REVIEW OF RELEVANT LITERATURE

In this chapter, the researcher presents the review of relevant literature in the following format:

A. About HIV / AIDS per se:
   - History of HIV / AIDS
   - History of HIV / AIDS prevention in India
   - Modes of transmission
   - Tests to detect HIV
   - Window Period

B. Women and HIV / AIDS related issues:
   - Women and HIV / AIDS
   - Mother to child transmission
   - Women with HIV / AIDS as care-givers

C. Children and HIV / AIDS:
   - Children as vulnerable groups in HIV / AIDS
   - The Rights of the Child in the context of HIV / AIDS

D. Factors promoting care of People Living with HIV / AIDS (PLWHA):
   - Support systems

E. Child Care:
   - Essentials of good child care
   - Factors impeding child care
   - Single-headed families

F. Social Work Interventions in the field of HIV / AIDS:
   - AIDS as a Social Problem.

G. Others:
   - Ignorance
   - Needs assessment
A. ABOUT HIV / AIDS PER SE:

➢ History of HIV / AIDS:

1981

A drug technician at the Centre for Disease Control (CDC) in the USA noticed an unusually high number of requests for the drug pentamidine used in the treatment of Pneumocystis Carinii Pneumonia (PCP). This led to a scientific report of PCP occurring unusually in five Los Angeles gay men. The search began for the cause not only of the PCP in gay men in Los Angeles, but also of the Kaposi's Sarcoma (KS) occurring in gay men in New York. The alternative explanation was that an infectious agent caused it. Later in the year the first cases of PCP appeared in drug addicts.

1982

The syndrome, that is the collection of symptoms, was called GRID (Gay-Related Immune Deficiency) by some scientists and it started to be clearer that it was caused by an infectious agent, possibly a virus that could be spread through blood. The first article appeared in the Wall Street Journal about how GRID also affected women and male heterosexual drug users. Haitian refugees in Miami were also discovered to be affected by the syndrome, as were haemophiliacs.

The syndrome was renamed because it was clear that it did not just affect gay men. It was given the new name AIDS, standing for Acquired Immune Deficiency Syndrome. It had become clear that it was an illness resulting from a failure, or deficiency, of the immune system to work properly. The word acquired was used because unlike other immune deficiency illnesses, it appeared that it was an illness that people acquired from someone else; as opposed to being something that happened to you, for example, the taking of immune suppressant drugs after an organ transplant. The first blood transfusion recipient
was identified with AIDS in the USA. AIDS had been reported in fourteen nations worldwide.

1983

Doctors at the Institute Pasteur in France believed that they had isolated a new virus, which was the cause of AIDS. The virus was called lymphadenopathy-associated virus or LAV. It became clear that the disease appeared differently in different parts of the USA. For example, in New Jersey gay men represented a minority of cases, while IV drug users accounted for nearly half. This was very different to the epidemic among gay men in other parts of the USA.

In Europe, there were also two AIDS epidemics, one linked to Africa; the other linked to gay men who had visited the USA. The UK Department of Health produced the first official report of AIDS in the UK. Three people in the UK had died. The first Australian death from AIDS was recorded in Melbourne.

In May 1983 a report of AIDS occurring in children suggested quite incorrectly the possibility of casual household transmission, and this caused great fear in a number of countries. It became a major issue in the United States where some bus drivers in San Francisco reportedly wore facemasks. Considerable public education was required before people were reassured that transmission only occurred in certain very specific ways, and that casual transmission did not occur. Later in the year the number of children with AIDS had increased, and it became accepted that the children had acquired the infection from their mothers in the womb or during birth. It also became clear that the virus that caused AIDS could be transmitted through blood transfusions.

The first United States conference on AIDS was held in Denver. AIDS had been reported in 33 countries. 3000 Americans had AIDS then, of whom 1283 had died.
1984

The US Government announced that Dr Robert Gallo, at the National Cancer Institute (NCI) had isolated the retrovirus that caused AIDS and that it has been named HTLV-III. Blood testing was started to detect antibodies to the virus. In San Francisco all the gay "bathhouses" were closed.

The United States Health and Human Services Secretary, Margaret Heckler, confidently predicted a brief epidemic and said "There will be a vaccine in a very few years and a cure for AIDS before 1990". By the end of 1984, 7000 Americans had AIDS.

1985

The Food and Drug Administration (FDA) in the USA approved Dr. Robert Gallo's AIDS diagnostic kit based on the Western blot technique. Soon after the first commercial kit for antibodies was licensed.

Actor Rock Hudson died of AIDS. He was the first major public figure known to have died of AIDS. Also in the USA, Ryan White a 13-year-old haemophiliac with AIDS, was barred from school.

The first international conference on AIDS was held in Atlanta. Large numbers of people were known to be infected in Central Africa. In Uganda, AIDS was known locally as "slim disease", because of the wasting effect it caused.

The initial definition of AIDS had been developed in the USA in 1982, but this definition required laboratory facilities that were not available in most African countries. So in 1985 a new WHO clinical definition of AIDS in Africa was adopted in order that African countries could more accurately assess and report the number of people in their countries who had AIDS. By the end of the year, AIDS had been reported in 51 countries.
1986

It has become clear that the viruses Lymphadenopathy virus (LAV) and HTLV-III were actually the same. An international committee ruled that both names should be dropped and replaced by the new name Human Immunodeficiency Virus (HIV).

At the second international AIDS conference in Paris, there were preliminary reports of the use of the drug Zidovudine (AZT) for the treatment of AIDS. The World Health Organisation (WHO) launched its global AIDS strategy. At a WHO meeting on the spread of AIDS among drug abusers, it was recommended that providing sterile needles and syringes to drug abusers should be amongst the preventative action to be taken by individual countries to prevent the spread of AIDS.

1987

The FDA in the USA approved AZT as the first antiretroviral drug to be used as a treatment for AIDS. The CDC in the USA also revised their definition of AIDS to place a greater emphasis on HIV infection status. The British government launched a major advertising campaign "Don't Die of Ignorance", and delivered a leaflet about AIDS to every household.

Princess Diana opened the first specialist AIDS hospital ward in England. The fact that she did not wear gloves when shaking hands with people with AIDS, was widely reported in the press and helped to change attitudes to people with AIDS. President Kaunda of Zambia announced that his son had died of AIDS. In the United States legislation was passed which prohibited entry to the United States of HIV infected immigrants, aliens and short-term visitors. In San Francisco gay rights activist Cleve Jones made the first panel for the AIDS Memorial Quilt in memory of his friend Marvin Feldman.

President Reagan gave his first speech on AIDS, by which time 36,000 Americans had been diagnosed with AIDS and 20,000 had died. Worldwide, by November 1987, 62,811
cases of AIDS had been officially reported to the World Health Organisation (WHO),
from 127 countries throughout the world.

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<tr>
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These were only the cases that had actually been reported, and the number of reported cases was a marked under-estimate of the true incidence of AIDS. WHO estimated that by late 1987 between 100,000 and 150,000 cases of AIDS had actually occurred worldwide.

There was still little information available about the number of infected children. When the antibody test first became commercially available in 1985, it was thought that when it was positive it indicated infection with HIV even in children infected at birth. This led to some quite erroneous estimates about the number of infected children. However, by 1987 it was clear that the test was actually measuring antibody passed from the mother, rather than the child's own antibody. Many children became clear of their mother's antibody by the time they were 18 months old, and it was clear that children previously thought to be infected, were not actually infected with the virus after all.

1988

The FDA implemented new regulations that would shorten the time taken for the development of new treatments for AIDS.
The United States became the last major Western industrialised nation to launch a co-ordinated education campaign. The distribution took place of 107 million copies of "Understanding AIDS", a booklet by Surgeon General C. Everett Koop.

In the UK, funding was provided for the expansion of the needle exchange schemes to prevent more drug users from becoming infected. The city of New York began a needle exchange program.

A world summit of ministers of health was held in London to discuss a common AIDS strategy. It focused on programmes for AIDS prevention, and there were delegates from 148 countries. One outcome of the conference was the London Declaration on AIDS prevention, which emphasised education, the free exchange of information and experience, and the need to protect human rights and dignity. Another outcome was that the WHO's (World Health Organisation) Global Programme on AIDS instituted World AIDS Day as an annual event on December 1st each year.

1989

A number of new drugs became available for the treatment of opportunistic infection. Burroughs Wellcome lowered the price of AZT by 20%. A new antiretroviral drug didoxyninosine (DDI) was authorised by the FDA for use by patients intolerant to AZT. The trial of AZT in the United States was ended prematurely, after it was discovered that those people who were taking AZT were fighting HIV more effectively than those taking placebo treatments. The decision was taken so as to allow AZT to be available to everyone, and not just those receiving it in the trial. In the UK the Government Cabinet Committee on AIDS was disbanded.

