Chapter 7

Issues and Challenges of HIV/AIDS:
A Case Study of the State of Gujarat

7.0 Introduction

More than thirty years after the first clinical evidence of acquired immunodeficiency syndrome was reported, AIDS has become one of the most devastating diseases humankind has ever faced. Since the epidemic began, more than 60 million people have been infected with the virus and nearly 30 million people have died of HIV-related causes. AIDS has become the sixth-largest cause of death worldwide.

At the end of 2009, an estimated 33.3 million people globally were living with HIV. In that year alone, there were an estimated 1.8 million AIDS-related deaths and 2.6 million new HIV infections. Data from 2009 shows that the AIDS epidemic is beginning to change course as the number of people newly infected with HIV is declining and AIDS-related deaths are decreasing. This is in large part due to more people living longer as access to antiretroviral therapy increases, but these gains remain fragile and disparities continue to exist among countries and within countries. Sub-Saharan Africa continues to be the region most affected with 69% of all new infections and in seven mostly Eastern European and Central Asian countries, new HIV infection rates have increased by 25%. Furthermore, 90% of governments reported that they address stigma and discrimination in their HIV programmes, however, less than 50% costed of budgeted such programmes. Vulnerability to HIV linked to a number of human rights challenges remains a concern (see the 2010 Global Report on the AIDS Epidemic (UNAIDS)).
7.1 What do Human Rights have to do with HIV and AIDS?

Human rights are inextricably linked with the spread and impact of HIV on individuals and communities around the world. A lack of respect for human rights fuels the spread and exacerbates the impact of the disease, while at the same time HIV undermines progress in the realisation of human rights. This link is apparent in the disproportionate incidence and spread of the disease among certain groups which, depending on the nature of the epidemic and the prevailing social, legal and economic conditions, include women and children, and particularly those living in poverty. It is also apparent in the fact that the overwhelming burden of the epidemic today is borne by developing countries, where the disease threatens to reverse vital achievements in human development. AIDS and poverty are now mutually reinforcing negative forces in many developing countries.

7.2 The relationship between HIV/AIDS and Human Rights is highlighted in three areas

Increased vulnerability: Certain groups are more vulnerable to contracting the HIV virus because they are unable to realize their civil, political, economic, social and cultural rights. For example, individuals who are denied the right to freedom of association and access to information may be precluded from discussing issues related to HIV, participating in AIDS service organizations and self-help groups, and taking other preventive measures to protect themselves from HIV infection. Women, and particularly young women, are more vulnerable to infection if they lack of access to information, education and services necessary to ensure sexual and reproductive health and prevention of infection. The unequal status of women in the community also means that their capacity to negotiate in the context of sexual activity is severely undermined. People living in poverty often are unable to access HIV care and treatment, including antiretrovirals and other medications for opportunistic infections.
Discrimination and stigma: The rights of people living with HIV often are violated because of their presumed or known HIV status, causing them to suffer both the burden of the disease and the consequential loss of other rights. Stigmatisation and discrimination may obstruct their access to treatment and may affect their employment, housing and other rights. This, in turn, contributes to the vulnerability of others to infection, since HIV-related stigma and discrimination discourages individuals infected with and affected by HIV from contacting health and social services. The result is that those most needing information, education and counselling will not benefit even where such services are available.

Impedes an effective response: Strategies to address the epidemic are hampered in an environment where human rights are not respected. For example, discrimination against and stigmatization of vulnerable groups such as injecting drug users, sex workers, and men who have sex with men drives these communities underground. This inhibits the ability to reach these populations with prevention efforts, and thus increases their vulnerability to HIV. Likewise, the failure to provide access to education and information about HIV, or treatment, and care and support services further fuels the AIDS epidemic. These elements are essential components of an effective response to AIDS, which is hampered if these rights are not respected.

7.3 What is a Human Rights approach to HIV and AIDS?

Where individuals and communities are able to realize their rights - to education, free association, information and, most importantly, non-discrimination - the personal and societal impacts of HIV and AIDS are reduced. Where an open and supportive environment exists for those infected with HIV; where they are protected from discrimination, treated with dignity, and provided with access to treatment, care and support; and where AIDS is de-stigmatized; individuals are more likely to seek testing in order to know their status. In turn, those people who are HIV positive may deal with
their status more effectively, by seeking and receiving treatment and psychosocial support, and by taking measures to prevent transmission to others, thus reducing the impact of HIV on themselves and on others in society.

The protection and promotion of human rights are therefore essential in preventing the spread of HIV and to mitigating the social and economic impact of the pandemic. The reasons for this are threefold. First the promotion and protection of human rights reduces vulnerability to HIV infection by addressing its root causes. The adverse impact on those infected and affected by HIV is lessened. Third individuals and communities have greater ability to respond to the pandemic. An effective international response to the pandemic therefore must be grounded in respect for all civil, cultural, economic, political, economic and social rights and the right to development, in accordance with international human rights standards, norms and principles.

