CHAPTER VI

STIGMA, DISCRIMINATION AND SOCIAL EXCLUSION
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Stigmatised Groups, Discrimination and Social Exclusion

Stigma has ancient roots. The origins of the word can be traced to classical Greece where outcast groups were branded, or physically marked, as a permanent measure of their status. It has been described as a quality that ‘significantly discredits’ an individual in the eyes of others (Goffman, 1963). In other words, it also has important consequences for the way in which individuals come to see themselves. In general, stigma refers to a brand or mark that turns a person into a different one because of certain negative connotations. Crocker (1998) highlighted that stigmatised people have or believe to have some attributes that is depreciative in social contexts.

But it was Erving Goffman (1963) who introduced the concept of stigma, perhaps the most used until today in sociology. Drawing on his research with individuals who had experienced stigmatisation, including people with mental illness, physical deformities or socially ‘deviant’ behaviours, Goffman argued that the stigmatised individual is a person with a ‘spoiled identity’ who is ‘rendered unworthy’ in the eyes of others. According to him, stigma can be seen as a relationship between an attribute and a stereotype and is a reference to depreciative attributes, weaknesses or disadvantages (Goffman, 1963). In other words, the stigmatised person is considered as possessing a different characteristic from the ones which are accepted in the society and is treated differently by the community, who have misinterpretations and misbelieves about the stigmatised one.
Three types of stigma were distinguished in Goffman's studies: 1. body abomination (physical deformities), 2. individual character failings (false and rigid faiths, alcoholism, homosexuality, unemployment, addictions), 3. race, nation and religion (social groups). It is the second type of stigma that the persons with HIV/AIDS experience. Reingold (2001) further enlarged the types of stigma to five groups: behaviours (abuse of alcohol and drugs, homosexuality, sexual abuse), structural abnormalities (facial anomalies, abnormalities of skin pigmentation — vitiligo and albinism, corporal abnormalities — obesity), functional abnormalities (physical, motor, speech, vision, hearing, mental and others — epilepsy), contagious diseases (leprosy, AIDS, tuberculosis, sexually transmitted diseases), others (cancer). Under this scheme, we may understand that the stigma associated with HIV/AIDS falls into both behavioural as well as disease based stigmatisation. However, the stigma based on disease includes the sexually transmitted diseases which are also associated with a particular kind of social behaviour of an individual.

Importantly, stigmatisation is a process (Aggleton and Parker, 2002). The qualities to which stigma adheres (e.g. the colour of the skin, the way someone talks, the things that they do) can be quite arbitrary. Within a particular culture or setting, certain attributes are seized upon and defined by others as discreditable or unworthy. Stigmatisation, therefore, describes a process of devaluation rather than a thing (Aggleton and Parker, 2002:8).

As Aggleton (2000) suggest, 'when stigma is acted upon, the result is discrimination'. Discrimination consists of actions or omissions that are derived from stigma and directed towards those individuals who are stigmatised. UNAIDS (2000a) developed a protocol for the identification of discrimination against people with HIV/AIDS.
According to the protocol, discrimination refers to any form of distinction, exclusion or restriction affecting a person, usually, but not only, by virtue of an inherent personal characteristic or the perception of belonging to a particular group- in case of HIV and AIDS, a person’s confirmed or suspected HIV positive status, irrespective of whether or not there is any justification for these measures (UNAIDS, 2000a: 9). In this sense, “discrimination” is the treatment of an individual or group with partiality or prejudice. Thus, it is an act or behaviour (UNAIDS, 2002a; Reingold, 2001; Goffman, 1963). Discrimination tends to fall into two categories: (i) legislative, which reflects stigma, enacted in law or policy, and (ii) community, which reflects stigma in less formal contexts, such as the family, workplace or and social settings such as the local market place, sports centre or bar (Foreman et al., 2003).

HIV may be a biologically complex virus, but this complexity pales in comparison to the complexity of the social forces involved in the production and reproduction of stigma in relation to HIV/AIDS (WHO, 2002). However, factors related to stigma, discrimination and denial are poorly understood, and there have been few attempts made to understand this very complex problem. Each country has responded to the consequences of this epidemic in its own ways.

HIV/AIDS may be actual infection or based on behaviours believed to lead to infection. Moreover, stigma is an attribute used to set the affected persons apart from the normal group and this separation implies devaluation (Gilmore and Somerville, 1994). According to International Centre for Research on Women (ICRW, 2002), stigma is most frequently associated with diseases that have severe, disfiguring, incurable, and progressive outcomes, specially when modes of transmission are perceived to be under the control of
individual behaviour. It is also common in diseases that are perceived to result from the transgression of social norms, such as socially sanctioned sexual activity (Gilmore and Somerville, 1994).

Ignorance and fear are said to underlie HIV related stigma (ICRW, 2002). Discrimination may stem from fear due to lack of knowledge about how HIV/AIDS can or cannot be transmitted. Inadequate understanding of the modes of HIV transmission leads to fear of transmission from casual contact (ICRW, 2002). This fear, combined with a better understanding of the deadliness of the disease, can lead to physical and social ostracisation of people living with HIV/AIDS and other forms of discrimination.

