

# India at the Crossroads

## Confronting the HIV/AIDS Challenge

A Report of the CSIS HIV/AIDS Delegation to India,  
January 3–10, 2004

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CSIS delegation members (front row from left): Samir Khalil, Richard Celeste, Teresita Schaffer, Mike Merson, Lisa Carty, Geeta Rao Gupta, J. Stephen Morrison, Dora Warren, Louis Sullivan, and Pramit Mitra, with workers of Michael's Care Home in New Delhi.



Geeta Rao Gupta talks to a patient at Michael's Care Home in New Delhi.



Counselor talks to truckers about HIV/AIDS at the SPYM Project in New Delhi.



CSIS delegation members examine an exhibit at Osmania Hospital in Hyderabad.

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*Teresita C. Schaffer and Pramit Mitra*

### Executive Summary

*This report incorporates extensive input from members of the CSIS delegation and reflects their broad consensus view. The report's findings and recommendations are based on the experiences of the delegation and do not necessarily reflect the policies and opinions of any individual, organization, corporation, or U.S. government agency.*

As the CSIS Task Force on HIV/AIDS begins to focus on the countries that could form the next wave of the HIV/AIDS pandemic, a team of prominent U.S.-based experts visited India, January 3–10, 2004. The group was led by Dr. Louis Sullivan, president emeritus of the Morehouse School of Medicine, cochair of the Presidential Advisory Council on HIV/AIDS, and former U.S. secretary of health and human services (1989–1992), and by Richard Celeste, president of Colorado College and former U.S. ambassador to India. Teresita Schaffer, director of the CSIS South Asia Program, and J. Stephen Morrison, executive director of the CSIS Task Force on HIV/AIDS and director of the CSIS Africa Program, organized the delegation. In addition, the nine-member team included prominent members of the pharmaceutical industry, philanthropic, public health, nonprofit, and scientific communities. The U.S. embassy in India and representatives of the U.S. Agency for International Development (USAID) and the Centers for Disease Control and Prevention (CDC) participated in a number of the delegation's meetings.

The group met with India's health and family welfare minister, senior health officials in the central and state governments, parliamentarians, opposition leaders, and the chief minister of Andhra Pradesh, and visited research institutions and a variety of AIDS projects run by both the government and private organizations. It participated in discussions with Indian and U.S. parliamentarians and with leaders of business and nongovernmental organizations (NGOs). It talked with people living with and affected by AIDS. Its goal was to understand India's experience with AIDS and its response to the epidemic in a multidisciplinary way, to establish partnerships with Indians seized by the issue of HIV, and to make recommendations about how the United States can most effectively support India's efforts to prevent a generalized epidemic and bring treatment to people living with HIV.

The basic dimensions of India's epidemic are familiar. Over 4.5 million people are infected, according to government figures. The main transmission chains are centered on sex workers and their clients, mobile populations, and intravenous drug users. The highest prevalence of infected people are in four large southern states and two small northeastern ones, but worrisome pockets of infection, less well known, exist in other areas. The government's strategy has emphasized prevention and work with high-risk populations and has been especially active in these high-prevalence states. India's highly stratified social structure and traditional taboos on public discussion of sex have contributed to stigmatizing the disease. The low status of women makes them especially vulnerable to infection.

The team came away with three strong conclusions. First, this is a critical moment for India, a moment of both hope and danger. India faces the threat of a generalized epidemic that, if not forestalled, will have grave consequences for its national interests, ours, and the region as a whole. The epidemic has begun to spread into the general population in several parts of India. Given India's size and the mobility of its population, the risk of further spread is real. The alarm expressed by the officials closest to the epidemic's "hot spots" is fully warranted.

But the reasons for cautious hope are equally real. Political leaders, starting with the prime minister, minister of health and family welfare, chief ministers of major states, and major opposition figures, have put the issue on the map politically. Awareness of the epidemic is up sharply compared with even one year ago. India has important assets in combating the epidemic. Its pool of health and science manpower is eager to make a difference. Awareness of the pervasive problems of stigma and vulnerability of women is widespread, although measures to help overcome these barriers have been insufficiently integrated into the AIDS program or India's impressive biomedical research on HIV/AIDS.

Second, the Indian government's recent decision to introduce antiretroviral drugs (ARVs) on a limited basis makes this a time of particular change and opportunity. This policy change confronts a severely overburdened and understaffed public health system with a need for dramatic improvements. The national AIDS program needs to use treatment as a spur to prevention efforts, which remain central to India's strategy. The people managing the health system are looking for changes that will make their task feasible. They are receptive to ideas and partnerships in bringing about this change. The stage may be set for a serious and welcome national discussion about public health in general. This is, in short, a moment when India needs to rise to a unique challenge, but also a moment when India and those who support its AIDS programs can make a difference.

Third, there is a strong case for the United States to make combating HIV/AIDS a priority element in the U.S.-India bilateral relationship.

The challenge is India's, but it is also ours. The U.S. government has concluded that worldwide HIV/AIDS represents a danger to U.S. security interests. This is the reasoning behind the President's Emergency Plan for AIDS Relief and for the president's decision to name a global coordinator for AIDS.

India puts this challenge into stark relief. Within India, and among close international observers, there is considerable disquiet over the possibility that India faces a generalized HIV/AIDS epidemic. With 1 billion people, one of the fastest-

growing economies in the world, and high mobility both within the country and increasingly around the world, India will weigh heavily in the future prosperity and stability of the world. In the past decade, and especially since September 11, 2001, India has become an important security partner for the United States. The largest power in a turbulent neighborhood, a nuclear weapons state with an unresolved dispute with a less-stable and less-prosperous nuclear neighbor, India can tilt the region toward greater peace or greater turmoil. The success of its efforts against HIV/AIDS will in part determine in which direction it goes.

For all these reasons, our most fundamental recommendation is that the U.S. government make a strategic decision now to deepen its engagement on HIV/AIDS in India. This can and should take multiple forms.

The most effective message of support the United States could send is to make India eligible for funding from the President's Emergency Plan for AIDS Relief. India's size is frightening to donors, but we cannot avert our eyes and wait for millions to die just because the problem is big.

We also recommend that the United States deepen the important professional relationships between Indian experts and their counterparts in the United States, including those in the Indian military; that it work with India to fill in some of the gaps in AIDS prevention, such as the problem of high-prevalence regions in low-prevalence states; that it use its special expertise and the extraordinary openness of the U.S. system to foster stronger multidisciplinary ties; that U.S. businesses join their Indian counterparts in moving from verbal support to action against AIDS; and that it apply to the epidemic in other parts of the world the lessons from India's unique experience in dealing with AIDS in a huge and democratic country.

This report will be the beginning of a continuing dialogue with the key people and institutions involved in fighting AIDS in both India and the United States. CSIS has benefited greatly from the wisdom and insights of those we spoke to in India. We will continue our partnership with the Ministry of Health and Family Welfare, the National AIDS Control Organization (NACO), the Parliamentary Forum on AIDS, HIV/AIDS professionals, business organizations, and scholars, and bring their insights to those in Washington, D.C., and elsewhere who can benefit from India's experience.

We owe special thanks to many people who graciously received our group and helped to organize the trip. In an impressive field, two contributions especially stood out: Dr. Dora Warren, representative in India of the Centers for Disease Control and Prevention; and the Bill and Melinda Gates Foundation, which has supported our work and is also undertaking the largest single intervention to promote AIDS prevention in India. Their representative in India, Ashok Alexander, provided us with support and wise counsel. Their partnerships, both with us and with Indian counterparts, have been and will be a critical part of this effort.

The guiding principle for our work was well expressed by Oscar Fernandes, the convener of the Parliamentary Forum on AIDS, when he urged that we "fight AIDS with compassion and with passion."

## Introduction: India at the Crossroads

As part of its continuing effort to probe the policy implications for the United States of the global HIV/AIDS pandemic, the Center for Strategic and International Studies (CSIS) organized a senior-level delegation visit to India from January 3–10, 2004. The purpose of the visit was to understand how HIV/AIDS is affecting India, how governmental and nongovernmental institutions in the country are mobilizing to slow the spread of the disease, and how the United States should work with India in this effort. This report reviews the overall state of the epidemic and India's response to it; it then lists the delegation's key findings and, finally, enumerates the delegation's recommendations.

The team was headed by Richard Celeste, former U.S. ambassador to India and former Ohio governor, and by Dr. Louis Sullivan, former U.S. secretary of health and human services (1989–1992) and current cochairman of the President's Advisory Committee on HIV/AIDS. It included Teresita C. Schaffer, former U.S. ambassador to Sri Lanka and director of the CSIS South Asia Program; Dr. Michael Merson, dean of public health, Yale University School of Medicine; Samir Khalil, executive director for HIV policy and external affairs, Merck & Co.; Lisa Carty, senior policy officer for global health, Bill and Melinda Gates Foundation; Dr. Geeta Rao Gupta, president, International Center for Research on Women; J. Stephen Morrison, director of the CSIS Africa Program and executive director of the CSIS Task Force on HIV/AIDS; and Pramit Mitra, research associate in the CSIS South Asia Program. The U.S. *chargé d'affaires* in New Delhi, the director of the USAID mission in India, and the representatives in India of the Centers for Disease Control and Prevention (CDC) participated in many of the delegation's meetings. About half the team had extensive prior experience in India, including work on HIV/AIDS; the rest had extensive experience with HIV/AIDS in other countries.

