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PJ-14 1996
SOUTH ASIA

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AIDS in India

Part II: Sex and Society

BOMBAY, India **August 1996**

By Pramila Jayapal

Falkland Road, at first glance, seems much like any other Bombay street. The glare of the morning sun hides the dirty painted walls of the tightly-packed cement housing structures, and the bustle of activity distracts my attention from the large number of girls milling about in the doorways. Outside the upper floors of the buildings, respectable cotton nighties are hung out to dry on laundry lines. Restaurants and tea shops are scattered between houses, and fruit and vegetable carts ply the street.

It definitely is not any other Bombay street. One of Bombay's largest red-light areas, Falkland Road houses an estimated 15-20,000 commercial sex workers (CSWs). As I re-survey the street, I begin to notice: on the far side, a young woman wearing a T-shirt that pronounces "ONLY FAST LOVE" combs out her long black, newly-washed hair. In all the doorways, women sit or stand. Some are old, some are young; some are dressed in saris or salvaar kameez, others in skirts or dresses. As they smoke, they watch the passing men and women, sometimes almost unseeingly and at other times intently, probingly.

We are with the mobile van of the Indian Health Organization (IHO), a non-governmental organization that has worked in Bombay's red-light areas for the past five years. IHO's Saheli project created a unique structure of support and education within the ranks of CSWs. CSWs called *sahelis* (for 'friend') are grouped under a *tai* (sister), who is also a CSW. The *tais* are then grouped under a *bai* (mother), who is a brothel mother. IHO provides the *tais* and *bais* with information about AIDS, sexually transmitted diseases (STDs) and condom usage, with free condoms and with regular visits from an IHO doctor. The *tais* and *bais*, in turn, act as peer educators for the *sahelis*, working to increase awareness about AIDS and improve condom usage. The structure created gave credibility to the program, and at the same time provided readily available support and information to CSWs from their own peer group rather than from outsiders.

According to an IHO study, the project has been successful in changing attitudes among CSWs regarding the need for condoms. Five years ago, CSWs used to tear apart condoms to get the rubber rings at the end and then use them to tie their hair up. Today they understand that condoms offer them protection from a deadly virus. The study says that the spread of HIV has also been controlled to a limited extent. HIV-prevalence in the group of CSWs participating in the Saheli project increased from 32 percent in 1991 to 44 percent in 1993, versus an increase from 32 percent to 60 percent in the same years for CSWs not covered by the Saheli project.[1]

The eight CSWs we met impressed us with their commitment to the project, and their understanding of the need to change behavior in order to arrest the rampage of HIV through their streets and homes. Armed with small photo albums that contain graphic pictures of emaciated people dying of AIDS, and close-ups of open sores on genitalia caused by STDs, they say they have been able to convince clients to use condoms.

Sitting there in the hot, humid van, talking with these articulate women, it

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

The women of Falkland Road

A Falkland Road CSW shows off her beautifully decorated hand (atraditional art caled Mehndi).

occurred to me that projects like Saheli, though indisputably praiseworthy, are addressing only the symptoms of a culture that refuses to discuss issues of sex and sexuality. India needs to understand that these women are not the root cause of the HIV problem, but rather the "supply" side of an equation where an enormous and unhealthy demand for commercial sex is created by a society that represses and condemns — at least overtly — sex and sexuality. To be truly successful in stemming the tide of the epidemic, projects need to focus on understanding where the massive demand for commercial sex comes from: how can an estimated population of 80 – 100,000 commercial sex workers thrive on the streets of Bombay alone? Why do men of all classes, occupations and areas come to seek sex here? What interventions will change this type of sex-seeking behavior, and encourage honest dialogue about sex at home?

The approaches of increasing awareness and condom usage among CSWs seemed to me to be more appropriate to countries that are in Phase I of the epi-

AIDS Awareness boards at the ARCON AIDS out-patient clinic in Bombay

demic (described in AIDS in India — Part I, as the initial phase of the epidemic when transmission is limited to "high-risk" groups). India is about to enter Phase III of the epidemic, and yet our approaches continue to be stuck in time. Media reports that focus on HIV/AIDS in "high-risk" populations serve only to exacerbate the problem. The women of Falkland Road know far more about HIV and AIDS than even a large part of the medical community, let alone the general population. Even ten years after the first AIDS case was diagnosed in India, misconceptions about HIV and AIDS abound, (see, page 4) and the general public still believes that HIV is a problem only of the "promiscuous." What they fail to understand is that the "promiscuous" could be their husbands or wives, their sons or daughters, their good friends or relatives.

