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SOUTH ASIA

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AIDS in India Part I: A Government in Denial

BOMBAY, India

July 1996

By Pramila Jayapal

July 1994: "AIDS is not a problem in India."

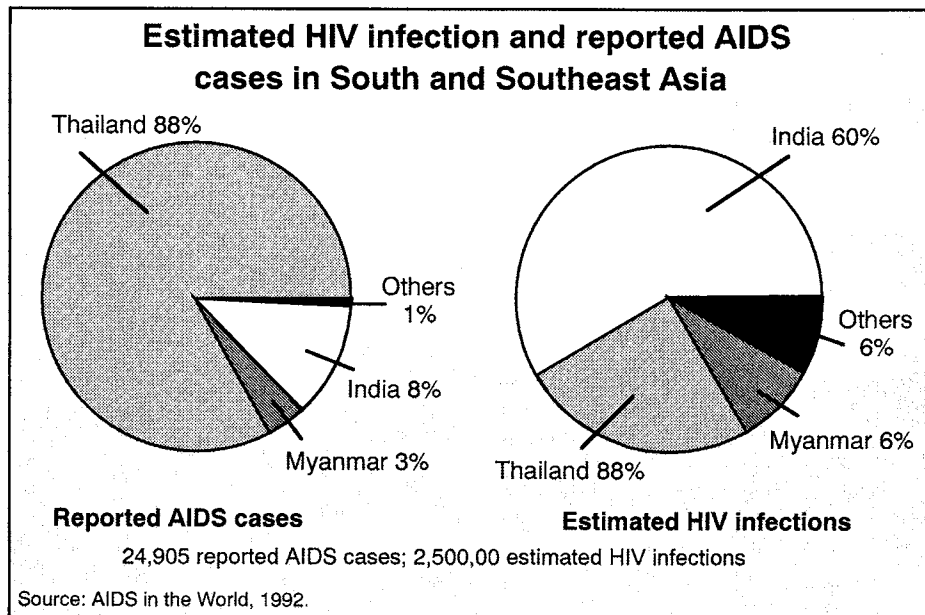
—India's Health Minister B. Shankaranand, at the 12th Annual convention of the American Association of Physicians from India¹

July 1996: "It is estimated that India now has the largest number of HIV-infected people in the world."

—Dr. Peter Piot, head of the Joint U.N. Program on HIV/AIDS* (UNAIDS) at the 1996 International Conference on AIDS²

Health Minister Shankaranand was in the tight clutches of denial or ignorance when he made his statement in 1994. Either is unforgivable for the ultimate "protector of health" in this country. Had he learned from the lessons offered by HIV/AIDS around the world, perhaps Peter Piot's statement would not have come so early — or perhaps at all.

According to a recent study conducted by the Thames Valley University in London, India is becoming "an express train hurtling down the tracks into the whirlwind" of an AIDS epidemic.³ UNAIDS estimates that India now has over three million HIV-infected individuals. Put into perspective, this is over three times the number of



1. Dr. Raj Bothra, member of the National AIDS Commission, *AIDS Asia*, October 1994.

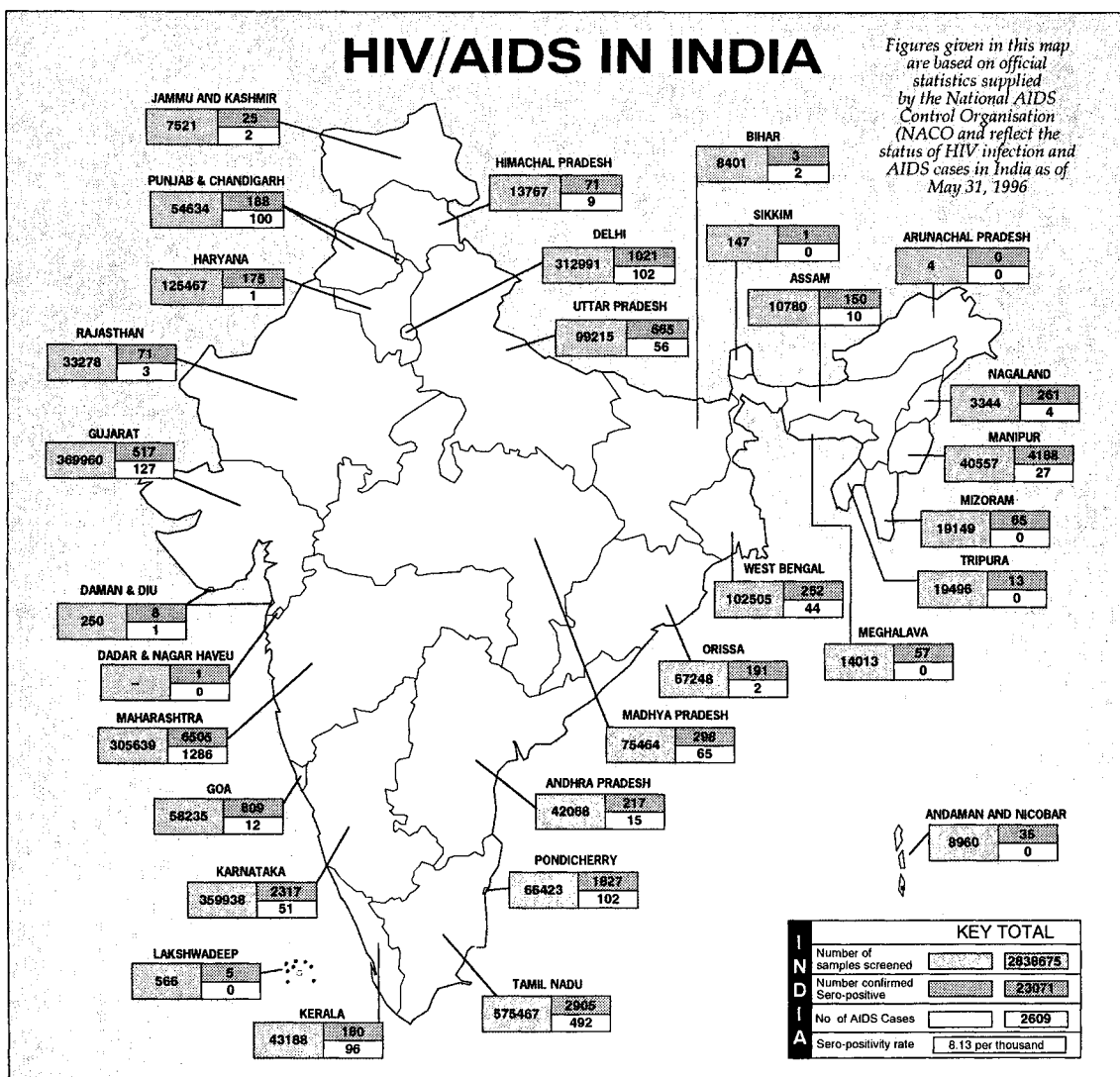
2. *The Times of India*, July 10, 1996.