During the weeklong visit, the delegation visited New Delhi, Hyderabad, and Pune. In Delhi, the delegation met with Sushma Swaraj, minister of health and family welfare, J.V.R. Prasada Rao, health secretary, and Meenakshi Datta Ghosh, director of the National AIDS Control Organization (NACO). It also called on Dr. Manmohan Singh, leader of the opposition in the Rajya Sabha (upper house of the parliament) and interacted with business leaders at events organized by the Confederation of Indian Industry (CII) and Federation of Indian Chambers of Commerce and Industry (FICCI) to discuss the role of Indian business in combating the pandemic. It met with members of the Indian Parliamentary Committee on HIV/AIDS, together with a group of members of the U.S. House of Representatives including Barbara Lee (D-Calif.), Joseph Crowley (D-N.Y.), Steny Hoyer (D-Md.), and Linda Sanchez (D-Calif.), as well as Senator John Cornyn (R-Texas).

In addition, the delegation conducted a number of site visits to get a first-hand glimpse of how the AIDS epidemic is affecting India. The delegation visited three projects in Delhi: Michael's Care Home, a shelter for intravenous drug users and homeless AIDS patients run by Sahara, a nonprofit organization; a NACO-supported targeted intervention program aimed at truckers run by the Society for Promotion of Youth and Masses (SPYM) that provides information, counseling, and medical facilities to approximately 1,000 truckers every day; and a program run

by Swaasthya, a nonprofit organization, that works with housewives and adolescents from low-income households on reproductive and sexual health issues.

In Hyderabad, the delegation met with Chandrababu Naidu, chief minister of Andhra Pradesh state, and with key state health officials. It conferred with senior business figures, NGOs, Indian Railways officials, and scientists at two sessions on HIV/AIDS organized by the Confederation of Indian Industries. Dr. Sullivan, Ambassador Celeste, Dr. Merson, and Mr. Khalil addressed these sessions. The CSIS team also visited Osmania Hospital, one of the leading participants in the national program for prevention of mother-to-child transmission, and met with a group of sex workers involved in an AIDS prevention project sponsored by the state AIDS control society. Finally, the delegation visited the National AIDS Research

### **A Sense of Community at Sahara Michael's Care Home (New Delhi)**

On a narrow street in the Neb Sarai neighborhood in New Delhi, a beat-up sign in front of two adjacent houses identifies Michael's Care Home, one of the first shelters in the country to cater to people infected with AIDS, many of them homeless or without any family support. Funded by Catholic Relief Services, USAID, India's National AIDS Coordinating Organization (NACO), and individual contributions, it offers nutritional and medical care, counseling, advocacy, and a community for people suffering with AIDS. It also offers treatment along with AIDS prevention for drug addicts. "Our biggest contribution is that we provide a home for people suffering from this disease," Neville Selhore, director of the shelter told the CSIS delegation. "Here they don't suffer the stigma and neglect they encountered on the streets."

Each of the approximately 400 patients that the shelter helps every year has a tale of poverty, abuse, and rejection. The majority are former drug addicts, who were rejected by their families and refused treatment by government-run hospitals. But at the shelter, there is a sense of home where the patients provide each other with moral and emotional support. The facilities are rudimentary. In the 36-bed inpatient unit, medications and supplies are crowded along the walls, leaving barely room enough to walk around the beds. A new patient, a woman from Bihar, shivered in the chilly Delhi winter as the delegation arrived. The doctor on duty said she was "in very grave condition." Two staff members tenderly spoon-fed her some warm soup. The clinic has no funding for antiretroviral drugs, but with basic care and treatment of opportunistic infections, it provides hope and a better quality of life.

Most nonresident patients at the shelter go through rehabilitation and learn simple skills such as candle making, weaving, computer skills, carpentry, and woodcarving. Their cheerful gift shop, set up and run by the patients in the basement of the shelter, features well-designed and carefully made wood carvings and textiles woven in the traditional designs of Nagaland, the original home of many of the patients. "The biggest challenge in India is the stigma associated with the disease," Selhore said. "Acceptance of AIDS and HIV-infected people by the Indian society will be the biggest test in the months to come."

Michael's Care Home handles patients that the standard thumbnail sketch of India's HIV/AIDS epidemic does not acknowledge: drug addicts in Delhi, not in the remote states of India's northeast. It has grown over the years and handled 5,200 outpatients and 360 inpatients in 2002–2003, but there are limits to how much further it can expand. Still, it illustrates the importance of creating a community and the people-intensive nature of caring for people dealing with AIDS and with drug addiction.

Institute (NARI) in Pune, where it interacted with senior scientists working on AIDS research, including preparations for vaccine testing in collaboration with the International AIDS Vaccine Initiative.

India will probably have the largest number of HIV-infected people in the world within a few years. The size of India's population puts it, along with China, in a special category in assessing the impact of their response to the epidemic. India's important strategic relationship with the United States, and its role in a violence-prone region, make its future especially important to the United States. The interactions and site visits provided an opportunity for the delegation to assess India's preparedness to fight the pandemic and discuss ways to promote collaboration between the United States and India. Some of the key questions that this trip raised were: What can U.S. policymakers learn from India's experience? How can the United States effectively partner with India as it fights the epidemic? India's scientific and other expertise offers a wealth of potential lessons for other countries confronting the same challenge.

## The Dimensions of the Epidemic

### The Numbers

The Indian government estimates that 4.58 million individuals, or slightly less than 1 percent of the adult population, are infected with the HIV virus. The increase in this estimate in each of the past two years has been on the order of 500,000 cases, or 10 percent. The total number of AIDS cases in 2002 was estimated to be about 600,000. The number of actual positive cases registered is only about 60,000, so most of the people living with HIV do not know that they are infected.

The epidemic is present in all of India's 35 states. Six states—Andhra Pradesh, Karnataka, Maharashtra, Tamil Nadu, Manipur, and Nagaland—are considered high-prevalence states, with more than 1 percent of antenatal mothers testing positive for HIV. Three additional states—Gujarat, Goa, and Pondicherry—have concentrated epidemics, with prevalence of 5 percent or more among high-risk groups. Most of India's states have populations the size of relatively large countries; 10 have populations above 50 million.

Projecting the future of the epidemic is uncertain and controversial. Meenakshi Datta Ghosh, NACO director, estimated in late 2002 that if NACO met its program goals, HIV infections would grow to 9 million nationwide by 2010; if it fell short of its goals by 50 percent, infections would rise to 14.7 million. Based on the average 10-year median survival in India from the date of HIV infection, she estimated that 1.9 million people would die of AIDS by 2010.<sup>1</sup> By any measure, India has a serious problem on its hands. With India's population of 1 billion, even a small shift in the prevalence rate will result in tremendous increases. This is a critical time for India. The HIV virus is beginning to spread to a broader swath of India's mainstream

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1. J. Stephen Morrison and Jennifer G. Cooke, *The Second Wave of the HIV/AIDS Pandemic: China, India, Russia, Ethiopia, Nigeria*, a conference report of the CSIS Task Force on HIV/AIDS (Washington, D.C.: CSIS, December 2002).

society and economy. The experience of the United States and several African countries have shown that failure to adopt an aggressive approach early in the epidemic can reap a harvest of tremendous suffering and pain later on.

### **Strategic Focus on High-risk Populations and States**

In India, 75 to 80 percent of HIV transmission is through heterosexual sex. HIV prevalence rates are highest among sex workers and their clients. The latter, in turn, take the disease back to their homes and infect their wives. Mobile populations, notably truckers, have been especially important in spreading the disease. Four of the high-prevalence states are economically well off and have relatively strong state governments and local health systems. Prosperity tends to bring in migrant populations and thus increases the risk of spreading the HIV virus. Condom use remains low among high-risk populations. Many sex workers are afraid to ask their clients to use one, since that may drive clients away. Apart from sex workers and truckers, high-risk populations include migrant laborers, prisoners, and military troops stationed in remote areas, especially in the northeast.

A second focus of transmission is intravenous drug use. Observers note that drug users are switching from inhaling to injecting drugs, thereby increasing the risk of spreading HIV. This phenomenon is more localized in the northeastern states, mainly Nagaland and Manipur. Sharing of syringes, mainly driven by poverty, is causing a sharp increase of HIV infections in these states and even in low-prevalence places such as Delhi. Lack of economic opportunities and support has forced many drug users to fall back on their old habits even after going through rehabilitation.