"AIDS is much more a societal problem than a viral problem, and it should be treated as such," writes Dr. Jonathan Mann of the Harvard AIDS Institute.[2] Unfortunately, the barriers of society are sometimes even more difficult to break through than the barriers of medicine. Sex is rarely discussed in Indian society, and just as rarely studied. And yet widespread study and discussion seem to hold the key to designing effective HIV control and prevention programs. Until Indian society begins to understand attitudes to sex, and accepts that extramarital and premarital, dual- and multiple-partner sex (and with them, HIV transmission) take place in the *center*, not the outskirts, of society, HIV/AIDS efforts will have limited impact. Like drops of water in a thirsty man's mouth, these efforts will make headway with only small groups of individuals while the epidemic claims millions of lives.

Sex and Sexuality

Sir Richard Burton, in his introduction to the Illustrated Kamasutra, India's ancient and well-known practical discourse on various aspects of sexuality, once wrote that "Sexual frankness — without a hint of guilt or prurience — is the greatest legacy which the Eastern, and in particular Indian, traditions have give us."[3] The variety of sexual acts described frankly in the Kamasutra, and the erotic carvings at many Hindu temples across the country seem to indicate that attitudes towards sex were not always what they are today.

Or were they? Quipped Gita Sethi, a Program Officer at the Population Council, "We have always had one standard for the Gods and another for the general public. We shouldn't confuse something that was in books or in temples with the common practices of average

2. Dr. Jonathan Mann, *AIDS Asia*, September - December, 1995.
3. "Preventing AIDS Through Kamasutra," *AIDS Asia*, August 1994.

Misconceptions about HIV: Mosquitoes and Masturbation

The lack of awareness that persists in India ten years after the diagnosis of the first AIDS case has given rise to an enormous number of misconceptions about HIV/AIDS. The most common is that HIV is confined to CSWs or IV-drug users. This assumes — wrongly — that HIV/AIDS are concerns of *populations*, rather than of those who practice high-risk *behaviors*. Other common misconceptions are listed below. This is by no means an exhaustive compilation.

- A 1996 mini-survey conducted by the Rajiv Gandhi Foundation found that, of 25 general medical practitioners in Delhi who had been practicing for the last 10-20 years, 35% believed that AIDS was a problem of promiscuous rather than "ordinary, moral people." 25% of the GPs sampled did not know what AIDS stood for. 38% believed that AIDS was "invented in a lab and accidentally spread."[4]

- A larger study conducted in 1992 with 200 physicians from Madurai Medical College showed that 50-60% of them were unwilling to take up AIDS/HIV cases; and 86% of them felt that there was no real need to worry about AIDS because it was still a rare disease.[5]

- HIV/AIDS is commonly associated with activities that people feel are "morally wrong" like masturbation. An Indian Family Planning Association study showed that many men believed masturbation weakens a person,[6] and one study of doctors showed that they felt masturbation was sufficient to transmit HIV![7]

- Large numbers of doctors and the general public believe that HIV is transmitted through mosquito bites (perhaps a reflection of the fact that many diseases in India are mosquito-borne), casual contact, hugging, and sneezing.[8]

- Medical professionals remain largely untrained in clinical diagnosis of AIDS, nor is training widely available. India's sole public health school in Calcutta has yet to revise its curriculum to include full training on AIDS. As a result, AIDS cases are commonly misdiagnosed or attributed to individual diseases that are part of the syndrome. For example, HIV-infected individuals are 10-30 more likely to develop clinical TB than HIV-negative individuals.[9]

- A recently-released National Family Health Survey found that knowledge of AIDS among women is particularly low. Even in Delhi, only 36% of women had heard of the disease.[10] Women are prone to misinformation about HIV/AIDS, primarily because of low literacy levels, isolation from the general public, and lack of exposure to "high-risk" populations where HIV/AIDS information is often first disseminated.

- Large numbers of people believe that AIDS can be cured, even though they are aware that modern science says there is no cure. This has led to many a patient's empty pocket and many a quack's full one. Many people first go into a frenzy of trying various ayurvedic and other treatments that promise cures. When they ultimately accept there is no cure, anger and hope give way to belief in fate (*karma*) and faith. According to one HIV-positive woman we talked to, "Science is great, but God is greater. God can do anything; we pray that there will be a cure soon." God is also believed to keep HIV/AIDS away. As one blood bank owner in Bihar said in 1992 "There is no need to test blood against AIDS virus because Bihar is the land where Gautam Buddha attained enlightenment. The killer disease dare not come here."[11]

4."Fatal Ignorance," *Outlook*, March 6, 1996.

5. Nag, *"Sexual Behavior..."*

6. "Problems of Adolescent Sexuality," *Indian Express*, December 21, 1993.

7. Ibid.

8. Ibid, and "Fatal Ignorance," *Outlook*.

9. "TB and HIV on Deadly Collision Course," *The Statesman*, February 22, 1996.

10. Nitin Jugran Bahuguna, "In the Dark," *Nexus*, February-March 1996.

11. "Silent Killer," *The Week*, June 28, 1992.

men and women." Certainly, most Hindu scriptures seem to advocate repression of sexual urges, and abstinence from sex as a virtue. Sex was (and is) seen more as a necessity for procreation rather than for recreation — at least, that is what people espouse.