States' obligations to promote and protect HIV-related human rights are defined in existing international treaties. HIV/AIDS-related human rights include the right to life; the right to liberty and security of the person; the right to the highest attainable standard of mental and physical health; the right to non-discrimination, equal protection and equality before the law; the right to freedom of movement; the right to seek and enjoy asylum; the right to privacy; the right to freedom of expression and opinion and the right to freely receive and impart information; the right to freedom of association; the right to marry and found a family; the right to work; the right to equal access to education; the right to an adequate standard of living; the right to social security, assistance and welfare; the right to share in scientific advancement and its benefits; the right to participate in public and cultural life; and the right to be free from torture and other cruel, inhuman or degrading treatment or punishment.
The United Nations human rights instruments and mechanisms provide the normative legal framework as well as the necessary tools for ensuring the implementation of HIV-related rights. Through their consideration of States reports, concluding observations and recommendations, and general comments, the UN treaty monitoring bodies provide States with direction and assistance in the implementation of HIV-related rights. The Special Procedures of the Human Rights Council, including special representatives, thematic and country rapporteurs, and working groups also are in a position to monitor respect for HIV-related rights. The Human Rights Council also requests the Secretary-General to solicit comments from Governments, United Nations bodies, programmes and specialized agencies and international and NGOs on steps they have taken to promote and implement, where applicable, programmes to address the urgent HIV-related human rights of women, children and vulnerable groups in the context of prevention, care and access to treatment.\textsuperscript{[1]}

7.4 Social and legal issues:

Employment\textsuperscript{[2]}

Information about employment law and the Equality Act, with suggestions on dealing with workplace issues that people with HIV may face.

Anti-discrimination legislation\textsuperscript{[3]}

How the Equality Act protects people with HIV against discrimination when using businesses and services, including health care.

Housing\textsuperscript{[4]}

Advice on housing issues for people with HIV, including homelessness, social housing and harassment from neighbours.

Personal finance\textsuperscript{[5]}

Information on insurance, mortgages, pensions and savings for people living with HIV in the UK.
Making a will[6]
Why it’s important to have a will and how to prepare one.

Travel[7]
Information on travel restrictions, travelling with medication, vaccinations, travel insurance and obtaining health care abroad.

Immigration and asylum[8]
An overview of immigration law and the asylum process as it may affect people with HIV.

Access to health care[9]
Information on the provision of NHS health care to non-UK citizens.

Transmission of HIV as a criminal offence[10]
Information about policing and prosecutions of HIV transmission.

Powers to regulate people with HIV[11]
Information about judicial orders given to individuals who have an infection and are putting others at risk.

Confidentiality[12]
Information about the law of confidentiality, both in medical and non-medical settings.

Consent to HIV tests and treatment[13]
The right to refuse medical tests and treatment, and how this applies to adults without mental capacity, pregnant women, children and young people.

End-of-life issues[14]
Information about delegating decisions, declaring future treatment wishes and financial planning, as well as formalities after a death.

Prisoners
How health care is provided in prison and which HIV prevention materials can be supplied
7.5  **HIV/AIDS and Stigma to interesting facts**

7.5.1  **Introduction**

Stigma is a common human reaction to disease. Throughout history many diseases have carried considerable stigma, including leprosy, tuberculosis, cancer, mental illness, and many sexually transmitted diseases. HIV/AIDS is only the latest disease to be stigmatized.\[15\]

Understanding the concept of stigmatization

Goffman\[2\] defines stigma, in general, as an undesirable or discrediting attribute that an individual possesses, thus reducing that individual's status in the eyes of society.\[16\] Stigma can result from a particular characteristic, such as a physical deformity, or it can stem from negative attitudes toward the behaviour of a group, such as homosexuals or commercial sex workers. Herek and Mitnick\[17\] brings us closer to our topic of discussion when they define AIDS-related stigma as prejudice, discounting, discrediting and discrimination directed at people perceived to have AIDS or being infected with HIV and at the individuals, groups and communities with which they are associated.

Stigma is such a very powerful force that it will persist despite protective legislation or even disclosures by well-known public figures that they have AIDS or are infected with HIV.

7.5.2  **Why do people manifest stigma towards people living with HIV or AIDS (PLHA)?**

Sources of stigma include fear of illness, fear of contagion, and fear of death. Fear of illness and fear of contagion is a common reaction among health
workers, co-workers, and caregivers, as well as the general population. Stigma is one means of coping with the fear that contact with a member of an affected group (e.g. by caring for or sharing utensils with a PLHA) will result in contracting the disease.\cite{18}

HIV-stigma is often layered on top of many other stigmas associated with such specific groups as homosexuals and commercial sex workers and such behaviours as drug abuse by using needles and casual sex. These behaviours are perceived as controllable and are therefore assigned more blame, receive less sympathy, but instead, more anger and are less likely to receive assistance as opposed to people with AIDS who were infected through circumstances where there was no control, such as receiving a blood transfusion.

### 7.6 Effects of stigma

Consequences of stigma can be viewed along a continuum from mild reactions (e.g., silence and denial), to ostracism and ultimately violence.

The way in which individuals discover and disclose their HIV status to others, as well as how they cope with their HIV status, is influenced by cultural and community beliefs and values regarding causes of illness, learned patterns of response to illness, social and economic contexts, and social norms. However, whatever the form of stigmatization, it inflicts suffering on people and interferes with attempts to fight the AIDS epidemic. In this regard research has found that not knowing one's HIV status is far preferable to being tested. The fear is that the lack of confidentiality, which is highly likely in many settings, forces disclosure and that individuals can then face prejudice, discrimination, the loss of a job, strains on or the break-up of relationships, social ostracism, or violence\cite{6}. By displaying this kind of behaviour the transmitting of the virus can continue. A more recent study (May 2004) completed by Dr. Ben Olley\cite{7}, concluded that HIV/AIDS is usually associated with high rates of psychiatric and emotional problems. This research has found that these problems contribute to people not sticking to their drug regiments. It can even speed up the progression of the disease and hasten the death of a patient.\cite{19}
7.7 Women and stigma