The epidemic, however, is no longer confined to high-risk populations. In the more seriously affected states, the epidemic has spread into the general population. In Hyderabad, the Osmania Maternity Hospital, which is deeply involved in AIDS prevention work with pregnant women in a high-prevalence state, told the delegation that 77 percent of the husbands of their HIV-positive patients are themselves positive. The occupations of these men were quite evenly divided, including agricultural labor, business, driving, and skilled and unskilled labor. Data compiled by the Andhra Pradesh State AIDS Control Society show little variation between rural and urban districts in HIV prevalence. Moreover, low-prevalence states include high-prevalence areas that require attention. The chairman of the Indian Oil Company told the delegation that six employees had identified themselves as being HIV positive in one of the company's plants in Bihar.

India's AIDS prevention work is nationwide, but the systems it uses to track the epidemic are strongest in the high-prevalence states. They have the lion's share of surveillance sites. Because most of them are economically successful, they also have the best-developed local health systems.

### **Stigma Remains a Big Hurdle**

Reducing stigma against HIV-infected people—social barriers and legal uncertainties that impede access to prevention services and treatment—is a very important issue for India. Awareness that AIDS is a fatal disease is high, but understanding of

how it is transmitted is at best erratic. One survey indicates that more than 60 percent of Indians still mistakenly believe that they can contract AIDS by mosquito bites or by sharing a meal or shaking hands with an HIV-infected person. The result is that infected people are ostracized, and vulnerable groups—women, lower castes, and marginal populations—are so afraid of the consequences of raising the AIDS issue that they will not take measures to protect themselves lest they be accused of immorality or of spreading the virus themselves.

Public understanding of specific ways to prevent infection, though rising, remains very low in the general population. Even at the best medical facilities, there have been troubling cases of turning away HIV-positive patients. The emphasis on biomedical measures for fighting HIV/AIDS has tended to take attention away from the equally necessary task of fighting social stigma.

### **Social and Cultural Taboos Remain Strong**

India's complicated social norms and conservative attitudes toward sex make it hard to remove taboos. For instance, prostitution is illegal yet widespread. Fear of retribution by local police, their pimps, and families prevent many sex workers

#### **Promoting Gender Equality at Swaasthya (New Delhi)**

An impressive team gathered in the basement offices of Swaasthya (Hindi for health), an NGO based in Delhi, to brief the delegation on a wide range of gender issues. Since its inception in 1994, the organization has been working on reproductive and sexual health issues in Tigri, a low-income neighborhood in south Delhi. "Low status of women in India makes them particularly vulnerable to HIV/AIDS, unwanted pregnancies, violence and exploitation," said Geeta Sodhi, the pediatrician who runs the project.

Half an hour later, delegation members made their way to the neighborhood to talk at length with some of the women associated with the Swaasthya program. One victim of domestic violence who has been attending Swaasthya meetings for some time narrated how the program had taught her about the laws against such abuse. Armed with this knowledge, she told her husband and her in-laws—"calmly and quietly," she stressed—that there were laws against violence and that she would invoke them if she were beaten "when I haven't done anything wrong." She credited Swaasthya with giving her the tools to change her life. Others recounted how going through the program had helped them to set up their own small businesses, become financially independent, and thus make their lives more meaningful.

In 1996, Swaasthya undertook a study of sexual behavior of unmarried adolescents with the support of the Rockefeller Foundation. Among other things, the study found that this group was particularly vulnerable to HIV/AIDS and sexually transmitted diseases (STDs). Myths about sexual practices were widespread, and access to reliable information was limited. It found that because of social taboos on pre-marital sex, adolescents placed a higher value on secrecy than safety in sex. Indeed, these fears were reiterated during our discussions with Swaasthya members. Based on the findings, the NGO has developed an intervention program designed to address these issues. The hope is that the Tigri model could be implemented successfully elsewhere in India.

from coming forward for testing and treatment. Fear of losing their clients and thus their livelihood leads many sex workers to refrain from demanding the use of condoms by their customers.

Discussions about sex remain off limits in most Indian households and even in elite private schools in big cities like Delhi. AIDS is often seen as a disease restricted to marginal, morally suspect populations, who “brought it on themselves.”

Homosexuality is also illegal and frowned on by most Indians. The government has been hesitant to focus on men who have sex with men as a significant risk group, though logic suggests that it is an important transmission vector. Interestingly, some common instances of male-on-male sex are not considered “homosexual” by the people involved. These include the practice of boys experimenting with sex with other boys before marriage, in a society where dating is generally not allowed, and the relationship between truckers and their young assistants.

### **Women Are Especially Vulnerable**

Low status and poverty make women especially vulnerable or, as one health official put it, “doubly cursed.” Despite India’s remarkable array of women leaders in government and civil society, most ordinary women live a life of systematic vulnerability. The proportion of women in the population is also one of the lowest in the world: 933 women to every 1,000 men. It is universally acknowledged that couples prefer sons to daughters and that selective abortion of girls is widespread despite legal prohibitions. Gender gaps in literacy and employment confirm the picture. Violence against women is notoriously underreported in many countries, and India is no exception. In these circumstances, women are unlikely to be able to protect themselves against infection by their husbands, since to insist on a condom would open them to accusations of infidelity and to probable physical violence. With the government’s decision to provide treatment for AIDS to mothers of young children, it will need to find a way of ensuring that the women actually receive medication, in a society where their husbands would normally expect to take priority.

### **Less Awareness of Problem in Low-prevalence States**

Some of the current low-prevalence states are particularly vulnerable because of their large populations, high incidence of migration, low literacy levels and per capita income, and early age at marriage. The surveillance system covers the low-prevalence states less densely than those with high prevalence. Other data, such as levels of sexually transmitted infections, suggest that there are “hot” districts in a number of low-prevalence states. Several of these districts track the major national highways, which is consistent with the observation that truckers and migrant populations are a major transmission source.

The government’s decision to provide ARV therapy only in high-prevalence states will undoubtedly lead to pressures to extend the treatment program to other states, either because local politicians will press the national government to give their people the same benefits or because patients in low-prevalence states will move into states where treatment is available.

## India's Response

India's AIDS programs are implemented through the National AIDS Control Organization, a semi-independent organization established in 1992 within the Health Ministry. Its special status was intended to prevent the bureaucratic delays that normally plague India's decisionmaking process. By 1999, the organization had established a decentralized framework. Much of the burden of work and responsibility was pushed down to the states, which established state AIDS control societies. NACO has also worked closely with NGOs. NACO and the state societies are allowed to accept international donor funds and private funding, a significant change from standard government practice.

India's plan for dealing with HIV/AIDS focuses first and foremost on prevention. Its operational objective is to contain HIV prevalence at 3 percent in the states with a generalized epidemic, 2 percent in those with a concentrated epidemic, and 1 percent in the rest of the country. It also aims to increase awareness to 90 percent among youth and other vulnerable parts of the population and to increase condom use to 90 percent among high-risk groups. The Indian government's health budget is on the order of \$400 million per year, but only a small portion of that is earmarked for HIV/AIDS. International funding has provided the largest share of financial backing for the HIV/AIDS program.

Although estimates of the five-year commitments of India's international donors run as high as \$850 million, the prevailing estimate for expenditures on HIV/AIDS in the current year is approximately \$60 million. Even if all the commitments were disbursed on schedule, however, this would represent a rather modest investment in AIDS prevention and treatment—about 17 cents per person in India. By way of comparison, estimated per capita spending on AIDS in Uganda is \$1.85 and in Thailand 55 cents.

Besides the national and state AIDS control programs, the Indian government is involved in HIV/AIDS prevention and treatment through a number of health care programs for its own employees. Indian Railways, which operates the largest health care system in the country, the military, and the central government health scheme all provide testing and counseling as well as treatment. Health officials estimate that there are currently 15,000 people receiving ARVs through these plans, some of them in government hospitals and others through referrals to private hospitals.

### Political Leadership on the Rise

India is moving in the right direction. Members of the delegation who have worked on HIV/AIDS issues in India in the past were all struck by the quantum increase in awareness of the epidemic in the last couple of years. The epidemic is now recognized as a major threat to India's health and economy by elites throughout the country. Indian NGOs have done much to raise the visibility of AIDS in the country.

The strong commitment shown by India's political leaders is especially encouraging. Prime Minister Atal Behari Vajpayee has spoken very movingly about the

plight of AIDS patients. Minister of Health and Family Welfare Sushma Swaraj described the public impact of her embrace of two HIV-infected children who had been refused admission to school in Kerala. The huge publicity given to this incident in the Indian media has contributed to de-stigmatizing people suffering from the disease. The leader of India's opposition party, Sonia Gandhi, represented the government at the recent special session of the United Nations General Assembly devoted to HIV/AIDS, a rare demonstration of common commitment across political lines. Her party's leader in the upper house of India's parliament, Dr. Manmohan Singh, expressed a similarly strong commitment to reversing the current trends. Indian lawmakers have established a parliamentary committee on HIV/AIDS to involve politicians from a wide range of parties in discussions and the preparation of legislation.