3. *The Economic Times*, May 28, 1996.

* The Joint U.N. Program on HIV/AIDS (run by the UNDP) replaced what used to be the World Health Organization's Global Programme on AIDS (WHO/GPA).

HIV/AIDS IN INDIA

Figures given in this map are based on official statistics supplied by the National AIDS Control Organisation (NACO) and reflect the status of HIV infection and AIDS cases in India as of May 31, 1996



Source: Nexus, June-July 1996. Published by Population Services, International, New Delhi

estimated HIV infections in Thailand (often thought of until now as the center of the Asian epidemic),⁴ double the number in Uganda, and three times the number in Kenya. By the turn of the century, UNAIDS projects, India will have between 5 million and 8 million HIV-infected individuals and 1.5 million AIDS cases.

Given that cumulative, reported HIV and AIDS cases as of May 1996 total only 22,529 and 2,528 respectively, the gap between estimates or projections and the actual number of reported cases looms large. Estimates are based on the assumption that only one in every 100 HIV infections is reported. Projections for the year 2000 have been calculated using a model derived from epidemiological patterns of HIV transmission in other countries.

The under-reporting of HIV/AIDS cases is due to several factors, including: lack of access to public health facilities where screening occurs; India's gener-

ally poor public-health reporting and monitoring system; problems with clinical diagnosis of HIV/AIDS; political denial that, some suspect, contributes to suppression of real numbers; and the social stigma attached to the disease. Even AIDS deaths are often not reported as such, but are rather recorded as death due to a secondary infection such as TB, which thrives in the weakened immune system of an HIV or AIDS patient. HIV-infected individuals, for example, are said to be 30 times more at risk of developing clinical TB than the public at large.

The large gap between estimates and reported numbers leaves room for differing opinions about estimates of HIV and AIDS cases in India. The first person I interviewed, Dr. I.S. Gilada of the voluntary Indian Health Organization (IHO) in Bombay*, projects 20-50 million HIV cases in India by 2000 (Gilada and his estimates are quoted in the recent July 29 *TIME* Magazine

4. "India Has Largest Number of HIV-Infected People," *Express Standard*, October 27, 1995.

* The official name of Bombay has been changed to Mumbai. However, for the sake of reader familiarity, I have continued to use the name Bombay throughout this article.

article on AIDS in India). At the other extreme are individuals like a senior consultant to the National AIDS Control Organization (NACO) in Delhi who, although going along with the UNAIDS projections publicly, privately assured me that they were overstated. This official, who asked to remain anonymous, believes personally that the true numbers are only half those estimated by UNAIDS. Trying to separate the fears, denials and ulterior motives from the facts about HIV/AIDS prevalence in India turned out to be a remarkably difficult task.

What is the truth? Who is "right?" Only time will tell, and in the absence of certainty, each of us must come to our own informed decisions about who and what to believe. This means understanding that no estimates or projections represent "truth," but some are grounded in sound logic and the experiences with the spread of HIV/AIDS in other countries around the world. The NACO consultant made several contradictory statements to me that led me to believe his comments were designed to make the government "look good." At the same time, I do not give much credence to Gilada's numbers, which often get publicity only because they are sensational. They are based on extrapolating HIV prevalence in large urban areas to the country at large. However, epidemiological studies from other countries have shown that it is more appropriate to assume that prevalence rates at the district and rural levels are one-half and one-tenth (respectively) of metropolitan city prevalence rates. Gilada's extreme projections may serve to raise awareness abroad and within India about the seriousness of the problem, but they are even more likely to be seen as improbable, and will give critics within the society one more excuse to discredit the seriousness of the disease.

UNAID's projections appear to be the most substantiated and credible, supported by epidemiological trends and experiences of other countries with similar socio-economic conditions and modes of transmission. While not as dramatic as those offered by IHO, they still remain extremely ominous for India as she looks into the next century.