1990

In April Ryan White died in the United States aged 19. He was a haemophiliac infected with HIV through the use of infected blood products. He had become well known a few years earlier as a result of his fight to be allowed to attend public school.
Just a few months after Ryan White’s death the Ryan White CARE Act was passed by Congress. The particular aim of this act was to provide systems of care for people with AIDS who did not have adequate health insurance or other resources.

The needle exchange scheme in the city of New York was closed down for political reasons.

The sixth international conference on AIDS was held in San Francisco amid worldwide protests about the US immigration policies regarding HIV positive people.

Also during this year it was reported that a large number of children in Romanian orphanages had become infected with HIV mainly as a result of multiple blood transfusions.

By December 1990 over 307,000 AIDS cases had been officially reported to WHO (World health Organisation), but the actual number was estimated to be closer to a million.

The estimate of the number of people worldwide with HIV was 8-10 million. Of the 8 million it was estimated that about 5 million were men, and that 3 million were women.

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It was estimated that the 3 million women had collectively given birth to about 3 million infants, of whom over 700,000 were estimated to have been infected with HIV. It had been known for several years that transmission from mother to child could occur before or during birth. It had now become clear that transmission could also occur through breast-feeding.

1991

There was great public concern over the connection between the dental profession and HIV infection, as Kimberly Bergalis neared death, apparently as the result of becoming infected with HIV from her dentist David Acer. She testified before Congress as well as writing to the American Medical Association requesting the mandatory testing of health care workers.

Earvin (Magic) Johnson announced that he had tested HIV positive and that he was retiring from professional basketball as a result, on the advice of his doctors. He decided to become a spokesperson to promote AIDS awareness and safe sex. Two weeks later, Freddie Mercury the lead singer with the rock group Queen, confirmed that he had AIDS, and just a few hours later it was announced that he had died.

The red ribbon was launched as an international symbol of AIDS awareness, and was first shown on television at the New York theatre Tony Awards.

The decision was taken to hold the 1992 international AIDS conference in Amsterdam, rather than its planned location in Boston, because of the US policy requiring short-term visitors to declare their HIV infection status.

The third antiretroviral drug dideoxycytidine (DDC) was authorised by the FDA for use by patients intolerant to AZT. All three of these drugs were in a group known as nucleoside analogues.
However, by this time it had become clear that AZT and these other drugs were only of limited use in the treatment of AIDS, as HIV developed resistance to these drugs, and so the drugs stopped being effective, on average after just one year of use.

By the end of 1991 the second 100,000 AIDS cases had been reported in the United States and there had been 133,000 deaths.

1992

The tennis star Arthur Ashe announced that he had been infected with HIV as a result of a blood transfusion in 1983.

The FDA approved the use of DDC in combination with AZT for adult patients with advanced HIV infection who were continuing to show signs of clinical or immunological deterioration. This was the first successful use of combination drug therapy for the treatment of AIDS.

1993

In January the Russian ballet star Rudolf Nureyev died of AIDS. In February the tennis player Arthur Ashe also died, less than a year after announcing that he had been infected with the virus.

A European trial known as Concorde, found that AZT was not after all a useful therapy for HIV positive people who have not yet developed symptoms.

1994

The filmmaker Derek Jarman died of AIDS, and the actor Tom Hanks won an Oscar for playing a gay man with AIDS in the film Philadelphia.
A study, ACTG 076, showed that AZT reduced by two-thirds the risk of transmission of HIV from infected mothers to their babies.

AIDS had become the leading cause of death amongst Americans between the ages of 25 and 44. 400,000 people in the United States had developed AIDS since 1981, and over 250,000 people had died.

1995

The Delta trial was a major clinical trial of combination antiretroviral therapy. In September 1995 the results of that trial showed that combining AZT with DDI or DDC, did provide a major improvement in treatment compared with AZT on its own. The success of this approach was confirmed by other studies and treatment with dual combination therapy became the standard approach to treatment.

The FDA also during the year approved the use of Saquinavir, the first of a new group of Protease Inhibitor antiretroviral drugs. They also approved the use of 3TC in combination with AZT, and by the end of the year Saquinavir had been authorised for use in combination with the nucleoside analogue group of antiretrovirals.

For years the World Health Organisation (WHO) had led the international campaign against AIDS. However, it had become increasingly criticised for doing too little at grassroots level and for focusing too narrowly on medical issues and vaccines. The WHO global program on AIDS was as a result closed at the end of 1995, to be replaced at international level by UNAIDS.

1996

The Joint United Nations (UN) Programme on AIDS (UNAIDS) became operational in January 1996. UNAIDS was designed to combine and replace the AIDS work previously undertaken by the WHO Global Program on AIDS, the UN Children's Fund, the UN
Population Fund, the UN Educational Scientific and Cultural Organisation, the UN Development Program and the World Bank.

Magic Johnson returned to professional basketball as an active player. Just one month later the heavyweight boxer Tommy Morrison was identified as HIV positive after being tested prior to a fight, and as a result he was totally barred from the ring everywhere.

During 1996 an increasing number of drugs received approval from the FDA in the United States, both for use on their own, and/or in combination with other drugs. Another treatment development that had taken place was the viral load test that provided information about the risk of disease progression.

By the time of the international AIDS conference in Vancouver had also begun to be realised that triple combination therapy, that is three drugs taken together was likely to be even more effective than dual therapy. Three drugs were more likely to suppress the virus, to prevent it from replicating, and so prevent the development of drug resistance.

This was a time of great optimism with respect to the treatment of HIV infection and AIDS but there were still a number of unknown factors and difficulties. These included the question of how long the effect of the drugs would last, the side-effects of the drugs, and when several drugs were being taken together the complicated regimes that needed to be followed.

At the end of the year UNAIDS reported that the number of new HIV infections had declined in many countries due to safer sex practices, although world-wide the rate of infections continued to grow rapidly. Countries that reported a successful slowing of the epidemic included the United States, Australia, New Zealand, northern European countries and parts of Sub-Saharan Africa.

The first AIDS hospice founded in San Francisco closed because fewer people were dying of AIDS in the United States as a result of the new treatments.
1997

The FDA granted approval for delavirdine, the first in the latest group of drugs, the non-nucleoside reverse transcriptase inhibitors.

But also during the course of the year it became apparent that the number of people affected by the side effects of the protease inhibitor drugs was greater than that had previously been thought. It was also clear that some of the side effects could be serious with the FDA issuing a specific warning concerning diabetes and hyperglycemia in-patients receiving protease inhibitors. The development of drug resistance also continued to be of considerable concern, with many of the new drug combinations being extremely complicated and quite difficult to permanently take.

However, for many people with HIV who had access to the new drug combinations, and who could take them without serious side effects, the new drugs continued to bring extended life as well as renewed hope. Worldwide though, the vast majority of people did not in 1997 have access to any antiretroviral drugs at all.

At the end of the year, UNAIDS reported that worldwide the HIV Epidemic far worse than had previously been thought. Updated surveillance techniques suggested that 30 million people were now living with HIV/AIDS and 16,000 new infections were occurring every day.

Worldwide, 1 in 100 adults of the 15-49 age group were thought to be infected with HIV; and only 1 in 10 infected people were aware of their infection. It was estimated that by the year 2000 the number of people living with HIV/AIDS would have grown to 40 million.

It was also estimated that 2.3 million people died of AIDS in 1997 - a 50% increase over 1996. Nearly half of those deaths were in women, and 460,000 were in children under 15.
UNAIDS reported that they considered that in terms of AIDS mortality the full impact of the epidemic was only just beginning.

1997

Brazil becomes the first developing country to provide antiretroviral therapy through its public health system.

1998

The first short-course regimen to prevent mother-to-child transmission is announced.

1999

The first efficacy trial of a potential HIV vaccine in a developing country starts in Thailand.

2000

The UN Security Council discusses HIV/AIDS for the first time.

2001

UN Secretary-General Kofi Annan launches his call to action, including the creation of a global fund on AIDS and health.

➢ History of AIDS and HIV prevention in India:

When the first case of HIV was discovered in Chennai in 1986, the Indian Government responded to the HIV epidemic immediately. Recognising the seriousness of the situation, the Government constituted a high powered committee under the Ministry of
Health and Welfare. Subsequently, a National AIDS Control Programme was launched in 1987. The program activities covered surveillance, screening blood and blood products and health education.

In 1990, HIV levels were high amongst high-risk groups such as sex workers and STD attendants in Maharashtra and injecting drug users in Manipur; infection rates reached over 5%. This period saw the beginning of a largely research-based national programme. Surveillance activities were launched in 55 cities in three states. The programme activities were left to the states and did not have strong central guidance.

The National AIDS Control Organization (NACO) was established in 1992. NACO carries out India’s National AIDS Programme, which includes the formulation of policy, prevention and control programmes. The same year that NACO was established, the Government launched a Five-Year Strategic Plan for HIV/AIDS prevention under the National AIDS Control Project. The Project established the administrative and technical basis for programme management and also set up State AIDS bodies in 25 states and 7 union territories. The Project was able to make a number of important improvements in HIV prevention such as improving blood safety. To strengthen surveillance the Government established 140 centres and 180 sentinel sites across the country, to monitor HIV trends and the geographical spread of HIV among the general population at-risk groups.