### **Legislation on HIV/AIDS to Be Introduced Soon**

Since May 2002, parliamentarians have been working on a draft HIV/AIDS law, and this process is now in the final stages. In an unusual move, they have worked closely in drafting the legislation with the Lawyers' Collective, a group of lawyers deeply concerned about the problem of HIV/AIDS. The legislation is designed to combat stigma and prevent discrimination, and it reflects extensive research on laws, policies, and practices on HIV/AIDS to make the legislation appropriate to the Indian context. Comments were also sought from people living with HIV and AIDS, health care providers, and people on the ground. These experiences have been consolidated in the form of a book, *Legislating an Epidemic: HIV/AIDS in India* (Mumbai: Lawyers Collective Universal Law Publishing Co., 2003). The legislation is to be introduced in the Indian parliament for voting by the end of April 2004, though this schedule could be affected by the upcoming national elections.

### **Ambitious Plan to Provide ARV Treatment**

The Indian Health Ministry has announced an ambitious plan to provide ARV therapy starting in April 2004 to HIV-positive new parents (in practice, primarily mothers), infected children under age 15, and patients coming in to government hospitals, in the six high-risk states. Previously, the government program provided ARVs only to pregnant women for prevention of parent-to-child transmission and to medical personnel exposed in the line of duty. The government plans to provide ARVs to 100,000 patients in the first year, starting in the major tertiary public hospitals and eventually moving down to less-specialized facilities. This will expand access to ARVs at least six fold. The cost of drugs has until now put them out of reach for most Indians, even at the prices normally charged by the generic drug manufacturers. It is not clear how this treatment will be funded, but the health minister assured delegation members that the Finance Ministry would provide the necessary budgetary support.

### **India's Pharmaceutical Industry Poised to Play Significant Role**

Several Indian pharmaceutical companies manufacture generic drugs at competitive prices. Cipla, Ranbaxy Laboratories Ltd., Matrix Laboratories, and Hetero

Drugs Ltd. recently announced an agreement with the Clinton Foundation to provide drugs to four African and nine Caribbean countries for about 37 cents per patient per day. The Indian Health Ministry hopes to obtain a price below the one Indian generic producers negotiated with the Clinton Foundation. One of the key issues in this negotiation will be providing the companies an assurance about levels of procurement. From the perspective of those providing care, continuity of supply is a big worry.

### **Lack of Public Health Care Capacity Poses Problems**

Moving into ARV treatment is a momentous change in government policy, and everyone the delegation spoke to was conscious of its importance. It presents an unprecedented challenge to the overburdened public health system, but it also represents an opportunity to address the deficiencies in that system in ways that will strengthen it across the board.

The country's public health care system lacks sufficient capacity to cope with HIV/AIDS. India has an impressive number of dedicated people working in the health field, but the system does not give them the support they need. Most government-operated hospitals are inadequately staffed and plagued by erratic power supply and poor maintenance, making it difficult for them to treat even basic ailments, let alone AIDS. Hospitals in villages are often run out of makeshift buildings where doctors with only the bare necessities have to cope with hundreds of patients. Public hospitals are free, but patients are often told to bring their own drugs and other materials because of inadequate resources. Very few doctors and nurses are trained to diagnose and treat HIV infections and AIDS. Training, technical assistance, and financial support across a wide range of disciplines—epidemiological, medical, scientific, and training—are sorely required at the local level to make the government's plan a success.

### **NGOs Are an Important Asset**

Nongovernmental organizations, philanthropic organizations, and other nonprofit institutions have played a significant role in the battle against AIDS in India. India's large network of such organizations has extensive experience dealing with health and social issues at the grass roots. They are uniquely suited to do the people-intensive work needed to change behavior, which is at the heart of AIDS prevention at the local level. Projects undertaken by these organizations include direct care of people with HIV/AIDS, general awareness campaigns, care for AIDS orphans, and work with high-risk groups such as sex workers and drug users. Funding for NGOs comes from a variety of sources: the Indian government, state governments, international donors, and local charities.

Many of the NGOs engaged in AIDS work in India are small and local. One private donor, the Bill and Melinda Gates Foundation, has taken on the challenge of a large-scale project, based on operating models drawn from business. The lion's share of its five-year, \$200-million project will be devoted to HIV/AIDS prevention work, primarily with truckers and sex workers, in high-prevalence districts around the country. They hope to have a strategic impact on two levels: first, by signifi-

### Healthy Highway Project: Confronting AIDS on India's Roads (New Delhi)

Truckers on India's long highways stop for the night at *dhabas*, roadside truck stops, to rest, load their vehicles, or do repair work. Many drivers also use this opportunity to have sex with local prostitutes in their trucks. They then carry the disease back to their homes. At any given point, hundreds of trucks line these dusty roads, which serve as a hub for northern India. The *dhaba* outside Delhi that the delegation visited consisted of a ramshackle restaurant and a small clinic used to provide basic treatment to truckers.

The Society for Promotion of Youth and Masses (SPYM) is engaged in information dissemination and condom demonstration and distribution with truckers at these *dhabas*, to prevent the spread of HIV/AIDS in this high-risk group. Low awareness of sexually transmitted diseases and high mobility has made truckers in India one of the key vectors through which the HIV virus is spreading the length and breadth of the country.

"We attempt to develop some trust with the truckers which can help us to persuade them to change their sexual practices," said Bilal Naqati, director of programs at SPYM, "but it is hard since they are here only for a day or two, and we may never see them again." In front of the restaurant, counselors demonstrated condom use to a group of drivers who uneasily sipped cups of tea. Amidst the nervous giggles and the occasional joke, most listened attentively, and a few asked questions. The delegates spoke to some of the truckers and saw a clinic where drivers can get treatment for sexual diseases and can receive individual counseling from SPYM-trained counselors. SPYM counselors said that up to 70 percent of the men who walk into the clinic already have some kind of sexually transmitted disease, which means they are especially vulnerable to HIV infection. "We can only hope that they pass on the message to their colleagues and practice what they learn here," said Naqati.

The Bill and Melinda Gates Foundation has decided to devote most of its \$200-million, five-year project to interventions like this, principally in the states and districts of India where HIV infection is most prevalent. They will be working in partnership with the Indian Oil Company and the Transport Corporation of India. Besides the counseling and AIDS-prevention messages that we saw, the Gates Foundation's projects will include a standardized model for clinics to treat sexually transmitted infections. This strategic intervention, designed to operate on a national scale, should have a major impact in reducing the spread of HIV. It needs to be complemented, however, by the kind of people-intensive interventions needed to reach vulnerable women and unsuspecting communities.

cantly reducing transmission in the areas where they are working; and second, by developing models that can be replicated, so their work can spread beyond their own activities.

### Official Foreign Donors Are Making a Substantial Contribution

India has also benefited from funding from foreign governments and international agencies, although India's enormous size guarantees that its share of funding will be far lower on a per capita basis than that of smaller countries. Among the most important participants have been:

- *The Global Fund to Fight AIDS, Tuberculosis, and Malaria*, which has agreed to provide India with \$100 million over five years for prevention, treatment, and voluntary testing and counseling. India may also be considering asking for Global Fund support for the government's ARV program.
- *The World Bank*, which has supported two major projects that have been the backbone of funding for the HIV/AIDS program in India. The first project provided the Indian government with an \$84-million credit in 1991 to broaden prevention efforts and to establish institutions to curb the spread of HIV/AIDS. The second project, for \$191 million over five years, provides funding for intervention programs such as information and awareness campaigns and voluntary testing and counseling through blood banks and sexually transmitted disease (STD) clinics and home-based and community-based care.
- *USAID*, which has committed \$104 million for five years for AIDS prevention work in Tamil Nadu, Maharashtra, and Pondicherry. Its projects in Tamil Nadu in particular are credited with a substantial reduction in high-risk behavior by truck drivers and other high-risk groups. Additionally, USAID supports major NGO activities by Family Health International (FHI) to reach out to children affected by AIDS in high-risk communities across India and by Population Services International (PSI) in 12 major ports of India where prevention activities, including voluntary counseling and testing, are focused on high-risk groups.
- *The Centers for Disease Control and Prevention (CDC)*, which at about \$3 million per year have provided primarily technical support for a range of activities, including capacity building in the public-sector health system, improvement of key laboratories, exploration of advanced surveillance techniques, and work with community groups. They are working primarily in Tamil Nadu, Maharashtra, Delhi, and Andhra Pradesh. Beyond its program support, CDC and the National Institutes of Health represent a prized source of professional training and collaborative research.
- *The National Institutes of Health (NIH)*, which have provided extensive research support to scholars and projects around India, with an estimated aggregate value of \$12 million per year. Of particular significance are the collaborations established under the Fogarty International Center's AIDS International Training and Research Program (AITRP). India has eight collaborations under this program, the largest number of any single country in the world.
- *The UK Department for International Development (DFID)*, which has committed \$180 million over five years to AIDS work in Andhra Pradesh, West Bengal, Kerala, Gujarat, and Orissa.

