AIDS AND LAW

GURMEET HANS

This paper was presented by the author at the 'Seminar on AIDS and Laws', organised by the Young Lawyers Forum on November 23, 1996, at Pune. It discusses the ethical and legal aspects of HIV/AIDS and cautions against short-sighted legal solutions to the complex issue. Legislation must play a positive role of integrating affected persons in society by protecting them from discrimination. Besides the protective role, the proactive and instrumental role of law is seen to be important in containing the HIV/AIDS pandemic.

Ms. Gurmeet Hans is Head of the National Service Scheme Unit, Tata Institute of Social Sciences, Mumbai.

Five years after Columbus returned from his encounter with the New World in 1497, there was an outbreak of disease, supposed to be venereal, in the city of Edinburgh, Scotland. It spread quickly through Europe. The King of Scotland and his council, terribly alarmed at this contagious 'distemper', issued a proclamation of the Sovereign Lord's will and command. The sickness was named Grandgor. Those who suffered from it were commanded to pass far out of the town to the Island of Frith. If their bodies survived, they were obliged to take an unspecified cure. Anyone who did not comply with this command, was ordered to be :

> Burnt on the cheek with the marking of iron that they may be known in the times to come and thereafter if any of them remain they shall be banished.

The question for us in the context of HIV/AIDS is whether we will subscribe to panic, alarm, banishment, cruelty and public stigmatisation 500 years after King James IV issued his proclamation against Grandgor. Hopefully not, as during these long years we have advanced

in our appreciation of the limits and opportunities of law in the face of a public health crisis.

Legal Responses to AIDS in the World

Protection against epidemics is one of the main tasks of the public health authorities emanating from the human right to health. Additionally, in the international law, public health has been accepted as a legitimate ground for limiting human rights. Public health developed through centuries by coercion, compulsion and restriction, does not readily adjust to the requirements of human rights. The ways in which many countries have responded to the AIDS epidemic have created a wide range of human rights problems by imposing coercive or restrictive AIDS control measures.

In the first decade of HIV/AIDS (1981-90), 104 countries adopted some or the other AIDS related legislation. The period 1985-87 represented the peak of the global epidemic of AIDS legislation. During this period, the cumulative number of countries with AIDS legislation quadrupled, from 18 in the beginning of 1985 to 78 by the end of 1987 (Mann, David, Tarantola and Netter, 1994:543-44). Thus where technology was unable to provide a solution to the spread of disease, people looked to the law. It is not confirmed that countries which had high prevalence enacted laws as even those without any single reported case of AIDS or HIV infection (for example Vietnam and Mongolia) too adopted AIDS related laws. Excessive AIDS control measures have been adopted in some countries not as a HIV/AIDS response inside their own borders, but ostensibly to prevent its importation.

The first legislation, requiring the reporting of suspected and confirmed cases of AIDS was enacted in Sweden in March 1983, and was followed by similar laws in many European countries. Most often this early legislation established safeguards to promote blood safety (through donor referral) and introduced compulsory notification of AIDS cases. Until 1985 no country adopted a comprehensive law on AIDS, in part because a test for HIV infection had not yet been developed.

Analysis of subsequent laws reveal that the availability of a test to detect HIV antibodies was the driving force behind the legislation. Most of the laws dealt directly with testing, and many authorised public health authorities to carry out compulsory tests. The legal authorisation to isolate people, detain them or force them into hospitals often

appeared alongside provisions of compulsory testing. Only Cuba has officially adopted mandatory and automatic hospitalisation of all HIV infected people (it has not been actually implemented fully). Those found to be infected went underground out of fear of isolation.

Many other countries have passed laws empowering public health authorities to resort to restrictive measures. These include placing HIV infected people under surveillance, isolation or segregation, mandatory hospitalisation, or imposing specific restrictions on their behaviour. Information on the actual application of restrictions is not available for many countries.

The early phase of HIV/AIDS in India was dominated by responses that aimed to isolate those infected. Foreigners were blamed for the spread of HIV and opinion was in favour of their strict regulated entry into the country. In 1988, the Ministry of External Affairs, Government of India introduced compulsory medical examination for foreign visitors to contain the AIDS problem. All foreign visitors above 18 years, foreign students, and journalists seeking accreditation intending to stay for a year or more were expected to go through compulsory medical examination. Despite this provision, it is known that some universities have stopped taking African students out of fear that most of them are carriers of the virus.