When surveillance systems in the Indian state of Tamil Nadu, home to some 60 million people, showed that HIV infection rates among pregnant women were rising, tripling to 1.25% between 1995 and 1997, the State Government acted decisively. It set up an AIDS society, which worked closely with non-governmental organizations (NGOs) and other partners to develop an active AIDS prevention campaign. This included hiring a leading international advertising agency to promote condom use for risky sex in a humorous way, without offending the many people who engage in risky behaviour. The campaign also attacked the ignorance and stigma associated with HIV infection, encouraging compassion for those affected. The bold safe-sex campaign was a hit with its target
market of young sexually active men. Regular behaviour surveillance shows that the number of visits to sex workers and sex with other irregular partners has fallen, and condom use during risky sexual encounters has rise dramatically.

The Situation Now

Although HIV prevalence rate is low (0.7%), the overall number of people with HIV infection is high according to estimates by UNAIDS. The official Indian figures do not reveal such a scale of infection, but weaknesses in the serosurveillance system, bias in targeting groups for testing, and the lack of availability of testing services in several parts of the country suggest a significant element of underreporting. Given India's large population, a mere 0.1 percent increase in the prevalence rate would increase the number of adults living with HIV/AIDS by over half a million people.

HIV infection in India is currently concentrated among poor, marginalized groups, including commercial sex workers, truck drivers, and migrant labourers, men who have sex with men and injecting drug users. Transmission of HIV within and from these groups drives the epidemic, but the infection is spreading rapidly to the general community. The epidemic continues to shift towards women and young people with about 25% of all HIV infections occurring in women. This also adds to mother to child HIV transmission and paediatric HIV.

About 90% of the total reported AIDS cases occur in the sexually active and economically productive 15 to 44 age group. Men account for 79% of HIV infections in India. The predominant mode of HIV transmission is through heterosexual contact, the second most common mode being injecting drug use. Previously blood transfusion and blood product transfusion were also major causes, but blood safety measures are now in place to prevent such transmission.

In 2001, the HIV infection rate went above one per cent in six states, and the Prime Minister urged the Chief Ministers to intensify prevention activities. Three states,
(Maharashtra, Tamil Nadu and Manipur), account for 75% of the country's estimated HIV cases. The burden of AIDS cases is beginning to be felt in states affected early. Mumbai and Manipur have recorded 20 to 49 percent bed occupancy by HIV positive people in certain hospitals.

In the most affected state of Maharashtra, HIV has reached 60% in Mumbai's (Bombay) sex workers, 14-16% in sentinel STD clinics, and over 2% among women attending antenatal clinics. The prevalence rate in women attending antenatal clinics can be treated as an indicator for the prevalence in general population. This prevalence rate has reached 6.5% in Namakkal in Tamil Nadu and 5.3% in Churachandpur in Manipur.

The last four years have seen a broadening of the epidemic across the southern and western states of India, as well a concentration of HIV among the injecting drug users in the North Eastern states. The sharp increases in Andhra Pradesh and Karnataka reveal that these two states have overtaken Tamil Nadu as states with the highest prevalence rates. In other parts of the country, the overall levels are still low with some areas reporting no cases at all.

The AIDS epidemic in India consists of a number of local epidemics. Around 70% of India's population live in rural areas, once thought to be relatively immune to the epidemic. Some recent studies, however, suggest that HIV has begun to spread in several rural areas. The epidemic is now moving beyond its initial focus among sex workers and injecting drug users and is shifting towards the general population; making women and young people the most vulnerable for HIV infection.

In India, as elsewhere, AIDS is perceived as a disease of "others" - of people living on the margins of society, whose lifestyles are considered 'perverted' and 'sinful'. Discrimination, stigmatisation and denial (DSD) are the expected outcomes of such values, affecting life in families, communities, workplaces, schools and health care settings. Because of HIV/AIDS related DSD, appropriate policies and models of good practice remain underdeveloped. People living with HIV and AIDS continue to be
burdened by poor care and inadequate services, whilst those with the power to help do little to make the situation better.

In a recent study by UNAIDS different levels of discrimination and stigmatisation were found among people living with HIV/AIDS in India. UNAIDS found that there was uncertainty among health care staff about basic HIV-transmission information and about the need for and purpose of universal precautions. Also, the study revealed a depressing picture of widespread labelling and stereotyping and a lack of care throughout the health sector, with the possible exception of a small number of hospitals where good practice and policies have been established.

UNAIDS also found that HIV/AIDS related DSD in India is in some respects a gendered phenomena. Women are often blamed by their parents and in-laws for infecting their husbands, or for not controlling their partners urges to have sex with other women. Children of HIV-positive parents, whether positive or negative themselves, are often denied the right to go to school or are separated from other children. People in marginalized groups (female sex workers, hijras (transgendered) and gay men) are often stigmatised in India on the grounds of not only HIV status but also being members of socially excluded group.

The Future

For India, to respond effectively to infection trends and limit the costly social and economic impact of HIV and AIDS, its efforts need to be accelerated, intensified and expanded while the country remains at a low prevalence of HIV and there is still time to slow the spread of the epidemic. With HIV prevalence doubling every one to two years in certain groups, there is still a narrow window of opportunity over the next few years in which to prevent the HIV epidemic from becoming generalised and much harder to control.
India's socio-economic status, traditional social ills, cultural myths on sex and sexuality and a huge population of marginalized people make it extremely vulnerable to the HIV/AIDS epidemic. In fact, the epidemic has become the most serious public health problem faced by the country since the Independence.

The Indian Government and individual state Governments have launched prevention programmes to reduce high-risk sex and, there is evidence that in some states these programmes are resulting in safer behaviour. There are some success stories for effective prevention and control of HIV infection. An intervention programme among commercial sex workers in Sonagachi, Calcutta has been able to increase condom use from 0% in 1992 to more than 70% in 1992-1994 and sustained this at over 70% until 1998. If current prevention efforts can be scaled up and sustained, India may be able to bring down the rates of HIV infection in particularly exposed groups and avert a widespread heterosexual epidemic. (Source: Website: www.avert.org)

➢ Modes of transmission:

HIV is transmitted by certain specific behaviours involving the exchange of bodily fluids between people. Unlike many other diseases, HIV is not transmitted through routine casual contacts, through the air or through insect bites. Sexual activities can transmit HIV when they involve direct contact between the HIV-infected bodily fluids (such as semen, vaginal secretions and blood) of one person and the mucous membranes such as in the vagina, rectum, and mouth) of another. This transmission can be reduced by avoiding these behaviours or by proper use of barriers such as condoms and dental dams.

Needles used to inject drugs can transmit HIV when they are used by more than one person. Needles should never be shared, but if they are shared, they should be thoroughly cleaned between uses. HIV can be transmitted from person to person through the transfusion if blood and blood products.

However, routine screening for HIV of the blood supply has dramatically reduced this mode of transmission, at least in the developed world.
HIV can be transmitted from mother to fetus / baby while it is still in the uterus, during the delivery process, and through breast-feeding. There is strong evidence that the use of antiviral medications during pregnancy can reduce maternal transmission of HIV.
(Source:www.naco.nic.in)

Tests to detect HIV / AIDS:

HIV antibody testing

As the body fights viruses, it creates antibodies to that virus. HIV antibody tests measure the presence of antibodies to HIV. They do not measure or detect the virus itself. There are three commonly used antibody tests.

The Three Kinds of HIV Antibody Tests

- **ELISA**

The ELISA is almost always the first screening tool; it is inexpensive and very sensitive. In most cases, a blood sample is tested, but other types of ELISAs that use saliva and urine have also been developed. Positive ELISA results must always be confirmed with a Western Blot test.

- **Western Blot (WB) assay**

The Western Blot test is a confirmatory test, it is only performed if the ELISA is positive. The Western Blot test can be positive, negative, or Indeterminate. Indeterminate tests are neither positive nor negative. An indeterminate result usually means that a person has just begun to seroconvert at the time of their test. In the rare cases in which this occurs, the person will need to be retested, usually about one month later. False positive results are extremely rare with the Western Blot, so it confirms that HIV antibodies are present.
Indirect immunofluorescence assay (IFA)

The IFA can be used instead of the Western Blot, to confirm ELISA results. Like the Western Blot, it uses a blood sample. Because it is faster than a Western Blot, some labs that use it can get results to the client more quickly.

Rapid Tests for HIV

A rapid test, the Murex-SUDS (Single Use Diagnostic System), has been approved by the FDA since 1996. It is currently the only "rapid" test approved. The SUDS is more expensive than ELISA testing, so it is not likely to be used by public health sites, and most private clinics that offer it will charge. The sensitivity of the SUDS is comparable to a traditional ELISA, but if positive, it must be confirmed by traditional Western Blot.