The lack of information about sex and sexuality available to girls and boys as they grow up creates an environment charged with sexual tension, and confused feelings of anticipation, fear, and excitement around sex. Youngsters pass through what famous psychologist Sudhir Kakar has termed a "sexual crisis," where boys develop fantasies about sex that translate into masturbation and visits to CSWs, and girls develop sexual frustration and desire that merge with notions of romance.[12]

In the modern city of Bangalore, I conducted a small focus-group discussion with 12 young women between the ages of 18-20 (all of whom were middle-upper class, and attending some of the best law and business schools in the country). When I brought up the topic of marriage, one of them provoked laughter and agreement from the others when she joked, "I thought we had already discussed bondage!" The joke was not far from the truth as these women perceived it. They all had romantic expectations of marriage but most felt they would have to give up on love and romance, and "settle for" arranged marriages. These unrealistic expectations of sex and romance, says Sethi, are rarely fulfilled through marriage. Enter "high-risk behaviors," like multiple-partner sex and seeking commercial sex.

Questions asked in a recent "Women in AIDS" project showed there is still strong reluctance to provide information about sex to children. At the beginning of the study, only 33 percent of over 700 people surveyed responded positively to a question that asked "Should we discuss sex with our children?" Even after intensive training that focused on the need for sex education for children, the percentage of positive responses to the same question increased to only 60 percent. The taboos around sex are so deeply rooted, it seems, that it is difficult to change opinions quickly. Perhaps this is why efforts like the National AIDS Control Organization's (NACO) country-wide program called University Talk AIDS (UTA) encountered fierce resistance from teachers and student volunteers who felt uncomfortable discussing some of the issues in the curriculum. Even in my small Bangalore group, where the women all knew each other well, the air was heavy with embarrassment and tension when topics dealing with contraception, sex or marriage were raised.

Whether Indians want to admit it or not, studies show generally-voiced attitudes about pre-marital and extra-marital sex may be quite different from practiced behaviors. Even people who come from conservative backgrounds or appear outwardly conservative in dress or manner indulge in pre-marital sex. We met one recently married couple where the man was from a conservative Muslim family and had contracted the virus sexually prior to marriage. His wife, who converted from Hinduism to Islam and now wears a *burkha*, had sex with him prior to getting married and with full knowledge that he had HIV. She has contracted the virus from him.

A 1996 Thames Valley University study estimated that 10 percent of India's sexually active male population regularly visits CSWs[13] — and this does not include the men who have sex with friends, colleagues or relatives. A behavioral study conducted by NACO in 35 cities across the country showed that a lot of multipartner sex happened outside the "formal" CSW community. To make things more complicated, the study showed that even the term "commercial sex worker" is not clearly definable. Many economically deprived women said that they would, out of economic necessity, perform sex for money from time to time to get money for children's food or school fees, but they did not consider themselves CSWs, nor would they have been included in any interventions targeted at CSWs.

There are very few studies done on extra-marital sex, but in the largest survey done that included 686 men and 296 women, 56 percent of men and 25 percent of women reported having extra-marital experiences.[14] Not surprisingly, there is a difference in societal and spousal acceptance of extra-marital sex for men versus women. Men seeking sex outside the marriage is far more acceptable, and is often taken with an attitude of "men will be men." There is a casual belief among males that "going to a commercial sex worker is like eating in a restaurant even if there is food available at home."[15] HIV-positive men who have contracted the virus through extra-marital sex were, for the most part, forgiven by both their spouses and their families. Said one woman: "No matter how good or how bad, we must stay with him. It is our duty." There is a sense that somehow men should be allowed such transgressions, or even (and this often from the woman's in-laws or other male relatives) that the need for a man to stray outside the marriage is the woman's fault, her inability to provide sexual fulfillment.

"Sex is taboo in India," says one senior NACO consultant. Perhaps this is why few studies have examined attitudes towards sex, and even fewer have documented sexual practices. "Researchers have focused primarily on reproductive biology and have carefully

12. Moni Nag, *"Sexual Behavior and AIDS in India"* (Vikas Publishing, New Delhi, 1996).
13. *The Economic Times*, May 28, 1996.
14. Nag, *"Sexual Behavior..."*
15. Shalini Bharat, *"Facing the Challenge: Household and Community Response to HIV/AIDS in Mumbai, India,"* (Tata Institute of Social Sciences, Mumbai, 1996).

skirted the politically and socially sensitive behavioral aspect of sexuality," writes Saroj Pachauri, the Asia Regional Director for the Population Council, in the foreword to a book on "Sexual Behavior and AIDS in India." Most AIDS prevention work currently focuses on bringing about behavioral change (like using condoms, or changing sexual practices), but these efforts have "had limited success primarily because of a lack of understanding of sexual behaviors."[16]