The only state in India to have a specific law on HIV is Goa. The Goa Public Health Amendment Act, 1988, provides for mandatory testing of persons suspected of being HIV positive. Those infected can be mandatorily isolated, thus, resulting in breach of confidentiality. Mandatory isolation was later made discretionary. To date, one case in 1988 was held under the Act.

On the same lines as the Goa Public Health Amendment Act 1988, the Government of India sought to introduce the AIDS Bill in 1989. However, on account of pressure from the World Health Organisation and the campaigns by voluntary groups, the AIDS Bill could not be enacted into law. There is a great need to protect and promote the confidentiality with respect to persons with AIDS. This confidentiality is also important with respect to implications on any legislation regarding AIDS and HIV. The AIDS Bill failed the test on this account and also as it was not helpful in the prevention of HIV/AIDS.

Most of these legal measures were characterised by mandatory testing, isolation of infected persons, breach of confidentiality and discrimination against positive person. Such coercive and punitive measures, are counter-productive and impede efforts to prevent

infection and provide care. They also tend to target at groups, while it is certain behaviors and practices that are responsible for transmission.

In other words these legal measures, so far, had a semblance to the command of the King of Scotland in response to Grandgor. After a decade of experience with HIV/AIDS, there is enough indication to show that none of the above measures are at all useful to contain the spread of infection — which is our prime concern. On the other hand, these measures tend to induce fear of isolation, deprivation, stigmatisation, thus pushing people into hiding their infection status even where it should be revealed say to the spouse, surgeon, and so on.

It is pertinent to recall that the Leprosy Act of 1912 permitted discrimination against those affected by leprosy. The Act was formulated before the cure for leprosy was found. It thoughtlessly continues to be there even after a cure for leprosy has been found. Maharashtra repealed the act some time ago. The stigma associated with leprosy is intense, even today, because of discrimination authorised by the Act. Today, even though leprosy is curable and it is well known that not all forms of leprosy are contagious, discrimination continues. There is no law to protect afflicted persons from this discrimination. It is necessary to refrain from enacting laws that justify violation of human rights.

In the case of HIV we need to remember that HIV is not contagious. It is communicable by very specific modes, which can be prevented by known, simple, specific measures. Further, infected persons are fit enough to perform their day to day duties without any adverse effects on their health until the first six to about 10-15 years of infection. If at all there is need to interpret any laws in the context of HIV/AIDS, a difference should be made between those who are carriers of infection and those who have developed AIDS.

Need to Avoid Scapegoating

Homosexuals and sex workers have been easy targets of discrimination. In some countries gays have reported more violent attacks on them since the onset of this pandemic. In India, sodomy/homosexuality has been a crime for 200 years that is, well before the advent of HIV/AIDS. But it continues to exist. Legislation has limited role to play in matters as private and personal as these. Neither is it fair to blame homosexuals for the pandemic. Besides, unprotected anal sex which puts homosexuals to risk of infection, is also practiced by heterosexual couples. Thus, heterosexual couples practicing unprotected anal sex are as much at risk as homosexuals are.

There is also a tendency to proscribe prostitution or to penalise those involved. Past experience suggests that repressive measures do not eradicate prostitution. They simply make it even more stigmatised and covert. Prostitutes are not problems; they are people. Prostitution is an ancient and well-established occupation. It is fostered by a huge demand and by a multiplicity of social, psychological and economic factors. If prostitution spreads AIDS, then this is because of something very basic in sexuality, especially that of the human male. Little will be gained by making scapegoats of a particular section of society. What we need to achieve is a condition away from multiple sexual partners. Legislation may have very limited role in that.