Urine Test For HIV

A test that detects HIV antibodies in urine was approved by the FDA in 1996, and is beginning to be marketed. This test is not generally available to consumers. It generally will be marketed to insurance companies and to other countries. (Note: urine has antibodies for HIV, not HIV itself, so HIV is not transmitted by urine.) Manufactured by Seradyn, it is called the "Sentinel" test. Because it is LESS sensitive THAN A BLOOD TEST, positive results must be confirmed by a traditional blood sample (ELISA plus Western Blot).

Orasure Test For HIV

The Orasure HIV antibody test method, also approved by the FDA in 1996, uses a sample of oral mucus obtained with a specially treated cotton pad that is placed between the cheek and lower gum for two minutes. (Note: the saliva and oral mucus contain
antibodies to HIV, not HIV itself, so HIV is not transmitted through these fluids.) Some public test sites are beginning to offer this test as an alternative to blood testing. It is somewhat more expensive, so the client may be asked to pay for it. The combined accuracy of Orasure, ELISA and Western Blot procedures is comparable to traditional blood testing, i.e., very high. (Source: www sfaf.org)

➢ Window Period:

The "window period" is the time it takes for a person who has been infected with HIV to SEROCONVERT (test positive) for HIV antibodies.

The Center for Disease Control (CDC) says about the window period: "Antibodies generally appear within three months after infection with HIV, but may take up to six months in some persons." (Source: www.cdcnac.org)

B. WOMEN AND HIV/AIDS RELATED ISSUES:

➢ Women and HIV/AIDS:

According to Gabriela, in Conveying concerns: Media Coverage of women and HIV/AIDS the profound impact of HIV/AIDS on the lives of women is one of the most critical reproductive health concerns of our times. The interplay of certain social, economic, and biological factors, including policies that undermine the rights of women, heightens women's vulnerability to a disease whose most common mode of transmission worldwide is sexual contact.

Women are especially vulnerable to HIV on two counts. Anatomical differences make transmission of the virus through sexual contact far more effective from men to women than vice-versa. Even more significant, though, is the fact that powerlessness, dependency and poverty serve to diminish a woman's ability to fend off the risks.

The platform for Action adopted by governments at the 1995 Fourth World conference on women in Beijing recognizes that low social status is at the root of women's
vulnerability to HIV. While individual behaviour is largely responsible for the spread of the infection, preventive measures are often beyond a woman's control. Her choices are often restricted by an inability to insist on safe sex, society's acceptance of different standards of behaviour for women and men, and economic dependence on men. For these reasons, married women—whether or not they are monogamous—are the largest group of women at high risk of HIV infection. Since most infected women are of childbearing age, they face the likelihood of infecting their children. As mothers, daughters, wives, grandmothers, sisters and aunts, women also care for dying family members and for children orphaned by the disease.

Access to Care

Several studies indicate that women come for care at later stages of disease and that they may access fewer services than men (1). A study of a small cohort of 200 women in a New York clinic indicated that women tend to seek treatment later in their clinical course of HIV disease and have a worse prognosis (2). The majority of the 200 HIV-infected women sought treatment at a relatively advanced stage of infection with a CD4 count <500. Most women were not tested until they or a child or partner developed symptoms. A study of use of health services by women with HIV infection showed that even after being diagnosed and after having accessed the medical care system, women with AIDS received fewer services than men with AIDS (3). Use of health services by women was examined more closely in the HERS study. Among women enrolled in this study with <200 CD4 cells, 49% were taking antiviral therapy. PCP prophylaxis was only being used in 58% recommended for everyone with <200 T-cells (4).

Patterns of access to care vary in different areas of the country. In Seattle, research about the effect of gender and race on access and utilization of care for HIV-infected clients found that women entered the system at the same stage of disease as men but were significantly younger, indicating they were infected at a much earlier age.

Mother to child transmission:
The following information is obtained from Conveying concerns: Media Coverage of women and HIV/AIDS.
For many HIV infected women, who may learn of their HIV positive status only when they become pregnant, choosing whether or not to have a child is amongst the toughest decisions they make. Mother to child transmission of HIV is by far the most common mode of HIV infection for children below the age of 15. More than a million children are living with HIV/AIDS around the world, and more than 4 million have died since the epidemic took hold two decades ago. These numbers will likely rise as the number of HIV positive women of childbearing age increases.

Without treatment, 25 percent to 35 percent of children born to HIV positive women in less developed countries become infected.

A baby may contract the virus during pregnancy, labour and delivery, or as a result of breast-feeding. Of the infants who become infected, two thirds are infected during pregnancy and at the time of delivery being the time of greater risk. While caesarian sections could reduce this threat, such an option is unavailable to the majority of the women worldwide who deliver their babies with the help of midwives at home, in villages, or at small health centres.

Once the baby is born, some women face yet another choice—whether to breastfeed their babies or provide an alternative milk formula. Given the fact that roughly one-third of mother to child transmissions of HIV occur through breast-feeding, families who have the means may provide commercial milk formulas. For millions of families with scarce resources, however, the alternatives to breast milk may be too expensive or their communities may lack the clean water and fuel necessary for the safe preparation of milk Formula. Moreover, in places where breast-feeding is common, the decision not to breastfeed a child may draw attention to the woman’s HIV status and invite abuse and discrimination.
For some women, anti-AIDS drug treatment is available. The treatment is administered late in pregnancy and during delivery and given to the infant for a period following birth. This option is also limited to those who can afford the treatment. The risk of mother to child transmission has been significantly lowered in high-income countries, where many HIV positive pregnant women, in addition to taking anti-retroviral drugs later avoid breast-feeding. These measures along with delivery of the baby by Caeasarian section, have decreased mother to child transmission of HIV in some places.

In addition to the provision of antiretroviral drugs, health experts stress the importance of prevention efforts, as well as appropriate counselling and testing services for women, and support for mothers and their infants, including information on infant feeding options.

- **Women with HIV / AIDS as care-givers:**

Samuel Kalibala in his article 'Providing support to care-givers and self-care' published in the Sexual Exchange (1993) states that "PHAs (People having AIDS) who are care-givers also need to seek care for themselves. They may experience difficulty in changing from their role as a provider to that of a patient. Sometimes their fellow-care givers may ostracize them because they associate HIV infection with a stigmatised behaviour such as being gay or having multiple partners. This makes it difficult or impossible for many care-givers to seek care, especially if they are professional health workers themselves."

C. **CHILDREN AND HIV / AIDS:**

- **Children as vulnerable groups in HIV / AIDS:**

HIV and AIDS can affect infants and young children in one of three ways. They may be:
- Infected with HIV.
- Affected by HIV.
• Vulnerable to HIV.

Children infected with HIV

At the beginning of the AIDS epidemic, children were not considered to be at risk of HIV infection. This changed as it became clear that infants and young children had been infected with HIV by contaminated blood transfusions and by use of unsterile medical equipment. It also became clear that the virus could be passed from an infected mother to her baby during pregnancy, birth or breast-feeding. Everyday an estimated 1,000 children become infected with HIV, mostly in the developing world.

Children Affected by HIV

The lives of many children who may not have HIV themselves are affected when family members have HIV and AIDS. Families face increased poverty and stress when adults are too sick to continue with paid employment. Mothers, who are ill, find it more difficult to care for young children, and young children themselves may end up caring for younger siblings or sick parents.

In addition to children who are living with HIV infected parents who are sick or dying, there are many who have been orphaned by AIDS. They may have lost mother or father or both. It is estimated that nine million children have already lost their mothers because of AIDS. At least thirty million children in the world are living with HIV positive parents and are at risk of being orphaned in the future. (UNAIDS:1998)

Children vulnerable to HIV

According to Kathy Attarel, in Caring with Confidence, Children without parents and displaced children are more vulnerable to rape and sexual abuse, and the associated risk of HIV infection. Sexual abuse of children is a taboo subject and rarely reported, and until recently was thought to occur infrequently in developing countries. However there is growing evidence of very young children being infected with HIV and other sexually
transmitted diseases following sexual abuse and rape. Although it is usually older children, especially girls, who are most at risk of sexual exploitation, younger children are also vulnerable to sexual abuse.

**Treatment and Care of children**

As given in AIDS action2000, in the article improving 'Access to care' most HIV related illness in children is caused by common infections that can be prevented and cared for at home or treated at a health centre. Early recognition and treatment of common illnesses can also prevent the development of more serious infections reducing hospital admissions and the demand on health services. Good care and treatment can improve the quality of life and life expectancy for children with HIV. Most early deaths are preventable with good management. But in many settings, health services are unable to provide the ongoing care that children with HIV and AIDS need at health faculties.

**Preventing Transmission of HIV at Home**

There is very little risk that care-givers will acquire HIV from looking after a child with HIV or AIDS, provided that they follow certain simple rules. These include minimising contact with blood and body fluids, being careful with sharp instruments and covering open cuts and wounds. Bed linen and clothing soiled with faeces or blood should be washed carefully with hot water and soap and handled as little as possible as given in 'Managing illness', AIDS action.1999.