The impact of HIV/AIDS on women is particularly acute. Especially in Africa, women are often economically, culturally and socially disadvantaged and will lack equal access to treatment, financial support and education. It has even been found that in a number of societies women are mistakenly perceived as the main transmitters of sexually transmitted diseases. HIV positive women are treated very different from men in many developing countries: men are likely to be 'excused' for their behaviour that resulted in their infection, whereas women are not. Women in the developing world face more stigmatization and suffer more negative effects than men. In the study of Olley, previously mentioned, 149 (44 male and 105 female) newly diagnosed HIV/AIDS patients in Tygerberg hospital, South Africa, were assessed. The most frequent diagnosis was depression (34,9%) followed by dysthymic disorder (21,5%). Women were more likely to suffer from post-traumatic stress disorder, while male patients were significantly more likely to abuse alcohol and have more protected sex. [20]

7.8 Employment

Unfortunately the risk of transmission has been used by numerous employers to terminate or refuse employment. It has also been found that if PLHA are open about their status at work, they may well experience stigmatization and discrimination by fellow employees. In developing countries some instances of compulsory pre-employment testing took place; some of these industries have used the information to deny employment to people with HIV or AIDS. [21]

7.9 What can be done to lessen stigma?

It has become just as important to combat the stigma as it is to develop medical cures to prevent or control the spread of HIV. Changing attitudes are not that easy. Eliminating stigma completely remains at this stage only a dream, but an overview of the
main research does suggest that something can be done through a variety of interventions, such as focussed information dissemination, counselling, coping skills acquisition and direct contact with someone that is living with HIV or AIDS. Some of the interventions are: People living with HIV/AIDS need to be educated on their basic human rights; These rights will enable them to enforce it through the legal process; In order to mitigate the effects of discrimination and stigma, institutions should implement their HIV/AIDS policies based on sound information and taking into account the rights of everybody; and HIV negative people need to be educated too, in order to create an environment free of fear of HIV biased social attitudes and no stereotypes towards HIV.[22]

7.10 Stigma and Discrimination

Over the past two decades, HIV has emerged from an unknown virus, to a pandemic of astronomical proportions. Millions of people worldwide have already succumbed to this virus and millions more lives have been disrupted because of the pain and suffering of loved ones. Today there are approximately 40.3 million people living with HIV/AIDS and the number looks set to only rise. Entire societies will be feeling the effects of the pandemic for decades to come, most notably in Sub-Saharan Africa where the epidemic is most advanced. The virus itself is relatively difficult to contract when compared to others such as Influenza, but a myriad mix of social issues has allowed the virus to gain a major foothold in every nation around the world. The immense nature of this epidemic has led to mass fear and hysteria and many misconceptions of the virus. This has led to stigma and discrimination of those infected around the world as people seek to explain what they do not understand. Unfortunately, this only hinders the fight against the global pandemic and actually makes populations more vulnerable to infection. In order to effectively combat HIV/AIDS around the world, stigma and discrimination must be adequately addressed.[23]
7.10.1 What is stigma and discrimination?

People living with HIV are often believed (and led to believe) to deserve their status as a result of their doing something inherently wrong. By so alienating and laying blame on others who are somehow different, people can somehow remove themselves from any risk and not confront the issue for the problem that it is. Stigma and discrimination is caused by a lack of understanding of HIV, how it is spread, lack of access to treatment, irresponsible media coverage of the epidemic, the fact that AIDS has no cure, and already existing prejudices related to sexuality, disease, drug use, and death.\(^{[24]}\)

Discrimination results when stigmatization is acted upon and can take many forms such as:

- Lack of access to equal health care
- Denial of equal opportunities for employment
- Denial of education to HIV positive children
- Detention of HIV infected persons

How does stigma and discrimination fuel the epidemic?

Preventing people from coming forward and getting tested

- “Internalized Stigma”
  - People with HIV can self-stigmatize themselves due to their own views on infected individuals as they seek to adjust to their new status
  - This can especially occur in already stigmatized groups such as men who have sex with men (MSM), sex workers, injecting drug users and migrants\(^{[25]}\)

People who do not know they are HIV positive can in no way use this knowledge to plan for their future.
Do not seek treatment until they begin showing symptoms of AIDS-related illnesses, by which time it may be too late to effectively begin anti-retroviral treatment.

Use knowledge of their HIV infection to protect their family members from infection or plan for their family's economic future after they have passed on.

Leaving AIDS orphans

Low perception of individual risk

Individuals do not see themselves at risk for contracting HIV because they do not belong to one of the stereotypically stigmatized groups (UNAIDS.org)

**Preventing people from disclosing their own status**

Individuals who know they are infected may not wish to disclose this information for fear of the stigma and discrimination that may follow. This does not always only occur to them, but also to others simply associated with them such as family members.

**Denial**

Denial goes hand in hand with discrimination. If one does not see themselves at risk, or see the potential for the epidemic to affect their community, they are at greater risk. Denial can even take the extreme form of not seeing the pandemic for the serious problem that it is. Either way, denial silences open conversation about the epidemic which hinders preventative measures.
7.10.2 What can be done?

In order to combat stigma and discrimination, all levels of society must be involved. The legal process must be involved at the international and national levels to ensure that the rights of HIV infected persons are protected. Measures must be put in place to ensure that this is enforced at the local level. In the end, education is the key. Stigma and discrimination is largely due to myths about HIV and its transmission. Education programs worldwide about the methods of HIV transmission (in particular the ways it is NOT transmitted), ways in which one can protect oneself from infection and treatment options will go a long way in the battle against stigma and discrimination and thus the battle against the worldwide pandemic as a whole.\[26]\[26\]

HIV/AIDS-infected individuals are no different. While they struggle to overcome significant challenges that affect their ability to live independently and return to the workforce, (re)entry becomes an important factor leading to independence. Benefits of permanent employment for individuals who are able to (re)enter the workforce include decreased depression symptoms and improved peer support than those who are unable to attain employment.

