providers. PLHIV and vulnerable populations themselves are largely unaware of their rights which make the

situation worse. • Addressing Human Rights, Legal and Ethical Issues National AIDS Prevention and Control Policy (2002) aims to respect the rights of people living with HIV/AIDS and vulnerable populations. • Addressing the Gender Equality The impact of HIV and AIDS reaches far beyond the health sector with severe economic and social consequences. Like other epidemics, it is much more severe on women than men. Biological, socio-cultural and economic factors make women and young girls more vulnerable to HIV and AIDS. • Addressing the needs of the Vulnerable and Specific Groups Apart from women, NACP III considers youth, especially in high prevalence districts, children, including girls in special settings, school drop outs, orphans of HIV/AIDS infected/ affected as vulnerable among the general population. Acknowledging their needs as special, NACP has initiated specific interventions. NACO has successfully implemented NACP- III and to a very large extent has come very close to its objective of halting and reversing the epidemic. According to recent estimates, the HIV prevalence overall in the country has come down, but new pockets have also emerged posing new issues and challenges. The challenges emerged in the of Coverage, Care and Support, Stigma and Discrimination, and Enabling Environment.

An article on Causes and Forms of Social Exclusion highlighted that social exclusion is often the effect of a process of discrimination or 'othering' on the basis of of cultural, social and/or racial identity. Such discrimination can generate powerful exclusionary processes. It can be systematic and intentional - resulting from policies which are embedded in the formal institutions of the state, as in the case of the Apartheid regime in South Africa. Discriminatory processes and practices can also be deeply embedded in the operation of labour markets. For example, Popay et al. (2008, see below) highlight the example of the

majority indigenous Tuareg in North Niger, who represent only 1% of upper management personnel and 15% of workers and employees in the uranium mining industry which has polluted their traditional lands and compromised their livelihoods. Discriminatory processes may also be reinforced by religion, tradition and cultural practices – as exemplified by India's caste system - and embedded in dominant social attitudes, behaviours and prejudicial practices.

Stigma, Social Reciprocity and Exclusion of HIV/AIDS patients with Illicit Drug Histories: A study of Thai nurses' attitudes studied by Kit yee Chan, Mark A Stooze, Daniel D Reidpath, states that stigma is a key barrier for the delivery of care to patients living with HIV/AIDS (PLHAS). In the Asia region, the HIV/AIDS epidemic has disproportionately affected socially marginalised groups, in particular, injecting drug users. The effect of the stigmatising attitudes towards injecting drug users on perceptions of PLHAS within the health care contexts has not been thoroughly explored, and typically neglected in terms of stigma intervention. Semi-structured interviews were conducted with a group of twenty Thai trainee and qualified nurses. Drawing upon the idea of 'social reciprocity', this paper examines the constructions of injecting drug users and PLHAS by a group of Thai nurses. Narratives were explored with a focus on how participants' views concerning the high-risk behaviour of injecting drug use might influence their attitudes towards PLHAS. The analysis shows that active efforts were made by participants to separate their views of patients living with HIV/AIDS from injecting drug users. While the former were depicted as patients worthy of social support and inclusion, the latter were excluded on the basis that they were perceived as irresponsible 'social cheaters' who pose severe social and economic harm to the community. Absent in the narratives were references to wider socio-political and

epidemiological factors related to drug use and needle sharing that expose injecting drug users to risk; these behaviours were constructed as individual choices, allowing HIV positive drug users to be blamed for their seropositive status. These attitudes could potentially have indirect negative implications on the nurses' opinions of patients living with HIV/AIDS more generally. Decreasing the stigma associated with illicit drugs might play crucial role in improving attitudes towards patients living with HIV/AIDS. Providing health workers with a broader understanding of risk behaviours and redirecting government injecting drug policy to harm reduction are discussed as some of the ways for stigma intervention to move forward.

Hilary Silver (1995) presented three major paradigms of exclusion viz., solidarity, specialization and monopoly which rooted in different conceptions of integration and citizenship. According to her, in the solidary paradigm, exclusion is seen as the rupture social bond between the individual and society that is cultural and moral. In the specialization paradigm, exclusion reflects discrimination while in the monopoly paradigm, exclusion is seen as a consequence of the formation of group monopolies. She felt that whatever way they were conceived the empirical manifestations of rising exclusion in the advanced countries question the adequacy of the existing welfare state arrangements. Silver also felt that the idea of exclusion could also serve a variety of political purposes. It could be useful to reformers who want to point to the inadequacies of current welfare states; it might conversely serve to distract attention from general rise in inequality, unemployment and family dissolution that affect all social classes.

Gerri Rodgers (1995) held that the special features of social exclusion approach include multidimensionality an interdisciplinary approach, focus on process, impact at multilevel viz., global, national, regional, institutional, family and individual. Rodgers

emphasized the need for broadening the concept encompassing levels of living, means of livelihood, social rights and their broader linkages with the pattern of development.

Vilmer E. Faria (1995) examined the main insights of Latin American literature on poverty and deprivation for conceptual understanding, theoretical explanation, and policy recommendations for social exclusion framework as well as the usefulness of the concept for understanding the social question in Latin America. Faria lauded the usefulness of Social Exclusion Framework (SEF) in providing a general framework for integrating loosely connected notions such as poverty, deprivation, and lack of access to goods, services and assets, precariousness of social rights etc. According to Faria, the main outstanding theoretical contribution of Latin American literature to social exclusion analysis was that of connecting poverty, deprivation and inequality to the way social systems function. Faria held that the literature viewed exclusion as the consequence of specific modes of integration both of the Latin American economies and societies into a changing world system and of social groups, families, individuals and regions into these national economies.

A.B. Atkinson (1998) analysed the three-way relationship between poverty, unemployment and social exclusion. According to him, though these concepts are related they should not be equated. The three elements or aspects of the concept of social exclusion were relatively, agency and dynamics distinguish it from poverty. According to Atkinson the link between social exclusion and unemployment is far from complete.

Judith Harwin and Gaspar Fajth (1998) contended that both perspectives poverty model and social exclusion framework as necessary to understand the changes and the policy responses adopted, a social exclusion framework captures for better the processes of change, the multi-dimensional nature of these and their underlying causes in the countries. They

contended that whatever paradigm of social exclusion is utilized, solidarity, monopoly the traditions of Durkheim and Weber seem to be more able than poverty perspectives to explain what happens when societies are split apart, and people have to rebuild both their material and social world and their inner belief systems. According to them by stressing rights, participation and inclusion a social exclusion perspective offers a more comprehensive and relevant approach to the parallel implementation of economic and social reforms. They held that its applications could be reconciled with both market or statist policy approaches and would not affect the size of public interventions. It would change the ways these interventions are organized, what they target, and how they are actually carried out. According to them it would promote the recognition of the multidimensionality of disadvantage and the need for multi-agency approaches to prevent risk situations and enhance well being.

Martin Evans (1998) argued that the discussion of policy assumptions on the paradigmatic differences between social exclusion and poverty should always be strongly grounded in their policy context. Evans contended that social exclusion has risen in the European discussion at a time when the failure of welfare states to prevent poverty has been criticized. Evans compared the policy context of French 'social exclusion' and British poverty concepts using social assistance as a template. It emphasized the need to maintain a social and institutional context beyond that of western industrialized countries and their welfare institutions.

Glenn C. Loury (1999) discussed the concept of Social Exclusion and assessed its utility in studying ethnic and racial inequality in the modern nation state. Loury examined race-based social exclusion in the United States and showed how race and ethnicity inhibit

the full participation of individuals in a society's economic life. Loury discussed the legitimacy of race-based remedies for the problem of exclusion.

Arjan de Haan and Amaresh Dubey (2003) emphasized the usefulness of the concept of social exclusion to further understanding of poverty, and applied the same to draw better insight into the dimensions and causes of poverty in one of India's poorest regions of Orissa. They described the characteristics of poor people in those areas, and emphasized the overlapping aspects of deprivation: remoteness, rural location, possibly immobility (despite large-scale distress migration), identity, education and health. According to them, the reason for exclusion are rooted in both structure and agency. To them, exclusion was resulting from lack of economic growth and policy failure. According to them, the relative failure of government response, in turn, is the result of lack of accountability. They also held that the relative lack of response or effectiveness is driven by social-cultural segmentation, the political dominance of coastal Orissa, and the unchallenged cultural domination of higher castes over lower castes and tribal groups.

The review of literature presented above suggests that there is a copious literature on social exclusion all over the world. They mainly focus on the patterns, process or levels, agencies and mechanisms of inclusion/exclusion at national level (Kanagaraj 2005). There are attempts to develop conceptual and operational frameworks of social inclusion in its multiple dimensions at multilevel viz. national, and state, levels (see United Nations 2010). There are studies at household (see Kanagaraj 2005) and individual (see Jehoel-Gijsbers, & Vrooman 2007; Bayram et al 2011; Bayram, Firat and Gonul 2012), levels which throw light on the determinants and consequents of social inclusion/exclusion of elderly, poor, ethnic minorities in varied contexts.

As regards the methodology we could notice studies using quantitative, qualitative as well as mixed methods are found though many scholars emphasize judicious combination of quantitative and qualitative methods.

The brief literature survey presented above helps us not only to identify the substantive dimensions of the research problem but also to lay down the theoretical, conceptual and methodological foundations of the present study. Further, the overview suggests a few research gaps.

Firstly, studies on social inclusion/exclusion of PLHAS are a few which were in the global, national, regional contexts though policy frameworks at multilevel increasingly emphasize social inclusion as a major goal of intervention. However, the aspects of social life of PLHAS like stigma, discrimination, care and support are widely studied.

Secondly, there are a few studies which operationalize the concept of social inclusion of PLHAS, identify its determinants, agencies and mechanism of inclusion/exclusion.

Thirdly, though use of mixed methods design is emphasized in the study of exclusion elsewhere in the studies on social inclusion/exclusion of PLHAS there are very few attempts in this direction. The present study attempts to fill these research gaps by proposing a study on social inclusion of persons living with HIV/AIDS in Mizoram.



## **CHAPTER III**

### **METHODOLOGY**

This chapter describes the setting and the methodology of the present study. This chapter has been presented into two major sections. The first section deals with profile of the study, whereas the second section presents the methodological aspects of the present study.

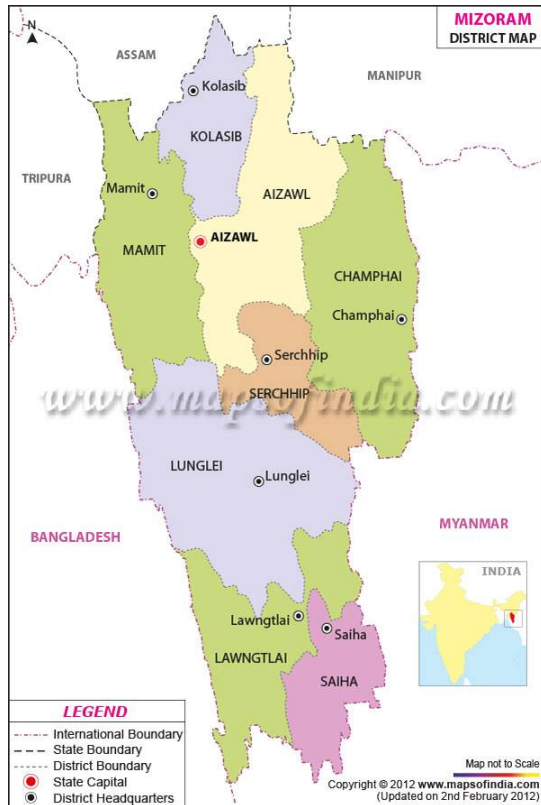
#### **3.1 The Setting: Profile of the Study Area**

The present study has been conducted in two districts of Mizoram. Various localities of Lunglei District represented non-autonomous district, and various localities of Saiha town represented autonomous district of the study.

##### **3.1.1 Mizoram**

Mizoram is one of the twenty eight states of India with an area of 21,087 square kilometers, and a population of 1,091,014 persons according to 2011 census. It is located in the North Eastern India. The people living in Mizoram are called 'Mizo' with literacy of 88.49% which is considered to be the second highest in the country. Mizos are a close-knit society with no class distinction and very little discrimination on grounds of gender. Birth of a child, marriage in the community and death of a person in the community are important occasions in which the whole community is involved.

There are eight Districts in the State, viz; Aizawl District, Lunglei District, Saiha District, Lawngtlai District, Kolasib District, Serchhip District, Champhai District, and Mamit District. The prevalence rate of HIV/AIDS is very high in Mizoram. Mizoram stands second in prevalence of HIV/AIDS amongst the North Eastern States and was only next to Manipur.

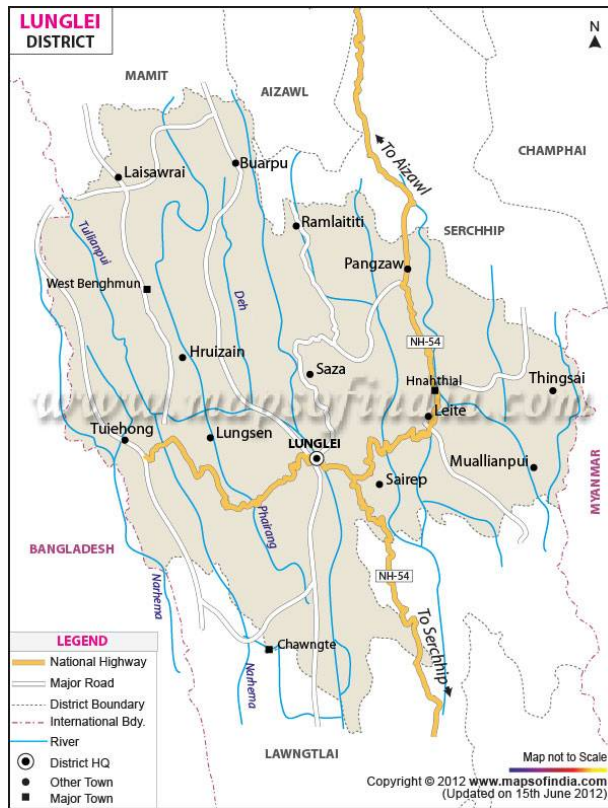


**Fig 3.1. Map of Mizoram**

### 3.1.2 Lunglei

Lunglei is one of the eighth districts of Mizoram state in India. As of 2011, it is the second most populous district in the state, after Aizawl. The district is bounded on the North by Mamit and Aizawl Districts, on the west by Bangladesh, on the South by Lawngtlai District, on the Southeast by Saiha District, on the east by Myanmar and on the northeast by Serchhip District. The district occupies an area of 4538 km sq. Lunglei town is the administrative headquarter of the district. According to the 2011 census, Lunglei district has a population of 154,094, roughly equal to the nation of Saint Lucia. This gives it a ranking of 597<sup>th</sup> in India (out of total of 640). The district has a population density of 36 inhabitants per square kilometre (93/sq

mi). Its population growth rate over the decade 2001-2011 was 17.64%. Lunglei has a sex ratio of 947 females for every 1000 males, and a literacy rate of 88.86%.