The strategy of HIV prevention and control through behavior change necessitates an understanding of the behavior one is attempting to change. Some of the most integral aspects of these behaviors are anchored in cultural norms that discourage open discussion about sex between husband and wife, and in traditional beliefs, *e.g.* men should not have sex with menstruating or pregnant spouses. "We need to move away from trying to change individual behavior, to trying to bring about a more over-riding social change," says Sethi of the Population Council. "We still have men who may use a condom with one CSW if she insists and he is desperate, but will not with other CSWs in other situations. Nor will he go home and use a condom to protect his wife. Can we call that single incident when he uses a condom *real* behavior change? We need to focus on changing societal attitudes towards women, changing attitudes of society towards open discussion of sex, romance and marriage, and improving economic conditions. I know it is a long way off, but I'm beginning to think that's the only way."

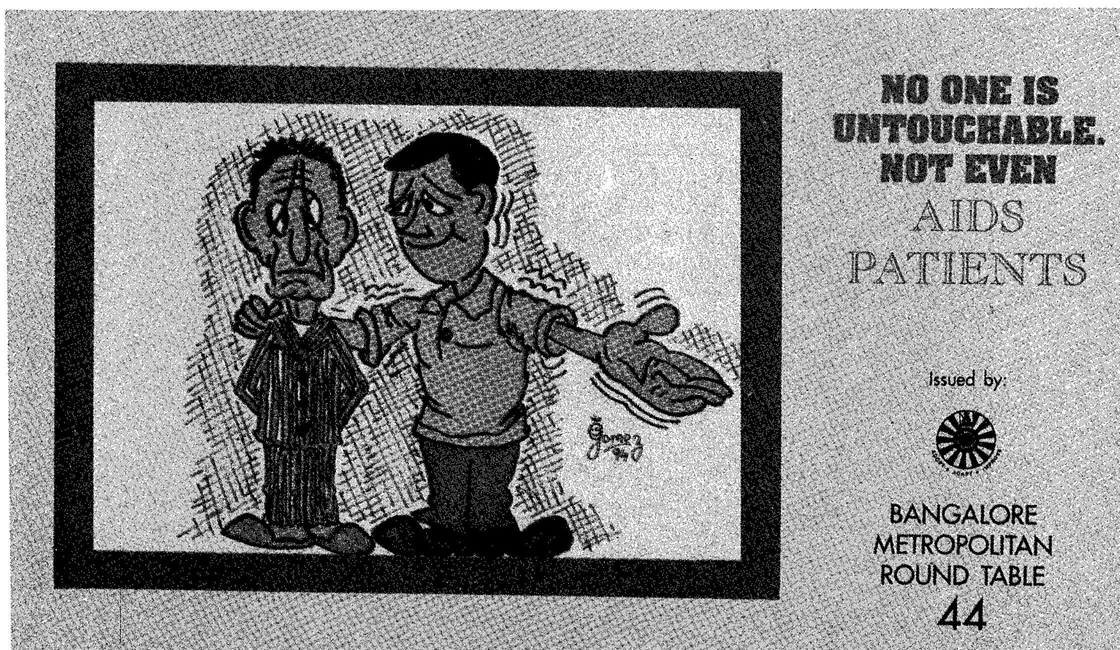
As she shows me out of her office, we laugh self-consciously about how passionate we have been in discussing the issue. "Forgive me," she says. "I suppose we all get 'infected' with this kind of passion when we work with AIDS."

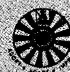
Living With HIV/AIDS: Men, Women and Children

A group of eight men files into the auditorium of a well-known hospital in Bombay. They sit in the pink plastic chairs that have been arranged in a circle. They are mostly between the ages of 20 and 40. What they have in common, which has brought them together on this hot, humid Saturday afternoon, is that each one of these men is HIV-positive.

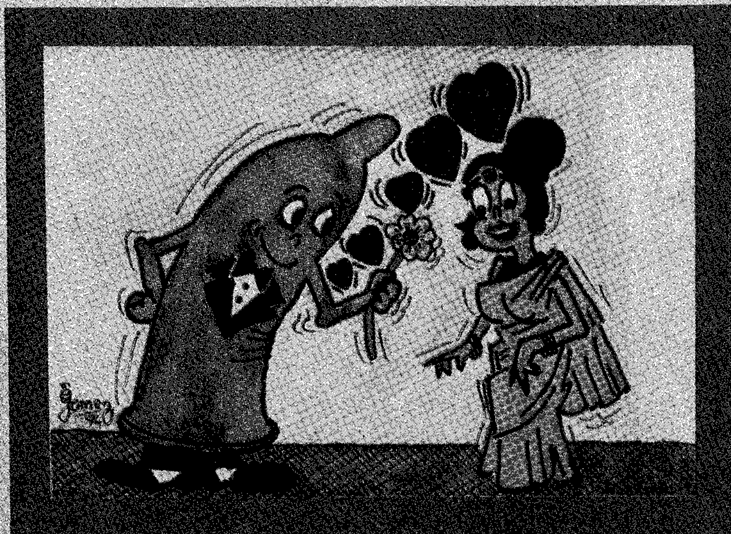
The group is quiet at first; the men (except for one who is completely open about his HIV status and has been attending group meetings for two years) are nervous, fidgeting with their watches and not looking at each other. Still, there is no overwhelming sense of sadness. Almost all the men indicate that they have received support and understanding from their spouses and the rest of their families; they have a place to vent their frustrations and fears. Most of the men had chosen to get tested of their own accord (or occasionally on a friend's suggestion), and had also decided whether, when, and how to disclose their HIV-status.