The Spread of HIV in India

Dr. Subhash Hira is the Director of the AIDS Research and Control Centre* (ARCON) at J.J. Hospital in Bombay. Prior to returning to India some years back, he lived through the Zambia epidemic, helping to establish and monitor that country's AIDS control program. For Hira, AIDS is not just a theoretical exercise in preparation, as it still is for many AIDS officials in India. He has watched it ruthlessly ravage Zambia and the rest of Africa, as if it were the fury of the Gods unleashed on the world.

"India has missed a vital opportunity to control

AIDS," says Hira in ARCON's office in the Skin and Leprosy Building of J.J. Hospital. "The HIV/AIDS epidemic progresses in distinct phases. Phase I is when high-risk individuals transmit the virus among themselves. For India, Phase I was from 1987 to 1992. This was the critical window of opportunity for the government to manage the spread of the epidemic. The world has seen through the experiences of other countries that after general prevalence rates reach one percent in major metropolitan areas, there is a geometric progression of infection rates in a country. It is when the infection is confined to a small community of individuals that we can be most successful in preventing its spread. By not acting quickly and decisively during Phase I, the Indian government missed its opportunity to control the spread of the epidemic."

Phase II, according to Hira, is when HIV spreads beyond "high-risk" communities to large numbers of the general public. India is currently at the end of this phase, which began in 1993 and will continue through 1997. Studies recently done on general populations of the community have shown high prevalence of HIV. Specifically, women tested at antenatal clinics and voluntary blood-donor agencies have shown HIV-prevalence rates of 2.6 percent and 2.2 percent, respectively. Although early statistics of high HIV infection came almost exclusively from studies of "high-risk" populations like commercial sex workers or IV drug users, those who believe it is still confined to these groups — and there are many — are in Health Minister Shankaranand's company of denial or ignorance.

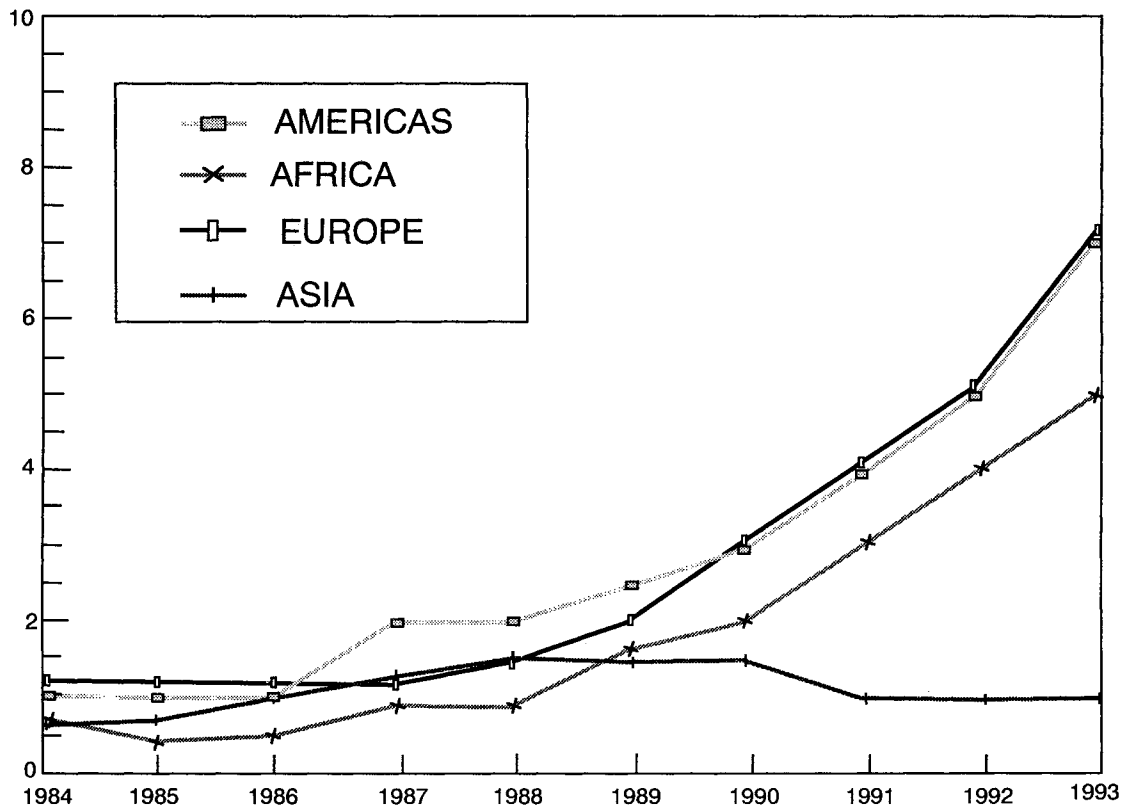
"Phase III in India will be from 1997 onwards," says Hira. "This is the time when 'high-risk' populations have become peripheral to the infection, and there is a large enough percentage of the community infected to keep the epidemic fueled. The most distinctive feature of Phase III will be vertical transmission from HIV-infected mother to child. A whole new generation of HIV-infected children will be born." Accepted estimates for vertical transmission from mother to child are that 30 percent of children born to HIV-positive mothers will also be HIV-positive.⁵

Experts measure the speed of the HIV/AIDS epidemic by its "doubling time," the estimated time it will take for the number of HIV or AIDS cases to double. They put India's AIDS-case doubling time at 12-18 months, and the HIV-case doubling time at two years. Rapid doubling times, like India's, are facilitated by other factors like low socio-economic conditions, prevalence of other diseases that aid the HIV virus in weakening the body's immune system, and the heterosexual mode of transmission. As the epidemic progresses, doubling times generally slow (see graph 1, page 4), due to prevention and control programs, and the fact that early statistics always focus on limited "high-risk" groups where prevalence increases more rapidly.*

5. Interview with Dr. Jagavkar, J.J. Hospital, Bombay, July 1996.

* ARCON is a 5-year collaborative project between The Government of Maharashtra State and The University of Texas.