Research shows there a number of reasons HIV/AIDS infected individuals have when considering workforce (re)entry. Some of these reasons include:

Increased income. For most disabled/unemployed HIV/AIDS infected individuals disability income (e.g., social security disability insurance (SSDI), supplemental security income (SSI)) represents only a fraction of their pre-disability income. Living on disability resources alone represents an ongoing challenge for many, if not most, disabled/unemployed HIV/AIDS infected individuals. Financial reasons are often times the catalyst for HIV/AIDS infected individuals return to work.\[27]\[27\]
Increased personal meaning. Many people derive a substantial amount of self-worth from their jobs; a person's self-image is closely tied to the work they do. Self-worth, or a reason for "existence", may be seriously undermined by disability and unemployment. Workforce (re)entry may, therefore, help to restore a sense of personal worth and meaning for many disabled/unemployed HIV/AIDS infected individuals.

Control and increased self-efficacy. Employment is a setting in which many people express and gain competence, receive positive feedback, expand abilities, and experience a sense of control and achievement. This may be a uniquely important anchor while dealing with a disease that is hard to control.

Reduction of family financial burden. Related to the need for increased income and personal financial stability, many HIV-infected individuals and others with disabilities feel they have become financial burdens to their families because of the financial support their families provide. Employment allows the disabled person to help reduce the financial burden (whether real or perceived).

Increased social interaction. Employment is a major source of social interaction, in contrast to the isolation experienced by many HIV-infected individuals disabled by their disease. Employment may help reduce this isolation.

Contribute to society. For many HIV/AIDS infected individuals, their diagnosis may have spawned a desire to leave a legacy or to make a positive contribution they can leave behind when they die. Finding a job that meaningfully allows such a contribution may help address this need.
Reduction of the role of HIV. Going back to work can add an important and absorbing set of activities that provide a balance to the often-overwhelming considerations that living with HIV/AIDS imposes in a life. Working can help relegate HIV/AIDS to the status of a medical problem, rather than a lifestyle.

However, despite compelling reasons for workforce (re)entry, a number of obstacles often make the transition from disability/unemployment to employment difficult. For people with longer histories of disability/unemployment, these obstacles may suggest that efforts at workforce (re)entry are not worthwhile, or that the costs outweigh the benefits. Research has found that concerns related to possible loss of or change in health benefits, fear and anxiety over the possibility of disclosure, the reality of HIV-related prejudice and discrimination, and relative lack of job skills and/or education are leading factors in not considering workforce (re)entry. Additional issues such as fear of stress that can contribute to overall declines in health outcomes, fear of failure which can lead to further self-disappointment, a loss of social support, and a change of lifestyle they may have grown accustomed to while un(der)employed and receiving social security benefits are additional concerns that should be assessed before workforce (re)entry.

Additional factors constituting barriers arise when looking at the issue from a psychosocial viewpoint associated with HIV/AIDS. As the demographics of HIV have changed, HIV has become increasingly associated with poverty indices and long-term unemployment such as substance abuse and homelessness. People with HIV/AIDS from such backgrounds may not be "disabled" according to the government's definition (either their disease or associated issues), but they are still unable to work. Due to poor employment histories, these individuals may need additional assistance with (re)entering the workforce, including job preparation and job-hunting.
A number of services HIV/AIDS infected individuals may need in order to assist them in their workforce-entry efforts have been identified (Brooks & Klosinki, 1999; Brooks et al. (1999). These services include employment services (referrals, job listing, interview-skills training), counseling (including benefits counseling), workshops on vocational opportunities, and educational activities. The need for these services was echoed in research by Watts and Kohlenberg (2003) who found the largest barriers to workforce (re)entry remained vocational rehabilitation, career counseling and planning, and employment services.

Although the listings have not changed, the categories for HIV disability allowances changed in December 2010. The categories for HIV disability currently include:

- **Low CD4 Count.** CD4 count is an important indicator of HIV stage and acts as a predictor of short-term mortality risk. A CD4 cell count at or below 50 cells/mm³ is the cut-off point for disability. Disability benefits under this category should be reviewed every 3 years.

- **Imminently Fatal Conditions.** HIV-induced diseases that warrant permanent disability allowance are those that are severely disabling, have a high short-term mortality risk, and respond minimally to convenient treatment. These conditions are generally untreatable and the average length of survival for people afflicted with these conditions ranges from 3-24 months (National Academy of Sciences, 2010).

  Documented presence of: HIV associated dementia; Multicentric Castleman's disease; Kaposi's sarcoma involving pulmonary parenchyma; primary effusion lymphoma; and, progressive multifocal leukoencephalopathy are considered permanent disability.
HIV-Associated Diseases without Listings Elsewhere or in Other Body Systems. Conditions that are associated with HIV infection or its side effects of treatment are considered as a disability if the affected person also has functional limitations using standards under existing listings. The combination of clinical severity and limited functional capacity allows for SSA to determine disability. Disability benefits under this category should be reviewed every 3 years.

Comorbidities induced by HIV and its treatment currently without listings elsewhere that warrant assessment of limitations in functioning to determination of disability include: diarrhea; distal sensory polyneuropathy; HIV-associated neurocognitive disorders; HIV-associated wasting syndrome; Kaposi's sarcoma; lipoatrophy or liphypertrophy; and, osteoporosis. Symptoms of fatigue, nausea, malaise, and pain should be considered limited functions for HIV-infected individuals with the above comorbidities.