## Key Findings

### General

- **This is a critical time for India's response to the epidemic. This is the ideal time for the United States to engage more deeply with India on HIV/AIDS and achieve important results.**

In the past year, India's political leaders have put the HIV/AIDS issue into the public consciousness. People in elite circles are strikingly more aware than in the past that HIV/AIDS matters deeply to India's future. The prime minister has spoken out, and an activist health minister and the political leaders of some of the most seriously affected states have taken on the issue. It is harder to mobilize political leaders at the local level, but even here the process has started. India has strong assets in its scientific community and, despite its problems, in the leaders of the health system.

The Indian government's decision to make antiretroviral medications available to mothers and children with AIDS and to AIDS patients in government hospitals in the six high-prevalence states starting April 1, 2004, makes the next six to twelve months critical. The new policy will increase demand for health services and for AIDS prevention services. The health system will need to perform in ways that it has not done before, and the AIDS program will need to sustain and strengthen prevention efforts even as it ramps up treatment. India's health officials and medical personnel are looking for ways to meet this challenge. In the next few months, India will have both a dramatically increased need for resources and a much-enhanced openness to ideas and experience for creating a more effective system. What happens now will affect India's prospects for stemming the epidemic, with profound consequences for the future. The United States needs to be part of this process.

- **Despite the good news about awareness and the success of some landmark programs, the situation in India warrants a sense of great urgency.**

India does not have the prevalence rates that have devastated some African countries, but it has an epidemic that already affects the general population in large parts of the country and that could explode with little notice in places that are not now considered high prevalence. Indeed, this is almost the definition of a "second wave" country. In India, there is an opportunity to prevent the devastation seen in Africa, and the United States needs to help turn that chance into a reality.

But a sense of alarm is largely limited to officials and health professionals directly involved with the epidemic in the high-prevalence states and to people who have seen friends or acquaintances sicken and die from AIDS. Outside this circle, there is still a tendency to look on HIV/AIDS as a problem that only affects identifiable high-risk groups. In fact, the communities from which mobile populations like truckers come are at risk; "hot spots" within low-prevalence states are in danger of being overlooked. We can only guess at the extent to which gender inequality will fuel the spread of the disease. There is no time to waste.

- **An effective strategy must address all aspects of the epidemic.**

The government and the major donors have put their primary emphasis on prevention—appropriate in a country where the primary goal is to avoid having the epidemic explode. However, the strategic focus cannot be limited to sex workers, truckers along major national highway routes, and intravenous drug users. The chain of risk goes out to home communities of truckers, other clients of sex workers, and beyond. Reaching these different audiences will require an array of interventions that may need to work in quite different ways to change people's behavior. In other words, an effective strategy needs to balance emphasis on the highest-risk groups with energetic outreach to the general population.

Some donors, notably the Bill and Melinda Gates Foundation, have made targeted interventions with sex workers and truckers in key hot spots their primary modus operandi. This approach has strong epidemiological justification. The magnitude of resources the Gates Foundation is bringing to bear and their results-oriented approach will make this a very important addition to India's fight. However, the effectiveness of this approach depends in part on how effectively other operators—Indian and foreign—can provide the other elements needed for an integrated and balanced program.

- **India will not allow outside donors to have the deciding voice in determining its strategy. At the same time, bureaucratic rigidity—both in India and its donors—can distort strategy and waste resources.**

Because of India's large size, foreign aid has always represented a substantially smaller share of its economy than is the case for smaller countries at a comparable income level. The same is true for HIV/AIDS. This reinforces India's insistence on maintaining policy control and its resistance to the sometimes-diverging pressures from different donors. But the urgency of the AIDS epidemic calls for loosening the bureaucratic rigidities that affect both India and its donor governments.

## **The Problem of Scale**

- **The epidemic needs to be tracked and managed through smaller units.**

The government is justifiably proud of its sentinel surveillance system, which has ramped up to monitor the epidemic from 55 sites in 1998 to 455 sites conducting unlinked, anonymous testing in different parts of this large and diverse country. The anecdotal evidence and project-specific data our team encountered generally corroborated the overall picture presented by surveillance data.

However, when one looks at the dynamics of the epidemic, it appears that the standard model of a nationwide surveillance system leading to aggregate state or national figures and estimates does not provide adequate information for India to manage its response. Focusing on the six high-prevalence states makes sense from the point of view of India's political and administrative structure. However, many states in India are comparable in size to some of the largest countries in the world. Andhra Pradesh, which the team visited, has a population of 76 million. Leaders at the state level need to have at their disposal information comparable to what national leaders might need elsewhere.

Worse, states that are classified as low prevalence run the risk of complacency and may ignore or miss localized epidemics. In India's largest state, Uttar Pradesh, 0.3 percent of women at antenatal clinics participating in the sentinel surveillance scheme tested positive, along with 0.8 percent of patients at STD clinics. Uttar Pradesh is one of the least progressive states in literacy, governance, and economic development. It has a population of 166 million. Several major national highways pass through it. Data from antenatal clinics come from only 17 of the state's 70 districts. Focusing on state aggregates in these circumstances leaves open the substantial likelihood of large undetected hot spots.

Hot spots can be temporal as well as geographic. Major religious festivals and other large gatherings may involve concentrations of risky behavior involving crowds from all over the country. The surveillance system provides broad coverage of antenatal clinics and sexually transmitted disease clinics—but only 13 sites that provide data on intravenous drug users, 3 on men having sex with men, and 2 on sex workers (2002 figures).

In 2002, the government of India convened a panel to review its surveillance data and to make recommendations for the future. The panel's report has not been made public, but since the panel met, the government has carried out one round of behavioral surveillance and is planning a second. It has also made some changes in the way it releases data, including the decision to publish a range of estimates rather than a single figure.

To get a better fix on patterns of disease and, more importantly, to deploy resources where they are most needed, we believe it would be highly desirable to track the disease through smaller territorial units. India's states are divided into 595 districts with an average population of slightly under 2 million. The Gates Foundation plans to supplement data from the surveillance system with rapid baseline studies among high-risk populations in potential hot spots in certain low-prevalence states. The results will help guide resource allocation for their targeted interventions.

Looking at HIV prevalence by district rather than by state would provide a more sophisticated assessment of where the disease is spreading and where it is stabilizing—and, more importantly, would provide a better barometer of where the program needs surge capacity. This would involve a very large expansion of the surveillance system and is probably not achievable in one jump, but the payoff in guiding early interventions to the places where infection is starting to spread could be very important.

- **“Scaling up” to respond to HIV/AIDS in a large country involves more than designing large-sized programs.**

The government, at both the national and state level, is trying to design programs that can be readily “scaled up.” The Gates Foundation is doing the same, relying on clinically tested interventions for the content of its programs and on business models for managing them. As part of its AIDS prevention work at truck stops, it will create a “brand” of clinics for sexually transmitted infections (STIs) with good quality control that will be recognized and used nationwide. Community involve-

ment is a key element in the program, but there is a strong focus on creating a replicable design.

The small NGO projects we visited, however, built their programs from the ground up, stressing responsiveness to the unique needs of a particular set of clients. The value of this approach is particularly strong in programs designed to appeal to women and to combat stigma. In a program that is trying to change people's most intimate behavior, a people-intensive approach that respects differences between communities is an essential ingredient. To multiply programs of this sort, scaling up may not always be possible or even desirable. Finding local leaders with the energy and temperament to start a new enterprise is probably the single most important step, with existing programs providing a loose model and a source of networking and ideas. An effective program for a large and diverse country, in other words, may have to combine both large-scale and small-scale elements. This also underscores the importance of partnerships between public and private actors. India's experience will be instructive for the United States in thinking about other relatively large countries.

## The Health System and ARVs

- **India has a wealth of human skills in science, health, and social development that bolster its capacity to respond.**

The world's second-largest pool of scientists and, by the estimates of the National Science Foundation, the fourth-largest technological infrastructure; research institutions like the National AIDS Research Institute, which are already part of the international research network; the staff of hospitals and state health organizations; the leadership and staff of a large number of NGOs, both large and small—these are assets that many of the other countries fighting AIDS cannot claim, and they will help India make good use of additional resources. India was one of the first countries to take up the challenge of developing and testing HIV vaccines and microbicides. Because the four largest high-prevalence states have been economically successful, and several of them are known for having among the most effective state governments in the country, India's human resources are concentrated where they are most needed.