AIDS CASE-DOUBLING TIME



Source: The AIDS Research and Control Centre (ARCON) in Bombay.

However, in many African countries, the current slow doubling time of five years indicates saturation of HIV/AIDS in the population, and not successful control and prevention efforts.

According to Hira, the single biggest difference in the fight against AIDS in Africa and in India is the lack of political commitment in India. "In Africa, [political commitment] was low in the early stages, but never absent. The Indian central government's commitment is nil," Hira says, his gentle voice belying the frustration he has faced in launching HIV/AIDS prevention efforts over the years. "Also, there is a huge bureaucracy in India that wasn't there in Africa — at least not to this level — that makes it difficult to get things done quickly, something that is of prime importance in checking the spread of HIV."

In spite of having reached Phase III of the epidemic, the Indian government has responded to HIV/AIDS sluggishly, at best. Its lack of concern has rubbed off on and facilitated a similar response from the general public. There appear to be two primary reasons for the lack of political commitment to HIV/AIDS. First, the Indian government tends toward fatalism and inaction, toward *not* doing anything until it is too late. "There has to be a huge reaction that forces an action," says Hira.

Second, as a virus that is sexually transmitted, HIV falls within the category of diseases that are culturally taboo to discuss, let alone deal with. Unfortunately, control and prevention of HIV *requires* open discussions about and understanding of Indian attitudes towards sex and sexuality. Without these, interventions will be treating only symptoms of the problem, not root causes. ("AIDS in India Part II" (PJ-14) will focus on this second issue.)

The Government's Response: Too Little, Too Late

I met the senior NACO consultant I referred to above at his home in New Delhi. As soon as I mentioned that I was writing about the government's response to HIV/AIDS, he interrupted me with "The government's response has been tremendous." With a professorial air, he recited the "accomplishments" listed in all of NACO's reports. According to him, the Indian Council of Medical Research (ICMR) "jumped into action" shortly after detection of the first AIDS case in India in 1986. It established 30 HIV-testing centers nationally that were to monitor the spread of HIV, determine the major modes of transmission and begin blood screening for transfusion safety.

Most people outside the Government disagree with

* Gilada's projections quoted in the recent *TIME* use an 18-month doubling time, and assume this will continue until the year 2000. Most experts do not agree with this method.



The crowded streets of Bombay, India's "AIDS capital." Over 50 percent of reported AIDS cases to date are from the state of Maharashtra.

the NACO consultant about his assessment of the Government's rapid response. They contend that although the HIV-testing centers were created, proposed surveillance and other activities — like awareness and counseling — never really took off. This, according to Dr. Khorshed M. Pavri, former Director of the National Institute of Virology at Pune, was due to "complacency and lack of implementation."⁶ Furthermore, during this critical first phase of the epidemic (1987-1992), funding for AIDS activities totaled only U.S.\$11 million, or an average of \$2.2 million annually. Of the total amount, the Government of India contributed \$6.5 million; the rest was supplemented by the World Bank.⁷ Compare this to the Government of Thailand, which, in 1991 alone (a few years after the epidemic had surfaced in the country), allocated U.S.\$120 million of its own funds to AIDS — for a country whose population is about one-seventh of India's!

Even with the funds available, only 15 percent was allocated to awareness and education activities. Rather, most funds were spent on purchasing HIV test kits and other testing hardware, and on ensuring blood safety.⁸ While these were critical initial activities, there was no planning for how to handle people who tested positive, no funds spent on overall coordination of efforts, no structure of accountability.

In 1991, the government finally developed a strategic plan for AIDS control and prevention for the period 1992-1997. It was not until 1992 that NACO was set up as the coordinating body that would oversee imple-

mentation of this strategic plan and all AIDS activities. But by 1992, India was already moving from Phase I to Phase II of the epidemic, and the opportunity to adopt truly effective control and prevention measures was lost.

The period 1992-1995 saw an increased amount of funds in the form of a five-year, \$85 million World Bank loan, with a larger 40 percent dedicated to awareness and education activities.⁹ However, as of December 1995 when 70 percent of the loan term had elapsed, India had utilized only one fourth of the available credit. The December 1995 NACO newsletter, *AIDS in India*, issued a call to states cautioning that "The [World Bank/NACO project] is coming to a close by March 31, 1997... This makes it necessary that the balance of the Credit is utilized within the remaining one year and three months. States/Union Territories are expected to make all efforts to utilize the full allocations [for this year and next year]." This push to disburse money has created a host of other problems, including disbursement of funds to groups that do not have the understanding and experience necessary to run effective AIDS programs.