HIV-Associated Diseases with Existing Listings Elsewhere. Many HIV-infected individuals experience higher rates of earlier onset of diseases already included in other body systems (e.g., diabetes, cardiovascular disease, etc.). The prevalence in the Listings for disabling chronic conditions has continued to grow and can be used to help determine disability for some HIV-infected individuals experiencing co-morbid conditions.

HIV-associated conditions that are not covered in the HIV Listing, but elsewhere (particular to HIV-infected individuals) may include: cardiovascular disease; chronic kidney disease; Diabetes, Hepatitis; and, malignancies.

- People with HIV/AIDS should receive accurate and adequate information on the effects of employment on disability benefits.
People with HIV/AIDS should have adequate health-insurance coverage, and this coverage should be uninterrupted during the transition from unemployment to employment.

People with HIV/AIDS-related disabilities need a "transitional work period" to allow incremental increases in work hours, adjustments to daily routine changes, and adjustment to work-related physical demands. Further, people with HIV/AIDS should be provided with information about and access to job-placement services, benefits counseling, skills training, and job-training programs in their community.

A need exists for adequate protection against HIV/AIDS-related discrimination in the workplace.

People with HIV/AIDS are entitled to reasonable accommodations in the workplace to address their medical and health needs.

A safety net of services is needed to insure service availability if people with HIV/AIDS need to leave work because of declining health.

Understanding the interplay of medical symptoms, medication side effects, immune system indicators, and client involvement within the medical care system in making informed work related decisions.

Understanding current financial and legal issues related to HIV and disability.

Understanding the array of employment and benefits services needed by HIV-infected individuals considering work related changes, including grassroots HIV and employment services.

Understanding the complexities in defining the nature of success in the consideration of work process, including-at times-identifying successful outcomes that either defer or exclude return to paid employment.
The risk analysis must take into account individual medical, vocational, financial, legal, and psychosocial factors. Additionally, an appraisal of the current state of medical opinion regarding long-term effectiveness of medical treatments should be revisited. Below are some recommendations for assessing the inter-related factors for considering work.

7.11 Social Factors

Take into consideration individual differences related to work values and tolerance of risk. Assess for co-existing, disabling psychiatric disorders such as schizophrenia, bipolar disorder, severe depression, and/or anxiety disorder. Assess other concurrent mental health concerns (e.g., substance abuse, depression, anxiety), which may have a deleterious effect on clients' physical health or poor medication adherence. Assess psychological barriers to work (e.g., fear, low self-esteem, self-efficacy, depression, and/or anxiety). Help clients to assess the potential demands (stressors) of specific work environments and determine whether they have the psychological and/or social resources to cope with these demands. Help clients to develop behavioral programs that will facilitate successful work entry (e.g., incremental increases (work hardening) in work or work-related activities to improve their resilience to stress). Help clients identify and monitor stress related symptoms and develop stress management coping skills. Assess for positive and negative sources of social support: personal involvement that will help or hinder making an informed decision and taking steps for successful work entry. This should include identifying sources of emotional and practical support, personal conflict, and persons who are encouraging (and discouraging) of work efforts.²⁸

7.12 Legal Factors

Help clients to understand the range of legal definitions of “disability” at the federal, state, local, and private insurance levels and the implications of these definitions for increasing their work activities. (e.g., under a client's current insurance policy, is she
permitted to experiment with returning to work without permanently jeopardizing disability coverage? Does a client risk triggering a disability review if s/he experiments with returning to work?) Help clients to understand the potentially negative impact of physicians' statements to insurers. Help clients to understand their legal rights under the ADA, as well as other relevant legislation, and ways to successfully apply these rights.[29]

7.13 An overview of case study of Gujarat

Since first HIV infection reported in 1986, Gujarat along with other southern states remained not only a medium prevalence state but showing declining trend since last 2-3 years due to efficient execution of HIV-AIDS prevention and control programme in the state.

The scale-up of HIV-AIDS services by Gujarat SACS is reached at all district head-quarters and further extended to taluka level. During the year 2011-12 our major focus was to scale up services up to the utmost target groups and we have achieved the earmark.

Gujarat State AIDS Control Society is striving for eradication of HIV/AIDS in the state by implementing strategic interventions under the aegis of NACO. During the year 2011-12 more than 13.00 lakh persons were tested, including 6.00 lakh pregnant women. The percentage of positive general clients noticed significant decrease from 9.8% (2007-08) to 1.7% (2011-12). More than 26,000 persons were taking ART treatment at 24 ART Centers. More than 5.00 lakh persons attended STI clinics for STD diagnosis and treatment. The state has covered nearly 3.5 lakh persons from High Risk and Bridge population under targeted intervention projects. Nearly 8.00 lakh blood units were collected during the year under Blood Safety Programme. Gujarat is the leading state in terms of percentage of blood collection against the requirement of blood.
The Gujarat state has certain money-spinning factors such as massive industrialization, urbanization (42%) and immigration (both intra and interstate), presence of national highways connecting high prevalence southern states with northern and central India which are important for HIV spread in the state. Presence of large band of tribal population with narrow literacy and diverse sexual norms make them vulnerable. Gujarat though reported the infection along with other southern states in 1986, has remained a medium prevalence states while others like Karnataka, Tamilnadu, Andhra Pradesh and Maharashtra have moved to high prevalence state.\[30\]