- **The leaders of India's health system want to keep the HIV/AIDS effort integrated within the health system. This makes sense, but will place an enormous burden on an overstressed system as it absorbs a complex new mission and a large new patient load.**

NACO is a hybrid organization: independent but still within the Health Ministry and working largely through the state AIDS control societies and in partnership with NGOs. As India approaches the introduction of ARVs, the accent is increasingly on integration rather than on creating a separate AIDS structure. NACO and the state AIDS societies continue to work independently and through NGOs for their prevention work, but programs like Prevention of Parent to Child Transmission and the new treatment programs operate within the government health system.

This represents a challenge and an opportunity. Government facilities are underfunded, plagued by neglected basic maintenance, lack of basic supplies, and cumbersome administrative systems. Even people with meager resources try to use private health facilities when they can. One estimate holds that government spending represents only 15 percent of what the country spends on health. The number of doctors in private practice substantially exceeds the number in government service.

The government's new policy on ARVs may pull more patients into the public system. Officials preparing for their introduction worry about the hospitals' ability to assure consistency of supply, prevent drug resistance, and deal with the side effects of the medication (e.g., in a malnourished population). Dealing with these problems requires above all logistical and administrative improvement and better follow-up with patients. These in turn will strengthen the system across the board, so that it is better able to support not just HIV/AIDS care, but the full range of preventive and curative services for India's health needs. In that sense, the stimulus of the new policy on ARVs presents an opportunity for India to make significant improvements in its public health system.

- **In order to reverse the spread of the epidemic, the introduction of ARVs will need to stimulate prevention programs.**

The government has included only a limited group of patients under its new policy, which operates only in the six high-prevalence states. How the program is to be implemented is still under discussion.

In all likelihood, however, this policy will be amended, sooner rather than later. The government of Kerala—not a high-prevalence state and hence not covered by the new policy—has already announced its intention to provide ARVs to patients who need them. High-prevalence districts will press for inclusion, especially if they are represented by powerful politicians. There will be social and political pressure for including fathers as well as mothers. The soundest basis for deciding who gets drugs is to think of the family unit, so that children and the adults who support and care for them are treated together.

But ARVs by themselves will not stop or even significantly slow the epidemic. To address that, it will be essential to make ARVs a focus for prevention programs. Voluntary counseling and testing then becomes not just a means of getting treatment for people who are HIV positive, but the entry point to prevent onward transmission.

- **The financial demands of AIDS treatment are only beginning. Given the levels of HIV and AIDS already present in India, the cost of drugs will be a major issue.**

At least for the foreseeable future, the decision to introduce ARVs means that the cost of care and treatment will only go up. Those on treatment will need medications for life. By the Indian government's estimate, the 100,000 persons it plans to start treating in April 2004 represent only 18 percent of those in need of immediate treatment and 2 percent of those infected with HIV. The number of persons under treatment is bound to rise. We were told that the Finance Ministry has committed

to funding the treatment program. It is impossible to tell at this point how far that commitment goes, or what assumptions the finance minister could reasonably make about the availability of international funding to support a national treatment program.

The Indian government is understandably concerned that treatment carry an affordable and reliable price and, as noted earlier, is still negotiating with local generic manufacturers. Competition among generic manufacturers, and the fact that some multinational pharmaceutical companies are supplying reduced-price drugs to African countries, will dampen prices. From the manufacturers' point of view, the sustainability of these reduced prices depends on reliable procurement volumes. There are plenty of patients who need the drugs; at issue is the consistency of supply in the public health system and the availability of funds to purchase drugs from the central or state governments.

The pharmaceutical companies' decisions on differential pricing in poor countries, and the trade agreement reached after the Doha and Cancun WTO meetings, suggest that the bitter dispute over antiretroviral drug prices has found at least a temporary resolution. The research-based pharmaceutical industry sees its primary role in addressing the challenge of HIV/AIDS throughout the world as a commitment to the research, discovery, and development of new HIV/AIDS medicines and vaccines. The industry accepts the concomitant obligation of making these medicines more affordable. It also sees a role for itself in improving health care systems around the world, in partnership with governments and NGOs.

The continued development of new innovative medicines for the treatment of HIV/AIDS is essential to address the need for therapies with improved safety, efficacy, and convenience. The introduction of these new medicines, however, will underscore again the need to ensure access in developing countries. It is noteworthy that the recent price negotiations do not cover protease inhibitors. Affordable drugs need to be an element in a global AIDS strategy. Ensuring that people in poor countries are able to receive safe and effective AIDS treatment will continue to challenge the trade system, national governments, the international health agencies, and both the research-based and the generic pharmaceutical companies. The issue of drug prices is one of the most politically visible aspects of the response to AIDS, and India's political leaders—both government and opposition—see the availability of affordable drugs as a basic human right. Their view of the responsiveness of the international community, including the United States, will reflect this passionate concern.

## Science and Research

- **Research in India touches on some of the most important aspects of the epidemic. The most promising new products, however, are years away. There is still an important gap between biomedical and behavioral research.**

The premier research institution, the National AIDS Research Institute (NARI), is part of the Indian Council of Medical Research and started out as an offshoot of the National Institute of Virology. It keeps a register of the different HIV subtypes present in India. It has extensive partnerships with research institutions outside of

India, including NIH in the United States. Two of the most interesting biomedical projects they are working on involve testing of a candidate vaccine and development of microbicides that women can use to prevent HIV transmission.

Both could be very important elements in an AIDS prevention strategy, but neither will be available for years. NARI is working on several candidate vaccines, and is set to begin phase 1 trials of a candidate vaccine with support from the International AIDS Vaccine Initiative (IAVI) this year. Even if all the technical hurdles are overcome, most experts feel it will be at least 10 years before a vaccine becomes available, and it may have only partial effectiveness. In short, important as these efforts are, a vaccine should not be seen as the “silver bullet” for the HIV/AIDS epidemic.

Microbicides would be especially useful for women who find themselves unable to negotiate condom use with their partners, whether married women or sex workers. The development efforts now taking place at NARI are getting close to testing of an experimental product, but it is unlikely that such a product would reach the market in less than five to seven years.

NARI has made commendable efforts to broaden its research agenda to include social and behavioral science. The institute’s history and strength, however, are in the biomedical field. India’s strongest social science research is taking place elsewhere, at institutions like the Tata Institute of Social Science Research and, at the operational level, in the projects of NGOs working on the social dimensions of the epidemic. Linkages between Indian and U.S. research institutions could be used to build bridges between medical and social science work, so that India’s scientific accomplishments could be more effectively mobilized to stop the epidemic.

## Communication

- **Messages about AIDS prevention need to come from a multiplicity of sources and reach a tremendously diverse audience in India.**

Although we found AIDS awareness high, the amount of communication about it in the public square varied widely. In Delhi, there was relatively little material in the press or on billboards around town. The print media and television have not yet been mobilized. In Hyderabad, there were graffiti and posters everywhere, reflecting the chief minister’s intense approach to public communications.

Different audiences will respond to different messages and messengers. There is considerable interest in mobilizing personalities from the entertainment world, from the news media, from the film and fashion industries. But we also heard from an impressive group of women who have been working with an NGO project that they would most like to hear from “people like us”—ordinary people who can relate AIDS prevention to their daily lives.

- **Local public officials need stronger training.**

Beyond the public debate, we heard considerable discussion about how to mobilize local administrators and politicians. All members of the elite Indian administrative service train at the service academy at Mussoorie. The elected Panchayats (councils) that are supposed to take an increasingly important role at the town and village

level, and one-third of whose members are women, are another key resource. An AIDS component in their training program could have a significant impact. The National Cadet Corps has been asked to include AIDS prevention in “health camps” that it conducts in different parts of the country.

## The Business Response

- Business leaders are conscious of the problem; more of them need to move to action.

### India's Political Leaders Put the Spotlight on HIV/AIDS

Sushma Swaraj, India's popular health minister, is known for her outspokenness. She created a stir in September 2003 by embracing an HIV-infected sister and brother, Betsy and Benson Chandy, in a village in the southern state of Kerala. The children had been tuned away from four local schools because they had the HIV virus. The incident got widespread publicity in the local and international media and helped to put the plight and discrimination suffered by India's HIV/AIDS patients under the spotlight. “It was totally spontaneous,” Minister Swaraj told the CSIS delegation during a meeting, adding, “stigma is a major problem that we have to deal with in our fight against this pandemic.”

The parents of Betsy and Benson Chandy had died of AIDS-related illnesses in 2000. The children later tested positive for HIV, which they apparently contracted from their mother. As the word spread about their HIV infection, they were forced out of their school and refused entry in others. The difficulties faced by the siblings came to light after intense lobbying by their grandfather, Geevarghese Johny. The Kerala state government eventually appointed a teacher to school the children at home.

As this incident illustrates, India's political leadership now recognizes HIV/AIDS as a major threat to the nation. Each expresses this in his or her own way. Prime Minister Atal Behari Vajpayee carried the same message to over 1,500 policymakers and local elected officials at a conference in July 2003. He admitted New Delhi had been slow in taking action to curb the HIV virus but pledged a speedy response from now on. Since then he has spoken forcefully and movingly at other venues to fight the pandemic.