**Multiple Contexts of Exclusion in terms of HIV/AIDS**

Stigma and discrimination may occur anywhere and everywhere. They occur in the family, community, schools, places of worship, workplace, and legal and health-care settings. People may discriminate, both in their personal and professional capacities, while systems and institutions can discriminate through their practices and policies. According to the ICMR Bulletin (2002), it is a depiction of life of an individual within the social and cultural milieu. In the context of HIV/AIDS, the stigma is associated with the devastating medical progression of opportunistic infection, moral transgression in the context of both homosexual and heterosexual relationships and afflictions transmitted through the notion of risky group as opposed to risky behaviour. These descriptions have led to the notions of “us” and “they”, where the latter are stigmatised through the values and attitudes based on moral judgments rather the medical aspects of the infection (ICMR Bulletin, 2002: 2).
HIV/AIDS-related stigma and discrimination take different forms and are manifested at different levels—societal, community and individual—and in different contexts (Malcolm et al., 1998). People living with the virus are frequently subjected to discrimination and human rights abuses such as banning entry of HIV infected individuals to isolating an individual in the family, deserting a pregnant wife on knowing her HIV status in the hospital, or removing a person from his job, or even denying a child admission into a school and some have even been killed (Mawar et al., 2005). Such fears of discrimination may deter individuals from being tested for HIV and from disclosing their seropositivity status to sexual partners, family, and friends.

**Individual Contexts**

As soon as an individual gets detected positive for the deadly virus, various questions start arising in the mind as whether to disclose to others the status of the disease, to whom to disclose, apprehensive about the other person’s reaction and his/her behaviour afterwards, etc. According to Hays et al., (1993), there are several consequences of disclosing the HIV status for the diseased individual like emotional support withdrawal, rejection and anger but research indicates that decisions about disclosure are also influenced by the perceived consequences to others. For example, some HIV positive individuals may refrain from informing their parents to prevent worrying about them rather than to avoid personal rejection. At the same time, the reason for not disclosing to family or friends was reportedly a feeling of shame and fear of rejection and discrimination (Manopaiboone et al., 1998).
Individuals with HIV and AIDS are stigmatised because their illness is associated with behaviours that are not acceptable socially, both as a product and producer of such behaviour. It is viewed as the responsibility of the individual, tainted by a religious belief as to its immorality (Alonzo and Reynolds, 1995). In contexts where HIV/AIDS is highly stigmatised, fear of HIV/AIDS-related stigma and discrimination may cause individuals to isolate themselves to the extent that they no longer feel part of civil society and are unable to gain access to the services and support they need (Daniel and Parker, 1993). This has been called internalised stigma. In extreme cases, this has led to premature death through suicide (Gilmore and Somerville, 1994). Even when laws exist to protect PLHA rights and confidentiality, few individuals are willing to litigate for fear that this will result in disclosure of their identity and HIV status. Given widespread negative community and family responses, many people choose not to know or reveal their serostatus (Parker and Aggleton, 2002).

Individuals who are already marginalised may be fearful of negative or hostile reactions from others, regardless of their serostatus (Daniel and Parker 1993), reflecting the interaction between HIV/AIDS-related and pre-existing sources of stigma and discrimination. Fear of telling the family about their homosexuality has been cited by HIV positive men in Mexico and Brazil as equal to the fear of revealing their serostatus (Parker and Aggleton, 2002). Similar fears have been reported from a range of countries by sex workers and injecting drug users (Castro et al., 1998). Even when the family response is positive, fear of stigmatisation and discrimination by the community may mean that an individual's serostatus is not revealed outside the home.
Family contexts

Family is the primary context in which illness occurs and, in most societies, it is also the context in which it is managed, and to some extent, treated as well (Ankrah, 1993). Thus, the family may play an important role in providing support and care for people living with HIV/AIDS. With the growing number of HIV/AIDS cases in the country, the health system is further burdened, tying up care and support roles even more firmly with the family. Even more crucial is the fact that family's responsibility in care giving is going to be long term, because of the prolonged 'living-dying interval' in HIV/AIDS (Bharat, 1995: 182). In a study by Pradhan and Sunder (2006), it was found that nearly 74 percent of the men and 70 percent of female PLHA have reported that their families are quite supportive. However, there is a gender gap in the family support. Compared with 1.9 percent of males, about 5.5 percent of females have been asked to leave home after being tested positive.

However, family response is not always positive and negative family responses are also common. Infected members of the family may find themselves stigmatised and discriminated against within the home. There is also mounting evidence that infected individuals often experience stigma and discrimination in the home (Bharat and Aggleton, 1999). Gender seems to be a strong determinant of the type of response one receives from the family: daughters, wives and daughters-in-law experience higher levels of discrimination than men (Bharat et al., 2001).

According to Bharat (1996), forms of discrimination against women with HIV included being refused shelter; being denied a share of household property; being denied access to treatment and care; and
being blamed for a husband’s HIV diagnosis, especially when the diagnosis was made soon after marriage. HIV-positive mothers have also reported separation from children or being forced to give up their babies (Bharat et al., 2001; ILO, 2003).

The women even though are not infected with HIV/AIDS were also found to be discriminated against by the neighbours as they provided physical assistance to the infected family members (Verma et al., 2002). Other factors influencing whether people received support included the quality of past familial relationships, age, economic and educational status, and the apparent or suspected source of infection. In many cases, HIV related stigma and discrimination has been extended to neighbours and friends of PLHA. This ‘secondary’ stigmatisation and discrimination has played an important role in creating and reinforcing social isolation of those affected by the epidemic, such as children and partners of PLHA (Parker and Aggleton, 2002).