➤ **The Rights of the Child in the context of HIV / AIDS:**

The rights of the child in the context of HIV / AIDS as given by the WHO (1995) (AIDS ACTION, 1999: Is 44-45, pg.3) are stated as under:

1. Children's right to life, survival and development should be guaranteed.
2. The civil rights and freedoms if children should be respected, with emphasis on removing policies which may result in children being separated from their parents or families.

3. Children should have access to HIV/AIDS prevention education, information, and to the means of prevention. Measures should be taken to remove social, cultural, political or religious barriers that block children’s access to these.

4. Children’s rights to confidentiality and privacy in regard to their HIV status should be recognised, this includes the recognition that HIV testing should be voluntary and done with the informed consent of the person involved, which should be obtained in the context of pre-test counselling. If children’s legal guardians are involved, they should pay due regard to the child’s view, if the child is of an age or maturity to have such views.

5. All children should receive adequate treatment and care for HIV/AIDS, including those children for whom this may require additional costs because of their circumstances, such as orphans.

6. States should include HIV/AIDS as a disability, if disability laws exist, to strengthen the protection of people living with HIV/AIDS against discrimination.

7. Children should have access to health care services and programmes, and barriers to access encountered by especially vulnerable groups should be removed.

8. Children should have access to social benefits, including social security and social insurance.

9. Children should enjoy adequate standards if living.

10. Children should have access to HIV/AIDS prevention education and information both in school and out of school, irrespective of their HIV/AIDS status.

11. No discrimination should be suffered by children in leisure, recreation, sport, and cultural activities because of their HIV/AIDS status.

12. Special measures should be taken by governments to prevent and minimise the impact of HIV/AIDS caused by trafficking, forced prostitution, sexual exploitation, inability to negotiate safe sex, sexual abuse, use of injecting drugs, and harmful traditional practices.
D. FACTORS PROMOTING CARE OF PEOPLE LIVING WITH HIV / AIDS:

➢ Support Systems:

Access to HIV/AIDS Care and Support

The following is the extract from India: HIV and AIDS related Discrimination, Stigmatisation and Denial, UNAIDS publications.

When it comes to improving care for people with HIV infection, world attention has recently focused mainly on drug prices, in particular the price of antiretroviral drugs. But access to drugs is just one of the many things that people with HIV infection need if they are to live healthy, productive lives for as long as possible.

- Millions of HIV-positive people do not benefit from care and support because they are unaware of being infected. Many are hesitant to find out if they have HIV because of the shame and blame that can be associated with AIDS. Also, facilities for voluntary counselling and HIV testing are woefully inadequate.

- HIV/AIDS-related care and support needs are extremely broad.
  - People with HIV infection develop "opportunistic diseases" and distressing symptoms such as itching, pain, and difficulty in breathing or swallowing that require medicines and other forms of health care.
  - They need support to cope with the psychological strain of repeated bouts of illness, and to counter discrimination and social isolation.
  - They and their families need help to alleviate the economic consequences of sickness and death due to AIDS.

- There has been some progress in meeting their needs in developing countries. Associations of people living with HIV/AIDS have been prime movers in bringing emotional and social support to those affected by the epidemic. Families and communities have stepped in with health care for those infected. Some governments
have recently begun to invest more of their AIDS resources in care, not just in prevention.

- But access to care and support is still poor in many developing countries.
- In Africa, where most HIV-positive people live, health care systems were already weak and under-financed before the advent of AIDS, and now are buckling under the added strain of millions of new patients.
- In many places, facilities for diagnosis are inadequate and drug supplies are erratic, even for HIV-related conditions that are easy to diagnose and inexpensive to treat. A UNAIDS survey of 22 big teaching hospitals found that only half were equipped to relieve difficulty in breathing, and just two-fifths had strong painkillers available.

Making health systems strong enough to ensure decent care for the millions of people living with HIV/AIDS requires an extraordinary push. "Business as usual" will not work.

In its comprehensive care strategy, UNAIDS puts the accent on seizing new opportunities for prioritizing action and accelerating progress. The strategy has five strategic axes: mobilizing political will and resources, expanding voluntary counselling and HIV testing, increasing access to psychological and social support, improving the staffing and infrastructure of the health services, and increasing access to drugs needed by HIV-positive people.

**HIV and AIDS-related Discrimination, Stigmatization and Denial:**

**Families and communities**

In most developing countries, families and communities are generally supportive settings for illness management and treatment (Bharat, 1996; Ankrah, 1993). However, data from some African and Asian countries report both supportive and non-supportive household responses to HIV-positive people. Negative responses are particularly evident in the case of HIV-positive women (Bharat, 1996; Bharat & Aggleton, 1999; Bharat, Singhametra-
Renard & Aggleton 1998; Warwick et al., 1998) and those whose lifestyles and sexual behaviour elicit popular disapproval (Panos, 1990; Warwick et al., 1998). An Indian study (Bharat, 1996) found that, although a majority of those who had shared their HIV status with their families received care and support, it was largely men rather than women who qualified for such care. 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.

Family responses to infected relatives are heavily influenced by community perceptions of the disease. Families that include an individual with HIV may fear isolation and ostracism within the community (McGrath et al., 1993; Warwick et al., 1998; Bharat & Aggleton, 1999). Consequently, they may try to conceal an HIV diagnosis, which in turn may cause considerable stress and depression within the family (Bharat & Aggleton, 1999). Because most people living with HIV/AIDS in India maintain such secrecy, the epidemic is not socially visible. Given this secrecy and invisibility, it would appear that there have been relatively few actual instances of community-based discriminatory responses. However, stigmatization and discrimination may arise when an individual identified as HIV-positive is seen as a source of infection to others, or when the physical appearance of someone with AIDS produces revulsion or fear. By contrast, a person who is known to have HIV, but whose behaviour or appearance is “non-threatening,” is sometimes tolerated and may even be offered support in the community (Bharat, 1996). Nevertheless, misconceptions about how HIV is transmitted continue to fuel discrimination.

Health care

The health care sector is perhaps the most conspicuous context for HIV/AIDS-related discrimination, stigmatization, and denial. Negative attitudes from health care staff generate anxiety and fear among PLHA. 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).

Globally, discrimination in these settings can be expressed in a variety of ways. The most commonly reported responses include a refusal to admit or treat HIV-positive patients (Tirelli et al., 1991; Shisam, 1993), the tendency to neglect patients (Daniel & Parker, 1990; Ogola, 1990), the habit of testing for HIV without consent, and breaches of confidentiality (New South Wales Anti-Discrimination Board, 1992; Bermingham & Kippax, 1998).

Employment

A study of seven large Mumbai-based businesses revealed that none had a policy on AIDS and that mid-level management have adopted a "wait and see" attitude - waiting to see how many workers became infected and whether this had an impact on productivity (Hira, Gupta & Godwin, 1998). At the same time, anecdotal evidence of employment-related discrimination and stigmatization has begun to emerge. Individual cases of job loss, emotional isolation, and denial of employment on the basis of HIV status have been reported in the media (Chimai, 1995), to NGO workers and social counsellors (V. Chitale, personal communication), and to medical practitioners (G. Bhave, personal communication). An industrial body with a specialized role in coordinating industry-based initiatives on the epidemic, the Industrial Response to AIDS (IRTA), has produced a booklet on corporate policy and HIV/AIDS (see Nangia, 1998).

The Joint United Nations Programme on HIV/AIDS provided financial and technical support to a research team from the Tata Institute of Social Sciences, Mumbai, in order that insights might be gained into the experiences of Indians living with HIV/AIDS, the negative social responses they encounter, and the roots of HIV/AIDS-related DSD. This report describes that research, conducted in Mumbai and Bangalore, India. This study aimed to examine forms, determinants, and outcomes of HIV/AIDS-related
discrimination, stigmatization, and denial in India, and to explore their possible social, demographic, and cultural correlates.

Specific objectives of the research were to:

- examine the forms in which HIV/AIDS-related DSD is experienced and manifested at the levels of individuals, households, and institutions, and for certain marginalized groups such as women, gay men, and commercial sex workers;
- understand the broader socio-cultural contexts in which HIV/AIDS related DSD operates;
- document and analyse the outcomes or responses to DSD associated with HIV/AIDS.

Both overt and covert forms of HIV/AIDS-related DSD were reported in each site: The main overt forms of discrimination experienced by respondents are listed below.