HIV/AIDS is one of the very few issues on which government and opposition have stood together. During the July 2003 conference, the leader of the opposition Congress party, Sonia Gandhi, asked for health insurance coverage to be expanded to include HIV/AIDS patients. Former finance minister Manmohan Singh, known for his thoughtful and intellectual approach to policy, called for a new social reform movement, comparable to the dramatic modernizing movements of the eighteenth and nineteenth centuries, to combat the gender and class inequalities that fuel the epidemic's spread. And Andhra Pradesh chief minister Chandrababu Naidu, long an energetic spokesman for mobilizing the power of the information age for India's poor, sees HIV/AIDS and more broadly public health as the big political issue in the next elections, five years hence. His style of political leadership involves relentless pursuit of a few high-profile goals. Eliminating HIV/AIDS is on his short list. The big vision behind this goal is bringing good health to the 76 million people in his state. “We get calls on this from 4:00 in the morning,” said K. Damayanthi, project director of the AP State AIDS Control Society.

The Confederation of Indian Industry and the Indian Business Trust have developed some pathbreaking guidelines for corporate policies on HIV/AIDS, which stress nondiscrimination in the workplace and AIDS-prevention messages. The government, at both the national and state level, is now challenging India's major businesses to go one step further and establish workplace health clinics that include voluntary counseling and testing. A representative of the Bajaj conglomerate described in some detail his company's policy in this area. This needs to become the norm. Members of the business community have also undertaken to help the government procure the equipment it needs for testing patients on ARVs for CD-4 cell levels.

## Stigma and Discrimination

- **The most difficult obstacle lies in social attitudes: the low status of women and the stigma attached to AIDS.**

Changing social mores is difficult and slow. Efforts to address stigma directly often wind up perversely reinforcing it by confirming that the affected person needs some kind of special status. At the political level, some of the most powerful gestures to address stigma have been very simple ones. The health minister showed us a picture of herself hugging two HIV-positive children who had been refused admission to school in Kerala. Their plight, in her words, "shattered her"; her gesture caught the imagination of the country.

But behind each such gesture is the need for a long-term effort to change behavior. A number of people we spoke to saw AIDS as a subject that needed to generate a social reform movement—comparable to those that swept through India in the eighteenth and nineteenth centuries—one that would deal in fundamental ways with the social attitudes that have fueled the growth of the epidemic. The critical dimension here is the status of women, which affects the epidemic at every stage, starting with the vulnerability of women to initial infection, often within monogamous marriages, and continuing through treatment, where women are in danger of having their drugs preempted by their partners even if the women are the intended recipients.

## Recommendations

- **The United States should make a strategic decision now to deepen its engagement with India on HIV/AIDS.**

From the point of view of overall U.S. interests, what happens in India is of great consequence to the United States, and AIDS is one of the principal question marks hanging over India's future. Strategic relations between the United States and India have dramatically strengthened in the past decade, especially since September 11, 2001. India occupies a key space—and has become a key U.S. friend—between the two traditional areas of heavy U.S. security involvement in the Persian Gulf and the western Pacific. The deeply troubled relations between India and Pakistan, both now nuclear powers, make South Asia a dangerous neighborhood. There is good

evidence that India's economic growth and political stability provide the most promising backdrop for India to manage its regional relationships peacefully and, one hopes, try to work out a more lasting settlement with Pakistan.

Acceleration of the spread of HIV/AIDS in India puts all this at risk, with potentially disastrous consequences for U.S. strategic interests. The parts of India that have been the engine of its impressive economic growth for the past 20 years include the states where the epidemic has already moved into the general population. Areas now considered low prevalence almost certainly include districts where the epidemic is well advanced. Many of these are plagued with governance problems, and they are currently receiving less attention than they need.

This is a moment of special opportunity in India, a time when a decisive increase in support for its HIV/AIDS programs can really make a difference. Elsewhere in this report, we have described the impressive human talents India brings to the table, the dedication of officials and others in the states most seriously affected, and especially the widespread recognition that the coming introduction of ARVs into the government program will require a reevaluation of how the whole health system works. Support is both needed and welcome, now more than ever.

- **The strongest way to signal real engagement is to make India eligible for funding under the President's Emergency Plan for AIDS Relief.**

The president's plan is intended to provide bold and decisive leadership and to have a major impact on a disease that the administration believes carries major strategic risks for the United States. The plan cannot meet that standard unless it operates in the major countries that are on the cusp of a disastrous epidemic. Congress has mandated the addition of a 15th country. India has the qualities the United States should be looking for: a large, potentially catastrophic, number of infected people, and a real chance of preventing this from happening.

The emphasis on treatment in the president's plan is another reason to include India. India is just beginning to provide treatment in significant quantities. This is an area where resources have not been needed in the past but will be needed in increasing quantities in the future. Deploying those resources so that they reinforce prevention is a critical challenge, and U.S. support through the president's plan can help India meet it.

We are mindful of some of the arguments that will be advanced against inclusion of India, but we believe that they can easily be countered.

- *India is too big and will absorb too large a share of the program's resources.* The president's program aims to change the course of the epidemic. It cannot do so by ignoring the big challenges. Large countries have historically received a less-than-proportionate per capita share of international economic aid. This plan should not be looked on as a "reward" that needs to be given out country by country, but as a strategic resource to deploy where it will matter most. If need be, there are ways of ensuring that India's inclusion does not deplete resources that are desperately needed in other countries (e.g., limiting funding from the president's program to certain regions or substantive

components of the program, or creating a cap, say 10 percent of the total, on the amount that can be allocated to any one country).

- *India does not have the HIV/AIDS prevalence levels found in the current 14 eligible countries.* India already has over 4.5 million infected people, virtually the same number as South Africa. If India had 20 percent prevalence among adults, it would have 100 million HIV-positive people, or two and a half times the total number in the world today. A decision to wait until India's aggregate prevalence levels have reached those in southern Africa is tantamount to waiting for millions of deaths. This is unacceptable and completely at variance with the spirit in which the president announced his plan.
- *India's track record on intellectual property rights for pharmaceuticals has been troublesome and will continue to be a problem in its treatment program.* The issue of intellectual property for AIDS medications is a complex one, but the reality is that the world is now responding to the needs of poor countries for affordable medicines. The decision by Merck and other U.S. pharmaceutical companies to provide the poorest countries with ARVs at a price that provides no profit is a case in point; the 2003 decision in the WTO on responding to HIV health emergencies is another. India is home to several of the most enterprising generic producers, but it is by no means the only country that intends to take advantage of their lower prices. Taken together with the pricing policies of pharmaceutical companies for the developing world, the result will be competition between multinational and generic producers at a lower price level. This is an epidemic that affects U.S. security interests; that recognition will need to affect policy on drug pricing as well.
- *India's social structure and taboos will inhibit its ability to fight AIDS.* The same can be said of practically every country in the world. This is not a reason to avoid working there; rather, it is an argument for developing a more effective set of skills for preventing the spread of HIV/AIDS in a complex social setting.

- **U.S. support for India's HIV/AIDS program requires not just money, but also relationships among key experts and institutions. U.S. policy needs to strengthen these systematically.**

Stepped-up support for India's HIV/AIDS program should include not just enhanced resources, but a determined effort across the board to intensify the professional relationships that Indian and U.S. scientists, NGOs, and government experts enjoy. This includes consultations between U.S. and Indian military officials. The United States has some unique capabilities for the fight against HIV/AIDS and should be prepared to make those available to India should the Indian government so desire. Enhanced techniques for monitoring epidemics could be especially useful if India decides to focus its policy efforts on districts rather than states.

One hitherto neglected area is public health education. The Indian government is exploring the possibility of starting two to four new public health schools, and

the Association of Schools of Public Health is planning a mission to India to discuss these plans. The U.S. Department of Health and Human Services is providing financial support for that mission. It should consider providing financial support for starting the schools as well, once a sound concept and plan has been developed.

The programs of the Fogarty International Center at NIH are much prized by their Indian participants and by India's health and science leaders. The steady stream of collaborations and training opportunities they provide are seen as one of the major sources of professional improvement for India's health scientists. This is another program that could well be expanded, with a particular focus on the issues raised by introducing ARVs.

To complement existing ties between Indian and U.S. scientific, business, NGO, and government counterparts, a special effort should go into creating networks that operate across disciplinary and bureaucratic lines, bringing together: medical and social scientists; NGO activists and businesses; government officials and private experts; legislators, entertainers, media personalities, and all the preceding categories. We recommend that the United States look for opportunities to introduce a strong multidisciplinary flavor to the forums in which Americans and Indians discuss HIV/AIDS.