Licensing commercial sex (male or female prostitution), with a view to stop them from practicing if they are infected, is not a solution. A commercial sex worker is herself exposed to the risk of infection from her male clients several times each day. How often will this testing be done ? What will be the dependability of a test that has the possibility of a false positive or a false negative result ? What will it cost ? Even if it was possible to test, and cancel or renew the license on the basis of its results, how would it be ensured that those without license do not practice ? Besides, the view in favour of testing commercial sex workers is based on prejudice towards them. One could well visualise a scenario, where the client should produce a HIV free result before utilising the services of a sex worker. The point is, if commercial sex workers are seen as sources of transmission so are their clients. Therefore, making the prostitutes scapegoats will not help. They need to have better health services and access to health education, including HIV/AIDS education. They need to understand the need for protected sex and opportunities for rehabilitation to take to other occupations, if they are HIV infected. Poverty and illiteracy, the two driving forces behind the increasing numbers of prostitutes, are wider social phenomenon which should be addressed.

That assumptions like prostitutes are a cause of HIV/AIDS are baseless is well evidenced by the report that follows in this paragraph.In a study of 4,500 persons referred by physicians to AIDS Research Control Organisation, Mumbai on suspicion of HIV infection, 52 per cent were found to test positive. This was between 1994-96. Most of them had not had contact with commercial sex workers. They were exposed to the infection through pre-marital sex and extra marital encounters, with sexual partners of their own community (Chinai, 1996). This finding reveals that the feeling of security

afforded by marital status is false. It also shows the false sense of security given by scapegoating prostitutes. It is equally unsafe to have direct or indirect multiple sexual contact with just anyone, including one's own spouse.

Need **to Integrate Persons with HIV/AIDS in Society**

A strategy that helps the infected persons to be integrated with the mainstream of society, will be a healthy compliment to education for responsible behaviour change programmes. No legislation can effectively control the behaviour of an individual. The controls for this lie within each individual. The challenge in the strategy for prevention and control is to create a motivational intrinsic and extrinsic environment for responsible behaviour.

This is not to say that legislation has no place. In fact the ongoing reports of serious and unjustified encroachments on the civil liberties of people with HIV have established beyond doubt that the law has a central role to play in the HIV/AIDS policy. What should these legal responses be? Can legislation assist in strategies for the care and treatment of people with HIV/AIDS?

Experience has shown that respect for human rights is necessary to protect public health and implement AIDS control programmes. Protective legislation that protects the basic human rights of persons with HIV/AIDS are necessary.

The Global Programme on AIDS (GPA), WHO, has identified the following key elements essential to protect human rights ethics vis-a-vis HIV/AIDS and law (GPA, 1995:1-3).

Access to Information, Education and Health Services

All people should have equal access to available information, health services and prevention methods that will enable them to reduce transmission of infection and receive counselling and care, if infected. Powerless sections must have equal access to these.

Testing/Informed Consent

Testing for HIV should be carried out on a voluntary basis after the individual has been informed of the nature and implications of the test and has consented to being tested during pretest counselling. Special protection regarding voluntariness should be afforded to those legally not competent to give consent, for example minors and the mentally

disabled. Informed consent should also be obtained for participation in HIV-related treatment and research.

It is known that patients who have to undergo surgery, in many hospitals are being tested for HIV without consent, and are being sent away if found positive.

Confidentiality

Confidentiality of HIV status should be ensured at all times, including during testing, treatment, notification and in the employment and health care settings. Any disclosure should be strictly justified on the basis of law and professional ethics.

Non-discrimination

There should be no discrimination or restriction of rights based on HIV status or suspicion of HIV status. People living with HIV/AIDS should have equal access to education, travel, employment, housing, health care and a non-discriminatory cremation or burial. Mandatory testing or disclosure of status should not be required to gain access to these. We may recall that Dominic D'Souza (who was held under the Goa Act) lost his job with the World Wildlife Fund after he was diagnosed as HIV positive. Children with HIV infected parents have been discharged from schools, even when they are themselves negative. Instances like these, reveal the ignorance and deep-rooted fears of people, including the educated community. In fact HIV poses no risk to colleagues or classmates as it does not spread through casual contacts. There is no ground for discrimination.