Community Contexts

In India, as elsewhere, AIDS is often seen as “someone else’s problem” – as something that affects people living on the margins of society, whose lifestyles are considered immoral (Kumari, 2008). Even as it moves into the general population, the HIV epidemic is misunderstood and stigmatised among the Indian public. In many places, people living with HIV have faced various forms of stigma and discrimination. They have been rejected by families, spouses, communities and institutions like orphanage; in some reported cases, are denied the burial rites or space in the cemetery after death. For instance, local churches in Kerala denied customary burial to AIDS victims. In Kottayam district, where there has been a spurt of AIDS
cases in the last three years, once the church comes to know that AIDS is the cause of death, the body is not allowed into the cemetery. Priests don’t visit the victim’s house (The Times of India, April 27, 2005). In Kutch district of Gujarat, two minor boys – aged six and nine years, were thrown out from the Jeevan Prabhat Orphanage, an orphanage run by the local chapter of the Arya Samaj. Their crime – they were HIV positive. Ever since their admission to the orphanage, the two boys had been ailing and doctors advised an HIV test. When they tested positive, the Arya Samaj authorities refused to let them stay on the orphanage (The Hindustan Times, October 21, 2006). Justifying their action, the orphanage said that children aged from 4 to 16 years lived there. The others might get infected by the two boys and they just didn’t want to take a risk. Thus, HIV-related stigma and discrimination is deeply rooted, operating within the values of everyday life.

According to Mechanic (1995), the way in which individuals discover and disclose their HIV status to others as well as how they cope with their infection is influenced by cultural and community beliefs and values regarding causes of illness, learned patterns of response to illness, social and economic context, and social norms. Cultural systems that place greater emphasis on individualism, HIV/AIDS may be perceived as the result of personal irresponsibility, and thus individuals are blamed for contracting the infection (Kegeles et al., 1989). However, for Warwick et al., (1998), in societies where cultural systems place greater emphasis on collectivism, HIV/AIDS may be perceived as bringing shame on the family and community. Thus, the type of cultural system and where it fits along the continuum of individualism and collectivism will influence the ways in
which communities respond to HIV/AIDS and the ways in which stigma and discrimination are manifested (Brown et al., 2001).

Local cultural beliefs and explanations about disease and the causes of disease may also contribute to HIV/AIDS-related stigma and discrimination. For example, where illness is believed to be the result of "immoral" or "improper" behaviour, HIV/AIDS may reinforce pre-existing stigma of those whose behaviour is considered to be "deviant" (Warwick et al., 1998). HIV/AIDS related stigma and discrimination in families and communities is commonly manifested in the form of blame, scapegoating, and punishment. Communities often shun or gossip about those perceived to have HIV or AIDS. In more extreme cases, it has taken the form of violence (Nardi and Bolton, 1991).

**The Context of Health Care Systems**

As Gangakhedkar (1997) observes, in India, public health officials until recently held that women in prostitution, homosexuals, or intravenous drug users (IDUs) only could contract AIDS largely ignoring a dramatic rise in new AIDS cases among monogamous, married women. Even diseases like tuberculosis (TB) carry stigma as children with TB were not permitted to return to classes even after successful treatment due to misconceived notions, that they would still spread the disease to others (Gangakhedkar, 1997). The HIV/AIDS scenario appears to be even worse as this still remains an incurable disease. Thus, people living with HIV/AIDS are stigmatised and discriminated against by health care systems. Many reports reveal the extent to which people are stigmatised and discriminated against by health care systems. For instance, Chief Minister Mayawati suspended two doctors of Lala Lajpat Rai Medical College in Meerut where an HIV positive woman was denied institutional delivery by the
doctors. The father had to act as mid-wife on the verbal instructions of the doctors and delivered a baby boy in the labour room (*The Tribune*, June 30, 2007). In another incident, eleven year old Chavi (name changed), an HIV patient, went to Ram Manohar Lohia Hospital, Delhi, complaining abdominal pain. She was diagnosed with appendicitis but necessary surgery was not undertaken. Chavi was denied treatment due to her HIV status (*The Hindustan Times*, April 11, 2007) These shocking incidents involving the doctors of the college not only makes a mockery of the multi crore rupee AIDS awareness programme, but also shows that health care is denied to even those who try to access to it.

Negative attitudes from health care staff generate anxiety and fear among PLHA. Fear of discrimination may prevent people from seeking treatment for AIDS or from acknowledging their HIV status publicly. Consequently, many keep their serostatus secret, fearing still worse treatment from others (Bharat, 1996). It is not surprising that among a majority of HIV positive people, AIDS-related fear and anxiety, and at times denial of their HIV status, can be traced to traumatic experiences in health care settings (Bharat, 1996).

According to Bharat *et al.*, (2001), globally, discrimination in health care settings may be expressed in a variety of ways. The most commonly reported responses include: denial of access to care and treatment, reduced standard of care, HIV testing without consent, breaches of confidentiality including identifying someone as HIV positive to relatives and outside agencies, negative attitudes and degrading practices by health-care workers (Bharat *et al.*, 2001).
**Workplace Contexts**

Stigma in relation to HIV/AIDS clearly presents serious problems for people with HIV in the workplace. While HIV is not transmitted in the majority of workplace settings, the supposed risk of transmission has been used by numerous employers to terminate or refuse employment. There have been reports of workers refusing to work next to those with HIV or AIDS or those perceived to be PLHA (Williams and Ray, 1993). Schemes providing medical assistance and pensions to employees have come under increasing pressure in countries such as Zimbabwe, seriously affected by HIV/AIDS, and some companies have used this as a reason to deny employment to PLHA (Williams and Ray, 1993). In India, the Army has removed from service nearly one hundred of its personnel, infected with HIV/AIDS in the past two years. Though the government norms prevent any discrimination against those infected by the disease, the Army says it has no place for them (*The Indian Express*, December 31, 2005). Hira *et al.*, (1998) also reported that in India most businesses had no policy on AIDS and managements have adopted the wait and see attitude – waiting to see how many workers became infected and whether this had an impact on productivity.