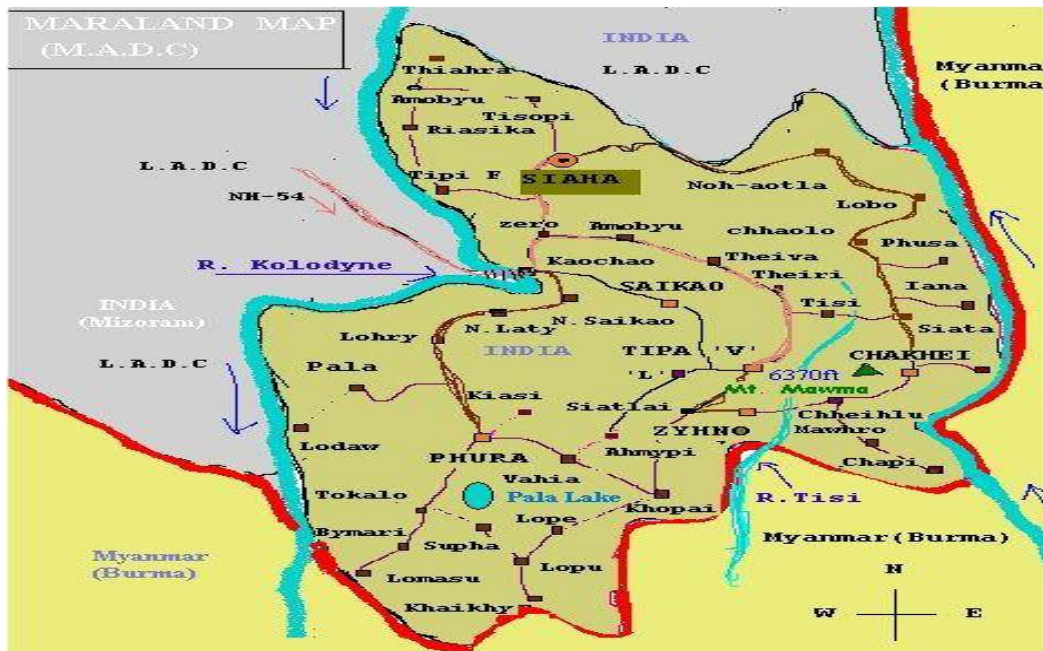


**Fig 3.1.2 Map of Lunglei District**

### 3.1.3 Saiha

Saiha District is one of the eight districts of Mizoram state in India. The district is bounded on the north and northwest by Lunglei district, on the west by Lawngtlai district and on the south and east by Myanmar. The district occupies an area of 1399.9 sq km as of 2011 census. Saiha town is the administrative headquarters of the district. The population had decreased from 60,823 (in 2001 census) to 56,674 (in 2011 census). It is the least populous district of Mizoram. (out of 8). Saiha District as formerly part of Chhimtuipui District. In 1998, when Chhimtuipui District was split in half, the half that Saiha District was briefly called by the old name

Chhimituipui District. Saiha is the third largest town in Mizoram after Aizawl, the state capital and Lunglei. In 2006, the Ministry of Panchayati Raj named Saiha one of the country's 250 most backward districts (out of a total of 640). It is one of the districts in Mizoram currently receiving funds from the Backward Regions Grant Fund Programme (BRGF). According to the 2011 census, Saiha District has a population of 56,574, roughly equal to the island of Greenland. This gives it a ranking of 628<sup>th</sup> in India (out of a total of 640). The district has a population density of 40 inhabitants per square kilometre (100/sq km). Its population growth rate over the decade 2001-2011 was -7.34%; the only district in Mizoram to have decreased population. Saiha has a sex ratio of 979 females for every 1000 males, and a literacy rate of Saiha is 90.01%. The majority of the district inhabitants are Mara people, who also have an autonomous district council called Mara Autonomous District Council composed of two R.D Blocks of Saiha and Tuipang.



**Fig 3.1.3 Map of Saiha District**

### **3.2.1 Methodology**

The present study is cross sectional in nature and descriptive in design. It is based on mainly the primary data collected with the help of qualitative and quantitative methods. Qualitative and quantitative methods were collected concurrently. Quantitative data was collected through field survey with pretested structured personal interview schedule to assess the patterns, levels and the determinants of inclusion of Persons Living with HIV/AIDS. The study was conducted during 20<sup>th</sup> August, 2014 to 21<sup>st</sup> September, 2014. Case studies constitute the qualitative methods and was used in the study to understand the dynamic processes of inclusion/ exclusion and the context of exclusion.

### **3.2.2 Sampling**

The universe of the study is individual adult persons living with HIV/AIDS (PLHAS) and the population includes all PLHAS in the state of Mizoram. A multistage sampling is used to select districts, towns and respondents. In the first phase, two districts- Lunglei District and Saiha District are chosen purposively. In the second stage, demographic details of PLHAS is compiled from the governmental and non-governmental organizations working with PLHAS ie; MCHP (Saiha), ICTC,Civil Hospital (Saiha), Grace Society (Lunglei), ICTC, Christian Hospital (Lunglei), ICTC Civil Hospital (Lunglei). The PLHAS are stratified on the basis of gender. From among men and women proportionately respondents are drawn. The sample size is sixty.

### **3.2.3 Tools for Data Collection**

Structured interview schedule was used for collection of primary data. The interview schedule contains twenty six sections with a number of sub-sections. Pilot study was

conducted with PLHAS for constructing interview schedule. The interview schedule contains identification information of the respondents, demographic profile and household profile of the respondents,

### **3.2.4 Data Processing and Analysis**

The primary data collected through field survey is processed with the help of Microsoft Excel and analyses with SPSS Package 20. Apart from simple percentages, ratios, averages, cross tabulation, Karl Pearson's product moment correlation is used for analysis of quantitative data.

### **3.2.5 Concepts and Operational Definitions**

In this section, the important concepts used in the study are operationally defined as under.

- HIV: HIV is the virus that causes AIDS. It stands for Human Immunodeficiency Virus.
- AIDS: It is the last stage of HIV.
- Immune deficiency: The capacity of the natural immune system of the body to fight against the disease.
- Virus: It is a Latin word, which means 'Poison'. A virus is an infectious particle that is too small to be seen with naked eye or even with a conventional light microscope.

### **3.2.6 Limitation**

The brief literature survey presented above helps us not only to identify the substantive dimensions of the research problem but also to lay down the theoretical, conceptual and methodological foundations of the present study. Further, the overview suggests a few research gaps.

Firstly, studies on social inclusion/exclusion of PLWHA are a few which were in the global, national, regional contexts though policy frameworks at multilevel increasingly emphasize social inclusion as a major goal of intervention. However, the aspects of social life of PLHAS like stigma, discrimination, care and support are widely studied.

Secondly, there are a few studies which operationalize the concept of social inclusion of PLHAS, identify its determinants, agencies and mechanism of inclusion/exclusion.

Thirdly, though use of mixed methods design is emphasized in the study of exclusion elsewhere in the studies on social inclusion/exclusion of PLHAS there are very few attempts in this direction. The present study attempts to fill these research gaps by proposing a study on social inclusion of persons living with HIV/AIDS in Mizoram.

## **CHAPTER IV**

### **PATTERNS AGENCIES AND MECHANISMS OF SOCIAL INCLUSION OF PLHAS**

In the present chapter, an attempt has been made to discuss the results of the analysis of data collected through structured interview schedule in two district headquarters of Mizoram. This chapter has been presented in six major sections each with sub-sections. They are profile of respondents and their households, pattern of social inclusion,

#### **4.1 Profile of Respondents and their Households**

The primary objective of the present study understands the demographic, social and economic characteristics of the respondents. The results of analysis of primary data collected on the background are presented in this section. The profile of respondents is presented into five subsections, viz; demographic characteristics of the respondents, family structure, social characteristics, economic characteristics and the profile illness.

##### **4.1.1 Demographic Characteristics of the Respondents**

The demographic characteristics of the respondents presented are gender, age group, marital status and educational status (see table 4.1).

Gender is a demographic characteristic, which has greater social and economic significance in any socio economic study like the present one. Male respondents constitute predominant majority of the respondents in both the districts i.e. Saiha and Lunglei. However, it was found out that there was a variation in the percentage. Male comprised of the two-third of the total respondents in both the districts (67%), while female comprised of the one-third of the total respondents (33%).

The age group was classified into Youth (18-35) and Middle (35-60). The results show that youth group constitutes a predominant majority of respondents in both the



communities. However, the proportion of youth is greater in non-autonomous district (93%) as compared to those in autonomous district (67%). On the contrary, the proportion of middle aged is relatively greater in autonomous district (33%) as compared to that of non-autonomous district (7%). There is no difference in age distribution. The overall mean age of respondents in Autonomous district (33 years) is slightly greater than that of Non-autonomous district (27.5 years).

As far as marital status is concerned, it confers power and prestige on the individuals in any society. Even the primitive tribes are no exception to this. Marital status is classified into unmarried, married, divorced and separated. The results show that unmarried respondents constitute a predominant majority of respondents in both the districts. However the proportion of unmarried respondents is slightly higher in Non-autonomous district(90%) as compared to those in Autonomous district(63%). On the contrary, the proportion of married respondents are slightly greater in Autonomous district (6%) as compared to that of Non-autonomous district (3%). The proportion of divorced/separated is relatively greater in Autonomous district (30%) to that of one-tenth (6%) in Non-autonomous district.

~~Educational status and its significance.~~ Most of the respondents were literate and with high educational background. Both the districts have similar level of educational attainment. The educational status of the respondents was classified into Primary (1-4), Middle (5-7), High School (8-10), Higher Secondary (11-12) and College (13 and Above). The results show that in Non-autonomous district, primary level constitutes 0 % of the respondents to that of one-tenth (3%) in Autonomous district. Middle School level in Non-autonomous district constitutes one-tenth (3%) of the respondents to that of one-fifth (13%) in Autonomous district. At primary and Middle School levels, the proportion is slightly greater

in Non-autonomous district as compared to Autonomous district. The variation is same in High School level at both the districts which constitutes one-fifth (26%) each. However, Non-autonomous district had a higher percentage from Higher Secondary to college level i.e.; one-fifth (23%) in the higher secondary to that of one-tenth (13%) in Autonomous district and almost one-half (47%) for College level in Non-autonomous district to that of above one-third (43%) of Autonomous district.

#### **4.1.2 Family Structure of Respondents**

The family characteristics comprises of Type of Family, Size of family, Form of family and Gender of head (see Table 4.2)

In reference to type of family, family sociologists classify family structure into nuclear family and joint family or extended family. The family with a couple and their unmarried children is known as nuclear, while the families with more than two generation is called joint or extended. The results show that nuclear family of respondents is predominantly found in both the studied districts (86%). However, the proportion of nuclear family is higher in Non-autonomous district (93%) as compared to those in Autonomous district (80%). On the contrary, the proportion of Joint family is slightly higher in Autonomous district (20%) as compared to Non-autonomous district (7%).

The size of family was divided into three categories i.e.; Small (1-3), Medium (4-6) and Large (7 and above). The medium size of a family was a dominant size in the two districts (71%). However, the proportion of the medium size of the family is relatively higher in Autonomous district (73%) as compared to those in Non-autonomous district (70%). On the contrary, the proportion of small family is slightly higher in Non-autonomous district below one-tenth (7%) to that of below one-tenth (4%) in Autonomous district. Moreover,

large family in both the districts held the same proportion, i.e. one-fifth (23%). The overall mean size of family is 6% in both the studied districts. This means that there are no variations in the mean size of the family.

In the context of Mizoram, three forms of family viz., stable, broken and reconstituted step were observed. The results show that broken and reconstituted family constitutes predominant majority of the respondents in both the studied districts (60%). However, it was found out that the proportion of broken/reconstituted family is greater in Non-autonomous district (63%) as compared to those in Autonomous district (56%). On the contrary, the proportion of stable family is greater in Autonomous district (43%) as compared to Non-autonomous district (36%).

Gender of head is one of the family characteristics probed in the present study. Male headed family represents the family of predominant majority of the respondents in both the studied districts (90%). However, it was found out that the proportion of male headed members is greater in Autonomous district (96%) to that of those in Non-autonomous district (83%). Female headed household comprises of only one-tenth (10%) in both the districts. However, the female headed household is slightly higher in Non-autonomous district (16%) as compared to Autonomous district (3%).

#### **4.1.3 Social Characteristics of Respondents**

The social structural characteristics include sub-tribe and denomination which were discussed below (See Table 4.3)

In respect to tribe, the respondent's households belonged to Lusei, Mara, Lai, Ralte and Hmar. Lai constitutes predominant majority of respondents in both the districts (41%). However, it was found out that the proportion of Lai is slightly greater in Non-autonomous

district (43%) as compared to those in Autonomous district (40%). Lusei constitutes slightly less than one-half (40%) in Non-autonomous district to that of only one-tenth (13%) in Autonomous district. Mara constitutes 0% in Non-autonomous district and around one-half (50%) in Autonomous district which was followed by Lai i.e. one-third in both the communities (43% and 30%). Ralte constitutes below one-tenth in both the communities (6%), followed by very a few round of Hmar i.e. one-tenth (10%) in Non-autonomous district and 0% in Autonomous district.

Several religious denominations seem to be familiar with the epidemic of HIV/AIDS and take up the initiatives to fight against alarming spread of HIV/AIDS. With reference to religious denomination, Baptist Church Of Mizoram held the dominant denomination within the studied districts (42%). However, the proportion is greater in Non-autonomous district (66%) as compared to Autonomous district which is slightly less than one-fifth (17%). Evangelical Church of Maraland constitutes one-half (50%) in Autonomous district to that of 0% in Non-autonomous district followed by Presbyterian, i.e. slightly more than one-fifth (23%) in Non-autonomous district and one-tenth(10%) in Autonomous district. United Pentecostal Church constitutes slightly around one-tenth (10%) in Non-autonomous district and 0 percentage among the respondents in Autonomous district. Isua Krista Kohhran constitutes one-tenth (14%) in Autonomous district and 0 percentage in Non-autonomous district, followed by Lairam Isua Krista Baptist Kohhran i.e. slightly more than one-tenth (13%) in Autonomous district and 0 percentage in Non-autonomous district.

#### **4.1.4 Economic Characteristics of Respondents**

To understand the economic conditions of PHAS in Mizoram, the study focuses on certain characteristics viz., earner/dependent, primary occupation, socio economic category, annual household income, per capital annual household income (see Table 4.4).

Primary occupation is one of the major economic structural parameters as well as indicator of standard of living. Primary occupation is categorised into dependent, government officer, government worker, wage laborer and skilled laborer. From the study, it was found out that dependent respondents constitute predominant majority in both the studied districts (73%). However, the proportion of the dependent respondents is slightly higher in Non-autonomous district (83%) as compared to those in Autonomous district (63%). There is no such proportion of government officer in Non-autonomous district, whereas not even one-tenth (3%) of the respondents in Autonomous district were government officer. Less than one-tenth (7%) in Non-autonomous district are government workers, while slightly more than one-tenth (13%) are government workers in Autonomous district. Less than one-tenth (3) in Non-autonomous district were engaged in wage labor while one-tenth (10%) were engaged in wage labor, followed by skilled laborer (7%) in Non-autonomous district and (10%) in Autonomous district. Earners constitute a greater proportion in Autonomous district.

It has been found out that dependent respondents constitute the predominant majority in both of the districts (73%) . However, it was found out that the proportion of dependent respondents is higher in Non-autonomous district (83%) as compared to Autonomous district (63%). On the contrary, it was found out that earners constitute a greater proportion in Autonomous district (36%) as compared to that in Non-autonomous district (17%)(see)

Socio economic category or class is one of the major economic characteristics, which determine the economic status of any community, group or individual. Socio economic is categorised into Very Poor (AAY), Poor (BPL) and Non-poor. The results show that the predominant majority of respondents falls under non-poor category in both the districts (50%). However, it was found out that the proportion of non-poor category is the same in both the districts (50%). On the contrary, the proportion of Very Poor (AAY) category is greater in Autonomous district (23%) to that of those in Non-autonomous district (13%). It was also found out that the proportion of poor category (BPL) is greater in Non-autonomous district (37%) as compared to those in Autonomous district (27%).

Income is the foremost indicator of development and progress of any unit of analysis both at micro and macro levels. The level of annual household's income was categorised into minimum and maximum levels of annual income of households. The total minimum annual household's income in both the districts was Rs.12,000. However, the minimum proportion of annual household's income of respondents is greater in Autonomous district (Rs.15,000) than in Non-autonomous district (Rs.12,000). The maximum annual household's income in both the districts was Rs. 1,410,00. However, the maximum proportion of annual household's income of respondents is greater in Autonomous district (Rs.1, 410,00) than in Non-autonomous district (Rs.1,380,00). Thus, the annual household income mean is higher in Non-autonomous district (Rs.59000) than in Autonomous district (Rs.53583).

Per Capita Annual Income was classified into minimum and maximum levels of annual income of households. The total minimum per capita annual income in both the districts was Rs.1714. However, the minimum proportion of per capita annual income is higher in

Autonomous district (Rs.3444) as compared to Non-autonomous district (Rs. 1714). The per capita annual household's income shows similar picture in both the studied districts (see)

#### **4.1.5 Illness Profile of Respondents**

Illness profile of respondents is categorised into year of detection of infection, probable mode of transmission and organisation where infection detected (see table 4.5)

As far as year of detection is concerned, it was categorised into 2005-2007, 2008-2011 and 2012-2014. During 2008-2011, detection of HIV infection happened for predominant majority in both the studied districts. However, it was found out that the proportion of year of detection between 2008-2011 is slightly higher in Non-autonomous district (53%) than in Autonomous district (40%). The study shows that the proportion of year of detection between 2005-2007 is greater in (Autonomous district 26%) as compared to Non-autonomous district (4%), followed by the proportion of year of detection between 2012-2014 is greater in Non-autonomous district (43%) to that of (33%) in Autonomous district.