7.13.1 Historical Background of Gujarat State

Historically, the state of Gujarat has been one of the main centers of the Indus Valley Civilization. It contains major ancient metropolitan cities from the Indus Valley such as Lothal, Dholavira, and Gola Dhor. The ancient city of Lothal was where India's first port was established. Also, Dholavira, the ancient city, is one of the largest and most prominent archaeological sites in India, belonging to the Indus Valley Civilization. The most recent discovery was Gola Dhor. All together, about 50 Indus Valley settlement ruins have been discovered in Gujarat. The ancient history of Gujarat was enriched by their commercial activities. There is a clear historical evidence of trade and commerce ties with Sumer in the Persian Gulf during the time period of 1000 to 750 BC. Gujarat gets its name from “Gujjar Rashtra”, the land of the Gujjars, a migrant tribe who came to India in the wake of the invading Huns in the 5th century. The history of Gujarat dates back to 2000 BC. It is also believed that Lord Krishna left Mathura to settle on the west coast of Saurashtra at Dwarka. The state saw various kingdoms like Mauryas, Guptas, Pratiharas etc, but it was under the regime of Chalukyas (Solanki) Gujarat witnesses progress and prosperity. Inspite of the plundering of Mahmud of Ghazni,
the Chalukyan kings were able to maintain general prosperity and well being of the state. After this glorious respite, Gujarat faced troubled times under the Muslims, Marathas and the British rules.[31]

7.13.2 Geography

Gujarat is the westernmost state of India. It is bounded by the Arabian Sea to the west and southwest, and Pakistan to the north. The state of Rajasthan is to the northeast, Madhya Pradesh to the east, and Maharashtra and the union territory of Dadra and Nagar Haveli to the south and southeast of Gujarat.[32]

7.13.3 Gujarat Now

The present state of Gujarat was formed in 1st May 1960, as a result of Bombay Reorganization act, 1960. The state is bounded by the Arabian Sea on the west, Pakistan and Rajasthan in the north and north-east respectively, Madhya Pradesh in the south east and Maharashtra in south. The state has witnessed all-round progress in every field. It has been recognized as one of the leading industrialized states in the country. The principal industries are textiles, chemicals, and petro-chemicals complex of IPCL and Gujarat Oil refinery located near Vadodara. Gujarat is also the main producer of tobacco, cotton and groundnut in the country.[33]

7.14 Profile of Gujarat

Gujarat state is situated on west coast of India and one of the well-industrialized and rapidly developed states of India. The state has an international boundary with Pakistan at the northwestern fringe, Rajasthan is in the northeast, Madhya Pradesh is in the east, Maharashtra and Dadara and Nagar Haveli is in the southeast and Arabian Sea is in the west and southwest. It has an area of 196022 sq. Km. representing around 6% of the total area of the country with 26 districts and 225 Taluka. As per the figures
of census 2011, the population of Gujarat stood at 6.03 crore which is 4.99% of total population of India. Of the total population, 57.4 per cent lives in rural areas and 42.6 per cent resides in urban areas. The urban population has raised from 37.4 per cent in 2001 to 42.6 per cent in 2011, making it one of the fastest growing urbanized states, according to the Census. Only two states - Tamil Nadu and Maharashtra - are more urbanized than Gujarat, Tamilnadu's urban population has been put at 46 per cent of the total, while that of Maharashtra's at 45 per cent.\textsuperscript{34}

**7.15 Gujarat State at a Glance in 2013 Census**

Gujarat is divided into three geographical regions namely South Gujarat, North Gujarat & Saurashtra & Kutch. Rural areas of Gujarat comprises of 18,225 villages. There are 242 cities/towns. Ahmedabad, Surat, Vadodara & Rajkot are four urban agglomerations with million plus population. Ahmedabad has been given the status of a metro city. There are 8 municipal corporations namely Ahmedabad, Surat, Vadodara, Rajkot, Bhavnagar, Jamnagar, Junagadh and Gandhinagar. Gujarat has 72,165 Km. networks of road and 5696 Km. railway lines. National highway number 8 traverses from south to north connecting Gujarat with Maharashtra and other southern State and the northern states. Gujarat has an area of 75,686 sq mi (196,077 km\textsuperscript{2}) with the longest coast line 1600 km, dotted with 41 ports; I major, I I intermediate and 29 minor ports.\textsuperscript{35}

**7.16 HIV/AIDS Control Program in Gujarat**

Gujarat has certain vulnerability factors such as massive industrialization, urbanization (42.6%) and immigration (both intra and interstate), presence of national highways connecting high prevalence southern states with northern and central India which are important for HIV spread in the state. Presence of large tract of tribal population with limited literacy and different sexual norms also make them vulnerable. Gujarat though reported the infection along with other southern states in 1986, has remained a medium prevalence states while
others like Karnataka, TN, AP and Maharashtra have moved to high prevalence state. Gujarat has created its special status in India with its institutionalized way of working and systems, evidenced based planning and reaching to the most at risk populations through strong partnership with Civil Society organizations (CSOs). [36]