There is also evidence that if people living with HIV/AIDS are open about their infection status at work, they may well experience stigmatisation and discrimination by others. Indeed, many asymptomatic individuals felt there was no need to reveal their status at work as long as they remained physically healthy (Bharat *et al.*, 2001). They mentioned fear of social discrimination and isolation, lowered prestige, and possible job loss as reasons for keeping their status secret. The ILO (2003) study noted that discrimination at the workplace could be higher than the reported 6.1 percent, considering
that many PLHA do not disclose their status for fear of losing their job. The study also found that HIV positive people are often compelled to leave their jobs on account of harassment such as denial of promotions, forced voluntary retirement, and ostracism by co-workers.

As Bharat et al., (2001) say, business and industry, by and large, do not have AIDS policies, and no special programmes are offered to workers with HIV. Pre-employment screening takes place in many industries, particularly in countries where the means for testing are easily available and affordable (Adeyemo and Oyinloye, 2007). In poorer countries screening has also been reported as taking place, especially in industries where health benefits are available to employees. According to William and Ray (1993), employer-sponsored insurance schemes providing medical care and pensions for their workers have come under increasing pressure in countries that have been seriously affected by HIV and AIDS. Some employers have used this pressure to deny employment to people with HIV or AIDS.

**Exclusion in Educational Settings**

An area of deep concern is the discrimination against children of school going age who have the right to education, but have been deprived of that right because of their HIV status. Children with HIV/AIDS or associated with HIV through infected family members are often stigmatised and discriminated against in educational settings in many countries (Parker and Aggleton, 2002). There have been instances where schools refused to admit children of HIV infected parents, or that the children were treated insensitively by teachers at the school. This stigma has led to teasing by classmates of HIV positive school children or children associated with HIV (Gilborn
In Kerala, two orphaned HIV positive siblings, Bency and Benson, were banished from their school in 2003, and then refused admission to other schools. Despite the efforts of the President of India and AIDS activists to dispel misconceptions about AIDS within the community, the children were forced to receive school lessons and write exams at home (Sridhar, 2003). In Mumbai, one HIV positive couple and one widow of a man who had AIDS was forced to withdraw their HIV-negative children from school (Bharat et al., 2001). No specific reasons were offered by the school management, and the affected parents were too afraid to pursue the matter – in one case, reluctant to expose/disclose their identity to others. In another incident, eleven year old Aksara and nine year old Anandu, residents of Kannur District of Kerala, had to fight several battles for their right to education. Citing their HIV status, the local Sree Narayana Mission School had expelled both from their school. A subject of ridicule and discrimination for almost two years, they fought their way to their school, opening many eyes (The Hindustan Times, May 5, 2006).

Discrimination against HIV positive children in the USA and Brazil, including exclusion from collective activities or expulsion from school, has led to non-discrimination legislation (Public Media Centre, 1995). However, less concern has been shown for young people who are perceived to be responsible for their HIV infection and who are already stigmatised and discriminated against because they are sexually active, homosexual, or drug users. In the USA, for example, HIV positive young gay men have been expelled from school and, in some cases, subjected to violence (Kirp et al., 1989). Thus, stigmatisation, discrimination, denial and exclusion have been recognised as important issues to be addressed in the context of HIV/AIDS.
In an Indian study, by Ambati et al., (1997) found that 36 percent of students, faculty and technical staff of the public health services felt it would be better if HIV positive individuals killed themselves and believed that infected people deserved their fate; 34 percent would not associate with people with AIDS; 42 percent believed that those with HIV should be quarantined; and, 31 percent favoured barring infected students from attending college classes. Thus, because of its association with behaviours that may be considered socially unacceptable by many people, HIV infection is widely stigmatised.

Negative responses and attitudes towards people living with HIV/AIDS (PLHA) are strongly linked to general levels of knowledge about AIDS and HIV and, in particular, to the causes of AIDS and routes of HIV transmission. Efforts to prevent new HIV infections and allowing people with HIV/AIDS to live without the burden of social exclusion are severely hampered by the persistence of stigma. There exists little or no research on how people with HIV/AIDS, or those suspected of having HIV/AIDS, are perceived and treated in Manipur because of their illness. It is quite evident from studies done elsewhere that people with HIV/AIDS are unfairly treated and are discriminated against because of their actual or suspected HIV/AIDS status.

Thus, the basic premise of this Chapter is that AIDS has certain socio-cultural notions of stigma emerging out of taboos and cultural practices relating to sexual behaviour, addiction to drugs, etc. Therefore, persons infected by HIV and AIDS are looked down upon as deviants, carry labels and therefore are excluded from the formal and informal settings. This Chapter provides the perceptions of the students on aspects of stigma and discrimination with respect to persons with HIV/AIDS. Attitudes relating to issues such as, whether
HIV positive students shall be allowed to attend college, their willingness to share a meal with an HIV positive person, the students' desire to keep secret when one of their family members infected with HIV, etc. are raised. Further, an attempt is made to describe a few case studies of HIV affected youth and their everyday experiences of stigma, discrimination and exclusion.

**Attitude of Students towards HIV/AIDS Patients**

The students are asked, "Do you know anyone who has HIV or died from AIDS? and, if they knew someone, "how are you related to the person who is infected?". Table 6.1 and table 6.2 show the distribution of students who knew the AIDS patients and their relationship with them. It may be observed that a majority (60.6 percent) of the students have reported that they personally knew someone who is infected with HIV or died from AIDS. Almost an equal proportion of men and women students mentioned that they knew someone who is infected with HIV or died from AIDS. These included persons from their neighbourhood or their own families or their relatives. A majority (78.7 percent) of these HIV/AIDS patients are from the students' community itself. It interesting to note that a few students (4.3 percent) revealed that the HIV/AIDS patient whom they knew is from their own family. However, they didn't know any student in their own college who is infected with the virus.