Unprotected sexual intercourse is the dominant mode of transmission within the studied districts (52%). However, the proportion of unprotected sex is higher in Non-autonomous district (57%) as compared to Autonomous district (47%). The proportion of sharing of unsterilized needles is higher in Autonomous district where it held one-half (50%) to that of more than one-third (37%) in Non-autonomous district. It has also been found out that there is a slight case of blood transfusion where both the communities held not even one-tenth i.e.; 6.7% in Non-autonomous district and 3.3 in Autonomous district (see)

ICTC is a place where a person is counseled and tested for HIV on his/her own free will or as advised by a medical provider. HIV counseling and testing are key entry points to

prevention of HIV infection to treatment and care of persons already infected with HIV. Mobile ICTC is the dominant agency where HIV blood test was done within the studied districts (47%). However, the proportion of Mobile ICTC is higher in Autonomous district (63%) as compared to Non-autonomous district (43%). On the contrary, the proportion of cases detected by ICTC is greater in Non-autonomous district (56%) to that of (37%) in Autonomous district (see)

## **4.2 Pattern of Social Inclusion**

Social inclusion is conceptualized in terms of PLHAs participation in three dimensions of social life viz., community, economic and political. Each dimension was measured in terms of frequency of participation. The present section presents discussion on the pattern of social inclusion in four subsections, i.e.; Pattern of Community Inclusion, Pattern of economic inclusion, pattern of political inclusion and pattern of social inclusion.

### **4.2.1 Pattern of Community Inclusion**

The pattern of community inclusion includes attending funeral services, attending marriages in the community, attending the church services, volunteering for community and attending meetings of community organisations (see table 4.6)

Attending funeral services is categorised into the frequency of participants among the community; i.e. 3=always, 2=Mostly, 1=Sometimes and 0=Never. From the table, it was clearly shown that attending funeral services is the predominant mode of community inclusion in both the districts (1.6). This was followed by attending marriage in the community where it scores the mean average of 1.5 in Non-autonomous district and 1.2 in Autonomous district. On average, Non-autonomous district scores 1.3 in attending church services, while Autonomous district scores 0.9. In volunteering for community, the mean



average was 0.9 in Non-autonomous district and 0.4 in Autonomous district and attending meetings of community organisation held the average of 0.9 in Non-autonomous district and 0.4 in Autonomous district.

Attending marriages in the community is also assessed in terms of the frequency of participants among the community; i.e. always(3), Mostly (2), Sometimes (1) and Never (0) and constitutes a mean average of 1.5 in Non-autonomous district and 1.2 in Autonomous district which means that Non-autonomous district is slightly higher regarding attending marriages in the community.

Attending the church services is categorised into the frequency of participants among the community; i.e. always(3), Mostly(2), Sometimes(1) and Never(0) and constitutes a mean average of 1.1 in total. However, it is seen that the church participation of community event is more in Non-autonomous district which held the average of 1.3 to that of 0.9 in Autonomous district.

The average of volunteering for community and attending meetings of community organisation held the same average and are extremely low both in Non-autonomous district and Autonomous district which constitutes a total average of both 0.6 in total. However, this has been practiced more in Non-autonomous district which held the average of 0.9 to that of 0.6 both in the two events.

The proportion of attending marriages, church services and volunteering for community is greater in non-autonomous district. From the table, it can be seen that community inclusion is slightly better in non- autonomous district.

#### **4.2.2 Pattern of Economic Inclusion**

The pattern of economic inclusion constitutes Adequacy of size of land, adequacy of present family income, Number of days of employment, adequacy of amount of loan getting when needed, wage rate/monthly salary and amount save every month and are categorised into adequacy of participants i.e. Highly adequate(3), Adequate(2), Inadequate(1) and Highly inadequate(0)(See table 4.7)

Adequacy of size of land constitutes the predominant economic inclusion among the studied districts (1.6) while amount save every month held the lowest mean average in total i.e.; 1.1. However, the mean average of adequacy of size of land is slightly higher in Non-autonomous district i.e. 1.7 to that of Autonomous district i.e. 1.5. The mean average of adequacy of present family income constitutes 1.4 in Non-autonomous district and 1.3 in Autonomous district. Number of days of employment held the same average in both the studied communities i.e.; 1.3, followed by adequacy of amount of loan getting when needed which constitutes 1.3 in Non-autonomous district to that of 1.2 in Autonomous district. Wage rate/monthly salary is slightly higher in Autonomous district which held the average of 1.3 to that of 1.2 in Non-autonomous district, followed by amount save every month which held the same average both in Non-autonomous district and Autonomous district, i.e. 1.1. Thus, economic inclusion held the average total of 1.6, whereas Non-autonomous district is slightly inclusive with respect to economic characteristics i.e. 1.6 to that of Autonomous district i.e.; 1.5.

#### **4.2.3 Pattern of Political Inclusion**

The pattern of Political Inclusion includes Voting in Assembly Election, voting in general election, voting in Village Council election, participation in election campaigns and attending meetings of political parties and are categorised into the frequency of

participation of the respondents, i.e. 3 Always, 2 Mostly 1 Sometimes and 0 Never(See Table 4.8)

Voting in Assembly Election is the predominant form of political inclusion in both of the districts which constitutes 2.3 mean average in Non-autonomous district and 1.5 in Autonomous district, while the mean average in total is 1.9 followed by Voting in general election which constitutes 2.3 in Non-autonomous district and 1.5 in Autonomous district followed by Voting in Village Council which constitutes 2.3 in Non-autonomous district and 1.5 in Autonomous district. In these three political events, Non-autonomous district participates more than Autonomous district which constitutes 1.9 in Non-autonomous district and 0.7 in Autonomous district.

Attending meetings of political parties held the lowest average in both the studied communities. Autonomous district has all the participations in this respective event i.e.; 0.5 in mean average to that of 0.0 in Non-autonomous district.

Participation in election campaigns constitutes a higher level in Non-autonomous district i.e. 0.4 to that of Autonomous district i.e. 0.2. However, it can be seen that both the communities less participated in election campaigns.

From the above findings, it is seen that political average has a mean average of 1.2 in total. However, the proportion of political inclusion is higher in Non-autonomous district which constitutes a mean average of 1.5 to that of Autonomous district i.e. 1.0

### **4.3 Social Inclusion**

The three dimensions of Social inclusion are aggregated with a simple average. They were further analyzed in terms of pattern, extent and determinants in three subsections.

#### **4.3.1 Pattern of Social Inclusion**

The pattern of inclusion is categorised into economic inclusion, political inclusion, community inclusion and social inclusion (see table 4.6)

From the above table, it can be seen that economic inclusion is the predominant mode of inclusion in both the districts, which constitutes 1.6 in Non-autonomous district and 1.5 in Autonomous district, followed by social inclusion which held the average of 1.5 in Non-autonomous district and 1.1 in Autonomous district. Community inclusion is least in comparison with political inclusion and economic inclusion which held the mean average of 1.5 in Non-autonomous district and 1.0 in Autonomous district, followed by political participation which is significantly greater in non-autonomous district and constitutes the average of 1.3 to that of 0.8 in autonomous district. From the study, it can be seen that social inclusion of PLHAS is significantly greater in non-autonomous district than autonomous district.

#### **4.3.2 Extent of Social Inclusion**

The extent of social inclusion is categorised into low (0.60-1.13), Medium (1.13-1.67) and High (1.67-2.2). (See table 4.7).

There is significant difference in the extent of social inclusion across districts. Most of the respondents are moderately included in the level of inclusion which constitutes nearly two-third of the respondents (58%), followed by the low category which constitutes slightly below one-third (28%) of the total respondents. However, the proportion of PLHAS at low level is greater in autonomous district which held slightly below one-half (47%) to that of only one-tenth (10%) in non-autonomous district.

The high category falls under the lowest which constitutes only one-tenth (13%) of the total respondents. However, the proportion of highly included PLHAS is higher in Non-

autonomous district which constitutes nearly one-fifth (17%) of the respondents to that of Autonomous district; ie one-tenth (10%). The proportion of moderately included PLHAS is higher in Non-autonomous district which constitutes slightly below three-fourth (73.3%) to that of Autonomous district which constitutes below one-half (43%).

#### **4.3.3 Determinants of Social Inclusion**

The determinants of social inclusion includes gender, educational qualification, size of family, socio economic category and annual household income and is categorised into community inclusion, economic inclusion, political inclusion and social inclusion(See Table 4.8).

From the table, it can be seen that males are better inclusive than the female respondents in terms of gender. Education has an effect on economic inclusion. Moreover, the size of family and socio economic determinant have no effect on community, economic, political and social inclusion. Household income is also positively related to economic and overall social inclusion.

#### **4.4 Agencies of Social Inclusion/Exclusion**

##### **4.4.1 Agencies of Social Inclusion/Exclusion: Knowing HIV Status of Respondents**

The agencies of social inclusion include PHC/Sub-centre, ICTC, ART, Church, Church based organisation, town, mobile ICTC, community organisations, peers, neighbors, and local NGOs, STI clinics, relatives/kins, families, political parties and MSACS (see Table 4.9).

Majority of the HIV status of respondents is known only to the tertiary groups like sub center, ICTC, ART and mobile ICTC in both the studied districts and only some of the peer groups in primary and secondary groups are not aware of the HIV status of respondents.

PHC/sub-centre held the highest percentage of knowing the status of respondents in total which constitutes two-third (67%) of the studied communities where in Non-autonomous district, it constitutes three-fourth (77%) to that of one-half (57%) in Autonomous district.

ICTC stands second in knowing the status of respondents with a percentage of 43% i.e.; slightly below one-half in Non-autonomous district to that of slightly below two third (63%) in Autonomous district. Here the probability level is higher in Autonomous district.

ART held nearly two-third (60%) of the respondents in Non-autonomous district to that of only one-third (37%) of the respondents reported that ART centre at Autonomous district is aware of their HIV status.

Church, church-based organisation and town are of the same level. They are slightly below two-third (57%) in Non-autonomous district to that of slightly more than one-third (37%) in Autonomous district in knowing HIV status of respondents.

Mobile ICTC constitutes one-half (53%) in Non-autonomous district to that of one-third (30%) in Autonomous district, followed by Community organisation which constitutes slightly below one-half (47%) in Non-autonomous district to that of slightly more than one-half (37%) in Autonomous district.

Peers constitute one-half (47%) in Non-autonomous district and one-fifth (20%) in Autonomous district, followed by neighbors who constitute around one-third in both the

communities i.e.; 30% and 37% followed by Local NGOS which constitute the same level i.e.; 30% in Non-autonomous district and 33% in Autonomous district.

STI Clinics constitute slightly less than one-half (43.3%) in Non-autonomous district, whereas knowing of HIV status of respondents' level is very low in Autonomous district which constitutes less than one-fifth (16.7%). Relatives of the respondents constitute one-third (33.3%) in Non-autonomous district and below one-third (26.8%) in Autonomous district followed by political parties where there is no case of knowing the status of respondents. MSACS constitutes 100% of the studied communities.

#### **4.4.2. Perceived Inclusiveness of Agencies**

The proportion of MSACS is the predominant mechanism in both the studied districts; ie 2.9 in total, while the mean average in Non-autonomous district is higher which constitutes 3.0 to that of Autonomous district i.e. 2.8. Mobile ICTC, ART and ICTC is the second most predominant mechanisms. ART stands second with a total mean average of 1.9 and it is the same in Non-autonomous district and Autonomous district which constitutes both 1.9. Mobile ICTC is inclusive with the mean average of 1.9 in Non-autonomous district and 1.8 in Autonomous district. ICTC held the mean average of 1.7 in Non-autonomous district and 1.8 in Autonomous district, followed by the inclusiveness of peers which constitutes 0.4 in Non-autonomous district and 1.5 in Autonomous district. Family held the mean average of 1.0 in Non-autonomous district and 1.2 in Autonomous district, followed by STI clinics which held higher mean average in Autonomous district i.e. 1.3 to that of Non-autonomous district i.e. 0.9. Church based organisations held the same mean average both in Autonomous district and Non-autonomous district i.e. 1.1. The inclusiveness of local NGOs is higher in Non-autonomous district which constitutes the mean average of 1.0 to that of

Autonomous district i.e. 0.9, followed by neighbors which constitutes 0.8 in Non-autonomous district and 0.6 in Autonomous district. The inclusiveness of relatives/kins is higher in Autonomous district which constitutes 1.0 to that of 0.4 in Non-autonomous district, followed by community organisations where Autonomous district held higher mean average i.e. 0.7 to that of 0.5 in Non-autonomous district. Town constitutes higher level in Autonomous district i.e. 0.7 to that of 0.4 in Non-autonomous district, followed by the inclusiveness of church groups where Autonomous district held a higher mean average i.e. 0.6 to that of 0.4 in Non-autonomous district. The inclusiveness of PHC/Sub centre is higher in Non-autonomous district which is 0.6 to that of 0.4 in Autonomous district, followed by political inclusiveness where Autonomous district is slightly higher which constitutes 0.2 to that of 0 mean average in Non-autonomous district(See Table 4.10)

#### **4.4.3. Agencies and Mechanisms of Inclusion/Exclusion**

The agencies and mechanisms of inclusion/exclusion are categorised into primary and secondary networks and tertiary groups.

#### **4.6.1 Primary and Secondary Networks**

The agencies and mechanisms of primary and secondary networks are categorised into wife/husband/family, friends, neighbors, relatives and kins(See Table 4.11)

Wife/husband/family is categorised into five options, i.e.; don't know/not supportive, financial support, emotional support, both financial and emotional support and ex-communication. From the table, it can be seen that financial and emotional support are acting as contributors by the family in the studied communities. None-supportive or ignorant about the respondent's status constitutes one-fifth in total, where the percentage is higher in Autonomous district which constitutes more than one-fifth (23%) to that of Non-autonomous



district which constitutes slightly less than one-fifth (17%). Financial support from the agency is higher in Non-autonomous district which held one-third (33%) to that of Autonomous district which constitutes less than one-fifth (17%) of the respondents. Emotional support is also higher in Non-autonomous district i.e. more than one-fifth (27%) to that of Autonomous district (23%). Both financial and emotional support constitutes more than one-fifth (23%) of the agencies in Non-autonomous district to that of less than one-tenth (0.6%) in Autonomous district. Exclusion of the family level exists in both the districts. The respondents were excommunicated by slightly below one-fifth (17%) of the agencies, to that of slightly more than one-tenth (13%) of agencies, i.e. family/wife/husband.

Friends are categorised into four categories, i.e.; don't know/ not supportive, emotional support, shunned/avoidance and ignorant. Emotional support among friends is the predominant mechanism which constitutes more than one-half (55%), followed by emotional support which is higher in Autonomous district which held two-third (67%) of the agency to that of more than one-third (43%) in Non-autonomous district. There is significant proportion respondents who are excluded by friends. The proportion shunned/avoidance of friends is higher in Autonomous district constituting more than one-tenth (13%) to that of one-tenth (10%) in Non-autonomous district. Ignorance of the agency is higher in Non-autonomous district which constitutes slightly below one-half (47%) to that of only one-tenth (10%) in Autonomous district.

As far as neighbors are concerned in the agency, they are categorised into healthy relationship, looking down upon, discrimination and ignorant. From the table, it can be seen that the proportion of healthy relationship with neighbors is the highest in both districts which constitutes more than one-half (55%), where it is higher in Non-autonomous district

slightly below two-third (63%) of the agency to that of slightly below one-half (47%) in Autonomous district followed by looking down the respondents by the agency which is higher in Autonomous district but constitutes only one-tenth (10%) to that of Non-autonomous district which constitutes below one-tenth (7%). Discrimination also takes place which constitutes below one-tenth (7%) in both the studied communities. The ignorance level of the agency is higher in Autonomous district which constitutes slightly more than one-third (37%) to that of more than one-fifth (23%) in Autonomous district.

The mechanism of inclusion by relatives is categorised into ignorance, emotional support, care and excommunication. Emotional support is contributed by relatives in both the districts where Non-autonomous district is higher i.e. more than one-third (37%) to that of one-third (30%) in Autonomous district. Care of the agency is higher in Autonomous district constituting one-third (33%) to that of below one-tenth (7%) in Non-autonomous district. Excommunication also takes place which is higher in Autonomous district constituting nearly one fifth (17%) to that of one-tenth (10%) in Non-autonomous district.

#### **4.6.2 Agencies and Mechanisms of Inclusion/Exclusion: Tertiary groups**

The agencies and mechanisms of inclusion/exclusion in tertiary groups constituted MYA/MTP/YMA, Counselor, Outreach workers of NGO, Staff members of NGO, Nurses and Doctors of NGO and Church groups (see table 4.12)

MYA is an association formed in Autonomous district and nearly two-third (60%) of the agency are ignorant about the status of the respondents and more than one-third (40%) of the agency are aware of the HIV status of the respondents, where is a good relationship between the agency which constitutes 40.0%. MTP is also the association formed in Autonomous district and nearly two-third (60.0%) of the agency are ignorant about the status

of respondents and good relationship and social support constitute the same level i.e. more than one-tenth (20%) each. YMA also takes place where there is a good relationship between the respondents and the agency.