7.17 HIV Epidemic Profile of Gujarat

The estimated adult HIV prevalence in Gujarat state as per the Spectrum results of NACO estimation declined from 0.43 % in 2006 to 0.31 in 2009. Out 2.4 million total estimated PLHA in India, Gujarat contributes 6% of it. In 2009, estimated PLHAs in the state are 1.36 Lakhs. Among the low prevalence states, HIV trends among the ANC clinic attendees are found to be rising. NACO has further analysed and stated that the rising trend is found to be more in the states of Gujarat, West Bengal, Orissa and Rajasthan among northern states. (NACO -Technical brief_2007 report). Apart from 10 districts in Category A & B, districts like Kachch, Jamnagar, Junagadh, Patan, and Kheda were identified as priority districts by NACO's triangulation method as more and more data is available now. This has helped in focusing on those districts where vulnerability and potential for HIV burden is high. Gujarat's epidemic is slowly increasing as per HSS data trend in consistent sites. The trend of new cases of HIV (15-24 years age) is increasing in state. The Behavioral Surveillance Survey-2006 report indicates that 86 % youths have heard of HIV/AIDS and more than 95% aware of condom availability, but there comprehensive correct knowledge about HIV transmission & prevention is limited to 28.5 %. The HIV Prevalence among high risk groups continues to be nearly six to eight times greater than that among general population. Hence, Gujarat continues to be in the category of concentrated epidemic mainly driven by hetero sexual route spread from sex workers & clients. As pr HIV Sentinel Surveillance report the epidemic is spreading from urban areas to rural areas, greater among males than females, decreases with increasing education level, and is found to be highest among women whose spouses work in transport, various factory and industries and doing unskilled jobs.[37]
Fig. 7.1 District with Vulnerability and potential for HIV burden is high
7.18 Epidemic of HIV in Gujarat

7.18.1 Global

UNAIDS and the WHO estimated that AIDS killed more than 25 million people between 1981, when it was first recognized, and 2005, making it one of the most destructive pandemics in recorded history. UNAIDS estimated that 33.3 million people were living with HIV at the end of 2009, up from 26.2 million people in 1999. They also estimated AIDS-related deaths in 2009 at 1.8 million people, down from a peak of 2.1 million in 2004, new infections at 2.6 million, down from a peak of 3.2 million in 1997, and the number of people in low- or middle-income countries receiving antiretroviral therapy in 2009 at 5.2 million, up from 4.0 million in 2008.

7.18.2 Region

Sub-Saharan Africa remains by far the worst-affected region, with an estimated 22.5 million people currently living with HIV (67% of the global total), 1.3 million deaths (72% of the global total) and 1.8 million new infections (69% of the global total). Asia is the second-worst affected region, with 4.9 million people living with HIV (15% of the global total).

7.18.3 India

It is estimated that India has an adult prevalence of 0.31 percent with 23.9 lakh people infected with HIV, of which, 39 percent are female and 3.5 percent are children based on HIV Sentinel Surveillance 2008-09. Analysis of epidemic projections revealed that the number of new annual HIV infections has declined by more than 50 percent during the last decade. It is estimated that India had approximately 1.2 lakh new HIV infections in 2009, as against 2.7 lakh in 2000. This is one of the most important evidence on the impact of the various interventions under NACP and scaled-up prevention strategies.
7.18.4 Gujarat

Although the adult HIV prevalence rate in Gujarat has showed a declining trend from 0.48% in 2004 to 0.37% in 2009 is greater than national prevalence. The estimates based on using Estimation Projection Package and Spectrum Package that had been customised using Indian data. The total number of people living HIV/AIDS in Gujarat is estimated at 1.37 Lakhs which contributes to 5.71% of the total national estimate. Of all HIV infection, 38% (52,433) are among women. The number of new HIV infections (Incidence of HIV) in 2009 estimated 4,283 while AIDS related deaths were 9,356 in the state.

The four high prevalence states of South India (Andhra Pradesh-5 lakhs, Maharashtra 4.2 lakhs, Karnataka-2.5 lakhs and Tamil Nadu-1.5 lakhs) account for 55 percent of all HIV infections in the country. Gujarat has been the 'Medium prevalence' state with concentrated nature of epidemic among Men Having Sex with Men and Female Sex Workers where prevalence is 20 times higher than the general population as per HIV Sentinel Surveillance.[38]

7.18.5 Drivers of Epidemic

The spread of HIV infection has been significant in state shifting from urban to rural geography, from high risk group to bride population. (HIV Sentinel Surveillance -2008 report) This may be due to intra-state migration of rural population to major cities like Surat, Kutch, Vadodara, Ahmedabad, Bhavnagar, and Rajkot. It is also observed that migrants travel from Gujarat to Mumbai, Delhi etc stay away from family for long period thus vulnerable for HIV transmission in rural areas. Above figure depicts that the Sex work continues to act as the most important source of HIV infection due to high prevalence among MSM and FSW. The large size of client who get infected from sex workers further transmit HIV infection to general population particularly low risk women. Single Migrants & truckers constitute a significant proportion of clients of sex workers.[39]
Fig. 7.2: Prevalence of HIV among various population groups is shown.
There is a rapid expansion of program in last four years of NACP-III in state. With this speed of expansion of prevention and control activities, goal (Halt & reverse HIV epidemic) of NACP-III program in the state may be achieved by 2012. However we still need to focus on few macroscopic vulnerability factors like:

- Virus is now gradually spreading in rural areas
- Increasing number of High Risk Groups population
- Urbanization and industrialization leading to huge burden of migrants -Intra and Interstate
- Surat City being an 'epicenter' of HIV/AIDS in the state.
- Proportion of clients with multiple sexual partners increased from 6.1 % to 31.7% as per the data of BSS-2001 &BSS-2006
- High STD prevalence among the FSWs followed by MSM and clients as per BSS-2006 data.
- After 2006 round of BSS, there is a need to assess the change in behaviour of High Risk Groups and general population in state with scale up of services on HIV/AIDS.\cite{40}
Fig. 7.3 Sexual activity (85% heterosexual & 2% homosexual) constitutes 87% of transmission followed by parent to child with 5%, through blood and blood products 4%.
The first case of AIDS patient was diagnosed in 1986 in Gujarat. To curb the menace of this epidemic, firstly a State AIDS Cell (SAC) was created in December 1992 which is the apex authority for implementation of National AIDS Control Programme (NACP) phase I. The programme was implemented in accordance with the guidelines and directions of NACP and the approval of the State Empowered Committee on AIDS as constituted in Gujarat.