There is a very peculiar kind of social discrimination in the case of HIV infection, not found in any other illness. People infected through the blood route are seen as being innocent victims and deserving care, while those infected by the sexual route are seen as immoral or guilty and, therefore, unworthy of care. A person injured by an accident is given the necessary medical care and family attention, without a thought regarding whether he/she was on the right or the wrong side of the road; a patient who suffers a heart attack is given due medical and family attention irrespective of the factors that may have triggered the attack, whether these are stress at work due to a nagging boss, or a raid in the house for suspected evasion of income tax or may be anything else. Persons infected by the HIV virus are also worthy of medical care and family love and attention, irrespective of how they

got infected. Infected persons must be protected legally from any discrimination arising from the source of infection.

Liberty and Freedom of Movement

People living with HIV/AIDS should not be denied liberty or freedom of movement by arrest, detention, isolation, quarantine, compulsory hospitalisation, segregation or exile, except as justly imposed by law; or be denied the right to seek and enjoy asylum from persecution. Travel restrictions which discriminate solely on the basis of HIV status have no public health justification and violate human rights.

The Goa Public Health Amendment Act must be repealed. Similarly, restrictions on entry of foreign visitors on this ground cannot be justified. Local infection has very much begun in India, and we can no longer live in the illusion that foreigners are responsible for this infection and restrictions on their entry is one of the solution.

In Manipur, patients infected with HIV have been known to be tied to chains, and kept in isolated villages or concentration camps. The law must protect persons with HIV/AIDS from this indignity.

Right to Marry and Found a Family

Counselling infected persons must be an important part of the HIV/AIDS control programme. Infected persons must be helped to see the consequences of their decisions in life matters, upon themselves, upon those who care for them and upon society. Given proper counselling, they may be trusted to generally take responsible decisions regarding marriage, having children, and so on. Even if they do not do so, it will not be possible to impose preferred choices on them by law. This will only lead to a situation where people will conceal their infection status. This will have several other unhealthy repercussions for society. Even if the infection status is known after marriage, couples must be encouraged to live together by adopting safety measures even if either partner is infected. It should not be a cause of divorce. The remedy of divorce in such cases at the societal level will be far worse than the disease itself. Divorce could probably be sought on grounds of cruelty if the infected member deliberately insists on unsafe behaviour that puts the spouse to risk of infection. Under the Indian law, divorce could be granted if the partner is suffering from an incurable disease. As AIDS is incurable so far, it would legally qualify as a reason for granting divorce. As it is possible to prevent the spread of infection by specific measures, there is no reason why a couple could

not continue to live together. To my view, existing laws like the one on divorce must be reviewed, to prevent people from seeking easy solutions to the problem of HIV/AIDS.

Premarital and prenatal HIV testing should be voluntary and based on informed consent. Women should be advised of the risk of perinatal transmission and means to avoid such transmission. If pregnant, women living with HIV/AIDS, should have equal access to assistance during pregnancy and after delivery. There should be no coerced abortions or involuntary sterilisation due to HIV status.

Premarital testing may provide a false sense of security. Infection status of an uninfected person need not be static. The risk of exposure to infection by the blood or sexual route can change one's infection status. Therefore, there is no point in making premarital testing mandatory. However if one wants to voluntarily opt for it one may have a choice to do so.

Freedom from Forced Servitude/Inhuman Treatment

People over whom power is exercised through tradition, custom, poverty or criminal organisations should be empowered so as to be able to protect themselves from infection. Such groups include women in economic and sexual subordination; men, women and children in the sex trade; illegal migrants; and disenfranchised groups.

Some Areas of Legal Action

The foregoing discussion points to some areas where legal provisions may be helpful. These are stated below:

1. Protective legislation seems to be necessary to protect those who are infected, to prevent discrimination against them where their infection status or their disease does not pose a threat to those whom they deal with at their work place, in public places, or elsewhere.

   Grover (1996) points out that there are certain articles like Articles 14, 15 and 16 in the Constitution of India that provide for anti-discriminatory provisions. However within the meaning of Article 12, these apply only to the 'State'. They do not apply to the private sector (Grover, 1996). This is a major loophole that needs to be plugged if discrimination is to be contained. A positive law that will protect the common citizen from forced testing, breach of confidentiality and discrimination and that which will

honour his/her right to treatment, education,employment, public accommodation, is the need of the hour.