From the table, it can be seen that outreach workers in all the agencies constitute a 100% where Non-autonomous district constitutes 50% and to that of 50% in Autonomous district, and the counselors of the NGOs also took an important role in the inclusiveness of the respondents where they provide counseling and support to all the respondents which constitute a 100.0% in the studied communities.

Staff members of the agency are also supportive, where they provide services like distribution of ART, distribution of OST for injecting drug users, testing of CD4 count of the respondents, advocacy and distribution of condoms for free among the registered clients. Here Non-autonomous district constitutes 50% and to that of 50% in Autonomous district, where there is no variation among the studied communities. Nurses and doctors of the agencies also provide free regular medical check-up and treatment to the respondents and Non-autonomous district constitutes 50% to that of 50.0% in Autonomous district. As far as church groups are concerned, more than one-half (53%) are supportive towards the respondents. However, Non-autonomous district held higher percentage in terms of support i.e. slightly below two-third (63%) to that of more than one-third (43%) in Autonomous district. Most of the church groups are ignorant which held a higher percentage in Autonomous district i.e. more than one-half (57%) to that of Non-autonomous district i.e. more than one-third (37%).

This chapter has presented discussion on the results of analysis of primary data collected through field survey with structured interview schedule demographic, social

economic and illness profile of the respondents, patterns of social inclusion, and agencies and mechanism of social inclusion. The next chapter presents how actually exclusion takes place with the help of case studies and analysis of qualitative data collected focus groups.

**Table 4.1 Demographic Profile of Respondents**

Sl.No	Characteristic	District		Total N = 60
		Lunglei n = 30	Saiha n = 30	
1	<b>Gender</b>			
	Male	20 (66.7)	20 (66.7)	40 (66.7)
	Female	10 (33.3)	10 (33.3)	20 (33.3)
2	<b>Age Group</b>			
	Youth(18 -35)	28 (93.3)	20 (66.7)	48 (80.0)
	Middle (35 -60)	2 (6.7)	10 (33.3)	12 (20.0)
	<i>Mean Age</i>	27 ±5	32 ± 8	29 ± 7
3	<b>Marital Status</b>			
	Unmarried	27 (90.0)	19 (63.3)	46 (76.7)
	Married	1 (3.3)	2 (6.7)	3 (5.0)
	Divorced/Separated	2 (6.7)	9 (30.0)	11 (18.3)
4	<b>Education Status</b>			
	Primary(1 - 4)	0 (0.0)	1 (3.3)	1 (1.7)
	Middle(5 - 7)	1 (3.3)	4 (13.3)	5 (8.3)
	High School(8 - 10)	8 (26.7)	8 (26.7)	16 (26.7)
	Higher Secondary(11 - 12)	7 (23.3)	4 (13.3)	11 (18.3)
	College(13 and Above)	14 (46.7)	13 (43.3)	27 (45.0)
	Mean Years of Education	13 ± 3	12 ± 4	12 ± 3

Source: Computed                      Figures in parentheses are percentages

Mean ± SD

**Table 4.2 Family Structure of Respondents**

SI.No		District		Total N = 60
		Lunglei n = 30	Saiha n = 30	
<b>I</b>	<b>Type of Family</b>			
	Nuclear	28 (93.3)	24 (80.0)	52 (86.7)
	Joint	2 (6.7)	6 (20.0)	8 (13.3)
<b>II</b>	<b>Size of Family</b>			
	Small(1 - 3)	2 (6.7)	1 (3.3)	3 (5.0)
	Medium( 4 - 6)	21 (70.0)	22 (73.3)	43 (71.7)
	Large( 7 and Above)	7 (23.3)	7 (23.3)	14 (23.3)
	<i>Mean Size of Family</i>	6 ±1	6 ±1	6 ±1
<b>III</b>	<b>Form of Family</b>			
	Stable	11 (36.7)	13 (43.3)	24 (40.0)
	Broken	15 (50.0)	14 (46.7)	29 (48.3)
	Reconstituted Step	4 (13.3)	3 (10.0)	7 (11.7)
<b>IV</b>	<b>Gender of Head</b>			
	Male	26 (83.9)	28 (96.6)	54 (90.0)
	Female	5 (16.1)	1 (3.4)	6 (10.0)

Source: Computed

Figures in parentheses are percentages

Mean ±SD

**Table 4.3 Social Characteristics of Respondents**

SI.No	Characteristic	District		Total N = 60
		Lunglei n = 30	Saiha n = 30	
<b>I</b>	<b>Sub tribe</b>			
	Lusei	12 (40.0)	4 (13.3)	16 (26.7)
	Mara	0 (0.0)	12 (40.0)	12 (20.0)
	Lai	13 (43.3)	12 (40.0)	25 (41.7)
	Ralte	2 (6.7)	2 (6.7)	4 (6.7)
	Hmar	3 (10.0)	0 (0.0)	3 (5.0)
<b>II</b>	<b>Denomination</b>			
	Evangelical Church of Maraland	0 (0.0)	14 (46.7)	14 (23.3)
	Baptist	20 (66.7)	5 (16.7)	25 (41.7)
	Presbyterian	7 (23.3)	3 (10.0)	10 (16.7)
	United Pentecostal Church	3 (10.0)	0 (0.0)	3 (5.0)
	Isua Krista Kohhran	0 (0.0)	4 (13.3)	4 (6.7)
	Lairam Isua Krista Baptist Kohhran	0 (0.0)	4 (13.3)	4 (6.7)

Source: Computed

Figures in parentheses are percentages

**Table 4.4 Economic Characteristics of Respondents**

SI.No		District		Total N = 60
		Lunglei n = 30	Saiha n = 30	
<b>I</b>	<b>Earner/Dependant</b>			
	Dependent	25 (83.3)	19 (63.3)	44 (73.3)
	Earner	5 (16.7)	11 (36.7)	16 (26.7)
<b>II</b>	<b>Primary Occupation</b>			
	Dependent	25 (83.3)	19 (63.3)	44 (73.3)
	Government Officer	0	1	1

		(0.0)	(3.3)	(1.7)
	Government Worker	2 (6.7)	4 (13.3)	6 (10.0)
	Wage Labourer	1 (10.0)	3 (3.3)	4 (6.7)
	Skilled Labourer	2 (6.7)	3 (10.0)	5 (8.3)
<b>III</b>	<b>Socio Economic Category</b>			
	Very Poor(AAY)	7 (13.3)	4 (23.3)	11 (18.3)
	Poor(BPL)	8 (36.7)	11 (26.7)	19 (31.7)
	Non-poor	15 (50.0)	15 (50.0)	30 (50.0)
<b>IV</b>	<b>Annual Household Income</b>			
	Minimum	12000	15000	12000
	Maximum	138000	141000	141000
	Mean	59000	53583	56292
	Std. Deviation	26501	27428	26878
<b>V</b>	<b>Per capita Annual Household Income</b>			
	Minimum	1714	3444	1714
	Maximum	40500	20143	40500
	Mean	11905	9812	10858
	Std. Deviation	7450	4737	6279

Source: Computed

Figures in parentheses are percentages

**Table 4.5 Illness Profile of Respondents**

SI.No		District		Total N = 60
		Lunglei n = 30	Saiha n = 30	
<b>I</b>	<b>Year of Detection of Infection</b>			
	2005 – 2007	1 (3.3)	8 (26.7)	9 (15.0)
	2008 - 2011	16 (53.3)	12 (40.0)	28 (46.7)
	2012 - 2014	13 (43.3)	10 (33.3)	23 (38.3)
<b>II</b>	<b>Probable Mode of Transmission</b>			
	Unprotected Sex	17 (56.7)	14 (46.7)	31 (51.7)
	Sharing of Unsterilized Needles	11 (36.7)	15 (50.0)	26 (43.3)
	Blood Transfusion	2	1	3



		(6.7)	(3.3)	(5.0)
<b>III</b>	<b>Organization where Infection Detected</b>			
	ICTC	17 (56.7)	11 (36.7)	28 (46.7)
	Mobile ICTC	13 (43.3)	19 (63.3)	32 (53.3)

Source: Computed

Figures in parentheses are percentages

**Table 4.6 Pattern of Community Inclusion**

SI.No	Dimension/ Indicator	District				Total N = 60	
		Lunglei n = 30		Saiha n = 30		Mean	S.D
		Mean	S.D	Mean	S.D		
1	Attending funeral services	1.9	0.8	1.3	0.6	1.6	0.8
2	Attending marriages in community	1.5	0.7	1.2	0.6	1.3	0.7
3	Attending the church services	1.3	0.6	0.9	0.5	1.1	0.6
4	Volunteering for community	0.9	0.6	0.4	0.5	0.6	0.6
5	Attending meetings of community organizations	0.9	0.6	0.4	0.5	0.6	0.6
	<i>Community Inclusion</i>	1.3	0.5	0.8	0.4	1.1	0.5

Source: Computed

**Table 4.7 Pattern of Economic Inclusion**

SI.No	Dimension/ Indicator	District				Total N = 60	
		Lunglei n = 30		Saiha n = 30		Mean	S.D
		Mean	S.D	Mean	S.D		
1	Adequacy of Size of Land	1.7	0.7	1.5	0.6	1.6	0.6
2	Adequacy of Present Family Income	1.4	0.7	1.3	0.6	1.4	0.7
3	No. Of days of employment	1.3	0.7	1.3	0.7	1.3	0.7
4	Adequacy of amount of loan getting when needed	1.3	0.7	1.2	0.8	1.2	0.7
5	Wage rate/Monthly Salary	1.2	0.8	1.3	0.7	1.2	0.7
6	Amount save every month	1.1	0.6	1.1	0.7	1.1	0.6
	Economic Inclusion	1.6	0.6	1.5	0.7	1.6	0.6

Source: Computed

**Table 4.8 Pattern of Political Inclusion**

SI.No	Dimension/ Indicator	District				Total N = 60	
		Lunglei n = 30		Saiha n = 30		Mean	S.D
		Mean	S.D	Mean	S.D		

1	Voting in Assembly Election	2.3	0.5	1.5	0.8	1.9	0.7
2	Voting in General Election	2.3	0.5	1.5	0.8	1.9	0.7
3	Voting in Village Council Election	2.3	0.5	1.5	0.7	1.9	0.7
4	Participation in Election Campaigns	0.4	1.0	0.2	0.5	0.3	0.8
5	Attending meetings of political parties	0.0	0.0	0.5	0.9	0.2	0.7
	<b>Political Inclusion</b>	1.5	0.4	1.0	0.6	1.2	0.5

Source: Computed

**Table 4.9 Pattern of Social Inclusion**

Sl.No	Dimension/ Indicator	District				't'	
		Lunglei n = 30		Saiha n = 30			
		Mean	S.D	Mean	S.D	Statistic	Sig
1	Economic Inclusion	1.6	0.6	1.5	0.7	0.36	0.72
2	Political Inclusion	1.5	0.4	1.0	0.6	3.36	0.00
3	Community Inclusion	1.3	0.5	0.8	0.4	4.17	0.00
4	Social Inclusion	1.4	0.3	1.1	0.4	3.36	0.00

Source: Computed

Figures in parentheses are percentages

**Table 4.10 Extent of Social Inclusion**

Sl.No	Extent	District		Total
		Lunglei	Saiha	
1	Low(0.60 -1.13)	3 (10.0)	14 (46.7)	17 (28.3)
2	Medium(1.13 - 1.67)	22 (73.3)	13 (43.3)	35 (58.3)
3	High(1.67 -2.2)	5 (16.7)	3 (10.0)	8 (13.3)
	Total	30 (100)	30 (100)	60 (100)
	Chi-Square Tests	Value	df	Asymp. Sig. (2-sided)
	Pearson Chi-Square	9.9**	2	0.01
	Cramer's V	0.4**		0.01

Source: Computed

Figures in parentheses are percentages

$P < 0.01$

**Table 4.11 Determinants of Social Inclusion: Zero Order Correlation Matrix**

**N = 60**

SI.No	Determinant	Community Inclusion	Economic Inclusion	Political Inclusion	Social Inclusion
1	Gender	0.41**	-0.08	0.23	0.23
2	Educational Qualification	-0.01	0.43**	0.02	0.24
3	Size of Family	-0.03	-0.18	-0.10	-0.16
4	Socio economic Category	-0.04	-0.05	-0.03	-0.06
5	Annual Household Income	0.17	0.29*	0.06	0.26*
	Per capita Annual Household Income	0.15	0.21	0.12	0.23

Source: Computed

Figures in parentheses are percentages

\*\* P<0.01 \* P<0.01

**Table 4.12 Agencies of Social Inclusion/Exclusion: Knowing HIV Status of Respondents**

SI.No	Agency	District				Total N = 60	
		Lunglei n = 30		Saiha n = 30		Frequency	Percent
		Frequency	Percent	Frequency	Percent		
1	PHC/Sub-center	23	76.7	17.0	56.7	40	66.7
2	ICTC	13	43.3	19.0	63.3	32	53.3
3	ART	18	60.0	11.0	36.7	29	48.3
4	Church	17	56.7	11.0	36.7	28	46.7
5	Church based organizations	17	56.7	11.0	36.7	28	46.7
6	Town	17	56.7	11.0	36.7	28	46.7
7	Mobile ICTC	16	53.3	9.0	30.0	25	41.7
8	Community organizations	14	46.7	11.0	36.7	25	41.7
9	Peers	14	46.7	6.0	20.0	20	33.3
10	Neighbors	9	30.0	11.0	36.7	20	33.3
11	Local NGOs	9	30.0	10.0	33.3	19	31.7
12	STI Clinics	13	43.3	5.0	16.7	18	30.0
13	Relatives/Kins	10	33.3	8.0	26.7	18	30.0
14	Family	6	20.0	8.0	26.7	14	23.3
15	Political parties	0	0.0	0.0	0.0	0	0.0
16	MSACS	0	0.0	0.0	0.0	0	0.0

Source: Computed

**Table 4.13 Perceived Inclusiveness of Agencies**

SI.No	Agency	District				Total N = 60	
		Lunglei n = 30		Saiha n = 30			
		Mean	S.D	Mean	S.D	Mean	S.D
1	MSACS	<b>3.0</b>	0.0	<b>2.8</b>	0.7	<b>2.9</b>	0.5
2	ART	<b>1.9</b>	0.4	<b>1.9</b>	0.4	<b>1.9</b>	0.4
3	Mobile ICTC	<b>1.9</b>	0.5	<b>1.8</b>	0.7	<b>1.8</b>	0.6
4	ICTC	<b>1.7</b>	0.7	<b>1.8</b>	0.7	<b>1.8</b>	0.7
5	Peers	<i>0.8</i>	1.1	<b>1.4</b>	1.2	<b>1.1</b>	1.2
6	Family	<i>1.0</i>	0.9	<b>1.2</b>	1.1	<b>1.1</b>	1.0
7	STI Clinics	<i>0.9</i>	0.3	<b>1.3</b>	0.8	<b>1.1</b>	0.7
8	Church based organizations	<i>1.1</i>	0.4	<b>1.1</b>	0.5	<b>1.1</b>	0.4
9	Local NGOs	<i>1.0</i>	0.0	<b>0.9</b>	0.6	<b>1.0</b>	0.4
10	Neighbors	<i>0.8</i>	0.9	<b>0.6</b>	0.8	<b>0.7</b>	0.8
11	Relatives/Kins	<i>0.4</i>	0.5	<b>1.0</b>	0.9	<b>0.7</b>	0.8
12	Community organizations	<i>0.5</i>	0.5	<b>0.7</b>	0.7	<b>0.6</b>	0.6
13	Town	0.4	0.5	<b>0.7</b>	0.7	<b>0.6</b>	0.6
14	Church	0.4	0.5	<b>0.6</b>	0.5	<b>0.5</b>	0.5
15	PHC/Sub-center	0.2	0.4	<b>0.6</b>	0.7	0.4	0.6
16	Political parties	0.0	0.0	0.2	0.7	0.1	0.5