Even issues that were supposedly given early attention remain problems. For example, despite the early focus on blood safety, blood is far from safe. NACO estimates that about 13 percent of HIV infections and 10 percent of AIDS cases have occurred through infected blood transfusions.¹⁰ The NACO consultant I spoke with assured me that "today, 100 percent of blood in

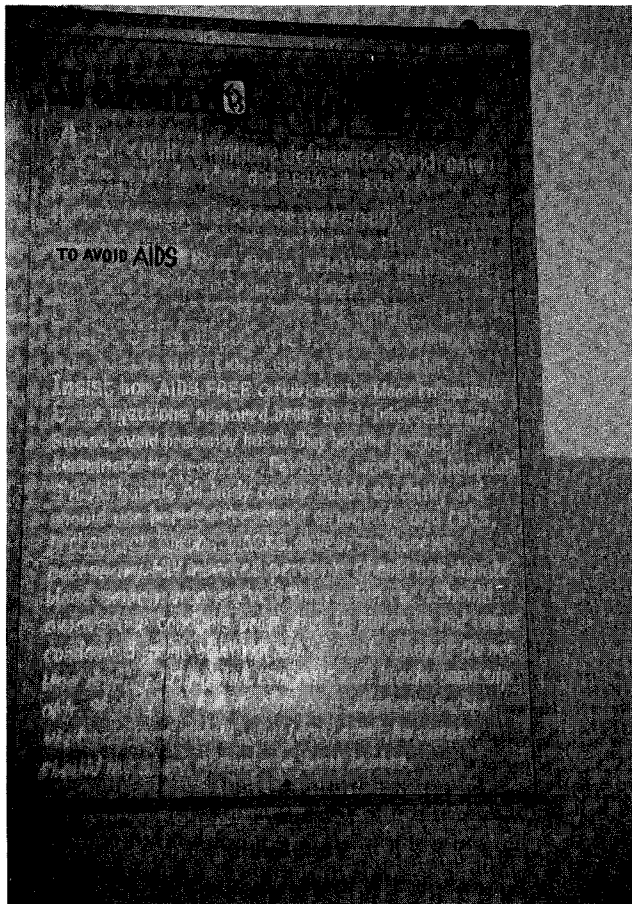
6. Dr. Khorshed M. Pavri, "Challenge of AIDS" (National Book Trust, New Delhi, 1992), p. 19.

7. *NACO Country Scenario Update*, December 1995.

8. *Ibid.*

9. *Ibid.*

10. *Ibid.*



AIDS Prevention messages are slowly becoming more common — some say too late.

government blood banks is screened, and only 2-3 percent of private blood banks do not screen blood.” However, this differs considerably from a 1996 outside study that reported only half of the two million units of blood used each year are actually screened for HIV and Hepatitis B. According to the study, part of the problem is that 30-50 percent of blood donations still come from professional donors, in spite of a law passed in 1992 that forbids professional blood donations.¹¹

India’s demand for blood units is double its supply, so there is a constant shortage of blood that creates incentive for blood banks to take any and all donations — and not much incentive to invest in expensive testing equipment. According to a Ministry of Health & Family Welfare report, 94 percent of units collected by commercial blood banks (which supply a quarter of India’s total blood units) were from professional blood donors. But it is not just the commercial banks that are under scrutiny. Surprisingly, almost half of government blood banks still remain unlicensed, and recent reported incidents of infected blood from even large institutions demonstrate that blood in India is far from

safe. In January 1996, The Supreme Court took Central and State governments to task, mandating that all unlicensed blood banks be licensed or closed down within a year, and that state and central governments undertake campaigns for voluntary blood donations to enable elimination of the professional blood donor system within two years.¹²

The effect that the AIDS epidemic will have on India’s public health facilities is almost unimaginable. Even without AIDS, India currently has only 0.7 hospital beds for every 1,000 people in India (compared to 1.7/1000 in Africa). Minimal resources will have to be stretched even tighter, and the most likely scenario is that the already-deprived will get only more deprived. In spite of this, the Indian government seems to be making few — if any — preparations.

It is no consolation that HIV is not alone in the shoddy treatment it receives from the government. It seems to be a pervasive malaise of the Government of India that it neglects the lives of its weaker citizens, the very ones it is supposed to protect. In PJ-9 on Child Labor, I discussed the meager amounts spent on primary education, and the lack of political commitment to education. Currently, the Government allocates only two percent of its total budget to health issues — in a country where fatal illnesses abound.

HIV/AIDS seems to bring out the ugliest sides of the Government, and of society in general. Attorney Colin Gonsalves of the Human Rights Law Network in Bombay, an organization that takes on many HIV/AIDS-related cases, believes that the lack of political commitment to AIDS is fueled by “a strong middle- and upper-class opinion (that pervades politics) that there is too much ‘dirt’ going around. HIV/AIDS is seen as an infection that relates to this ‘dirty’ population of commercial sex workers, for example. That’s why you see all these physical evictions happening in the areas where sex workers live, why the general public is not enraged over policies of mandatory testing of ‘sex-worker-infested’ areas. It’s almost fascist-like,” he concludes with disgust.