**Hospitals**

- Refusal to provide treatment for HIV/AIDS-related illness.
- Refusal to admit for hospital care/treatment.
- Refusal to operate or assist in clinical procedures.
- Restricted access to facilities like toilets and common eating and drinking utensils.
- Physical isolation in the ward (e.g. separate arrangements for a bed outside the ward in a gallery or corridor).
- Cessation of ongoing treatment
- Early discharge from hospital
- Mandatory testing for HIV before surgery and during pregnancy
- Restrictions on movement around the ward or room
- Unnecessary use of protective gear (gowns, masks, etc.) by health care staff
- Refusal to lift or touch the dead body of an HIV-positive person
- Use of plastic sheeting to wrap the dead body
- Reluctance to provide transport for the body
Home and community

- Severed relationships, desertion, separation
- Denial of share of property or access to finance
- Blocked access to spouse, children, or other relatives
- Physical isolation at home (e.g. separate sleeping arrangements)
- Blocked entry to common areas or facilities (toilet, etc.)
- Blocked entry to common places like village or a neighbourhood area
- Denial of death rituals
- Labelling and name-calling

Workplace

- Removal from job
- Forced resignation
- Withdrawal of health/insurance benefits
- Poor access to shared facilities
- Social distance
- Labelling and name calling

Hospitals

- Delays in treatment; slow service (e.g. made to wait in queues, asked to come again).
- Excuses or explanations given for non-admission (but admission not directly refused).
- Shunting patient between wards/doctors/hospitals.
- Keeping patient under observation without any treatment plan.
- Postponed treatment or operations.
- Unnecessarily repeated HIV tests.
- Conditional treatment (e.g. only on the condition that the patient will come for follow up or join a drug trial programme).
Chapter II

Home and community

- Disparaging remarks about the HIV-positive family member (e.g. "he is paying for past sins")
- "Guilt tripping" for burdening the family economy and for lowering family prestige

Discrimination was also reported in schools, and in relation to life insurance and post-death services. While instances of HIV/AIDS-related DSD were documented at work, in this study the workplace did not emerge as a major setting for negative experiences for HIV-positive people.

Health care context

A majority of key informants in the medical and NGO fields acknowledged that health care settings were a major source of discrimination and stigma, but these informants nearly always placed the greatest blame elsewhere. For example, a majority of the staff in all hospital types stated that, while they provided "proper and adequate" care to HIV-positive patients, the patients' families did not. The "family discriminates the most" was a common refrain from health care respondents. Family members, it was alleged, usually abandoned the patient with HIV infection to the health care system or kept a "safe" distance.

Doctors in Government hospitals in Bangalore tended to blame those in local private hospitals, claiming that they frequently transferred patients rather than treating them. Staff in private hospitals, on the other hand, argued that Government hospitals provided substandard treatment and care and that this led to a rise in the number of inpatients in the private sector.
"In private hospitals, the news of HIV-positive patients once detected is closely guarded and the patient is conveniently transferred to [a government hospital]." (Surgeon in a government hospital)

"Government hospitals are not doing their duty. The quality of care is so poor that the positive patients come to us. We give them all the necessary care without complaining." (Gynaecologist in a private hospital)

"The conditions in government hospitals are bad." (Doctor in a private hospital)

Government hospitals were reportedly "under orders" to provide suitable health care facilities to HIV-positive patients, although, in general, the perception was that care in Government hospitals was of poor quality. In Bangalore, one hospital was said to be "specially designated" for AIDS care. Staff at this hospital were of the view that because of this designation, all the city's hospitals "dumped" their AIDS patients on them. Indeed, HIV-positive respondents from corporation hospitals, trust-run hospitals, and a few private hospitals reported that they were routinely asked to seek treatment at this specialist institution. Doctors at these same hospitals also reported transferring seropositive cases there. Small private clinics, on the other hand, as was pointed out by doctors at different hospitals and by HIV-positive patients, sometimes denied care and treatment. Certain kinds of discrimination were also reported in care settings managed by NGOs. Some NGO staff assumed that all their HIV-positive women clients worked in the sex trade; as a result, staff had a casual attitude towards their rights and needs. People with HIV who had once been offered care by an NGO in Bangalore said that their care was provided with "attitude." One HIV-positive woman, for example, was photographed for an AIDS programme without her knowledge and was later rebuked for questioning the staff about this. "Look you are eating here without any payment, so don't make any fuss" (HIV-positive woman, age unknown).

Similarly, sex workers who were accessing support from a local NGO reported that the staff talked to them in derogatory terms and denied them services. Conflicts between NGOs often resulted in loss of services for the person with HIV.
Testing and related issues

In all hospitals, HIV testing was reported as being carried out on patients who did not respond to treatment for “marker diseases” such as tuberculosis, diarrhoea, and persistently swollen lymph nodes. Blood tests were also administered on the “suspicion” that a patient had HIV. Such suspicion could arise because of a patient’s thin physique, weight loss, or skin problems, or because he or she belonged to a perceived “risk group” such as truck drivers and sex workers. As a rule, pregnant women and patients for surgery were also subjected to mandatory testing in private hospitals. In both study locations, hospitals in general did not ask for consent prior to testing. Instead, doctors acted on the assumption that patients would comply with their instructions. In a Mumbai hospital, one doctor explained that patient consent is implied when the HIV test and its likely outcomes are explained during “counselling.” “There is no written consent taken [for the HIV test] but we explain the test to the patients. Only verbal consent is taken.” However, pre-test counselling was not uniformly practised, and patients were frequently asked to get an HIV test from the microbiology laboratory of the hospital or an outside laboratory before further action would be taken.

Private hospitals in both sites had a policy of mandatory testing both for pregnant women and those brought in for surgery (major or minor). Spouses of all HIV positive men were advised – and sometimes forced – to take an HIV test, irrespective of whether or not they required medical care. As a rule, consent was not requested, and pre and post-test counselling was not given. Doctors across the hospitals defended such action on the grounds that procedures such as childbirth and surgery were invasive and involved significant contact with blood. Patients argued, though, that in most cases HIV tests were conducted in order to enable the hospitals in question to refuse treatment and care. Several respondents reported that they were refused hospital services following a positive test result.
Similarly, the women caregivers of HIV-positive husbands and children reported that hospital staff drew blood repeatedly and unnecessarily for testing:

There were also problems relating to confidentiality, especially how and to whom HIV test reports were disclosed. In all hospitals in Mumbai and Bangalore, doctors alone had the right to disclose an HIV test result (although hospitals could also use AIDS counsellors to inform the patient of the results). However, what was told and to whom varied greatly across hospitals. In private hospitals, the most often quoted policy was that test results were disclosed only to the patient and to no one else. But in reality, and in nearly all hospitals, results were also shared with hospital staff, even when they were not directly involved in care (e.g. technical staff): “Confidentiality is maintained, and only the concerned staff – the lab technicians who have done the test, the nurses and doctors who are caring for the patient and the patient’s attendees [family members] only will know of it” (doctor in a private hospital, Bangalore).

Positive test results were also often shared with the family member accompanying the patient. If the patient had come to the hospital alone, relatives were often called in, sometimes from the village, to receive the results. In one Bangalore public hospital, parents, wives, and siblings were called in to receive test results. In the case of married, male patients, doctors had a tendency to share the diagnosis with the man’s wife.

Health care staff clearly believed that the principle of confidentiality extended to sharing test results with particular groups of people, including other health care staff and family members. However, the principle of confidentiality was often disregarded altogether in the case of women, the less educated, and the poor. In the case of pregnant women, confidentiality did not even appear to be an issue. Women were sometimes not told of their own HIV status. Their husbands, though, were often informed, based on the assumption that it was they who would decide the future course of action – that is, whether or not to continue with the pregnancy and whether or not to get tested for HIV themselves. Yet, the husband was not always the doctor’s first contact. Describing how HIV test results were communicated to the patients, one doctor told us:
"When a young woman who is first time pregnant is found to be HIV-positive, we ask her to call her mother-in-law. We explain the report to the mother-in-law. These patients who come here are from low-income group, and if the girls are newly married, they are really dumb and don’t understand anything, so the mother-in-law is called to explain." (Gynaecologist in a private hospital, Mumbai)

Considering the animosity sometimes encountered between daughters-in-law and parents-in-law, this is a particularly worrying development.

There is still a strong stigma associated with HIV/AIDS in Asia and many people living with the disease are discriminated against by their families, communities, and sometimes even by medical facilities. It was reported in March 2003, for example, that more than 90% doctors in Tamil Nadu, India refuse to treat people with HIV/AIDS, forcing patients "to go to the highly stigmatised sexually transmitted wards of Government Hospital even for common colds". (The Hindu)

Employment context

In both study sites, employment did not emerge as a major setting for discrimination and stigmatization - probably because most respondents had not disclosed their HIV/AIDS status at work. Many had a strong fear of social isolation and stigmatization, and they worried about losing their job if they were to reveal their status. This fear was validated by those who had shared their HIV/AIDS diagnoses with work colleagues and management. Felt stigma in relation to HIV/AIDS-related DSD clearly presents serious problems for people with HIV in the workplace. A majority of HIV-positive respondents, even those who were open at home, said they would not disclose their status to their colleagues or employers. They mentioned fear of social discrimination and isolation, lowered prestige, and possible job loss as reasons for keeping their status secret. Indeed, many asymptomatic individuals felt there was no need to reveal their status at work as long as they remained physically healthy. Business and industry by and large do not have AIDS policies, and no special benefits are offered to workers with HIV. As a result,
respondents had to make up other excuses whenever they needed to take leave for medical treatment or because of opportunistic infections. Such secrecy interfered with daily treatment schedules — for example, some workers avoided taking medication in the presence of colleagues. It also affected health and safety precautions: respondents were concerned that if they took particular care, they might make others curious.