Source: Computed

**Table 4.14 Agencies and Mechanisms of Inclusion/Exclusion:  
Primary and Secondary Groups**

SI.No	Agency/Mechanism	District		Total N = 60
		Lunglei n = 30	Saiha n = 30	
<b>I</b>	<b>Wife/ Husband/Family</b>			
	None	5 (16.7)	7 (23.3)	12 (20.0)
	Financial Support	10 (33.3)	5 (16.7)	15 (25.0)
	Emotional Support	8 (26.7)	7 (23.3)	15 (25.0)
	Both Financial and Emotional Support	2 (6.7)	7 (23.3)	9 (15.0)
	Excommunication	5 (16.7)	4 (13.3)	9 (15.0)
<b>II</b>	<b>Friends</b>			
	None	0 (0.0)	3 (10.0)	3 (5.0)
	Emotional Support	13 (43.3)	20 (66.7)	33 (55.0)
	Shunned/Avoidance	3 (10.0)	4 (13.3)	7 (11.7)
	Ignorant	14 (46.7)	3 (10.0)	17 (28.3)
<b>III</b>	<b>Neighbors</b>			
	Healthy Relationship	19 (63.3)	14 (46.7)	33 (55.0)
	Looking down upon	2 (6.7)	3 (10.0)	5 (8.3)
	Discrimination	2 (6.7)	2 (6.7)	4 (6.7)
	Ignorant	7 (23.3)	11 (36.7)	18 (30.0)
<b>IV</b>	<b>Relatives/Kins</b>			
	None	14 (46.7)	6 (20.0)	20 (33.3)
	Emotional Support	11 (36.7)	9 (30.0)	20 (33.3)
	Care	2 (6.7)	10 (33.3)	12 (20.0)
	Excommunication	3 (10.0)	5 (16.7)	8 (13.3)

Source: Computed

Figures in parentheses are percentages

**Table 4.15 Agencies and Mechanisms of Inclusion/Exclusion: Tertiary Groups**

Sl.No	Agency/Mechanism	District		Total N = 60
		Lunglei n = 30	Saiha n = 30	
<b>I</b>	<b>MYA</b>			
	No	30 (100)	6 (20.0)	36 (60.0)
	Good Relationship	0 (0.0)	24 (80.0)	24 (40.0)
<b>II</b>	<b>MTP</b>			
	No	30 (100.0)	28 (93.3)	58 (96.7)
	Good Relationship	0 (0.0)	1 (3.3)	1 (1.7)
	Social Support	0 (0.0)	1 (3.3)	1 (1.7)
<b>III</b>	<b>Counselor</b>			
	Counseling	0 (3.3)	1 (0.0)	1 (1.7)
	Both Counseling and Emotional Support	30 (100)	29 (96.7)	59 (98.3)
<b>IV</b>	<b>Outreach Workers of NGO</b>			
	All	30 (100)	30 (100)	60 (100)
<b>V</b>	<b>Staff Members of NGO</b>			
	All	30 (100)	30 (100)	60 (100)
<b>VI</b>	<b>Nurses and Doctors of NGO</b>			
	Both	30 (100)	30 (100)	60 (100)
<b>VII</b>	<b>Church Groups</b>			
	Supportive	13 (63.3)	19 (43.3)	32 (53.3)
	Ignorant	17 (56.7)	11 (36.7)	28 (46.7)

Source: Computed

Figures in parentheses are percentages

## CHAPTER V

### **Dynamics of Social Inclusion of Persons Living with HIV/AIDS**

Social Inclusion and exclusion are dynamic processes. One of the objectives of the present study is to understand how this occurs.

#### **5.1. Lived Experiences of PLHAS: Case Studies**

To understand the dynamic process of social inclusion and exclusion, five case studies were conducted. Based on the data collected from in depth interviews of some selected respondents case studies are attempted.

##### **Case I: A PLHA Rejected by his Family**

Hmangaihsanga Khenglawt (Fictitious name) is a 24 year old man who studied till BA and lives in Saiha. He is the 4<sup>th</sup> member of his family and he has grown in a stable family. His father is Lalrotluanga Khenglawt (57) who is a government servant and his mother is Vapawpi who is engaged in petty business. He has one sister Roneihsangi and a younger brother, Lallawmsanga. Hmangaihsanga is still unmarried. Their family is nuclear family which is of non-poor socio economic category.

The respondent, Hmangaihsanga has been living with HIV/AIDS for two years. He has been outlawed from his family members the his parents came to know his status. Right now, he is been living with his friend who stays in a rented house.

Hmangaihsanga has misused drugs since eighteen years of age. He reported that he, along with some of his friends at the first time took dendrite and later on, move to other substitution. Now, he takes every kind of drugs which he can see so far, like parvon, proxivon, and even sometimes take alcohol. In 2010, he went to Shillong for further studies, and continued to take several types of drugs. He had peers who can get along with him and



they sometimes share their injecting syringes where he tends to care free about using condoms when he gets high. In 2011, he had complained about his health and started to be health conscious. He had his blood test done at ICTC, Shillong where he came to know that he is being detected with HIV .

He then came back home with stress and burnt out and disclosed his HIV status to his parents after three months when he was detected. His family members did not support him, ill-treated him and that continues with excommunication. He said that he lost power and respect within his family. The bond in their family has been destroyed and after five years, he has been outlawed from his family members and there is excommunication between them, so far. He reported that even though there is excommunication with his family, he still continues to participate in community events like marriages in the community funeral services, church services, etc. He said that there exists a healthy relationship between him and his neighbours. He received care and emotional support from some of his relatives and friends too. He reported that he sometimes have the feeling of fear, anger, despair and thoughts of suicide due to his status. He dropped-in himself at MCHP, which is an agency dealing with HIV/AIDS, and attends counselling classes with counsellor. Nurses and doctors continue to provide free regular medical check-up. He also stated that the staff members and outreach workers of the agency help him and guide him in every possible ways. Right now, Hmangaihsanga has been undergoing one treatment, that is Oral Substitution Therapy.

### **Case II: A Female Sex Worker**

Beipawpi is a 35 years old divorced woman, who has studied till standard seven and who lives in Saiha. She is the fourth member of the family and she has grown up in a BPL family. There are seven members in their family and she lives with her elder brother and

his family and her mother. She has grown up from a broken family where her father had extra-marital affair fifteen years ago. Beipawpi is divorced with her husband five years ago.

The respondent, Beipawpi has been living with HIV/AIDS for four years. She is also on ART till date. She reported that she is physically and psychologically affected, and that she is always under stress and strain because of shame, ill health and terminal condition.

Since Beipawpi has come from a broken family, she had gone through many sufferings. She has not received enough education due to poverty. She has no money and had no idea the source to get money. She once had a husband, but after three years, they had divorced. Out of misery and sufferings, she got engaged in commercial sex trade since 2009. She then got her blood test done at mobile ICTC in 2006 and found out to be HIV positive. Her family had no other options, but giving emotional support. She feels that she is bringing shame to her family and losing family face. She had herself dropped in MCHP centre till date. She reported that she sometimes got ignored and shunned by some of her friends. She also said that she felt stigmatized and discriminated by her community. She herself isolated and somehow remained silence to participate in community events. She attended marriages, funeral services sometimes, but never get close to church services and meetings of community organization. She reported that there is a healthy relationship between her family members and neighbors. As her CD4 count is extremely low, she started taking ART since 2013. Right now, she is living with her eldest brother.

### **Case III: PLHA Accepted by Family**

Vanneihnsanga is a 24 years old unmarried man, who studied till BA and who lives in Lunglei. He is the fourth member of the family. His father is a government officer and his mother is a wage labourer. He has one sister, Doulsy and a brother Jack. He is the middle

among his siblings. Vanneihhsanga has grown up from a stable and nuclear family. He is an educated, young and talented boy. Vanneihhsanga has been living with HIV/AIDS for 1 year.

Vanneihhsanga was a good hearted, well educated man. He went to Aizawl for further studies in 2010 and had a girlfriend there. He reported that they went along for a year and had unprotected sex several times together. He did not use condoms. He then suffered from several symptoms of AIDS and then had his blood test done at ICTC, Civil Hospital, Aizawl and he came to know that he is HIV positive. He even disclosed his status to his family. They gave him a good support, care and treatment, but they wanted his status to be kept in confidential. They did not disclose his status to others due to fear of isolation from the community. The respondent still attends events in the community, attends marriages in the community, funeral services and others mostly. He even participates in political events like voting for elections. He receives counseling from a counselor till now, and even receives care, treatment and support from his family members.

#### **Case IV: PLHA who fears exclusion from family and community**

Baby Lalremtluangi Fanai is a 25 years old unmarried woman, who studied till highr secondary and lives in Lunglei. She is the second member of the family. She has a father who is government worker and a younger sister. Her father and mother got divorced in 2009, since her mother was claimed to have an extra-marital affair with another man. They are non-poor in socio-economic category, size of land and income are adequate, but are broken family.

The respondent, Baby reported that she has been taken drugs since 2010, which made her feel easy to hang out with different boys. She has gone for studies till higher secondary school, but failed to continue for further studies due to her misbehavior. Since she

is having sex with multiple partners, she had her blood test done in 2014 at ICTC, Civil Hospital, Lunglei and found out to be positive. But, till now, she has not disclosed her HIV status to her family members, friends and relatives due to fear of discrimination and rejection. She used to meet the counsellor of ICTC in secret, and lives a life of fear, secrecy and stress. Baby participates in community events and political events sometimes. She reported that she will disclose her status to her family when she is emotionally ready. Right now, Baby is doing a petty business. She opens a parlour at Lunglei.

#### **Case V: PLHA who tried to Transmit HIV**

Francis Lalrintluanga, a 27 years old gentleman who is graduated and who came out from a stable family was detected with HIV in 2010 at Mobile ICTC, Lunglei. The respondent reported that he has this status due to unprotected sexual intercourse with multiple partners. He said that he has the sexual urge since his adolescence phase and continues to be vulgar in sex life. He also mentions that he is good at heart, not indulge in any kind of drug, but he used to take alcohol occasionally. When he came to know his status, he was shocked and feeling of fear and anger took place in his life ultimately. He stated that at one point of time, he had a bad feeling of transmitting his HIV virus to others who are sensitive. He even practiced that bad deeds for five months, but through counselor's advice and guidance, he is now able to come out of that problem and begins to understand his situation. He participates sometimes in community and political events. The respondent reported that the members of his family know his HIV status, but he does not get enough support. They have lost trust in him and misunderstanding also takes place in the family. But he stated that he sometimes get emotional support, especially from his mother. Some of his friends are also aware of his HIV status, where he mentioned that some are supportive, while some are ignorant about the issue

and that they stigmatize him sometimes. He said that he receive a good care and treatment from ICTC, and the organization where he dropped-in. The counsellor provides him counselling, nurses and doctors continue to give treatment and regular medical check up. He also said that he gets a good support from the staff members of the organization where there is a good relationship between them. He receives advocacy, treatment and care at all times. He now starts to admit himself as HIV positive, and stops having unprotected sexual intercourse.

The case studies presented above illustrates the helplessness and fear of exclusion found among PLHAS. There are cases where PLHAS are excommunicated by family as well as cases that were accepted by the family members. But in almost all cases we find the PLHAS are afraid of revealing their HIV status to the members of the community for fear of rejection, stigma and discrimination.

## **5.2. Perception of PLHAs on Impact of HIV/AIDS**

To understand the dynamics of social inclusion of PLHAS, Focus Group Discussions were conducted in both the districts. Members of focus groups were the registered PLHAS in NGOs. One NGO viz., MCHP represented autonomous district and one NGO viz., Grace Society represented non-autonomous district. Members of the focus groups were PLHAS in the age group of 25 to 40 in both the districts. Male members and female members were not differentiated.

The focus group discussion conducted among the two districts reveals the different perceptions on impact of PLHAS. The group discussion was conducted for one hour. Ten members who were living with HIV/AIDS and registered in NGOs participated at focus

group discussion in non-autonomous district, and eight members living with HIV/AIDS and registered in NGO participated at focus group discussion in autonomous district.

From the focus group discussion, it may be concluded that a diagnosis of HIV is always profoundly shocking. Feeling of fear, anger and asking oneself is very common among PLHAS. Self-tigma is one that is most deeply felt when one has just received the HIV positive diagnosis. It is partly caused by fear of how people will relate to the infected persons- feeling of denial, exclusion, loss of property, employment, educational opportunities, eviction and abandonment by family and friends. The individuals often feel forced to do a self-withdrawal for fear of being judged, ostracized or shunned.

Many of the respondents could not cope up with their problems when they came to know that they are HIV positive. They are being overwhelmed with stress, fear of death; trauma and they are also likely to have psychological problems. All these lead to the changing of their lifestyles in which they seem carefree and started living confusing lives.

Most of the respondents have a normal family background and they are being supported by their families physically, mentally, financially and emotionally. They do not face problems within their families even though they are infected with HIV/AIDS. This shows that the awareness level amongst the general population is normal. But, some of the respondents do not get any support from their families due to their HIV status. This is due to miscommunication existing amongst the family members. Some of the respondents are not comfortable sharing their problems and difficulties with their family members and they do not get support from their families when they come to know their HIV status. Many of the respondents are being rejected by their family members. Some respondents choose to share

and inform their problems with their friend rather than with their family members. Some of the respondents are being ill-treated among their other siblings.

Majority of the respondents are single and are not married because they have an inferiority complex due to their HIV status and therefore scared to get married due to fear of discrimination and majority of the respondents are unemployed.

Most of the People living with HIV/AIDS grown up from a broken family and most of them were spoiled children since their childhood. They have misused drugs, alcohol and other substances which spoiled their mental and social being. They therefore, cannot concentrate on their studies due to the chronic illness which leads them to unemployment.

The sexual behavior of People living with HIV/AIDS in Saiha is highly influenced by the use of alcohol and drugs which decrease decision making skills and have a negative effect on behavior.

Most of the respondents have a low self-esteem due to their conditions and they do not feel comfortable settling with the community. They feel that they are being discriminated due to their status. So, they do not participate much in the society's or community's activities in which because of the feeling of isolation only sometimes they would be involved in the community's activities.

Most of the respondents said that the services which the organization or Drop-In-Centre provided are according to their needs and that they are very much benefited in them where their behaviors are being moulded and shaped and that the services are such a fruitful remunerative for the uplift of their physical, intellectual, emotional, mental and psychological aspects.

When the respondents came to know that they were infected with HIV/AIDS, many of them were burned out and they could not cope up with their problems due to an extreme shock. So counseling had been very effective since they would be able to cope up with the situation and how to live a normal life although affected. But for few respondents could not concentrate on what the counselor gave any information regarding HIV/AIDS. .

**Table 5.1 Summary of Results of FGDs with PLHLAS in Lunglei and Saiha**

<b>Question</b>	<b>Answers</b>	<b>Lunglei</b>	<b>Saiha</b>
Initial Reaction to HIV status	A Shocked	*	*
	B Asking oneself	*	*
	C Anger	*	
	D Fear	*	
Change of lifestyle after knowing HIV status	A Silence	*	*
	B Recurrent suicidal thoughts	*	*
	C Diminish pleasure in all activities	*	*
	D Self-isolated	*	*
	E Depressed mood	*	*
	F Fear of death	*	*
	G Trauma	*	*
Kind of support from family	A Financial	*	*
	B Emotional	*	*
	C Moral	*	*
Reason for remaining unmarried	A Inferiority Complex	*	*
Reason for unemployed	A Broken Family-spoiled children	*	



	B Misuse of drugs /alcohol/other substances	*	*
Influence of sexual behavior	A Misuse of alcohol	*	*
	B Misuse of drugs	*	*
Reason for low participation in community	A Low self esteem	*	*
	B Not comfortable	-	*
	C Fear of discrimination	*	*
Services of NGOs?	A Satisfied	*	*

Source: FGDs in Lunglei and Saiha

The present chapter has presented results of analysis of key informant interviews and case studies so as to arrive at a comprehensive understanding of the dynamics of social inclusion of persons living with HIV /AIDS in Mizoram. In the next chapter the conclusion of the present study is presented and suggestions are also put forth for policy making.

## **CHAPTER VI**

### **CONCLUSION**

The present study aims at understanding the pattern, agency, mechanism and dynamics of social inclusion of persons living with HIV in Mizoram. Quantitative and qualitative data have been collected from PLHS and results of their analysis were presented in the last two chapters. In this chapter the salient findings of them are summarized and conclusion derived and suggestion put forth for policy making are presented.

#### **6.1. Summary of Findings**

The summary of findings is presented in terms of profile of respondents, patterns of social inclusion, agency and mechanisms of inclusion, and dynamics of social inclusion of PLHAs.

##### **6.1.1. Profile of Respondents and their Households**

The profile of respondents is presented into five subsections, viz; demographic characteristics of the respondents, family structure, social characteristics, economic characteristics and the profile illness.

The demographic characteristics of the respondents presented are gender, age group, marital status and educational status. From the study, it has been found out that male respondents constitute predominant majority of the respondents in both the districts i.e. Saiha and Lunglei. There is no difference in age distribution: Four-fifth of the respondents belongs to the youth group in both the districts. Unmarried respondents constitute a predominant majority of respondents in both the districts. However, the proportion is slightly higher in Lunglei. Both the districts have similar levels of educational attainment.

The family characteristics comprises of Type of Family, Size of family, Form of family and Gender of head. From the study, it has been found out that broken family is predominant

in both the districts. The proportion of stable family is slightly greater in autonomous district and nuclear family is predominantly found in both the districts. Medium size of family is predominant in both the districts. Male headed family represents the family of predominant majority of the respondents in both the studied districts.