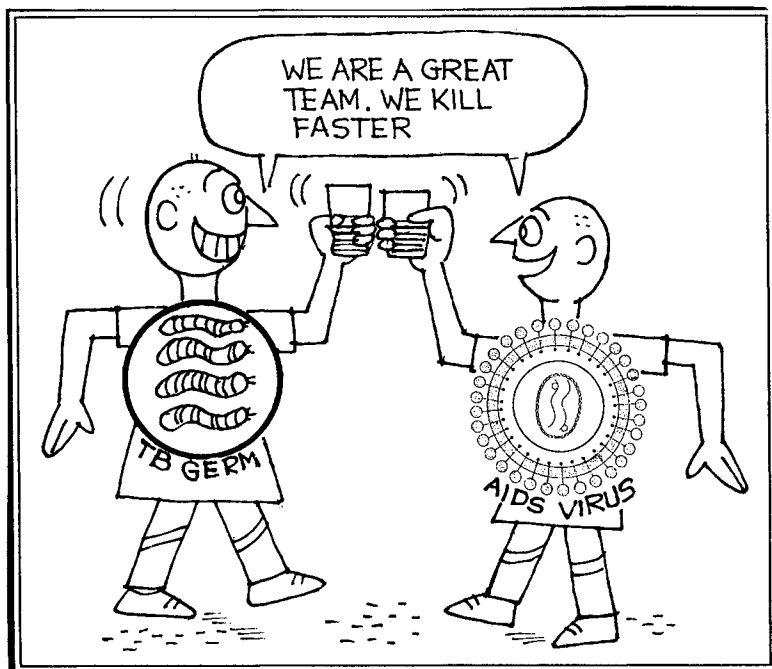
Laws and HIV: Protection or Persecution?

The most profound manifestation of the lack of political commitment to HIV/AIDS is in the area of legal protection of constitutional rights of HIV-positive individuals. There are currently *no* laws that protect HIV-positive individuals against discrimination. If anything, the legislative tendency has been toward persecution of those living with HIV/AIDS.

Anand Grover is an attorney with the Lawyers Collective, well-known for his work with AIDS cases. I met him late one evening after multiple clients had

11. Study by The London Valley Thames University in London, quoted in *The Economic Times*, May 28, 1996.

12. *AIDS in India*, December 1995 (Published by NACO).



Source: AIDS in India, Dec 1995

shuffled through his office. Grover, a charismatic man with curly graying hair, is blunt, informed and objectively critical. He began by explaining that the term "human rights" does not in and of itself mean something legally in India. "Human rights are not vested rights in India," he says emphatically. "People in the West — who should know this — think that because India has signed the Geneva Convention, it has to follow it. This is stupid! Just by signing a convention, the convention does not become law in the country. You have to have constitutional articles or statutes in the country itself in order to enforce human rights."

Grover first started his work with AIDS cases in 1988, when he took on the case of Dominic D'Souza, the celebrated Indian AIDS activist. The case was a challenge to the only HIV/AIDS law that did exist at the time, the State of Goa's Public Health Amendment Act of 1988. The State of Goa was relatively quick to take action — of draconian measure — against HIV, prevalence of which was significantly higher in Goa than in most other parts of the country. The 1988 Goa Act provided for mandatory testing of persons suspected of being HIV positive. Individuals who tested positive were to be isolated. The Goa Act had further provisions that stipulated burning of linen and mattresses used for deceased patients suffering from AIDS, and prohibited people with AIDS from receiving (not just giving) organs for transplants.¹³

Under the Goa Act, Dominic D'Souza was tested

against his will, and then forcibly kept in isolation after testing positive. Grover and the Lawyers Collective challenged the Goa Act on constitutional grounds, contending that both Articles 14 (equality and non-discrimination) and 21 (protection of personal life and liberty) of the Indian Constitution had been violated. Grover's arguments were:

"first, that the deprivation of a person's liberty under the Goa Act was arbitrary, unreasonable and discriminatory as there were no rational bases for concluding that by isolation of an HIV positive individual, HIV infection would be prevented from spreading; and secondly, that it was in breach of the principles of natural justice, as the Act provided for a conclusion to be reached that a person was positive without giving that person an opportunity to be heard on the issue."¹⁴

Grover lost. The Bombay High Court, Goa Bench, ruled in 1990 that since medical grounds were indicated for isolation of HIV-positive individuals, and since discretion about the isolate/not isolate decision was left to medically trained persons, the provision could not be held to be arbitrary or unreasonable.

The only other attempt to have a national AIDS law was in 1989, when a National AIDS Prevention Bill was introduced into the Rajya Sabha, India's appointed house. Modeled on the Goa Act, the 1989 Bill required anyone who suspected someone of having HIV to notify the local Medical Officer. This meant that a doctor, neighbor, colleague or anyone else could notify the MO, and the individual would have to be tested. Again, the Bill provided for isolation of the HIV-positive individual, "in the interest of such person and also to prevent the spread of HIV infection."¹⁵(Italics mine.) As under the Goa Act, HIV was being treated like other infectious diseases that are spread through being in the presence of others, or through mere physical contact.

Similar to some of the clauses that one signs with an adventure tourism company, the 1989 Bill also had a unique, total-indemnification clause stating that

"No suits, prosecution or other legal procedure shall lie against the designated health authority or any person for anything which is in good faith done or intended to be done under this Act."¹⁶

An article published in *The Lawyers* magazine de-

13. The State of Goa, Public Health Amendment Act of 1988.

14. Anand Grover, "The Crying Need for an HIV Statute, *The Lawyers Collective* (Vol. 11, June 1996), p. 5.

15. 1989 AIDS Prevention Bill, Chapter 14, Article II.

16. *Ibid.*

nounced the Bill as “a classic example of a medical problem being used to further a puritanical, moralistic, anti-people agenda, devoid of both common sense and compassion.”¹⁷ The Bill was ultimately withdrawn due to loud outcry from legal groups, advocacy groups and the World Health Organization. As of now, no other bill has been introduced. Similarly, although the Goa bill has not been repealed, outcry over the 1988 Act has essentially rendered the Goa Act *passé*. In April 1996, AIDS was also finally eliminated from the list of infectious diseases included in the 1989 Railways Act that prevented individuals with infectious diseases from riding the railways.¹⁸

Does all this mean persecution of HIV-positive individuals has stopped? Certainly not. In the absence of any law, either persecutive or protective, the inherent biases of a society will reveal themselves and flourish. In this case, that bias is gross discrimination against people with HIV and/or AIDS.