Social isolation, hostility, and attempts to dismiss HIV-positive workers were reported from both sites. Often this hostility came from co-workers and other staff, who put pressure on management to fire HIV-positive employees. Labelling and isolation sometimes forced HIV-positive workers to leave their jobs and either settle for poorer-paying work or keep moving between jobs to avoid being stigmatized at successive workplaces.

Family context

A majority of respondents had disclosed their seropositive status only within close familial relationships — parental, spousal, or sibling. Within each of these, gender was a significant factor determining the likely response. Daughters, wives, and daughters-in-law experienced greater levels of DSD than sons, husbands, and sons-in-law. The relationship most strained by HIV status was that between parents-in-law and daughter-in-law, followed by the spousal relationship (these observations held true in both study sites). Discrimination against daughters-in-law was blatant even when sons received good familial care. In both sites, women were stigmatized as being of “loose character” and a potential source of infection to their husbands, at the same time as they were expected to provide care:

"My in-laws do not have good opinion about me. They say that my husband got this disease from me. I sometimes feel "Why should I live with this insult? It is better to die." But I am living for the sake of my children." (HIV-positive woman, aged 40)
In most cases, after the death of the son, parents refused to take responsibility for the well-being of their daughter-in-law and asked her to leave. She either had to return to her birth family or was forced to support herself.

For both men and women, the contexts and forms of HIV/AIDS-related discrimination, stigmatization, and denial appear to be influenced by wider social expectations and relationships. Women in particular tended to be seen as wives, mothers, daughters, and daughters-in-law before they were seen as HIV-positive women in their own right. The impact of HIV/AIDS for most men was cushioned by their privileged position in society, while for women it was intensified.

In pregnancy, many women were discriminated against on the grounds of assumed HIV status. These were the wives of men suspected of high-risk sexual behaviour and were targeted for HIV testing before labour. There was a high probability that if found HIV-positive these women would be refused hospital care. No such case was reported by the respondents, but in Mumbai several women, and even men whose wives were pregnant, spoke of their high levels of stress as they went from hospital to nursing home trying to register for maternity services.

Some mothers were forced to give up their babies either because they were too weak to look after them, or because they hoped that if a child tested HIV-negative he or she would be adopted.

"I have sacrificed my child for this [AIDS]. I have kept him away from me so that he can live a happy life. He should learn to live by himself. Some children become HIV negative and then they go for adoption. I pray to God to give him long life – then I don’t mind dying." (HIV-positive woman, aged 28)

Women experienced DSD from their parents-in-law after a husband’s death. A clear distinction was made between the son and the daughter-in-law, even when both shared
he same HIV status. In Mumbai, several HIV-positive women spoke about being
denied medical treatment and a share in the husband’s property, pension, or insurance.

Discrimination was also evident in the quality of food provided and in the attitude of
family members. Widows were often blamed for the son’s death and told to leave the
family home; some were not welcome in their birth homes either. They then faced the
prospect of being both HIV-positive and homeless.

“My husband’s family is looking after me well even now. I prepare lunch and breakfast.
If I get a cut my mother-in-law says, “Put on a bandage quickly.” My husband used to
tell me, “You got this disease from me. You have earned a bad name because of me.”
(HIV positive woman, aged 28)

Such support and care tended to be observed in homes where the husband had been open
in admitting his risk behaviour to the wife and where the in-laws and other family
members had been counselled about HIV/AIDS. In such cases, fear of infection did not
create a rift between the infected daughter-in-law and others, and the daughter-in-law
tended not to be blamed.

Schools

NGOs in both study locations are beginning to acknowledge schools as a setting for
HIV/AIDS-related DSD. Problems – both for the HIV-positive parents of HIV negative
children and for HIV-positive children – were beginning to be observed at the time of the
study. In Mumbai, one HIV-positive couple and one widow of a man who had AIDS
were forced to withdraw their HIV-negative children from school. No specific reasons
were offered by school management, and the affected parents were too afraid to pursue
the matter – in one case, reluctant to have their identity become known to others. As the
grandmother of one child said, “I was afraid that people would talk more if I argued with
the school principal. So we moved the child to a municipal school”. Another school
displayed complete ignorance about HIV transmission routes when refusing to accept an
HIV-negative child of positive parents. The management of the school insisted that the child's presence would adversely affect the other students, even though they were aware that he was HIV-negative. In yet another case, an HIV-positive widow had to get help from social workers to enable her six-year-old son to attend a boarding school in a suburb of Mumbai, which had initially been worried about the possible impact on other children. Where a child was HIV-positive, school staff were generally worried about possible HIV transmission from cuts or injuries following playground fights or in the event of an accident. In Bangalore, such fears made one NGO conceal from the school authorities the sero-status of children in their care. In Mumbai, however, another NGO has been successful in educating the staff of a municipal school about transmission routes and health and safety precautions. As a result, all school-aged children in the care-home are now allowed into the school.

Other childcare institutions, however, continue to discriminate against children with HIV. In a few institutions in Mumbai, destitute children are tested for HIV at the time of admission; if positive — and despite adequate staffing levels and space in the childcare centre — they are either segregated or transferred to an NGO with a designated shelter programme.

HIV/AIDS-related DSD generates numerous fears for people living with HIV. These include:

- fear of AIDS stigma (of being identified with "deviant," "morally sinful" behaviour, mainly sexual promiscuity and visiting sex workers)
- fear of loss of reputation in the family and society
- fear of damaging the family's social reputation
- fear that HIV serostatus will be revealed and of being identified as sexually deviant
- fear of social discrimination and isolation, of being avoided or shunned by others
- fear of being judged and categorized as a member of a "deviant" group such as promiscuous people and gay men
- fear of death and of dying early
- fear of dying uncared for, and being denied last rites
- fear of social ridicule
- fear of various illnesses and debilitating ill-health, of painful conditions, of not receiving medical attention, and of being denied admission to hospital
- fear of being deserted, of loss of significant relationships, and of loss of trust and confidence
- fear of losing one’s job or source of income
- fear of passing the infection to others, whether spouse, children, or other family members.

E. CHILD CARE:

➤ Essentials of good child care:
The essentials of Good care and treatment as reported by UNAIDS in Caring with Confidence, 1997. Good care and treatment improves the quality of life for children with HIV. Providing supportive care at home may be less expensive for the family and more familiar and happier for the child. Providing regular, nutritious food helps the child grow and fight off infections.

Basic care and support needs for all children-with and without HIV
♦ Nutrition-safe weaning and nutritious food.
♦ Care-Consistent parenting, security and love.
♦ Recreation-something and some one to play with.
♦ Education
♦ Prevention of illness - immunisation, good hygiene and a safe environment.
♦ Appropriate management of illness-treatment and supportive care for common infections.

➤ Factors impeding Child care:
The factors impeding child care as quoted in 'HIV and Children' in Health Dialogue:
Many children are first affected by HIV when their parents develop HIV related illnesses. Parents may be too sick to work or they may be too ill to bring their children for
monitoring and growth monitoring. Older children often take over caring for younger brothers and sisters at this time, which means that they start to miss school. Children in households affected by HIV faces number of problems.

**Poverty**

The AIDS epidemic is leading to increasing poverty and wherever poverty increases, children's health gets worse. When poor children get sick they may not get adequate treatment because their care givers cannot afford transport charges, fees or medical costs, or because they cannot spare time away from work and family commitments.

Poverty is also associated with increased risk of HIV infection. Orphaned girls from poor households are vulnerable to HIV because of sexual exploitation by relatives.

**Nutrition**

Children from HIV affected families are often at risk of malnutrition. A sick mother will find it hard to provide nutritious food for her children. Malnutrition is especially likely when young children are cared for by elderly or adolescent care givers who may not be aware of good child feeding practices.

**Substitute parenting**

Mothers are important primary care workers. Health workers spend time educating mothers about good child health practices. If a young child has no mother, the child's health is often worse. As a result of AIDS, grand parents are looking after increasing numbers of children. Often grand parents are unable to care for children adequately. They may be poor, elderly and expected to care for large numbers of grand children. Orphans are often moved from one household to another, sometimes with relatives who neglect,
maltreat or abuse them. Increasingly in AIDS affected communities, relatives are unwilling to foster children, so they are left living alone in child headed households.

➢ Single-headed Families:

A single parent family is established when one of the parents is absent from home due to death, divorce, separation, desertion, migration or imprisonment. Shalini Bharat (1986) found that in India over 80% of all single parent family units likely to have dependant children are established due to the death of the one of the parents. Further it was found that more than 70% of the single parents are mothers. Thus in India, a large number of single parent children are living with mothers who are widows.