The social structural characteristics of respondents include sub-tribe and denomination. From the study, it can be seen that Baptist Church of Mizoram is the most dominant church in non-autonomous district and Evangelical Church of Maraland is the most dominant church in autonomous district.

To understand the economic conditions of PHAS in Mizoram, the study focuses on certain characteristics viz., earner/dependent, primary occupation, socio economic category, annual household income, per capital annual household income. Dependent respondents constitute the predominant majority in both of the districts. The proportion of dependent respondents is higher in non-autonomous district. Earners constitute a greater proportion in autonomous district. Government work is the predominant primary occupation in both the districts. The proportion of wage laborers is higher in non-autonomous district. The proportion of skilled laborers is higher in autonomous district. The predominant majority of respondents fall under non-poor category in both the districts. The proportion of Very Poor (AAY) category is greater in autonomous district. The proportion of poor category (BPL) is greater in non-autonomous district. Annual Household Income Mean is Greater in non-autonomous district than autonomous district. Per capita Annual Household Income shows similar picture.

Illness profile of respondents is categorised into year of detection of infection, probable mode of transmission and organisation where infection detected. During 2008-2011 detection

of HIV infection happened for predominant majority in both the studied districts. Unprotected sexual intercourse is the dominant mode of transmission within the studied districts. There are few cases of transmission through blood transfusion. Mobile ICTC was the dominant agency where HIV blood test is done in non-autonomous district. The proportion of cases detected by ICTC is greater in non-autonomous district.

### **6.1.2. Patterns of Social Inclusion**

The present study presents the pattern of social inclusion in four subsections, i.e.; Pattern of Community Inclusion, Pattern of economic inclusion, pattern of political inclusion and pattern of social inclusion.

The pattern of community inclusion includes attending funeral services, attending marriages in the community, attending the church services, volunteering for community and attending meetings of community organisations. The pattern of economic inclusion constitutes Adequacy of size of land, adequacy of present family income, Number of days of employment, adequacy of amount of loan getting when needed, wage rate/monthly salary and amount save every month. The pattern of Political Inclusion includes Voting in Assembly Election, voting in general election, voting in Village Council election, participation in election campaigns and attending meetings of political parties. The pattern of inclusion is categorised into economic inclusion, political inclusion, community inclusion and social inclusion.

From the study, it has been found out that attending funeral services is the predominant mode of community inclusion in both the districts. The proportion of attending marriages, church services and volunteering for the community is greater in non-autonomous district. The study shows that community inclusion is slightly better in autonomous district.

Adequacy of size of land is the predominant economic inclusion in both the districts. Adequacy of present family income is more or less the same in both the districts. Voting in assembly election is the predominant form of political inclusion in both of the districts. Other modes of political inclusion are more or less the same in both the districts. Economic inclusion is the predominant mode of inclusion in both the districts. There is no significant difference between the districts. Community inclusion is least in comparison with political inclusion and economic inclusion. The political participation and community inclusion is inclusion significantly greater in non-autonomous district. Social inclusion of PLHAs is significantly greater in non-autonomous district as compared to autonomous district.

The extent of social inclusion is categorised into low (0.60-1.13), Medium (1.13-1.67) and High (1.67-2.2). The study shows that there is a significant difference in the extent of social inclusion across districts. Most of the respondents are moderately included in the level of inclusion. The proportion of moderately and highly included PLHAs is higher in non-autonomous district. The proportion of PLHAS at low level is greater for autonomous district.

The determinants of social inclusion includes gender, educational qualification, size of family, socio economic category and annual household income and is categorised into community inclusion, economic inclusion, political inclusion and social inclusion. From the study, it can be seen that males are better included than the female respondents. Education has positive effect on economic inclusion only. Household income is positively related to economic and overall social inclusion. Sizes of family and socio economic category have no significant effect on community, economic, political and thus social inclusion.

### **6.1.3 Agencies and Mechanisms of Social Inclusion**

The MSACS is the predominant agency of social inclusion in both of the districts. Mobile ICTC, ART and ICTC are the second most predominant agencies. Financial and emotional support are mechanisms of inclusion by the family. Among primary and secondary groups, exclusion by the family exists in both the districts. Emotional support among friends is the predominant mechanism in both the districts. There is significant proportion of respondents who are excluded by friends. The proportion of healthy relationship with neighbors is the highest in both the districts. Emotional support is contributed by relatives/kins in both the districts.

Tertiary groups play an important role in controlling the alarming spread of HIV/AIDS and fighting against HIV/AIDS through SNEP, condom promotion, RMC, Counseling, awareness, advocacy, OST for IDUs etc, which means that there is no exclusion from tertiary groups in both the districts.

#### **6.1.4. Dynamics of Social Inclusion**

To understand the dynamics of social inclusion case studies and FGDs were conducted in both the districts. The case studies presented illustrate the helplessness and fear of exclusion found among PLHAS. There are cases where PLHAS are excommunicated by family as well as cases that were accepted by the family members. But in almost all cases we find the PLHAS are afraid of revealing their HIV status to the members of the community for fear of rejection, stigma and discrimination.

The focus group discussion conducted among the two districts reveals the different perceptions on impact of PLHAS. It was found that diagnosis of HIV is always profoundly shocking. The fear of negative impact sometimes prevents disclosure of HIV status to the community which leads to resentment, deterioration of interpersonal relations which interfere

with social inclusion process of PLHAS and the outcome is self-isolation and exclusion from family, friends and community.

## **6.2. Conclusion**

HIV/AIDS in Mizoram has affected people across gender the youth in the southern districts of Mizoram wherein the study was conducted. The people affected were mostly educated and were from broken or reconstituted step families. It has spread across the sub-tribe and denomination and economic classes during the last two decades. The main mode of transmission of HIV was reported as unprotected sex and sharing of unsterilized needles.

Social inclusion has been conceptualized in terms of participation in community, economic and political life of the society. The economic and political inclusion significantly higher than the community inclusion. The PLHAs are afraid of exclusion, excommunication and discrimination so that they rarely disclose their status to the other members of the community.

There were significant inter district variation in the levels of social inclusion was observed. The PLAS in non-autonomous district area were have greater level of social inclusion as compared to those in economically backward autonomous district though most of them are found at moderate level of social inclusion.

Social inclusion as a whole of PLHAs has been affected by only annual household income of the respondents positively. It has positive effect on only the economic dimension of social inclusion. However, female have lesser level of community inclusion as compared to men. Education has positive effect on economic inclusion of PLHAs.

As regards agencies of social inclusion the tertiary institutions play significant role in inclusion. Though the primary groups play significant role in providing care and social support there are some instances of exclusion and fear of exclusion.

### **6.3. Suggestions**

The following are the suggestions for policy.

1. The findings of the present study underlie the need for greater degree of awareness on HIV/AIDS and its related issues. Apart from general public the family members and peers of the PLHAS need to be given adequate knowledge on the problem.
2. Not only awareness but also change in the attitudinal towards of PLHS is needed Efforts should be made for removal of prejudice, discrimination of PLHAS in community life. Civil society organisations especially the Churches have to come forward to work for changing the attitudes and stereotypes towards PLHAS.
3. It is important to encourage the infected people to seek professional help and support and give the PLHAS psychological support.
4. Sex education is needed in middle school itself and youths need to be aware of the problems regarding sex and sexuality.
5. Creating awareness to go for HIV blood test before marriage is suggested.
6. Proper rehabilitation and vocational training for PLHAs is also suggested and positive network groups need to be encouraged, and supported with government funding.
7. Urge government officials to provide adequate funding for AIDS research, prevention education, and medical care and support services.
8. Government support for research to develop better treatments and a safe and effective AIDS vaccine in India.



## BIBLIOGRAPHY

- Alan Whiteside (2010), *Poverty and HIV/AIDS in Africa*, Routledge publications, *Third World Quarterly*, Vol 23, No 2, 313-332
- Anish Mahajan P, Jennifer Sayles N, Thomas Coates J (2008), *Stigma in the HIV/AIDS epidemic*, National Institute of Health public access, *AIDS* 2008, 22 (suppl 2), 67–79
- Barnett E, de Koning K, Francis V (1995), *Health and HIV/AIDS education in primary and secondary schools in Africa and Asia*, Educational Paper No. 14, DFID, London, UK, ISBN 0 902500 69 4, 94 pp.
- Bayram, Nuran, Bilgel Firat and Bilgel Nazan Gonul (2012) *Social Exclusion and Quality of Life: An Empirical Study from Turkey*. *Social Indicator Research*, 105:109-130
- Bayram, Nuran. Aytac, Serpil. Aytac, Mustafa, Sam, Neslihan. and Bilgel, Nazan (2011) *Measuring Social Exclusion: a Study from Turkey*. *Mediterranean Journal of Social Sciences*. 2(3) (September):285-298. accessed on 8<sup>th</sup> April 2014
- Berer M, Ray S (1993), *Women and HIV/AIDS: an international resource book*. Information action and resources on women and HIV/AIDS reproductive health and sexual relationships
- Brighton Gwezera, Noreen M Huni, *A study on 'Promoting Social Inclusion and Respect for Diversity in Terms of HIV and AIDS*
- Caceres CF, Aggleton P, Galea JT (2008), *Sexual diversity, Social inclusion and AIDS*, NIH of public access, *AIDS* 2008 Aug;22 Suppl 2:S45-55. doi: 10.1097/01.aids.0000327436.36161.80
- Catherine Bradshaw (2013), Ph.D., M.Ed.: University of Virginia and John Hopkins Bloomberg School of Public Health, *Social inclusion of youth with mental health conditions*, United Nations, New York
- Catherine Campbell, Andrew Gibbs (2009), *Inter-sectionality, Stigma, Gender and HIV*,
- Dan Allman (2013), *The Sociology of Social Inclusion*, DOI:10.1177/2158244012471957, Published on 8 January 2013
- Daniel Reeders (2001), *HIV and Social exclusion* , *HIV Australia* Vol. 9 No.2:July 2011
- Daniel Reeders (2011), *A study on HIV and Social Exclusion*

Daniel Reidpath D, Kit Chan Y, Sandra Gifford M, Pascale Allotey (2005), He hath the French pox, Stigma, social value and social exclusion, *Sociology of Health & Illness* Vol. 27 No. 4 2005 ISSN 0141-9889, pp. 468-489, Blackwell publications

Das, N.K. (2009), Identity Politics and Social Exclusion in India's North-East: The Case for Redistributive by the Bangladesh 2, *Journal of Sociology*, 2009

Department for International Development (2005), Reducing Poverty by Tackling Social Exclusion

Ella Libanova, Olena Makarova, Liudnyla Cherenko, Lidiia Tkachenko, Olena Palii (2002), Social protection and social inclusion in Ukraine, European Commission, Directorate-General for employment, social affairs and equal opportunities, manuscript completed on December 2009

Federick le R Booyesen, Tanza Amtz (2013), HIV/AIDS impact studies: a review of current practices

Feng, Wenmeng "Social Exclusion of the Elderly in Contemporary China: One Empirical Study Based on the Surveys in Six Provinces", Accessed on 8<sup>th</sup> April 2014

Gatchel RJ, Turk DC (1999), psychosocial factors in pain: critical perspectives, Guilford Press, 1999

Human Rights Watch, Epidemic of Abuse: Police harassment of HIV/AIDS Outreach Workers, Vol 14, No 5 (C), July 2002

Jafar Mahmud (2004), AIDS in the world- Global dimensions, social roots and responses, S.B Nangia APH publishing corporations publications

Jai Narain, P. (2004), AIDS in India: the challenge ahead, SAGE publication, accessed on 1<sup>st</sup> April 2004

Jean Paul Moatli, Bruno Ventelou (2007), The economic impact of HIV/AIDS in Developing Countries: An end to systematic under-estimation, Springa Netherlands Publications

Jehoel-Gijsbers, G., & Vrooman, C. (2007), Explaining social exclusion: A theoretical model tested in the Netherlands. The Hague: The Netherlands Institute for Social Research, Accessed on 8<sup>th</sup> April 2014

Jessica Oden (2009), Expanding the care continuum for HIV/AIDS: Bringing carers into focus

John Carvel (2011), Social Exclusion Hindering Treatment and Spread of HIV'

John Pierson (2010), Tackling Social Exclusion, Second edition, ISBN-10: 0415478340, Routledge publications

Kabeer, Naila (2000) 'Social Exclusion, Poverty and Discrimination: Towards an analytical framework'. *IDS Bulletin* 3(4)

Kanagaraj, E. (2005) Human Development and Social Inclusion of Scheduled Tribes in Tamil Nadu. Annamalai Nagar: Department of Economics Annamalai University. Unpublished Ph.D thesis

Kandwal, Garg PK, (2008), Health GIS and HIV/AIDS studies: Perspective and retrospective

Karolynn Siegel, Howard Lune, Ilan H.Meyer (1998), Stigma management among Gay/Bisexual Men with HIV/AIDS, *Qualitative Sociology*, Volume 21, Issue 1, 3-24. DOI: 10.1023/A:1022102825016

Kenneth H.Mayer, Hank Pizer (2005), The AIDS pandemic: Impact on science and society, Academic Press, 21 december 2004

Kit Yee Chan, Mark A Stoove, Daniel D Reidpath (2008), Stigma, Social Reciprocity and Exclusion of HIV/AIDS Patients with Illicit Drug histories: A study of Thai nurses' Attitudes, *Harm Reduction Journal Publications* 23 August 2008

Lather P. Smithies (2001), *Troubling the Angels: Women Living with HIV/AIDS*

Leslie E. Wolf, Bernard LO (2008), Ethical dimensions of HIV/AIDS, Leslie E. Wolf, JD, MPH, University of California San Francisco, Bernard LO, MD, University of California San Francisco, August 2011

Martha Morrow, MC Arunkumar, Emma Pearce, Heather E Dawson (2007), Fostering disability- inclusive HIV/AIDS programs in Northeast India: a participatory study

Marya Buvinic, Jacqueline Mazza (2010), Social Inclusion and Economic Development in Latin America, IDB publications

Mignone J (2007), *Social Determinants of HIV/AIDS*

Miriam Maluwa, Peter Aggleton, Richard Parker (2002), HIV and AIDS-related stigma, discrimination and human rights: a critical overview, The president and fellows of Harvard college publications

NACO (2007), HIV Sentinel Surveillance and HIV estimation in India: a technical brief

NACO (2012), Ministry of Health and Family Welfare, Government of India, December 2012.

Nidhi Khosla (2009), HIV/AIDS Interventions in Bangladesh: what can application of a social exclusion framework tell us?. *J Health Popul Nutr* v.27(4): August 2009

Opong Asante K (2011), A study on Social Support and the Psychological Wellbeing of People Living with HIV/AIDS in Ghana, Department of Human Development and Psychology, Regent University College of Science and Technology, Accra, Ghana, 2011

Radhika Ramasubban, Bhanwar Rishwasringa, AIDS and civil society- India's learning curve, Rawat publications, Jaipur, New Delhi, Bangalore, Mumbai

Rajan Gupta (2008), Risky sex, Addictions and Communicable diseases in India: Implications for Health, Development and Security

Reducing poverty by tackling social exclusion (2005), Department of International Development publications

Reidpath DD, Chan KY (2010), AIDS Care: Psychological and Socio-medical Aspects of HIV/AIDS, Routledge publications

Rene Laewenson (2004), Community responses to HIV/AIDS: strengthening social inclusion or carrying unfair burdens, Equinet publications, August 2004

Richard G.Marlink, Alison G. Kotin (2002), Global AIDS Crisis- A reference book

Rob Oxoby (2009), Understanding social inclusion, social cohesion and social capital, *International Journal of Social Economics*, Emerald Group Publishing, vol. 36(12),1133-1152, Accessed on 22<sup>nd</sup> January, 2009

Samiran Panda, Anindya Chatterjee, Aby S. Abdul –Quader (2002), Living with the AIDS virus- the epidemic and the response in India, Sage publications, ISBN:9780761996231

Sarker, Debnarayan (2011), Social and Economic Implications of HIV/AIDS: evidence from West Bengal, *Man and Development* Vol. XXXIII, No. 1 publications, 19-38, Accessed on 23<sup>rd</sup> September 2011

Sian Beilock (2012), Ph.D in Choke, Dealing with the pain of Social Exclusion, Accessed on 7<sup>th</sup> March 2012

Skinner D, Mfecane S (2004), Stigma, discrimination and implications for persons living with HIV/AIDS in South Africa, SAHARA J, 2004 Nov,1(3):157-164

Social Aspects of HIV/AIDS and Health (2012), A Research to inform HIV/AIDS prevention, care and impact mitigation, 750 Francois Road, Intuthuko Junction, Cato Manor, Durban, 4001, SouthAfrica, Private Bag X07, Dalbridge, 4014, South Africa

Stefano Bertozzi, Nancy S. Padian, Jeny Wegbreit, Lisa M. DeMaria, Becca Feldman, Helene Gayle, Julian Gold, Robert Grant, and Michael T. Isbelle (2011), HIV/AIDS Prevention and Treatment

The International Bank for Reconstruction and Development (2009), Inclusive responses to the HIV and AIDS challenge: Experience form the Indian Sector, Washington, DC 20433

United Nations (2010) Analysing and Measuring Social Inclusion in a Global Context, New York: Department of Economic and SocialAffairs, United Nations. Accessed on 8<sup>th</sup> April 2014

Wiseman Chijere Chirwa (2002), Social Exclusion and Inclusion: challenges to orphan care in Malawi, Nordic Journal of African Studies 11(1): 93-113, (2002)

**SOCIAL INCLUSION OF PERSONS LIVING WITH HIV/AIDS  
IN MIZORAM**

**K.LALREMPUII  
ABSTRACT**

**Department of Social Work  
Mizoram University**

## **1.1 Introduction**

HIV/AIDS is a worldwide epidemic which has an alarming increase in incidence over the recent years. It has an impact on the individual, family and society (The Henry J. Kaiser Family 2006; Lyons 2008; Donahue and Williamson 1999; Nelson Mandela Foundation 2010).