To date, countries have dealt with HIV/AIDS in one of two ways: *isolation*, or *integration*. The former, being practiced in Cuba, has four key components: mandatory testing, isolation if positive, breaches of confidentiality about an individual’s HIV-positive status and discrimination against HIV-positive people. The integrationist approach being practiced in some Western countries advocates voluntary testing, integration into society if positive, preservation of confidentiality and no discrimination.¹⁹ In the absence of laws [in India],” says Grover, “isolation is still being practiced.”

We were told of many incidents that reinforced Grover’s statement. Not only is mandatory testing being conducted in many hospitals without patient consent, but sometimes even without the patient’s knowledge. Hospitals often use the results of the test to decide whether or not to accept patients for treatment or surgery. Equally appalling are the instances where, if a patient is found to be HIV-positive, hospital staff will not tell the patient directly, but rather will call in his/her spouse, along with a relative or friend, and tell them. Naturally, the recommended pre-test and post-test counseling are never delivered in these situations.

Issues of HIV in the workplace are also surfacing now. There have already been a few cases of employers conducting testing and, in some cases, firing people who they find are HIV-positive. During company blood drives, testing is not de-linked or anonymous; if an employee tests positive, the blood banks often notify the *employers* (usually Human Resources) rather than the HIV-positive individual. Employer reactions appear to be mixed: in some instances, employers have chosen to keep the knowledge of a person’s HIV-

positive status from the individual himself. The reason? That “there does not seem to much point to informing the individual,” or perhaps that the company is not ready to cope with the issues that individuals will have to face. In other instances, employers have fired HIV-positive individuals.

Currently, there is little recourse for the employee. Meharukh Adenwalla, a lawyer with the Human Rights Law Network, says it is easier, though not easy, to defend people who have been discriminated against in State-owned facilities, like public hospitals or companies. The Indian Constitution — though broad in the scope of individual rights protected — specifies, in Articles 15 and 16, protection of individuals against discrimination *by the State*. It does not, however, specifically address protection of individual rights against private individuals.

Excerpts from The Indian Constitution

Article 14: The State shall not deny to any person equality before the law or the equal protection of the laws within the territory of India.

Article 15: (1) The State shall not discriminate against any citizen on grounds only of religion, race, caste, sex, place of birth or any of them. (2) No citizen shall, on grounds only of religion, race, caste, sex, place of birth or any of them, be subject to any disability, liability, restriction or condition with regard to a) access to shops, public restaurants, hotels and place of public entertainment; or b) the use of wells, tanks, bathing ghats, roads and places of public resort maintained wholly or partly out of State funds or dedicated to the use of the general public.

Article 16: (1) There shall be equality of opportunity for all citizens in matters relating to employment or appointment to any office under the state. (2) No citizen shall, on grounds only of religion, race, caste, sex, descent, place of birth, residence or any of them, be ineligible for, or discriminated against in respect of any employment or office under the State.

Therefore, if discriminatory activities take place in private institutions, first the link has to be made that private organization is under the jurisdiction of the State, and then the violation of constitutional rights argument can be presented. Ultimately, discretion as to how to apply the law in all HIV/AIDS discrimination cases rests with the judges, who have not to date been either informed about issues involving HIV/AIDS or

17. Siddharta Gautama, “The AIDS Prevention Bill, 1989,” *The Lawyers*, October 1989.

18. *The Economic Times*, May 28, 1996.

19. Grover, “The Crying Need for an HIV Statute.”

particularly interested in protecting liberties of HIV-positive individuals.

In the absence of laws protecting HIV-positive individuals, many NGOs working with HIV/AIDS do not encourage their clients to get tested for HIV. What good, they say, is testing when there is no cure, when testing is often done without pre-test or post-test coun-

selling that would enable the individual to understand the implications of testing positive, when there are few services to assist the individual in coming to terms with the illness, and when the results — if positive — will invariably be used to discriminate against the individual? "We do not discourage people if they come to us asking to be tested, but we also do not suggest testing. If they want to be tested, we make sure they un-

AIDS ?

DO YOU KNOW IT IS ACQUIRED THROUGH SEX ?

DO YOU KNOW THAT THERE IS NO TREATMENT FOR AIDS ?

AIDS CAN RESULT IN DEATH

STDs ?

SEXUALLY TRANSMITTED DISEASE (V.D.)

HAVE YOU EVER HAD SEX ?

DO YOU WANT TO KNOW WHETHER YOU HAVE ANY
DISEASE ? AIDS ? OR STD (V.D.) ?

COME TO THE HIV (AIDS) ANONYMOUS
TESTING AND COUNSELLING CENTRE.

COLLECT YOUR CONDOMS FOR FUTURE USE.

CONDOMS PREVENT AIDS & STD.

YOU NEVER HAD SEX ?