Some of the consequent experiences of children of single parents are studied and reported by Shalini Bharat which is mentioned below. The study was exploratory in nature and limited to the lower economic class. A majority of the single parent children reported missing the parent at some time or the other. Usually this sense of parental loss was maximum at the time of festivals, at social gatherings and upon seeing other intact families. Often there is a need among children who have lost a parent to have a substitute parent of the same sex. Feelings of sadness, regret, and at times anger were reported by single parent children on comparing themselves with others of their age from intact families. The children did not seem to have any specific idea about the maternal and paternal roles. The expectation here was that the children from one parent homes, more than those from intact homes, will perceive the maternal role not just as that of a care giver and house wife, but also as that of a bread earner. However the children merely gave descriptions of the mother's role and not their own perceptions. The shouldering of new responsibilities is one of the most likely outcomes for children, in the event of parental loss. The type of responsibilities depend on whether the absent parent is the mother or the father, and could mean earning money, assuming responsibility of the
family, sharing household chores, or looking after siblings. The absence of a parent is often associated with neglect of children and lack of control at home, sometimes resulting in juvenile delinquency, drug addiction and other bad habits. Plenty of school dropouts are reported in the single parent families.

F. SOCIAL WORK INTERVENTIONS IN THE FIELD OF HIV / AIDS:

➢ AIDS as a social problem:

The critical feature that distinguishes AIDS from the other life threatening and fatal illnesses, such as cancer or TB is that it selectively affects adults in their sexually most active ages, which coincide with their prime productive and reproductive years.

The multi-sectoral problems which HIV /AIDS have created are very severe for the following reasons:

1. HIV /AIDS affects the most productive age groups (15-49 years)
2. It exacerbates poverty because the poor have fewer resources to cope and are therefore more likely to experience negative consequences.
3. HIV leads to increased prevalence and incidence of other diseases including tuberculosis and other sexually transmitted diseases.
4. The basic human rights of people with AIDS are often violated through stigmatisation and discrimination. (Source: Integration:1998)

If an adult in a family gets infected with AIDS, the household resources which he earns will be reduced. And medical expenses increases. Reduced income in turn, threatens food supply, the ability to pay for the education or health of surviving family members, and the ability to invest in productive inputs. AIDS threatens more than the capability of a household to function as an economic unit; the entire social fabric of the family is potentially disrupted or dissolved. The loss of either or both parents leaves behind
dependants, both the very young and the elderly who may have been relying on their children for support in old age.

The following has been extracted from 'A Global Report-AIDS in the world', 1994. The HIV infection enters the family through the infected partner to the ignorant partner, and affects the newly born infant from the infected mother. Thus the entire family gets disrupted.

Excessive absenteeism from school or work, because of sickness of self or significant others, results in the loss of productivity. The responsibility of caring for the elders and the orphaned children is shouldered by the governmental and non-governmental organisations.

As heterosexual contact becomes increasingly the predominant mode of transmission worldwide, women and children will become more vulnerable, both as potential AIDS casualties and survivors. Another cause of deep concern is the children who are not affected with HIV, but whose parents are. Often the responsibility to support these children falls on the unwilling extended family members, or on elderly grand-parents with little means of financial or physical support. Another issue of growing concern is the inability of widows and children to acquire rights to the property after the death of the male head of the household. Without access to any decent means of income, widows and children may be forced to petty thefts and commercial sex work, a vicious cycle that could contribute to the increased rates of HIV infection.

➢ Role of a Social Workers in HIV / AIDS Care, Prevention and Treatment:

The contribution of social workers in combating HIV infection / AIDS is enormous right from the onset of the crisis. Social workers like Diego Lopez in New York, Judy Macks in San Francisco, Caitlin Ryan in Atlanta, David Aronstein in Boston, Bill Scott in Houston and Anthony Hillin in London pioneered the design and delivery of the first psycho-social services for people affected by AIDS. These early efforts by social
workers demanded that people with AIDS have their food trays be brought into their rooms instead of being left outside their hospital room doors. They also demanded that the patients not be left to wallow in their own excrement when nursing staffs were too fearful to change their linen. The social workers would be the first to meet and identify HIV infected persons in the community and encourage them to take and adhere to the treatment procedures. They also render counselling to the infected persons as well as their care-givers, assess their high risk behaviour and guide them to the appropriate organisations that cater to their needs. (Source: www.nasw.org)

Assessment of high risk behaviour

This is the initial phase where the social worker elicits information on the high-risk behaviour and which is very necessary because based on it the social worker can provide guidelines on safer sexual practices to the client and decide if she needs to be tested for HIV.

Case work with HIV infected people

Social case work deals with the individual, involving a face to face interaction. The components of social case work are: i) the person, ii) the problem, iii) the place, iv) the process, v) the case worker and client relationship and vi) the problem - solving method.

Every individual is unique in his or her own way. Likewise, the problem of each person too differs in many aspects. So the process of case work should be designed accordingly, to work tailor-made to every client. Therefore, the social worker needs to be enhanced with various skills of social work to be able to help the client in solving his problems.

For instance, a woman married for fifteen years, learnt one day that her husband has AIDS. This shock comes with the awareness of the fact that he has been infidel and is compounded by the need to decide what and how to explain to the children regarding the illness of their father. She would also be worried of the possibility of contracting the
infection herself. In this case, the client would surely be under a different psychological trauma from a person who has been infected through blood transfusion. Therefore, social workers need to handle every client as a unique case though the problems may evolve around the same disease. If a person is diagnosed positive, he/she generally goes through the following reaction, which is a common outcome. It proceeds from shock, disbelief, denial, anger / blame, shame, loss of self-esteem, depression and finally acceptance. The case work process should be formulated to modulate and deal with each and every transitional phase. (Source: www.naswnyc.org)

Counselling

According to WHO in 'Guidelines for Counselling about HIV infection and disease', 1990. Counselling is Dialogue between a client and a care provider aimed at enabling the client to cope with stress and take personal decisions related to HIV / AIDS. Counselling is not the same as giving advice or telling people what they should do. The counsellor's role is to listen to an individual's concerns, provide information and emotional support. There are various types of counselling viz.,

Pre-test counselling: anyone considering a HIV test should always have pre-test counselling to obtain full information about HIV and the test, to help assess if she or he has been at risk, to learn about the implications of testing, to decide whether or not to be tested, to consider the implications of a positive or negative result and to think about preventing HIV infection. Pre-test counselling is also necessary to obtain informed consent.

Post-test counselling: Counselling after a HIV test is as important as pre-test counselling whether or not someone is infected with HIV. It should be private.

The other major forms of counselling rendered to HIV / AIDS patients are supportive counselling, Preventive counselling, Grief counselling and crisis intervention techniques.
Awareness

Conducting awareness programs in the public is also the responsibility of a social worker. Social workers working in Non-governmental organisations (NGOs) identify different areas and design the awareness programs accordingly. They organise campaigns and training programmes in schools and colleges. For example, the NSS-TORC unit of the Madras School of Social Work, funded by the Tamil Nadu State AIDS Control Society, conducted periodical training programmes for many NGOs. They also created massive awareness in HIV/AIDS in High Schools for the standard ten and higher secondary school boys through the programme 'School Talk AIDS'.

The role of a social worker is a continuous process. It extends even after the death of the patient because certain follow-up procedure is necessary in many cases. A bereaved spouse, who may be again a patient, will need counselling and support. When both the parents are dead, it is necessary to follow-up to ensure that the orphaned children are properly taken acre of. The social worker also acts as a liaison between the client and the hospital, the client and the family and the client and the organisation.

G. OTHERS:

➢ Ignorance:

In the developing countries, the HIV/AIDS situation is alarming because of the following factors.

♦ Most people living there do not know what HIV infection is. Only a small fraction of people living with HIV in sub-saharan Africa and the developing countries of Asia know that they are infected with HIV.

♦ Most developing Governments can not take timely counter measures against HIV/AIDS, though they know how to prevent HTV and treat HIV/AIDS. The majority of people infected with HIV lack even the most basic treatment for opportunistic infections.
- HIV/AIDS is just one of health problems that affects developing countries. HIV/AIDS may not be a serious problem for those who have no access to safe drinking water, sufficient food, or adequate housing. (Integration, Fall, 1998)

Talking about counselling, Dr. Prasad says, 'I do the post test counselling. The reactions largely depend on the level of awareness. Some do not understand the seriousness at all. Some girls even giggle when I tell them that they are HIV positive. Many feel that it will not happen to them. If there is a programme on TV on a general health problem, they may watch it. But if it is anything on AIDS, they just switch channels. Some women, who know all about it, are shattered when they are told about being positive. The men are shattered too for they know that they infected their spouse.' (The Hindu, 24 Nov, 2002)

➢ Needs assessment:

Needs assessment was done for people with HIV by YRG centre for AIDS and it was found that the greatest needs were health care and medicines.

Priority of needs

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<td>Access to medicines</td>
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Source: (XIII International AIDS conference report, July 2001)