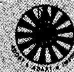
Ravi,* a good-looking, clean-cut young man who recently found out he had HIV, describes how he contracted the virus. It happened when his wife lived in the village for a year and their marriage was under some tension that he "took the wrong path," an often-used, oblique way of indicating that the individual had sought sex outside the marriage. "Now I must live





16. Ibid.
* All names of HIV-positive individuals have been changed.





with the consequences of that action," Ravi continues matter-of-factly. "I used to be so scared of dying. Now, it is my fate — if I die, I die. If I live, I live. I have told my family that I may die any day. I am not scared of dying anymore."

Although the men were receiving support from their families, they worried about discrimination at work. Blood testing at workplaces is on the rise, but still not conducted routinely, so many of them are able to withhold their HIV status from the workplaces. However, one man, who had such good relationships with his colleagues that he thought he would be able to share his HIV-positive status with them, was rudely disappointed. Once Anand disclosed his status to his "friends," they and other colleagues began to leave the room every time he entered. They went as far as to tell the owner of the tea shop they all frequented that if Anand was allowed to enter the tea shop, they would stop going. The tea shop owner told Anand that he had no choice but to refuse Anand entrance.

A week after attending the men's support group, I attended a women's HIV-positive support group. I was struck by the differences between the kinds of issues that men and women discuss and the atmosphere in the groups. I asked Brinelle D'Souza, a behavioral scientist at The AIDS Research and Control Centre (ARCON) in Bombay if she found similar differences in all the groups she runs. "Yes," she said. "Women tend to be much more concerned with their families, their children. They rarely have the choice that men (especially unmarried ones) have about disclosing their HIV-status. They often face discrimination at home and in their communities, and as a result, often do not have a place to express their feelings. They come here with a lot of bottled up emotions that emerge in the group. Men, on the other hand, are generally supported at home. They are more concerned with getting rid of their guilt feelings. They worry about how HIV or AIDS will affect their physical appearance, and about how their friends and colleagues will react. Although some do talk about how it will affect their children, men's concerns tend to be much more self-centered."

The women in the group I attended ranged from 20-60 years of age. They were from different states, some worked, all had children. Kamala was the youngest one, with a round, unlined face and a wide smile (when she smiles). That afternoon, she spoke as if the gates to her loneliness and despair had been thrown open, releasing floods of words. "It must be because of *bura karma* (bad past deeds)," she said, referring to the reason she has HIV. Another woman stopped her immediately, almost angrily. "It's not like that. It is not anything we have done. This is not our fault." "We keep hearing that it *is* like that, and we begin to believe it ourselves," countered Kamala. "Otherwise, why has this *bimari** come to me? I am too *young* to be a widow."

Her eyes filled with tears, and the group was silent. They knew what she was talking about. Six of the eight women were widows, having lost their husbands to AIDS. Some of them had children who are HIV-positive; those who did not, lived in constant fear that their children would become HIV-positive in the future. Many of the women cried as they shared how

• AIDS is often referred to simply as *bimari,* which means illness or sickness, rather than by its name.

Source: *AIDS in India*, Dec 1995 (NACO)

they had been alienated by their families and communities once their HIV status became known. Ironically, even though all of them had contracted the virus through their husbands, their families (mostly the in-laws with whom they were living) treated them as if they were responsible. One woman's sister-in-law refused to allow the woman to cook food anymore because she was afraid that she would spread the HIV infection. "People don't want my children to play or eat with their children. My children are not HIV-positive, but still people think that they have caught the infection from me and will spread it. I cannot talk to anyone at home about this. That is why I like to come here. At least some of the tension is released when we come here." Most of the women had no choice as far as revealing their HIV status, as it was decided for them by their husbands. Those that did have a choice were terrified of telling their families for fear of discrimination. Their choice was between the lesser of two evils: face possible alienation from my family, or live alone with the burden of knowledge that I am HIV-positive.

Throughout the group meeting, several women kept eyeing the clock on the wall. They were not supposed to leave the house, and had sneaked away without telling anyone. "If my mother-in-law finds out I left, then she will ask me where I have been and all kinds of other questions. If I tell her the truth, she will either not believe me and start spreading rumors to others that I'm leaving the house, or she will tell me to stop coming," said one.