- **The U.S. government agencies working on HIV/AIDS in India should develop projects that fill in some of the gaps in the Indian AIDS program.**

Two areas come to mind in particular:

- *High-prevalence regions in low-prevalence states.* Side by side with the established focus on Tamil Nadu and Maharashtra, USAID and CDC, with their Indian partners should begin identifying some of the hot spots outside the high-prevalence states and develop early intervention programs there.
- *Supporting the public health system.* To take advantage of the strategic opportunity created by the introduction of ARVs, the public health system needs to be strengthened across the board. This should be a priority for U.S. and other foreign donors.

- **AIDS prevention programs need to integrate gender and discrimination issues more effectively into basic project design.**

Awareness of the importance of gender inequality and stigma was high. Nonetheless, we found that in many projects measures to counteract the impact of these social attitudes were inadequately built into project design. One striking example was at the Osmania Hospital in Hyderabad, which had an extraordinary track record in persuading antenatal patients to accept HIV testing and an equally impressive record of bringing in for counseling the husbands of women who learned that they had tested positive for HIV. Some 40 percent of the women tested, however, did not return to learn the results of their tests. The officials we spoke with guessed at the reasons. Perhaps the women thought that testing was "doctors' business" and that they could leave the results to the doctors; perhaps the tests were not ready until after their bus left for the village. There were no data on whether these were the real reasons or, more importantly, on how to change the underlying situa-

tion. Even the most impressive projects we visited or read about could benefit from a much more systematic consideration of gender issues.

- **U.S. and international business groups, together with their counterparts from India, need to move the business community from concept to action.**

India's business organizations, chiefly the Confederation of Indian Industry, have taken the lead in spelling out guiding principles for corporate HIV/AIDS policies. They have dynamic relationships already with the Global Business Coalition to Fight AIDS and are well connected with the U.S.-India Business Council.

All these organizations need to move together now to create a new standard for good corporate citizenship that will include maintenance of workplace health facilities, establishment of confidential, voluntary counseling and testing facilities for HIV/AIDS, and provision for coverage of AIDS and related illnesses in employee health benefit plans. Both India's corporate sector and foreign businesses that have invested in India should participate. The mechanisms for corporate assistance with procurement of the CD-4 machines coupled with the provision of ARVs, and perhaps rapid HIV/AIDS test kits as well, should be made clear and well publicized. Putting principles into action in a visible way will not only contribute to the HIV/AIDS program: it will also help people in India and elsewhere understand that there are practical steps that can be taken to stop the epidemic.

- **The United States can learn from India's experience and should reflect what it has learned in other regions.**

Four lessons seem especially important at this point:

- *Reconciling scale with diversity.* Within India's enormous population are countless regional and social micro-zones, each with its own dynamics. India's experience developing a strategy that is valid for the whole country and now trying to introduce ARVs will demonstrate what it takes to operate on a large scale. At the same time, some of its most effective programs, especially those run by NGOs, are small and not readily scalable. The experience of meshing both small programs, which may need to be adapted rather than expanded, with a huge state or national structure will undoubtedly provide lessons for dealing with the epidemic elsewhere.
- *Integrating the social and biomedical dimensions.* Research on the social issues that are so critical to the epidemic, especially gender and stigma, needs a special emphasis. These issues are important everywhere, and each society's dynamics are different. However, those in the United States who are trying to fight this epidemic need to learn from India's experience, and medical officials and research scholars in India need to learn from the practical experience of NGOs and other projects that have been working in the field. Research cannot take place only in the laboratory or in an academic setting.
- *Fighting AIDS in the context of caste, gender, and class differences.* These issues are common to many countries, but India's highly stratified society makes them especially visible. The approaches that are used in India to

overcome society's divisions could provide lessons useful in other settings as well.

- *Fighting AIDS in a democracy.* Democratic politics in the past have complicated the fight against HIV/AIDS. Issues of sexual behavior and the marginalized populations that figure so prominently in the epidemic are not easy subjects for public discussion. However, this picture is changing. The parliament is set to consider wide-ranging HIV/AIDS legislation. Its preparation and introduction is the work of the Indian Parliamentary Forum on AIDS, a dedicated group of legislators, with the assistance of a private group, the Lawyers' Collective. There are signs that AIDS is becoming a political issue, at least in selected areas. The health minister clearly expects to be judged on her ability to reverse the epidemic in her district, for example. And though access to primary health care has not been a major campaign issue in the past, the HIV/AIDS epidemic could change that, especially in seriously affected constituencies. Understanding how politicians turn the politics of AIDS into a constructive force would be a powerful asset as the United States moves ahead in fighting the epidemic.

## Conclusion: Looking Ahead

The delegation's visit to India and this report will be the beginning of a continuing dialogue with the key people and institutions involved in fighting AIDS in both India and the United States. CSIS has benefitted greatly from the wisdom and insights of those we spoke to in India. We will continue our partnership with the Ministry of Health and Family Welfare, the National AIDS Control Organization, the Parliamentary Forum on AIDS, HIV/AIDS professionals, business organizations, and scholars, and bring insights to those in Washington, D.C., and elsewhere who can benefit from India's experience.

The guiding principle of our work was best expressed by Oscar Fernandes, convenor of the Indian Parliamentary Forum on AIDS, in a roundtable discussion in Delhi. He urged that we fight AIDS "with compassion, and with passion." That is a challenge we must meet together.

## Appendix A. CSIS HIV/AIDS Delegation to India

### Delegation Coleaders

Ambassador Richard Frank Celeste  
*President, Colorado College*  
*Former U.S. Ambassador to India*

Dr. Louis W. Sullivan  
*President Emeritus, Morehouse School of*  
*Medicine*  
*Cochairman, Presidential Advisory*  
*Council on HIV/AIDS*

### Delegation Members

Teresita C. Schaffer  
*Director, CSIS South Asia Program*

J. Stephen Morrison  
*Executive Director, CSIS HIV/AIDS Task*  
*Force*  
*Director, CSIS Africa Program*

Samir Khalil  
*Executive Director of HIV Policy &*  
*External Affairs, Europe, Middle East*  
*& Africa, Merck & Co.*

Geeta Rao Gupta  
*President, International Center for*  
*Research on Women (ICRW)*

Michael H. Merson  
*Anna M.R. Lauder Professor & Dean of*  
*Public Health, Yale School of Medicine*

Lisa Carty  
*Senior Policy Officer for Global Health,*  
*Bill & Melinda Gates Foundation*

Pramit Mitra  
*Research Associate, CSIS South Asia*  
*Program*

### Observers

Robert Blake  
*Chargé d'affaires, U.S. Embassy, New*  
*Delhi*

Walter North  
*Director, USAID Mission, New Delhi*

Dora Warren  
*Country Director, India, Global AIDS*  
*Program, Centers for Disease Control &*  
*Prevention (CDC)*

Nancy Nay  
*Deputy Director, India, Global AIDS*  
*Program, Centers for Disease Control &*  
*Prevention (CDC)*

## Appendix B. Delegation Agenda

### **Sunday, January 4, 2004**

Briefing by officials from the Centers for Disease Control and Prevention, the Bill and Melinda Gates Foundation, USAID, and the U.S. Embassy in New Delhi.

### **Monday, January 5, 2004**

Site visit to Michael's Care Home (Sahara project) in New Delhi.

Discussion organized by the Federation of Indian Chambers of Commerce and Industry (FICCI) to discuss the role of Indian business in combating the HIV/AIDS pandemic.

Meeting with Meenakshi Datta Ghosh, director of the National AIDS Control Organization (NACO).

Meeting with Sushma Swaraj, minister of health and family welfare.

Meeting with J. V. R. Prasada Rao, health secretary.

Dinner hosted by Robert Blake, U.S. chargé d'affaires in New Delhi.

### **Tuesday, January 6, 2004**

Site visit to Swaasthya in New Delhi.

Site visit to Healthy Highway Project run by the Society for Promotion of Youth and Masses (SPYM) in New Delhi.

Meeting with Dr. Manmohan Singh, member of parliament and leader of the opposition, Rajya Sabha.

Dinner hosted by Ashwini Kumar, member of parliament.

### **Wednesday, January 7, 2004**

Meeting with the Indian Parliamentary Forum on HIV/AIDS and visiting U.S. House of Representatives members.

Depart for Hyderabad.

### **Thursday, January 8, 2004**

Site visit to Osmania Hospital in Hyderabad.

Meeting with Chandrababu Naidu, chief minister of Andhra Pradesh state and senior health officials.

Roundtable on HIV/AIDS sponsored by the Confederation of Indian Industry (CII). Addresses by Ambassador Richard Celeste, Michael Merson, and Samir Khalil.

Plenary session on HIV/AIDS. Address by Dr. Louis Sullivan.

Dinner hosted by Chandrababu Naidu, chief minister of Andhra Pradesh state.

**Friday, January 9, 2004**

Depart for Pune.

Site visit to National AIDS Research Institute (NARI). Interaction with senior scientists working on AIDS research.

Depart for Mumbai.