The HIV virus that causes AIDS has become one of the world's most serious health and development challenges. There are 33.4 million people living with HIV/AIDS till 2012 and more than 25 million people have died of AIDS worldwide since the first cases were reported in 1981. In 2008, 2 million people died due to HIV/AIDS, and another 2.7 million were newly infected. While cases have been reported in all regions of the world, almost all those living with HIV (97%) reside in low and middle-income countries, particularly in sub-Saharan Africa. According to the World Health Organization (WHO), most people living with HIV or at risk for HIV do not have access to prevention, care and treatment, and there is still no cure.

The HIV epidemic not only affects the health of individuals, it impacts households, communities and the development and economic growth of nations. Many of the countries hardest hit by HIV suffer from other infectious diseases, food insecurity, and other serious problems. Despite these challenges, there have been successes and promising signs. New global efforts have been mounted to address the epidemic, particularly in the last decade. The statistics indicated that prevention has helped to reduce HIV prevalence rates in a small but growing number of countries and new HIV infections are believed to be on the decline. In addition, the number of persons living with HIV receiving treatment in resource poor countries has increased 10-fold since 2002, reaching an estimated 4 million by 2008.

The adult HIV prevalence in India is 0.27 percent, as of 2011. Whilst this figure is small relative to other middle-income countries, the large population of 1.2 billion inhabitants means

there are still around 2.1 million persons living with HIV in India. Overall, India's HIV epidemic is slowing down, with a 57 percent decline in new infections between 2000 and 2011, and a 29 percent decline in AIDS-related deaths between 2007 and 2011. India's HIV epidemic varies across its 28 states. The four states with the highest number of persons living with HIV (Andhra Pradesh, Karnataka, Maharashtra and Tamil Nadu) are all in the south, and account for 53 percent of all HIV infections in India. Despite this, the adult HIV prevalence is falling in these high prevalence states. However, in a few states in the north and northeast, HIV infections are rising. Of all persons living with HIV in India, 39 percent are women and 7 percent are children. In many low- and middle- income countries, women are disproportionately affected by HIV, but men are more affected in India. This is because HIV transmission here is concentrated among high-risk groups that are predominantly male, such as truck drivers, migrants and clients of sex workers. The vast majority of infections occur through heterosexual sex.

According to National AIDS Control Organization of India, the prevalence of AIDS in India in 2013 was 0.27, which is down from 0.41 in 2002. While the National AIDS Control Organization estimated that 2.39 million people live with HIV/AIDS in India in 2008 – 2009, a more recent investigation by the Million Death Study Collaborators in the British Medical Journal (2010) estimates the population to be between 1.4 – 1.6 million people. The last decade has seen a 50% decline in the number of new HIV infections. According to more recent NACO data, India has demonstrated an overall reduction of 57 per cent in estimated annual new HIV infections (among adult population) from 0.274 million in 2000 to 0.116 million in 2011, and the estimated number of persons living with HIV was 2.08 million in 2011.

HIV/AIDS is a serious epidemic which does not have any cure. Persons Living with HIV/AIDS are physically and psychologically affected. They are always under stress and strain because of shame, ill health and terminal condition (Gatchel and Turk 1999; Reidpath and Chan



2010). Persons Living with HIV/AIDS are being stigmatized and discriminated by the people at large and they face many problems in their lives. A diagnosis of HIV infection is always profoundly shocking. Feeling of fear, anger, despair and thoughts of suicide are common among the HIV infected people. Stigma is also one of the major challenges that Persons living with HIV/AIDS face. Stigma, silence, discrimination and denial undermine prevention and care strategies and increase the exclusion of the epidemic on an individual (Mahajan and Coates 2008; Skinner and Mfecane 2004).

It is now a common knowledge that in HIV/AIDS, it is not the condition itself that hurts the most (because many other diseases and conditions lead to serious suffering and death), but the stigma and the possibility of rejection and discrimination, misunderstanding and loss of trust that HIV positive people have to deal with. Many people have done research on HIV/AIDS considering stigmatization and discrimination as the number one reason why HIV/AIDS cannot be curbed.

Persons living with HIV/AIDS may be excluded from family and community events and experience a loss of power and respect in the community. The effects may be akin to social death. In a stigmatized environment, opportunity for HIV test is rejected for fear of being identified, leading to a delay in diagnosis and access to supportive counseling, treatment and care and as a result, both the individual and public suffer (Reidpath and Chan 2010).

The fear of negative impact prevents disclosure of status within the family and community which may lead to resentment, deterioration of interpersonal relations which interfere with social integration process of the Persons living with HIV/AIDS and the outcome can be self-isolation and exclusion from family and the community. Not only is HIV-related discrimination a human rights violation, but it is also necessary to address such discrimination and stigma in order to achieve public health goals and overcome the epidemic (Laewenson 2004).

Many organizations and institutions offer a broad range of services from emotional support to referrals for community resources. They may provide counseling services, advocate for a patient, or work with community groups that will aid the patients and other constituencies. A social inclusion perspective on HIV prevention and AIDS-related care implies the adoption of strategies to understand and confront social vulnerability (Panda; Chattarjee and Quader 2002).

Social inclusion is the positive steps an organization or institution can take to combat the risk of individuals or communities being excluded from mainstream society for reasons such as Unemployment, Low income, Poor housing and Family conflict/breakdown. It is basically the steps taken to avoid marginalization of particular people in the society. According to Rebecca Fraser (2011), “With regard to relationships and human behavior, social inclusion means accepting someone into interpersonal interactions and social networks.”

Social exclusion is defined in the bewildering diversity of ways. European foundation (1995) defines social exclusion as the process through which individuals or groups wholly or partially excluded from full participation in the society in which they live. This definition focuses on the process nature of social exclusion. Others lay greater stress on multiple deprivations as a defining feature of social exclusion; low income and insecure job, poor housing, family stress and social alienation (Paugam 1995). Some definitions integrate both of the features. For instance, Paul Appasamy et al (1995) defined social exclusion as “a process which restricts the access of certain social groups to valued resources and entitlements, relegating them to the status of social outsiders. It is a multidimensional concept, conceived to capture different forms of social disadvantage – economic social political and cultural – that persist, in multiple variants and with different intensity, across nations.”

## **1.2 Overview of Literature**

A review of literature helps to understand and support more of the present study. The social exclusion of Persons Living with HIV/AIDS exists worldwide, although they manifest themselves across countries, communities, individuals and religious groups.

As HIV/AIDS is a socio economic problem of global scale, there are numerous policy initiatives at international, national and state levels to combat it. There are state and civil society actors playing active role in prevention, treatment and care of persons living with HIV/AIDS. As part of these initiatives, there were a number of research projects undertaken to understand the multiple dimensions of the problem. This has contributed to rapid growth of literature on HIV/AIDS over the past three decades.

A significant portion of this literature includes studies on persons living with HIV/AIDS (PLHAS). This section of the literature mainly focuses on interrelated aspects of the life of the PLHAS viz., the social and economic characteristics (see Mahmud 2004; Moatli and Ventelou 2007; Debnarayan 2011), psycho social aspects (see Gatchel and Turk 1999; Reidpath and Chan 2010), care and support (see Barnett, Koning and Francis 1995; Duer 2004; Khondom 2009), quality of life (see Narain 2004; Shippy and Karpiak 2010), stigma and discrimination (see Miriam, Peter and Richard 2002; Skinner and Mfecane 2004; Anish, Jennifer and Thomas 2008) as well as social inclusion (see Laewenson 2004; Caceres, Aggleton and Galea 2008; Oxoby 2009; Allman 2013; Catherine 2013) and exclusion (see Wiseman 2002; Carvel 2001; Daniel 2001; Peirson 2010; Sian 2012). In fact application of the theoretical frame work of social exclusion in understanding the social life of people would enhances the effectiveness of policy making and social work practices.

The social exclusion framework has become very popular in development studies all over the world though it emerged in the North as a social policy discourse. The SEF is lauded for its

ability to understand the multiple dimensions of institutional well-being of people viz. social, economic and political. It helps to comprehend the situations of those who are hitherto excluded (like ethnic minorities, SC/ST) and those who are excluded due to the operation of the forces of globalization (unemployed, PLHAS). Its ability to promote comprehensive understanding of the dynamics of the process of exclusion/inclusion as well agencies and mechanisms of exclusion are appreciated by the social scientists from the South (see Kabeer 2000).

There is a copious literature on social exclusion all over the world. They mainly focus on the patterns, process or levels, agencies and mechanisms of inclusion/exclusion at national level (Kanagaraj 2005). There are attempts to develop conceptual and operational frameworks of social inclusion in its multiple dimensions at multilevel viz. national, and state, levels (see United Nations 2010). There are studies at household (see Kanagaraj 2005) and individual (see Jehoel-Gijsbers, & Vrooman 2007; Bayram et al 2011; Bayram, Firat and Gonul 2012), levels which throw light on the determinants and consequents of social inclusion/exclusion of elderly, poor, ethnic minorities in varied contexts

As regards the methodology we could notice studies using quantitative, qualitative as well as mixed methods are found though many scholars emphasize judicious combination of quantitative and qualitative methods.

### **Statement of the Problem**

The prevalence rate of HIV/AIDS is very high in Mizoram. Mizoram stands second in prevalence of AIDS/HIV amongst the North Eastern states and was only next to Manipur. Since October 1990 to October 2014, there were 9637 cases declared as positive out of 297375 cases blood tested. During this period, 587 AIDS deaths were also reported. According to MSACS, the predominant mode of transmission of HIV during this period was sexual contact (64%) while injecting drug use (24%) was reported as another significant mode of transmission (NAACCO)

Many organizations like Mizoram State AIDS Control Society (MSACS), Chhawmdawlina In, Disciple AIDS Intervention Ministry, Jericho Inn, Protective Home, Samaritan Society of Mizoram etc have taken up the initiatives to control the alarming spread of HIV/AIDS and to fight against HIV/AIDS in Mizoram. They do offer a wide range of services like Syringe and Needles Exchange Programme, Condom Promotion, Awareness Programme, Counseling, Free regular Medical Check-up, Oral Substitution Therapy for Injecting Drug Users etc.

In this context, the present study attempts to probe into the patterns of social inclusion of persons living with HIV/AIDS (PLHAS). It tries to locate the patterns and levels of social inclusion of PLWHS in the broader socio economic structural context and developmental disparities in the state. It attempts to understand the role played by state and civil society actors in the process of inclusion of PLHAS. Further, it throws light on the mechanisms adopted in inclusion and exclusion of PLHAS. In the light it offers suggestions for policy making and social work practice towards promoting social inclusion of PLHAS.

The results of the present study will be useful to policy makers, planners, and social workers interested as well as committed to the cause of promotion of social inclusion and well-being of PLHAS and prevention of the AIDS pandemic. They will find adequate information for developing interventions with general public as well as PLHAS.

#### **1.4 Objectives**

The specific objectives of the present study are as follows.

1. To probe into the socio-economic characteristics of Persons living with HIV/AIDS (PLHAS).
2. To probe into the pattern of social inclusion of PLHAS
3. To assess extent of social inclusion of PLHAS and identify its determinants.
4. To understand the process of social inclusion and exclusion of PLHAS.

5. To identify the agencies and mechanisms of the inclusion and exclusion of Persons living with HIV/AIDS.

### **1.5 Chapterization**

The study is organized into the following five chapters.

1. Introduction
2. Review of Literature
3. Methodology
4. Results and Discussions
5. Conclusions and Suggestions

### **1.6 Methodology**

The present study is cross sectional in nature and descriptive in design. It is based on mainly the primary data collected with the help of qualitative and quantitative methods. Qualitative and quantitative methods were collected concurrently. Quantitative data was collected through field survey with pretested structured personal interview schedule to assess the patterns, levels and the determinants of inclusion of Persons Living with HIV/AIDS. The study was conducted during 20<sup>th</sup> August, 2014 to 21<sup>st</sup> September, 2014. Case studies constitute the qualitative methods and were used in the study to understand the dynamic processes of inclusion/ exclusion and the context of exclusion.

The universe of the study is individual adult persons living with HIV/AIDS (PLHAS) and the population includes all PLHAS in the state of Mizoram. A multistage sampling is used to select districts, towns and respondents. In the first phase, two districts- Lunglei District and Saiha District are chosen purposively. In the second stage, demographic details of PLHAS is compiled from the governmental and non-governmental organizations working with PLHAS ie; MCHP (Saiha), ICTC, Civil Hospital (Saiha), Grace Society (Lunglei), ICTC, Christian Hospital

(Lunglei), ICTC Civil Hospital (Lunglei). The PLHAS are stratified on the basis of gender. From among men and women proportionately respondents are drawn. The sample size is sixty.

Structured interview schedule was used for collection of primary data. The interview schedule contains twenty six sections with a number of sub-sections. Pilot study was conducted with PLHAS for constructing interview schedule. The interview schedule contains identification information of the respondents, demographic profile and household profile of the respondents,

The primary data collected through field survey is processed with the help of Microsoft Excel and analyses with SPSS Package 20. Apart from simple percentages, ratios, averages, cross tabulation, Karl Pearson's product moment correlation is used for analysis of quantitative data. The major limitation of the present study is that it was confined to only two district head quarters in Mizoram. Hence, the generality of the findings will be limited.

## **1.7 Results and Conclusion**

The present study aims at understanding the pattern, agency, mechanism and dynamics of social inclusion of persons living with HIV in Mizoram. Quantitative and qualitative data have been collected from PLHS and results of their analysis were presented in the last two chapters. In this chapter the salient findings of them are summarized and conclusion derived and suggestion put forth for policy making are presented.

The summary of findings is presented in terms of profile of respondents, patterns of social inclusion, agency and mechanisms of inclusion, and dynamics of social inclusion of PLHAs.

### **1.7.1. Profile of Respondents and their Households**

The profile of respondents is presented into five subsections, viz; demographic characteristics of the respondents, family structure, social characteristics, economic characteristics and the profile illness.

The demographic characteristics of the respondents presented are gender, age group, marital status and educational status. From the study, it has been found out that male respondents constitute predominant majority of the respondents in both the districts i.e. Saiha and Lunglei. There is no difference in age distribution: Four-fifth of the respondents belongs to the youth group in both the districts. Unmarried respondents constitute a predominant majority of respondents in both the districts. However, the proportion is slightly higher in Lunglei. Both the districts have similar levels of educational attainment.

The family characteristics comprises of Type of Family, Size of family, Form of family and Gender of head. From the study, it has been found out that broken family is predominant in both the districts. The proportion of stable family is slightly greater in autonomous district and nuclear family is predominantly found in both the districts. Medium size of family is predominant in both the districts. Male headed family represents the family of predominant majority of the respondents in both the studied districts.

The social structural characteristics of respondents include sub-tribe and denomination. From the study, it can be seen that Baptist Church of Mizoram is the most dominant church in non-autonomous district and Evangelical Church of Maraland is the most dominant church in autonomous district.

To understand the economic conditions of PHAS in Mizoram, the study focuses on certain characteristics viz., earner/dependent, primary occupation, socio economic category, annual household income, per capital annual household income. Dependent respondents constitute the predominant majority in both of the districts. The proportion of dependent respondents is higher in non-autonomous district. Earners constitute a greater proportion in autonomous district. Government work is the predominant primary occupation in both the districts. The proportion of wage laborers is higher in non-autonomous district. The proportion of skilled laborers is higher in



autonomous district. The predominant majority of respondents fall under non-poor category in both the districts. The proportion of Very Poor (AAY) category is greater in autonomous district. The proportion of poor category (BPL) is greater in non-autonomous district. Annual Household Income Mean is Greater in non-autonomous district than autonomous district. Per capita Annual Household Income shows similar picture.