COME TO GAIN KNOWLEDGE EVEN IF YOU HAVE NO DISEASE.

derstand the issues — the possible discrimination, the fact that there is no cure, and just the implications of living with the knowledge of HIV or AIDS,” says Pamela Dorrell of Naz Trust in New Delhi, an organization that works with street children and youth around issues of HIV/AIDS. Rather than testing, Naz encourages empowerment of marginalized populations, and action to make their circumstances better. Their view on testing of street children, for example, is that “Until alternative, safe forms of income can be found or until child slavery can be stopped, knowing about HIV/AIDS will not stop children from earning money through sex work. Testing cannot stop children from having sex. Testing cannot give the children the power to change.”²⁰

The Constitution of India is a beautiful document. Reading the Preamble sends shivers down my spine:

“We, the people of India, having solemnly resolved to constitute India into a sovereign socialist secular democratic republic and to secure to all its citizens:

Justice, social, economic and political;
Liberty of thought, expression, belief, faith and worship;
Equality of status and of opportunity;
And to promote among them all;
Fraternity assuring the dignity of the individual and the unity and integrity of the Nation.”

The authors of this Constitution had a dream of equality and of individual rights. The Socialist State was to be the ultimate protector of rights, the mediator of justice, the entity — according to a 1983 Supreme Court case — whose “principal aim is to eliminate inequality of income and status and stands of life, and to provide a decent standard of life to the working people.”²¹ Our forefathers trusted the State, and therefore endowed it with wide-sweeping powers to fulfill these tasks.

As an Indian, I find it particularly painful to see the sharp contrast between the Constitution’s intent and today’s reality, where the Government again and again abdicates its responsibility and makes little good-faith use of its power. I alternate between anger and sadness that the vision for India was so golden, the actuality so tarnished.

“Individual rights are in our Constitution, just like in the U.S.,” says Anand Grover. “Our Article 21 is your due process, our Article 14 is your equal protection clause, and so on. The difference is that we have no acts or statutes through which we can prosecute violations of these individual rights. This is where the lack of political commitment comes in.” Laws themselves do not change the mindset that creates discrim-

ination, but without them, discrimination and inequality are given free reign to flourish.

Grover and his colleagues are now starting a long campaign to generate support for an HIV statute. First, they will have to educate people. “If we just scream for laws, we’ll get bad ones,” said Grover, echoing Australian Justice Michael Kirby’s comment that

“AIDS laws must not be based on ignorance, fear, political expediency and to pandering the demand of the citizenry for ‘tough’ measures. Good laws, like good ethics, will be formulated in good data. One of the real dangers of AIDS is that it will produce a new virus — HIL — Highly Inefficient Laws.”²²

The campaign will have to include education, awareness and advocacy work with different levels of society from the grassroots, to the medical profession, to NGOs working in HIV/AIDS issues, to policy makers and law makers. Most NGOs involved in HIV/AIDS prevention or care do not seem to understand the importance of laws — or, if they do, they do not have the time or funding to devote to this in addition to their existing activities.

At a recent International Conference on “AIDS — Law and Humanity,” India’s President in his inaugural speech indicated that he personally endorsed a “humane approach [toward AIDS law], one that regards those suffering from the disease as its victims, rather than a danger to society.” But a humane approach to AIDS requires that the government commit itself openly and unequivocally to the cause.

I used to find it difficult sometimes to answer people when they asked me why AIDS should get any attention at all. “We have so many other diseases like cholera, TB, malaria, that take millions of lives every day. Why should government resources be divided further with spending on AIDS?” Although I knew intuitively that the attention being devoted to AIDS was not only necessary but insufficient at present, I was unclear myself as to why. After talking to researchers, HIV-positive individuals, government officials and NGOs, I can better articulate the reasons for singling it out from the bunch of illnesses that pervade our country today.

First, diseases like cholera and polio manifest themselves acutely and overtly, and thus elicit concrete responses. HIV, on the other hand, grows “under the carpet,” both in terms of manifesting itself only at late stages, and in terms of being denied because it is a sexually transmitted disease. Second, unlike diseases like TB and malaria, which are already part of the government system, AIDS is yet to become part of the consciousness

20. Pamela Dorrell and Poonam Joshi, “Street Children & HIV/AIDS: To Test or Not To Test,” Unpublished paper, 1995.

21. *Nakara v. The Union of India*, 1983 Supreme Court Decision.

22. Justice Michael Kirby, “AIDS and the Law: Opportunities and Limitations,” *AIDS Asia*, December 1994.

of most of the public health system. Unless it gets separate attention, it will be lost in the milieu. According to Hira, any disease should be incorporated vertically (*i.e.* have separate facilities within the public health system to deal only with AIDS — such as separate AIDS cells, special AIDS doctors, possibly even separate AIDS clinics — as well as separate funding) into the public health system for the first five years to anchor itself and increase awareness and knowledge about it. Once people are trained in managing the disease, then it can become completely integrated with the existing system.

Third, unlike TB or malaria, HIV transmission is sexual and preventable through awareness and education. Fourth, research shows that HIV actually worsens

other diseases. This is particularly worrisome in illnesses like TB, estimated to be present (though latent) in over 50 percent of the Indian population and the cause of half a million deaths per year nationwide. Research shows that individuals with HIV are 10-30 times more likely to develop fatal clinical TB. Fifth, as will be discussed in PJ-14, the rapid spread of HIV/AIDS is facilitated by deeply-rooted cultural misconceptions and beliefs about sex and sexuality. Addressing these fundamentally unhealthy attitudes to sex and sexuality would positively impact not only HIV transmission, but also a host of other societal issues. Finally, though estimates of the magnitude of HIV/AIDS in India differ, all of them spell devastation for India and her people. □