It is important to note here that students had known someone with AIDS within their family, community and relatives, even though they did not know the difference between HIV and AIDS. In the present study, only 38.7 percent of the students knew the difference between HIV and AIDS (see Chapter IV). Here, a majority (60.6 percent) reported that they knew someone who has HIV or have died
from AIDS. This reflects a serious gap in the way students are getting exposed to the disease and its effects on the general well being within the society. The study clearly brings out the need to address this gap through socialisation of students by adopting certain pedagogical interventions and also sensitisation programmes.

Further, to assess the attitude of students towards HIV infected persons and AIDS patients, the students are asked the question: "Should HIV positive students be allowed to attend the college or not?". Table 6.3 shows the distribution of students in this regard.
<table>
<thead>
<tr>
<th>Variables</th>
<th>Should HIV positive student be allowed to attend college?</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>78(97.5)</td>
<td>2(2.5)</td>
</tr>
<tr>
<td>Women</td>
<td>59(78.7)</td>
<td>16(21.3)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>137(88.4)</td>
<td>18(11.6)</td>
</tr>
<tr>
<td><strong>Place of residence</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rural</td>
<td>67(48.9)</td>
<td>17(94.4)</td>
</tr>
<tr>
<td>Urban</td>
<td>70(51.1)</td>
<td>1(5.6)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>137(100.0)</td>
<td>18(100.0)</td>
</tr>
<tr>
<td><strong>Category of students</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tribal</td>
<td>34(24.8)</td>
<td>17(94.4)</td>
</tr>
<tr>
<td>Meitei</td>
<td>103(75.2)</td>
<td>1(5.6)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>137(100.0)</td>
<td>18(100.0)</td>
</tr>
</tbody>
</table>

It is clear that a majority (88.4 percent) of the students are sympathetic towards HIV positive persons and are against isolating them from the everyday life. These students have a positive attitude towards HIV/AIDS patients and they reported that they wouldn’t have any problem when HIV positive students are allowed to attend the college. They expressed that HIV is not transmitted in sitting together, shaking hands with people with HIV or AIDS, casual contact such as sitting next to an infected person, gathering, touching each other, etc.
At the same time, there were a small number (11.6 percent) of students who expressed their fear that if the HIV positive students attend the college, the virus may spread to other uninfected students.

These findings could be related to the awareness of the students about the modes of HIV transmission (Chapter IV). An overwhelming majority of the students (89.6 percent) reported that they knew two or more than two correct modes of HIV transmission. Though small in proportion, but significant, nearly 10 percent of the students knew just one correct mode (8.4 percent) or nil (1.9 percent). Most of these students mentioned the transmission of HIV through sharing of infected syringes among the intravenous drug users.

Interestingly, there is significant difference between men and women students in their attitude towards the HIV/AIDS patients. More women than men students were against allowing the HIV positive students attending college. For instance, about 21.3 percent of the women students were against them are women while the corresponding figure for men is only 2.5 percent. Similarly, there are also differences in proportion in terms of place of residence and ethnicity. Table 6.3 shows these differences.

It may be observed that there is a significant difference in the proportion of students who didn't want HIV infected students to attend the college. For instance, out of those who didn't want HIV infected students to attend college, a majority (94.4 percent) are from the rural areas. This reflects the low level of awareness about the modes of HIV transmission among the rural students.

It is also clear that there are significant differences in the perception in terms of their ethnic backgrounds (tribal and non-tribal) with reference to those who wanted to allow HIV infected students to
attend college and those who didn’t want. For example, among those who wanted HIV infected students to attend the college, a majority (75.2 percent) belonged to Meitei community. However, among those who didn’t want HIV infected students attending college, a majority (94.4 percent) belonged to the tribal community. Thus, we may note that the proportion of Meitei students is more compared to the tribal students who are sympathetic towards HIV positive persons and are against isolating them from the society.

However, it is interesting to discuss some of the responses of the students. According to a tribal student, “they (HIV infected students) are the most dangerous to attend the college. We should not allow them to attend college in any condition, because the virus may spread to other uninfected students”. Another Meitei student argues, “why shouldn’t, they are also human beings. HIV is not transmitted to others when they attend the college. Those students who reported that HIV positive students should not attend college, might not know how the virus is transmitted from an infected to another uninfected person”. For yet another student, “I don’t have any problem when HIV positive students attend college. I know how HIV is transmitted and how it is not transmitted. But I do not have interest to interact with them”. Such responses from the students arise because of their lack of knowledge and awareness about HIV/AIDS and STDs, specially from those tribal and rural home backgrounds whose educational levels are found to be lower than that of the urban and Meitei family backgrounds.

The students are asked, “Would you be willing to share a meal with an HIV infected person or not?” (Table 6.4). Interestingly, an overwhelming majority (83.2 percent) of the students expressed their willingness to share a meal with an HIV positive person or AIDS
patient. A small number of students even reported that they have shared meals with HIV positive person. But a few who have expressed their willingness to share a meal mentioned that the person should be known to them, otherwise they are unwilling to share a meal with HIV/AIDS patients. For instance, according to a women student, “I know how HIV is transmitted and how it is not transmitted. So, I don’t have any problem in sharing a meal with an HIV positive person or AIDS patient. But he/she should be a known person to me. Otherwise, I wouldn’t share. With strangers, I feel uncomfortable in sharing a meal. This is not related to his/her HIV status at all”. This perception may be in line with the general apathy shown by individuals to interact with those who are complete strangers in an interactive situation. Thus, it is not surprising that some students do not want to share a meal if the HIV/AIDS infected person is not known to them.