For women, being diagnosed as HIV-positive is one more of many factors that lead to discrimination. Since women are seen as caregivers, it is accepted that they should take care of their HIV-positive husbands. However, when the woman becomes HIV-positive, who will look after her? In addition, when her husband dies, she is left to care for her children and herself, often while still living with in-laws who may not want her. Many women are also less able to seek counseling, often needing permission from their in-laws or husbands to leave the house and generally more isolated from the community. In her recent study in Bombay on household and community responses to HIV/AIDS, Shalini Bharat found — not surprisingly — that HIV/AIDS places the greatest burden on the women of the family.[17]

As I sat through the women's support group, I felt a depression come over me, not unlike what I feel when I walk through a slum area, or when I see caste discrimination. I feel trapped in a web of deeply rooted prejudices where poverty, culture, tradition, and attitudes are so closely entangled that it is sometimes difficult to see a way out. It was starkly obvious how differently families and communities treat HIV-positive women versus HIV-positive men. It seems particularly unfair given that these women had become HIV-positive through their husband's high-risk behavior, not their own.

The common factor in both the men's and the women's group meetings is that people who have tested HIV-positive need to have an outlet in which to release their fears, their guilt, their thoughts. Although there are a few progressive organizations like Naz Trust in Delhi, ARCON in Bombay, and Samraksha in Bangalore, counseling is still a very new thing in India. In fact, according to Dr. Subhash Hira of ARCON, even the World Bank only recently agreed to allow part of

17. Ibid.

their funds to be used for counseling activities.

"We really have not had much real counseling in the past," concurred Sheila Remedios of the Committed Communities Development Trust (CCDT), a Bombay-based NGO that works with children of HIV-positive parents. "Now, with HIV/AIDS and the need to provide counseling to people who find out they are positive, it becomes an absolutely necessary area of concentration." Another social worker, upon learning that we used to live in America, said to us enviously, "We do not have anything close to the services you have in America for HIV-positive individuals." She is right — little counseling, no social welfare measures like disability allowances, no anti-discrimination laws, and few facilities to cope with the special needs of HIV and AIDS patients.

Of particular concern is the growing number of orphaned children of HIV-positive parents. The volume of children infected through vertical transmission (from mother to child) is increasing; and more and more mothers and fathers are dying, leaving behind orphans. Many single mothers (who usually die after their husbands) do not know they are required to leave a will that allows the child to be placed for adoption. Without this, the child will stay stuck in an ill-equipped, over-crowded government home somewhere, or will fall through even the hands of the government into the dark underworld of street children.

Even if the mother does take the necessary steps to allow the child to be put up for adoption, as one social worker said, "In a country where even adoption of 'normal' children is not accepted, what will we do with scores of HIV-positive orphans?" For the children of parents who have died of AIDS, but who are still not HIV-positive, the social stigma of the circumstances of their parents' deaths is enough to leave them without many possibilities of adoption.

Currently, there are only a handful of homes that cater specifically to children of HIV-positive parents. One of them is CCDT. CCDT launched Project CHILD (Children of Parents with HIV Living with Dignity) in June 1995. The project covers 100 children, 75 of whom still have at least one living HIV-infected parent (usually the mother). The other 25 are orphans who live in CCDT's home, Ashreya. Ashreya takes children under six years and moves them out at the age of eight into foster care or adoption. Sheila Remedios, Project CHILD's Coordinator, admits that this is a difficult task and will only become more difficult as numbers increase.

What happens when the project funding ends in a few years? I asked. Are they attempting to work on the political level to get the government to provide for children in any way? Remedios does not respond to the question directly; she speaks in terms of the individual parents they are working with, who they are training to become job-worthy so that they can sustain themselves without financial support from CCDT. Her answer is an example of the micro-level orientation that service organizations like CCDT tend to take — often out of necessity, because the task of changing government policy or societal attitudes is huge, and the immediate needs of the "here-and-now" are so great. When Remedios understands my real question, she acknowledges the need for advocacy work, but says this is too big a job for them to take on. "Do you know, in 1995, the Government of India spent seven rupees per annum per person on health care nationally? To get them to provide for HIV-positive orphans requires a whole social re-orientation!"

* * * * * *

As people with HIV/AIDS languish at home or on the streets, it is not just they and their families who will suffer. According to Dr. Shiv Lal of NACO, "[in India] the economically productive age group 19-49 years old is most affected by the disease. This has serious implications for economic development as a whole."[18] As we have seen in many African countries, there is a massive toll on a country's economy, a strain on the resources of the government, and an emotional toll on a society surrounded by death and dying.

Although the recent Vancouver Conference ended in an atmosphere of hope following the announcements about possible new drugs for treatment of AIDS, Indian HIV/AIDS workers do not hold much faith that these drugs will ever be affordable enough for widespread use in India.