With a view to execute speedy and effective implementation of HIV/AIDS program through inter sectoral coordination for AIDS prevention & control and also to involve NGOs, the State AIDS Empowered Committee decided to convert the existing State AIDS Cell into a registered society under administrative control of Health & Family Welfare Dept. of Gujarat State. Government of India also advised to constitute State AIDS Control Society for effective implementation of the programme, especially during the second phase of NACP which begin from April 1999. Since then, National AIDS control programme is being implementing through Gujarat State AIDS Control Society (GSACS). At present GSACS is executing NACP Phase - III (2007-2012) with the prime goal is to halt and reverse the epidemic in India over the next five years by integrating programmes for prevention, care and support and treatment.

As per the directions of National AIDS Control Organization (NACO) under the National AIDS Control Programme Phase II, States AIDS Control Societies have been formed in the year 1999 in all the States of Country. In Gujarat also Gujarat State AIDS Control Society (GSACS) has been established in the year 1999 under Societies Registration Act 1860. GSACS implements various HIV/AIDS Projects approved by NACO in Annual Action Plans and as per Guidelines issued by NACO. The 100% financial assistant is provided by NACO to GSACS since 1999.
✓ GSACS has its own Governing Body with Principal Secretary (Health) to Government of Gujarat as Chairman and Project Director GSACS as the Member Secretary

✓ GSACS also has its Executive Committee, which is chaired by Project Director GSACS.[41]

7.19 Gujarat State Council for Blood Transfusion (GSCBT)

There is also a separate body named Gujarat State Council for Blood Transfusion (GSCBT) which is a registered society facilitated and financed by the State Government. GSCBT undertakes various promotional activities for voluntary blood donation, different IEC activities, advocacy and capacity building programs in the state. At present (As on 3 Ist March 2012) there are 143 blood banks are functioning under GSCBT.[42]

7.20 Targeted Intervention

Targeted Intervention provides services to FSW, MSM, Migrants and Truckers with the help of Non Governmental Organizations (NGOs). These services include BCC, Counseling, STD treatment and Condom Distribution and Promotion. STI case detection and treatment is institutionalized and reported regularly by NGOs. During this period, Apr to Sep 2012, the total coverage for FSWs is 31217, for MSMs is 34293 clients, for Migrant HRG is 65502 and Truckers is 75034.[43]
Fig. 7.4: Coverage of Female Sex Workers (FSW), Men having Sex with men (MSM), Migrants, Truck Drivers (2009-2013)
7.21 Integrated Counseling and Testing Center (ICTC - Vatsayan Kendra)

An integrated counseling and testing centre is a place where a person is counseled and tested for HIV, on his own free will or as advised by a medical provider. The increasing number of clients Accessing, Testing and Counseling services also continues during this quarter. Number of clients tested for HIV at ICTC in the period of Apr to Sep 2012 is 172982. The total HIV positivity among the general clients of ICTC in the State is reported to be 1.62%.[44]

Fig. 7.5 : Trend of HIV Tested & Posivity - General (2009-2013)
7.22 Integrated Counseling and Testing Center (ICTC - Mamta Clinic)

At PPTCT, about 139011 pregnant women were tested for Ante Natal Care (ANC) during the period of Apr to Sep, 2012 out of which 361 underwent found HIV Positive. The coverage of MB Pairs administration is 94.3 % in the state. The overall percentage of positivity reported at PPTCT is 0.14 in the reporting period.[45]

Fig. 7.6 : Trend of HIV Tested & Posivity - Pregnant Women (2009-2013)
7.23 **Sexually Transmitted Disease (STD Clinics - Suraksha Clinic)**

STD Clinics (Suraksha Clinics) are places where patients suffering from Sexually Transmitted Infections counseled, tested and treated. Apr to Sep 2012, total no. of patients attendance at Govt. STD clinics is 50777 & 186W6 at NGO-TISTD clinics.[46]

![Graph showing attendance at STD Clinic (2009-2013)](image)

**Fig. 7.7 : Attendance at STD Clinic (2009-2013)**
7.24 Blood Safety Programme

Under the blood safety programme, the blood banks collect the blood units for the people in need. Some blood banks also have the facility for component separation. Presently there are 141 functional blood banks across the state. Total blood collection during this reporting period was about 418861 units, out of which 343403 units (82%) were collected through the voluntary blood donation. Total HIV positivity rate for the state has been reported to be 0.12%.\textsuperscript{47}

![Attendance at STD Clinic (2009-2013)](image)

Fig. 7.8: Attendance at STD Clinic (2009-2013)
7.25 Care Support and Treatment (CST)

The main objective of Anti-retroviral Therapy (ART) Centre is to provide comprehensive services to eligible persons with HIV/AIDS. Till the end of Sep 2012, there are about 81596 patients registered at ART centers with about 50391 (61.8%) patients were ever started on ART. Among the patients ever started the treatment, about 29450(58.4%) patients are alive and on ART.[48]

Fig. 7.9: Yearwise Trend for CST activities upto Sept. 2012

Fig. 7.10: Patients ever started & on Antiretroviral therapy (ART) after registration
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