Further, interestingly, there is a small proportion of students who expressed their unwillingness to share a meal in fear of the virus. It may be noted from the table 6.4 that about 16.8 percent of the students did not want to share a meal with HIV positive person. Again, more men than women students expressed their willingness to share a meal with HIV infected or AIDS patient. Further, more women than men students expressed their unwillingness to share a meal. For instance, about 92.5 percent of the men students expressed their willingness to share the meal and the corresponding figure for women is 73.3 percent.

It is also found that there is no significant difference in proportion of students coming from rural and urban areas in terms of their willingness to share a meal with an HIV infected or AIDS patient.
However, there are significant differences in terms of those who expressed their unwillingness to share the meal. Out of those who expressed their unwillingness in sharing a meal, a majority (76.9 percent) are from the rural areas. Similarly, it is also clear that those who have expressed their willingness to share a meal with HIV infected or AIDS patients, a majority (76.7 percent) are Meiteis. However, those who expressed their unwillingness to share a meal, a majority (80.8 percent) are tribal students. According to many Meitei students, HIV is not transmitted by sharing a meal, drinking water or eating food from

Table 6.4: Are you willing to share a meal with an HIV positive person?

<table>
<thead>
<tr>
<th>Variables</th>
<th>Are you willing to share a meal with an HIV positive person?</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>74(92.5)</td>
<td>6(7.5)</td>
</tr>
<tr>
<td>Women</td>
<td>55(73.3)</td>
<td>20(26.7)</td>
</tr>
<tr>
<td>Total</td>
<td>129(83.2)</td>
<td>26(16.8)</td>
</tr>
<tr>
<td>Place of residence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rural</td>
<td>64(49.6)</td>
<td>20(76.9)</td>
</tr>
<tr>
<td>Urban</td>
<td>65(50.4)</td>
<td>6(23.1)</td>
</tr>
<tr>
<td>Total</td>
<td>129(100.0)</td>
<td>26(100.0)</td>
</tr>
<tr>
<td>Category of students</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tribal</td>
<td>30(23.3)</td>
<td>21(80.8)</td>
</tr>
<tr>
<td>Meitei</td>
<td>99(76.7)</td>
<td>5(19.2)</td>
</tr>
<tr>
<td>Total</td>
<td>129(100.0)</td>
<td>26(100.0)</td>
</tr>
</tbody>
</table>
the same utensil used by an infected person, casual contact, etc. All these could be related to the lower level of awareness about the ways of HIV transmission among the rural as well as tribal students. In the present study, it is found that about 10.3 percent of the students knew only one correct mode or didn't know other modes of HIV transmission. Almost all these students are either from rural or tribal backgrounds (Chapter IV).

**Stigma attached to the disease**

In order to examine the stigma attached to HIV/AIDS, the students are asked if a member of their family got infected with HIV, would they want to keep it a secret without revealing it to others. Table 6.5 shows the responses of students in terms gender, place of residence and ethnicity. Surprisingly, an overwhelming proportion (93.5 percent) of students expressed that they would not keep it a secret when one of their family members is infected with HIV. The students reported that keeping it as a secret wouldn't bring any good to the family. This would help in further spread of the virus to other uninfected persons. Some of them even explained by giving examples the harm of keeping it a secret. For instance, a Meitei women student said, "If my brother/sister gets infected with the virus and tries to keep it a secret, this may result in long lasting adverse consequences. My brother/sister will get married someday. If he/she keeps it without revealing his/her HIV status to his/her partner, the virus will be transmitted to his/her partner, then to their children. So, what is the need of keeping it a secret". Another student reported, "HIV positive people need social support, encouragement and wishes to remain healthy, good thinking so that their lives may extend for atleast few
Table 6.5: Do you want to keep it a secret when a member of the family gets infected with HIV?

<table>
<thead>
<tr>
<th>Variables</th>
<th>Do you want to keep it a secret when a member of the family gets infected with HIV?</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>8(10.0)</td>
<td>72(90.0)</td>
</tr>
<tr>
<td>Women</td>
<td>1(1.3)</td>
<td>73(97.3)</td>
</tr>
<tr>
<td>Total</td>
<td>9(5.8)</td>
<td>145(93.5)</td>
</tr>
<tr>
<td>Place of residence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rural</td>
<td>1(11.1)</td>
<td>82(56.6)</td>
</tr>
<tr>
<td>Urban</td>
<td>8(88.9)</td>
<td>63(43.4)</td>
</tr>
<tr>
<td>Total</td>
<td>9(100.0)</td>
<td>145(100.0)</td>
</tr>
<tr>
<td>Category of students</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tribal</td>
<td>2(22.2)</td>
<td>48(33.1)</td>
</tr>
<tr>
<td>Meitei</td>
<td>7(77.8)</td>
<td>97(66.9)</td>
</tr>
<tr>
<td>Total</td>
<td>9(100.0)</td>
<td>145(100.0)</td>
</tr>
</tbody>
</table>

more years. By keeping it a secret without letting others know may help in the further spread of the virus to other persons who didn’t know that the family member is HIV positive. The family member who is HIV positive may donate blood to somebody”.

Further, it is found that a few (5.8 percent) of the students expressed their desire to keep it a secret when any of their family members get infected with the AIDS virus. This group of students reported that the people infected with HIV are looked down with hatred and the family is ostracised sometimes from the
neighbourhood. It is due to the fear of loss and rejection, they expressed that it is better not to reveal the infection to anybody. It will be interesting to discuss here a few responses of the students. A tribal woman student narrated some incidents that were happening in her village.

"When a person becomes infected with the virus and if other villagers come to know about this, they would inform the village chief/head. The village chief/head would call up the head of the family where the HIV infected person lives. He would advise the head of the family not to keep the HIV positive member in their family or in the village. If the head of the family fails to follow the village chief/head's advice, the family has to face many consequences like social boycott of the family in the village. At the same time, if a person or family show sympathy to the affected family by continuing the normal ties, that person or family also may face the same fate".