Who is worrying about HIV/AIDS in India? Who will protect and care for HIV/AIDS-positive individuals? Who is working to minimize the impact of the epidemic? In the wake of the government's failure to take responsible action, there are few others who have proven capable of filling the enormous gap.

Not for the first time in looking at societal issues in India, I find that what should be the government's responsibility is falling back down on the already overburdened shoulders of non-governmental organizations (NGOs). Unfortunately, NGOs are too few (one report says only one-half of one percent of the over-7,000 NGOs in the country are involved in AIDS) to carry out all the tasks at hand. These include, among others: 1) educating the general public about HIV/AIDS; 2) providing special training for physicians and the rest of the medical community; 3) instituting real education about sex and sexuality in schools and colleges; 4) enacting statutes that protect the constitutional rights of HIV-positive individuals; 5) designing societal responses that are integrationist rather than

18. Dr. Shiv Lal and Dr. D. Sengupta, "HIV/AIDS in India: The Urgent Need for Advocacy," *AIDS in India* (published by NACO), December 1995.

isolationist; 6) preparing counseling and care services for HIV/AIDS patients and their families; and 7) funding and conducting research that explores basic attitudes toward sex and sexuality, and working to begin honest dialogues about the findings. Finally, and most importantly, NGOs *must* begin to unite around pushing the government to acknowledge its responsibility: through education and awareness efforts, through lobbying, through somehow "personalizing" HIV for those who think it cannot affect them.

Efforts to motivate the private sector into action have had mixed — and limited — results. A few companies, like Tata Iron and Steel Company (TISCO), have actively incorporated AIDS prevention into existing company health programs, offering counseling and even condom distribution to employees. Most companies, however, still remain skeptical and unwilling to commit their own precious funds to AIDS activities. In Bombay — perhaps motivated by estimates that by the year 2015, 30 percent of Bombay's population would be "unavailable for employment on account of HIV[19] — a group of 13 large industries formed a private-sector consortium called Industry Response to AIDS (IRTA). However, only three of the 13 companies have as yet contributed funds to the effort. The situation was made worse when the U.S. Agency for International Development (USAID) agreed to fund the Indian Industries Confederation (a body made up of Indian businesses) to do AIDS awareness work. Hira of ARCON, who is working with Bombay's IRTA consortium, fears that the USAID grant will cause the remaining ten IRTA companies to shirk their responsibility to commit themselves to AIDS prevention with talk *and* money. "They may begin to question why they should commit their own funds to AIDS work if there are grants coming from outside. Particularly companies, who have resources, should not get dependent on outside grants. We learned this lesson in Africa. IIC has loads of money. Why should USAID be funding it to do work that is really part of corporate responsibility?"

It is not just the private sector that should not depend on international assistance. India, too, needs to wean herself off international funding. International commitment to HIV/AIDS is decreasing at the very time when the epidemic is about to balloon and burst. The recent shift in responsibility from the former Global Programme on AIDS managed by WHO to the current UNAIDS program managed by UNDP has also caused confusion for NACO officials in India. "It is not a good program anymore," said one NACO official. "I do not know what is happening, but there is not much support or interest any more from this program."

Says Hira, "When I was working in Africa, it was really the beginning of the epidemic, and international commitment and support was strong. The epidemic in India is becoming visible at a time when there is international inertia. This year's Vancouver AIDS Conference, for example, only has a $14 million budget — two years ago, at the Japanese conference, there was a $200 million budget. And this year, *all* the money is coming from the Canadian Government, and none from any of the international sources. At a time when the epicenter of the epidemic is supposed to be in developing countries, there are only a fraction of the total delegates who are even from the developing world."

What is the reason for the decrease in interest in HIV/AIDS? I ask Hira. He pauses, and then reflects, a little sadly, "I think people are realizing that after all this time working in AIDS, we have no success stories. We have addressed issues only on a surface level. Though people might say that we in Zambia had a successful AIDS control and prevention program, I and my colleagues cannot agree. We might be able to point to a small decrease in the spread of HIV, but so many people died and are still dying. This is not a true success story. The truth is there are no real success stories."

The most important reason that India needs to begin to look inward for answers to the HIV/AIDS epidemic is that the root causes for rapid transmission of HIV lie within Indian sexual behavior and attitudes, and the lack of political willingness to tackle the issue. International funding could certainly help, but the commitment to search for new ways to approach the situation must come from within.

The void created by government denial and complacency places the ultimate burden of responsibility on individuals to bring about their own behavioral and attitudinal change — a task that seems unrealistic given the low levels of awareness about HIV/AIDS and the lack of willingness to discuss issues of sex and sexuality. Moreover, for populations like women and children who often are infected through behavior that is *not* their own and therefore not controllable, individual behavior change offers no channels of action.