An exercise to review existing laws seems to be necessary, to see if special provisions are required to prevent the discrimination of persons with HIV/AIDS.

2. Proactive legislation to control of infection spread through health-care professionals seems to be necessary. The workshop on 'Ethical Concerns in the AIDS Problem', organised by the F.I.A.M.C. Bio-medical Ethics Centre, in 1991 addressed itself to the obligations of health care professionals, patients and society in the face of HIV/AIDS challenge (Vas and D'Souza, 1991). The conclusions of the workshop are based on ethical considerations revolving around human rights. If one studies the conclusions of this workshop, it is clear that the medical ethics cover a range of issues that arise in the treatment of persons with HIV/AIDS. What is required is probably a stricter enforcement of medical ethics by the professional bodies. This has been a weak area in our health care system. There are hardly any reported cases of breach of ethics or where any substantial action had been taken where breach has been confirmed.

Besides medical ethics, the quality of medical care also cause concern in the case of the HIV/AIDS pandemic. Though it appears that the government hospitals are relatively better monitored on these accounts, the mushrooming private nursing homes are infamously trespassing the dignity of patients even otherwise. The HIV/AIDS persons are likely to be even further affected in this scenario. There is a strong case for legal provisions to enforce stricter licensing of private nursing homes, polyclinics, blood banks and adherence to ethics of medical practice. Currently there is a multi-agency monitoring of private nursing homes/polyclinics. Apathy of monitoring agencies, combined with the apathy of the users of these services has played havoc in a climate where demand exceeds supply. Though medical services are now covered under the Consumer Protection Act, in the absence of standardisation of norms of expected service, clients are not quite sure of what was due to them and what they get. There is need to debate whether the law could play a more instrumental role in this matter, if norms of expected services are specified, standardised and made public.

3. Whether legal provisions could make HIV/AIDS education a responsibility of the government, whereby it is bound to create

mechanisms of reaching remote corners of the country through networking of various government and non-government bodies equipped/or may be equipped to undertake the task in a given time frame, with a follow up on a sustained basis. It is popularly known that the money spent on HIV/AIDS runs into very high figures, yet the coverage of these programmes has been limited. If we go on tinkering at this pace, it may be a bit too late for us to contain the pandemic.

4. Finally legislation has an instrumental role to play in the improvement of women's status as women are likely to be the worst sufferers of HIV/AIDS, due to their subordinate status in society. Their suffering could be reduced, if they have equal opportunities for employment and inheritance of property. The Civil Law has made some favourable amendments in this regard, but in India many communities are governed by their Personal Laws, which are discriminatory.

Poverty leaves people with options which are hardly safe from the risk of infection. After five decades of the country's independence, the problems of poverty and unemployment have multiplied. Simultaneously, the provision of social security seems to be unthinkable. Legislation that calls for compulsory public audit of government policy and programmes, needs to be considered. Winning an election by majority votes cannot be considered to be a substitute for public audit, particularly where poverty and illiteracy are rampant. A lot more creative thinking needs to go into areas of this kind.

There is much that could be achieved if lawyers could be trained to acquire skills in the positive interpretation of existing laws in the context of HIV/AIDS. They must be trained to see it as a disease rather than a crime. Education and awareness of all sections of people — public, educationists, doctors, nurses, lawyers, and so on holds the key to managing the AIDS crisis with dignity.

REFERENCES

Chinai, R. 1996 — AIDS Virus Spreading Fast in Suburban Areas, *The Times of India,* 26, November 3.

Global Programme on **AIDS** 1995 — *HIV/AIDS: Human Rights Ethics and Law,* Geneva: World Health Organisation.

Grover, A
1996
The Crying Need for an HIV Statute, *Bulletin: From the Lawyers Collective*, 11(6), 6.

Mann, J., David, J.M., Tarantola, T. and Netter, W. (Eds.)
1994
AIDS in the World: A Global Report (Indian Edition), Bombay: Tata Institute of Social Sciences.

Vas, C.J. and D'Souza, E.J.
1991
Ethical Cancers in the AIDS Problems, Mumbai: FIAMC Bio-medical Ethics Centre.