Thus, this example clearly presents how the stigma, discrimination and exclusion take place in the case of individuals, families and the communities in a traditional social setting.

It is also observed from the table 6.5 that genderwise, there is not much significant difference except that almost all the women students reported that they wouldn't keep it a secret when one of their family members get infected with the virus. More men than women students reported that they didn't want to reveal to others when one of their family members get infected with the AIDS virus. They expressed that it is better to keep it a secret instead of facing the societal stigma and discrimination.
Furthermore, it is found that among those who want to keep it a secret, urban students (88.9 percent) are more than those from rural areas (11.1 percent). This finding is contradictory from the general belief that urban people have better knowledge about HIV/AIDS than rural people and that the stigma and discrimination related to HIV/AIDS arises because of low awareness of HIV/AIDS among the general people. So, stigma and discrimination is higher among rural people where there is low level of awareness of HIV/AIDS. However, it may be noted that there are no significant differences in the proportion of students from Meitei and tribal communities who want to keep HIV infection a secret when one of their family members get infected with the virus.

Thus, the responses of a small proportion of students who want to keep it a secret when one of their family members gets infected with HIV are relevant. It is the HIV patients themselves who do not want to reveal their status of infection to anybody because of fear of loss of prestige to himself/herself as well as that of the family. Interview with a few HIV infected persons during the fieldwork, makes this amply clear. For instance, according to one HIV positive person:

"Before I got infected with the AIDS virus I had seen how other people think about the HIV patients and how they try to avoid them. So, I don't want to reveal my HIV status to anybody, even to all of my family members.......Only when people become aware of the important aspects of the HIV/AIDS I would like to reveal my HIV status to others, otherwise it is better to die in this situation without revealing".
For another HIV positive person:

"...Nobody will come near me, eat/share with me in the hotel, nobody will want to work with me, I will be an outcast there if once I reveal my HIV status to others. I have seen people change when they interact with HIV positive or AIDS patients. All these are happening because many people don't know how HIV is not transmitted and how it spreads from one person to another".

For yet another HIV positive IDU:

"...I went for treatment at a hospital in the beginning. Then, I stopped. I sometimes felt that government hospital(s) discriminate (against) drug users ... and use bad language ...If my illness was not severe I treated (myself) at home, specially when I have abscess due to drug injecting. But when the abscess is not cured easily...I went to Community Care Centres for treatment. Latter I came to think, it was better not to go to the hospital and reveal my HIV positive status there..."

Thus, there are evidences of stigma and discrimination against HIV positive patients.

**Personal Experiences of HIV/AIDS Patients: Case Studies**

The following section furnishes the accounts of three HIV/AIDS infected persons, representing different social backgrounds, in order to know more about the multiple contexts of HIV/AIDS related stigma and discrimination. Of the three HIV positive persons, one is a man
and two are women. All the names mentioned here are changed to protect the identity of the persons.

**Case 1: Ibosana**

Ibosana, 30 year old, Meitei, unmarried, is the only child to his parents. His father was a medical attendant in a hospital. Ibosana stayed in the school boarding during his school days. He started using drugs since his school days under the pressure of two of his friends. For quite sometime the school authorities didn’t know about their behaviour. But in due course, they became suspicious of their behaviour. It was during his class X, one day, the Principal caught him along with one of his friends while taking CalmPose tablets. The Principal expelled both of them the next day from the boarding as well as from the school.

After expel from the school, Ibosana was at home without studying for about one year. During 1992-93, he along with two others, one from his neighbourhood and the other his uncle’s son, started consuming drugs. After almost one year, they started consuming drugs by injection along with some elders who had been injecting for long before. One of the elders died a year latter. Ibosana continued injecting drugs for almost three years. His father sent him to Delhi for studying a language course. There he didn’t use any drugs. But within a few months, he came back home after falling sick for three months. His father, being a medical attendant, took blood samples from him for testing. But his father didn’t tell him the result. He came to know about that one day at night when his father told his mother that Ibosana is HIV positive. After that also, Ibosana ignored and went for life as usual. He also didn’t have knowledge about the implications of HIV at that time.
Ibosana went to Lucknow for studying some courses. But shortly, due to some problems, he had to come back from there. He came to Delhi, stayed with a relative who works in a private organisation. There, he helped him in his work and he gave him some amount of money in return. With that money he started buying drugs but not the injecting ones. After few months, the relative had to shift his work from there to some other state. After his departure, he started looking for jobs to earn money for buying drugs. He worked as an attendant in a PCO and the small amount got that he got from there, he used it in buying drugs.

While working at a PCO in Delhi, Ibosana fell sick for sometime with similar symptoms which he had earlier. He went on his own to All India Institute of Medical Sciences (AIIMS) for consulting with doctors. There the doctor tested his blood and latter informed him about his infection. Ibosana wept that whole night. At that time he was well aware of the implications of HIV. According to him, though many NGOs under Manipur State Control Society (MACS) do hold programmes/camps to bring awareness, the awareness level is low among the drug users. Many still share syringes without sterilisation. Today, Ibosana doesn’t know the exact stage of his infection though he knows he is HIV positive. But he is sure that he doesn’t have AIDS as yet. AIDS is the last stage, he declared with confidence.