Even for those who have the awareness and understanding to bring about behavior change that would protect them and their families, cultural attitudes toward death and fate may play a detrimental role in bringing about quick change in India. Unlike the West, where the terrifying end-point that death represented in the HIV/AIDS epidemic may have contributed to bringing about behavior changes, in India there is an acceptance of fate and of *karma,* the idea that past deeds have dictated present circumstances and events. This acceptance can contribute to a sense of irresponsibility, a sense that "what will happen, will happen — and my behavior cannot affect my destiny." What can substitute for death as the end-point, I wonder? What can motivate people to be responsible for their behavior? "Possibly pain and suffering," says Hira. But it will take time before people understand the extent of

19. Dr. Subhash Hira, as quoted in "AIDS in the Workplace," *Business India*, September 1-24, 1995.

pain and suffering that HIV/AIDS will bring to communities across India.

For the average person in India who faces multiple diseases and deaths every day, it is difficult to imagine that the impact of AIDS will affect them more than any of these other diseases — particularly now, when the epidemic is in the early stages of actually demonstrating its devastating potential. The time has not yet come when everyone in India knows someone who has died of AIDS. This, perhaps, is one of the great tragedies of AIDS: by the time one realizes the extent to which HIV/AIDS can cripple a family, a society, a nation, or a world, it is too late. ❑

Institute Fellows and their Activities

Adam Smith Albion. A former research associate at the Institute for EastWest Studies at Prague in the Czech Republic, Adam is spending two years studying and writing about Turkey and Central Asia, and their importance as actors the Middle East and the former Soviet bloc. A Harvard graduate (1988; History), Adam has completed the first year of a two-year M. Litt. degree in Russian/East European history and languages at Oxford University. [EUROPE/RUSSIA]

Christopher P. Ball. An economist, Chris Ball holds a B.A. from the University of Alabama in Huntsville and attended the 1992 International Summer School at the London School of Economics. He studied Hungarian for two years in Budapest while serving as Project Director for the Hungarian Atlantic Council. As an Institute Fellow, he is studying and writing about Hungarian minorities in the former Soviet-bloc nations of East and Central Europe. [EUROPE/RUSSIA]

William F. Foote. Formerly a financial analyst with Lehman Brothers' Emerging Markets Group, Willy Foote is examining the economic substructure of Mexico and the impact of free-market reforms on Mexico's people, society and politics. Willy holds a Bachelor's degree from Yale University (history), a Master's from the London School of Economics (Development Economics; Latin America) and studied Basque history in San Sebastian, Spain. He carried out intensive Spanish-language studies in Guatemala in 1990 and then worked as a copy editor and Reporter for the *Buenos Aires Herald* from 1990 to 1992. [THE AMERICAS]

Sharon Griffin. A feature writer and contributing columnist on African affairs at the *San Diego Union-Tribune*, Sharon is spending two years in southern Africa studying Zulu and the KwaZulu kingdom and writing about the role of nongovernmental organizations as fulfillment centers for national needs in developing countries where governments are still feeling their way toward effective administration. [sub-SAHARA]

John Harris. A would-be lawyer with an undergraduate degree in History from the University of Chicago, John reverted to international studies after a year of internship in the product-liability department of a Chicago law firm and took two years of postgraduate Russian at the University of Washington in Seattle. Based in Moscow during his fellowship, John is studying and writing about Russia's nascent political parties as they begin the difficult transition from identities based on the personalities of their leaders to positions based on national and international issues. [EUROPE/RUSSIA]

Pramila Jayapal. Born in India, Pramila left when she was four and went through primary and secondary education in Indonesia. She graduated from Georgetown University in 1986 and won an M.B.A. from the Kellogg School of Management in Evanston, Illinois in 1990. She has worked as a corporate analyst for PaineWebber and an accounts manager for the world's leading producer of cardiac defibrillators, but most recently managed a $7 million developing-country revolving-loan fund for the Program for Appropriate Technology in Health (PATH) in Seattle. Pramila is spending two years in India tracing her roots and studying social issues involving religion, the status of women, population and AIDS. [SOUTH ASIA]

John B. Robinson. A 1991 Harvard graduate with a certificate of proficiency from the Institute of KiSwahili in Zanzibar, John spent two years as an english teacher in Tanzania. He received a Master's degree in Creative Writing from Brown University in 1995. He and his wife Delphine, a French oceanographer, are spending two years in Madagascar with their two young sons, Nicolas and Rowland, where he will be writing about varied aspects of the island-nation's struggle to survive industrial and natural-resource exploitation and the effects of a rapidly swelling population. [sub-SAHARA]

Teresa C. Yates. A former member of the American Civil Liberties Union's national task force on the workplace, Teresa is spending two years in South Africa observing and reporting on the efforts of the Mandela government to reform the national land-tenure system. A Vassar graduate with a *juris doctor* from the University of Cincinnati College of Law, Teresa had an internship at the Centre for Applied Legal Studies in Johannesburg in 1991 and 1992, studying the feasibility of including social and economic rights in the new South African constitution. [sub-SAHARA]