Illness profile of respondents is categorized into year of detection of infection, probable mode of transmission and organization where infection detected. During 2008-2011 detection of HIV infection happened for predominant majority in both the studied districts. Unprotected sexual intercourse is the dominant mode of transmission within the studied districts. There are few cases of transmission through blood transfusion. Mobile ICTC was the dominant agency where HIV blood test is done in non-autonomous district. The proportion of cases detected by ICTC is greater in non-autonomous district.

### **1.7.2. Patterns of Social Inclusion**

The present study presents the pattern of social inclusion in four subsections, i.e.; Pattern of Community Inclusion, Pattern of economic inclusion, pattern of political inclusion and pattern of social inclusion.

The pattern of community inclusion includes attending funeral services, attending marriages in the community, attending the church services, volunteering for community and attending meetings of community organizations. The pattern of economic inclusion constitutes Adequacy of size of land, adequacy of present family income, Number of days of employment, adequacy of amount of loan getting when needed, wage rate/monthly salary and amount save every month. The pattern of Political Inclusion includes Voting in Assembly Election, voting in general election, voting in Village Council election, participation in election campaigns and

attending meetings of political parties. The pattern of inclusion is categorized into economic inclusion, political inclusion, community inclusion and social inclusion.

From the study, it has been found out that attending funeral services is the predominant mode of community inclusion in both the districts. The proportion of attending marriages, church services and volunteering for the community is greater in non-autonomous district. The study shows that community inclusion is slightly better in autonomous district. Adequacy of size of land is the predominant economic inclusion in both the districts. Adequacy of present family income is more or less the same in both the districts. Voting in assembly election is the predominant form of political inclusion in both of the districts. Other modes of political inclusion are more or less the same in both the districts. Economic inclusion is the predominant mode of inclusion in both the districts. There is no significant difference between the districts. Community inclusion is least in comparison with political inclusion and economic inclusion. The political participation and community inclusion is inclusion significantly greater in non-autonomous district. Social inclusion of PLHAs is significantly greater in non-autonomous district as compared to autonomous district.

The extent of social inclusion is categorized into low (0.60-1.13), Medium (1.13-1.67) and High (1.67-2.2). The study shows that there is a significant difference in the extent of social inclusion across districts. Most of the respondents are moderately included in the level of inclusion. The proportion of moderately and highly included PLHAs is higher in non-autonomous district. The proportion of PLHAS at low level is greater for autonomous district.

The determinants of social inclusion includes gender, educational qualification, size of family, socio economic category and annual household income and is categorized into community inclusion, economic inclusion, political inclusion and social inclusion. From the study, it can be seen that males are better included than the female respondents. Education has

positive effect on economic inclusion only. Household income is positively related to economic and overall social inclusion. Sizes of family and socio economic category have no significant effect on community, economic, political and thus social inclusion.

### **1.7.3 Agencies and Mechanisms of Social Inclusion**

The MSACS is the predominant agency of social inclusion in both of the districts. Mobile ICTC, ART and ICTC are the second most predominant agencies. Financial and emotional support is a mechanism of inclusion by the family. Among primary and secondary groups, exclusion by the family exists in both the districts. Emotional support among friends is the predominant mechanism in both the districts. There is significant proportion of respondents who are excluded by friends. The proportion of healthy relationship with neighbors is the highest in both the districts. Emotional support is contributed by relatives/kins in both the districts.

Tertiary groups play an important role in controlling the alarming spread of HIV/AIDS and fighting against HIV/AIDS through SNEP, condom promotion, RMC, Counseling, awareness, advocacy, OST for IDUs etc, which means that there is no exclusion from tertiary groups in both the districts.

### **1.7.4. Dynamics of Social Inclusion**

To understand the dynamics of social inclusion case studies and FGDs were conducted in both the districts. The case studies presented illustrate the helplessness and fear of exclusion found among PLHAS. There are cases where PLHAS are excommunicated by family as well as cases that were accepted by the family members. But in almost all cases we find the PLHAS are afraid of revealing their HIV status to the members of the community for fear of rejection, stigma and discrimination.

The focus group discussion conducted among the two districts reveals the different perceptions on impact of PLHAS. It was found that diagnosis of HIV is always profoundly

shocking. The fear of negative impact sometimes prevents disclosure of HIV status to the community which leads to resentment, deterioration of interpersonal relations which interfere with social inclusion process of PLHAS and the outcome is self-isolation and exclusion from family, friends and community.

### **1.7.5 Conclusion**

HIV/AIDS in Mizoram has affected people across gender the youth in the southern districts of Mizoram wherein the study was conducted. The people affected were mostly educated and were from broken or reconstituted step families. It has spread across the sub-tribe and denomination and economic classes during the last two decades. The main mode of transmission of HIV was reported as unprotected sex and sharing of unsterilized needles.

Social inclusion has been conceptualized in terms of participation in community, economic and political life of the society. The economic and political inclusion is significantly higher than the community inclusion. The PLHAs are afraid of exclusion, excommunication and discrimination so that they rarely disclose their status to the other members of the community.

There were significant inter district variation in the levels of social inclusion was observed. The PLAS in non-autonomous district area were have greater level of social inclusion as compared to those in economically backward autonomous district though most of them are found at moderate level of social inclusion.

Social inclusion as a whole of PLHAs has been affected by only annual household income of the respondents positively. It has positive effect on only the economic dimension of social inclusion. However, female have lesser level of community inclusion as compared to men. Education has positive effect on economic inclusion of PLHAs.

As regards agencies of social inclusion the tertiary institutions play significant role in inclusion. Though the primary groups play significant role in providing care and social support there are some instances of exclusion and fear of exclusion.

### **1.8 Suggestions**

The following are the suggestions for policy.

1. The findings of the present study underlie the need for greater degree of awareness on HIV/AIDS and its related issues. Apart from general public the family members and peers of the PLHAS need to be given adequate knowledge on the problem.
2. Not only awareness but also change in the attitudinal towards of PLHS is needed Efforts should be made for removal of prejudice, discrimination of PLHAS in community life. Civil society organizations especially the Churches have to come forward to work for changing the attitudes and stereotypes towards PLHAS.
3. It is important to encourage the infected people to seek professional help and support and give the PLHAS psychological support.
4. Sex education is needed in middle school itself and youths need to be aware of the problems regarding sex and sexuality.
5. Creating awareness to go for HIV blood test before marriage is suggested.
6. Proper rehabilitation and vocational training for PLHAs is also suggested and positive network groups need to be encouraged, and supported with government funding.
7. Urge government officials to provide adequate funding for AIDS research, prevention education, and medical care and support services.
8. Government support for research to develop better treatments and a safe and effective AIDS vaccine in India.

## **Bibliography**

Alan Whiteside (2010), *Poverty and HIV/AIDS in Africa*, Routledge publications, *Third World Quarterly*, Vol 23, No 2, 313-332

Anish Mahajan P, Jennifer Sayles N, Thomas Coates J (2008), *Stigma in the HIV/AIDS epidemic*, National Institute of Health public access, *AIDS* 2008, 22 (suppl 2), 67–79

Barnett E, de Koning K, Francis V (1995), *Health and HIV/AIDS education in primary and secondary schools in Africa and Asia*, Educational Paper No. 14, DFID, London, UK, ISBN 0 902500 69 4, 94 pp.

Bayram, Nuran, Bilgel Firat and Bilgel Nazan Gonul (2012) *Social Exclusion and Quality of Life: An Empirical Study from Turkey*. *Social Indicator Research*, 105:109-130

Bayram, Nuran. Aytac, Serpil. Aytac, Mustafa, Sam, Neslihan. and Bilgel, Nazan (2011) *Measuring Social Exclusion: a Study from Turkey*. *Mediterranean Journal of Social Sciences*. 2(3) (September):285-298. accessed on 8<sup>th</sup> April 2014

Berer M, Ray S (1993), *Women and HIV/AIDS: an international resource book*. Information action and resources on women and HIV/AIDS reproductive health and sexual relationships

Brighton Gwezera, Noreen M Huni, *A study on ‘Promoting Social Inclusion and Respect for Diversity in Terms of HIV and AIDS*

Caceres CF, Aggleton P, Galea JT (2008), *Sexual diversity, Social inclusion and AIDS*, NIH of public access, *AIDS* 2008 Aug;22 Suppl 2:S45-55. doi: 10.1097/01.aids.0000327436.36161.80

Catherine Bradshaw (2013), Ph.D., M.Ed.: University of Virginia and John Hopkins Bloomberg School of Public Health, *Social inclusion of youth with mental health conditions*, United Nations, New York

Catherine Campbell, Andrew Gibbs (2009), *Inter-sectionality, Stigma, Gender and HIV*,

Dan Allman (2013), *The Sociology of Social Inclusion*, DOI:10.1177/2158244012471957, Published on 8 January 2013

Daniel Reeders (2001), *HIV and Social exclusion*, HIV Australia Vol. 9 No.2:July 2011

Daniel Reeders (2011), *A study on HIV and Social Exclusion*

Daniel Reidpath D, Kit Chan Y, Sandra Gifford M, Pascale Allotey (2005), *He hath tha French pox, Stigma, social value and social exclusion*, *Sociology of Health & Illness Vol. 27 No. 4 2005* ISSN 0141-9889, pp. 468-489, Blackwell publications

Das, N.K. (2009), *Identity Politics and Social Exclusion in India's North-East: The Case for Redistributive by the Bangladesh 2*, *Journal of Sociology*, 2009

Department for International Development (2005), *Reducing Poverty by Tackling Social Exclusion*

Ella Libanova, Olena Makarova, Liudnyla Cherenko, Lidiia Tkachenko, Olena Palii (2002), *Social protection and social inclusion in Ukraine*, European Commission, Directorate-General for employment, social affairs and equal opportunities, manuscript completed on December 2009

Federick le R Booyesen, Tanza Amtz (2013), *HIV/AIDS impact studies: a review of current practices*

Feng, Wenmeng "Social Exclusion of the Elderly in Contemporary China: One Empirical Study Based on the Surveys in Six Provinces", Accessed on 8<sup>th</sup> April 2014

Gatchel RJ, Turk DC (1999), *Psychosocial factors in pain: critical perspectives*, Guilford Press, 1999

Human Rights Watch, *Epidemic of Abuse: Police harassment of HIV/AIDS Outreach Workers*, Vol 14, No 5 (C), July 2002

Jafar Mahmud (2004), *AIDS in the world- Global dimensions, social roots and responses*, S.B Nangia APH publishing corporations publications

Jai Narain, P. (2004), AIDS in India: the challenge ahead, SAGE publication, accessed on 1<sup>st</sup> April 2004

Jean Paul Moatli, Bruno Ventelou (2007), The economic impact of HIV/AIDS in Developing Countries: An end to systematic under-estimation, Springa Netherlands Publications

Jehoel-Gijsbers, G., & Vrooman, C. (2007), Explaining social exclusion: A theoretical model tested in the Netherlands. The Hague: The Netherlands Institute for Social Research, Accessed on 8<sup>th</sup> April 2014

Jessica Oden (2009), Expanding the care continuum for HIV/AIDS: Bringing carers into focus

John Carvel (2011), Social Exclusion Hindering Treatment and Spread of HIV'

John Pierson (2010), Tackling Social Exclusion, Second edition, ISBN-10: 0415478340, Routledge publications

Kabeer, Naila (2000) 'Social Exclusion, Poverty and Discrimination: Towards an analytical framework'. *IDS Bulletin* 3(4)

Kanagaraj, E. (2005) Human Development and Social Inclusion of Scheduled Tribes in Tamil Nadu. Annamalai Nagar: Department of Economics Annamalai University. Unpublished Ph.D thesis

Kandwal, Garg PK, (2008), Health GIS and HIV/AIDS studies: Perspective and retrospective

Karolynn Siegel, Howard Lune, Ilan H.Meyer (1998), Stigma management among Gay/ Bisexual Men with HIV/AIDS, *Qualitative Sociology*, Volume 21, Issue 1, 3-24. DOI: 10.1023/A:1022102825016

Kenneth H.Mayer, Hank Pizer (2005), The AIDS pandemic: Impact on science and society, Academic Press, 21 december 2004



Kit Yee Chan, Mark A Stoove, Daniel D Reidpath (2008), Stigma, Social Reciprocity and Exclusion of HIV/AIDS Patients with Illicit Drug histories: A study of Thai nurses' Attitudes, Harm Reduction Journal Publications 23 August 2008

Lather P. Smithies (2001), Troubling the Angels: Women Living with HIV/AIDS

Leslie E. Wolf, Bernard LO (2008), Ethical dimensions of HIV/AIDS, Leslie E. Wolf, JD, MPH, University of California San Francisco, Bernard LO, MD, University of California San Francisco, August 2011

Martha Morrow, MC Arunkumar, Emma Pearce, Heather E Dawson (2007), Fostering disability-inclusive HIV/AIDS programs in Northeast India: a participatory study

Marya Buvinic, Jacqueline Mazza (2010), Social Inclusion and Economic Development in Latin America, IDB publications

Mignone J (2007), Social Determinants of HIV/AIDS

Miriam Maluwa, Peter Aggleton, Richard Parker (2002), HIV and AIDS-related stigma, discrimination and human rights: a critical overview, The president and fellows of Harvard college publications

NACO (2007), HIV Sentinel Surveillance and HIV estimation in India: a technical brief

NACO (2012), Ministry of Health and Family Welfare, Government of India, December 2012.

Nidhi Khosla (2009), HIV/AIDS Interventions in Bangladesh: what can application of a social exclusion framework tell us?. J Health Popul Nutr v.27(4): August 2009

Oppong Asante K (2011), A study on Social Support and the Psychological Wellbeing of People Living with HIV/AIDS in Ghana, Department of Human Development and Psychology, Regent University College of Science and Technology, Accra, Ghana, 2011

Radhika Ramasubban, Bhanwar Rishwasringa, AIDS and civil society- India's learning curve, Rawat publications, Jaipur, New Delhi, Bangalore, Mumbai

Rajan Gupta (2008), Risky sex, Addictions and Communicable diseases in India: Implications for Health, Development and Security

Reducing poverty by tackling social exclusion (2005), Department of International Development publications

Reidpath DD, Chan KY (2010), AIDS Care: Psychological and Socio-medical Aspects of HIV/AIDS, Routledge publications

Rene Laewenson (2004), Community responses to HIV/AIDS: strengthening social inclusion or carrying unfair burdens, Equinet publications, August 2004

Richard G.Marlink, Alison G. Kotin (2002), Global AIDS Crisis- A reference book

Rob Oxoby (2009), Understanding social inclusion, social cohesion and social capital, International Journal of Social Economics, Emerald Group Publishing, vol. 36(12),1133-1152, Accessed on 22<sup>nd</sup> January, 2009

Samiran Panda, Anindya Chatterjee, Aby S. Abdul –Quader (2002), Living with the AIDS virus- the epidemic and the response in India, Sage publications, ISBN:9780761996231

Sarker, Debnarayan (2011), Social and Economic Implications of HIV/AIDS: evidence from West Bengal, Man and Development Vol. XXXIII, No. 1 publications, 19-38, Accessed on 23<sup>rd</sup> September 2011

Sian Beilock (2012), Ph.D in Choke, Dealing with the pain of Social Exclusion, Accessed on 7<sup>th</sup> March 2012

Skinner D, Mfecane S (2004), Stigma, discrimination and implications for persons living with HIV/AIDS in South Africa, SAHARA J, 2004 Nov,1(3):157-164

Social Aspects of HIV/AIDS and Health (2012), A Research to inform HIV/AIDS prevention, care and impact mitigation, 750 Francois Road, Intuthuko Junction, Cato Manor, Durban, 4001, SouthAfrica, Private Bag X07, Dalbridge, 4014, South Africa

Stefano Bertozzi, Nancy S. Padian, Jeny Wegbreit, Lisa M. DeMaria, Becca Feldman, Helene Gayle, Julian Gold, Robert Grant, and Michael T. Isbelle (2011), HIV/AIDS Prevention and Treatment

The International Bank for Reconstruction and Development (2009), Inclusive responses to the HIV and AIDS challenge: Experience from the Indian Sector, Washington, DC 20433

United Nations (2010) Analysing and Measuring Social Inclusion in a Global Context, New York: Department of Economic and Social Affairs, United Nations. Accessed on 8<sup>th</sup> April 2014

Wiseman Chijere Chirwa (2002), Social Exclusion and Inclusion: challenges to orphan care in Malawi, Nordic Journal of African Studies 11(1): 93-113, (2002)