Ibosana had faced discrimination only once, that also, from one of his relatives. It happened during having food together. The relative was unwilling to share food with him. Whatever utensils he used the relative didn’t touch/use. However, people in his locality, though they knew he is HIV positive, behaved as usual. He thinks that why he should hide his HIV status to others. He is getting for what he had done. Today, Ibosana wants to live on his own. If he gains his health
as normal, he would like to work for the cause of HIV/AIDS, to make youth aware about HIV/AIDS particularly among the drug users. His message/advice to youngsters, “intoxicants have been there from ancient times and will remain in future also. We cannot stop or abolish. Once you start using intoxicants, one day you will become the servant of the intoxicant. So always avoid or stay far away from these substances”.

**Case 2: Reena**

Reena, Meitei, 28 year old, Class XII pass out, came to know about her infection four years back and continues to live life to the full. When she feels weak, she goes to a Community Care Centre, meet doctors and sometimes stay there for 1-2 weeks.

Reena married her boyfriend; abandoning her graduation course mid-way, knowingly that he is a drug user, much against the wishes of her parents. She met him when she was doing her second year of graduation at Imphal. At that time, she thought that as the boy came from a rich family, she would have a happy married life in the city. However, everything went against her wishes. Her husband was an HIV positive and died from HIV-Hepatitis C co-infection in May 2002. Thus, the young widow came back to her parental home. Her family did not have much awareness about HIV/AIDS at that time. In her locality also, most of the people were not aware of the HIV/AIDS and, therefore, did not treat her differently. Now, as more information is available, there is also misinformation. Stigma and discrimination continues to increase as more people become aware of HIV/AIDS. It is really important to spread the right kind of information about HIV, Reena expressed.
Reena had faced discrimination of being a HIV positive patient. After the death of her husband everyone in her husband’s locality avoided her and started looking down on her. That was the most difficult period of her life. Living in those unsympathetic surroundings, Reena did not have the courage to undergo testing for HIV on herself for two and a half years after the death of her husband.

From the parental home, one day she went to a hospital at Imphal for a routine medical check up and was made to wait for hours because the hospital staff was scared to test her. But she knew her rights and was able to assert herself, so they carried out her medical examination. Since that day, she stopped going for routine medical check up to hospitals. Reena met women who are forced to leave their own homes, and live apart, eating and drinking alone.

Joining the Community Care Centre has made a big difference to Reena’s life. Here, she was able to get counselling as well as begin her treatment. She now works for the Centre as a Counselor and believes that she has much to accomplish. Reena’s message to the people is “HIV positive people are part of the society and should not be discriminated against. It is just a medical condition. You cannot get HIV if an HIV positive person touches you, hugs you or eats or drinks with you. The young girls should be aware, what HIV means and how it is acquired. Only then they can protect themselves from getting infected”.

Case 3: Elizabeth

Elizabeth, 33 year old tribal woman, was infected with HIV through her husband. Before that, life was full of cheer and good spirits. Sometimes, Elizabeth felt depressed as the infection was passed on to her by her husband, a Contractor by profession. At
present she is staying in a Community Care Centre along with her husband and daughter, Rosy who is also HIV positive.

Her husband had asked Elizabeth to keep his illness (HIV status) a secret without revealing to others even to other family members. But in due course when she also fell sick, many people started asking her about the causes of their health condition. With her husband, she went to a district hospital for HIV test and found that she was also infected with the virus. They went to a hospital at Imphal for the test again which confirmed her positive status. This was in 1999. The situation then was different, since not many people had heard of HIV/AIDS. She too was unaware of it. The doctor called her husband and informed him that she would die within one year. Elizabeth never questioned her husband on this issue. She was sure if her husband had information about HIV and its spread, he would have never done this to her.

At the beginning of their infection nobody in their locality had correct information about HIV/AIDS as well as nobody knew about their HIV infection. So they remained away for few years from the different forms of stigma and discrimination which are faced by other HIV infected people. Elizabeth received lots of support from her family at the initial years of infection. Today, Elizabeth had heard people saying their children can not go to their house, not to be near other children and play with other children. Their family started avoiding them. Finally, they left their home and have been staying in a rented room away from their home where they are not disclosing their HIV status till today. Whenever anyone of them- herself, husband or daughter become sick and weak, they used to come together to the Community Care Centre and stay for sometime. Elizabeth believes that HIV/AIDS is just another disease. Lack of correct information
helps in further spread of the virus and leads to stigma and discrimination.

From the above three case studies, it is revealed that HIV/AIDS stigma, discrimination and exclusion is strongly associated with the awareness level of the disease itself among the people. People heard of HIV/AIDS but it includes misinformation as well. Lack of correct information, like 'IDUs and sexual workers are the only people who can get infected with HIV', 'HIV/AIDS once infected, the person would die soon', etc. increase the stigmatisation and discrimination. HIV/AIDS-related stigma and discrimination take different forms and are manifested in different contexts. Family responses to infected members are also influenced by community awareness of the disease. Families that include an individual with HIV fear isolation and ostracism within the community.

To summarise, while a majority of the students are sympathetic towards HIV positive persons and are against isolating them from the everyday life in the society, there are a few students who expressed their fear that if the HIV positive students attend the college, the virus may spread to other uninfected students. There are also differences in attitudes of students in terms of gender, ethnicity and place of residence. Similarly, while, a majority of the students expressed their willingness to share a meal with an HIV positive person or AIDS patient, a few have reported that they would do so only if the person is known to them. More importantly, a small proportion of students expressed their unwillingness to share a meal in fear of contracting the virus. Surprisingly, almost all students expressed that they would not keep it a secret when one of their family member gets infected with the AIDS virus for various reasons. For some, keeping it a secret may further spread the virus to other uninfected persons. But, when
it comes to the everyday life experiences of the HIV/AIDS affected, there has been a definite evidence that once the general public know of the HIV/AIDS status, they discriminate and treat them with apathy, indifference and contempt.

The next Chapter is the summary of the findings and conclusions of the study.