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India at the Crossroads: Battling the HIV/AIDS Pandemic

Eighteen years ago, the first HIV infection case was diagnosed in India. Today, the world's largest democracy has entered a critical period in its fight against the HIV/AIDS pandemic. In late 2002, India's HIV-positive population reached 4.6 million; if present trends continue, that number could reach a staggering 20–25 million by decade's end, meaning that a single country could have a greater number of people with the HIV virus than the population of the state of New York. The disease still does not have the high prevalence rate of infection in India that has devastated some African countries, yet India already has the second-largest number of people living with HIV/AIDS after South Africa; and with a population of more than one billion, even a small shift in the prevalence rate could result in a staggering number of infections.[1] The United Nations Program on HIV/AIDS warned in 2003 that India and her neighbors stand at what epidemiologists call the "tipping point" in the trajectory of the disease.[2]

The spread of HIV/AIDS historically has been associated primarily with sub-Saharan Africa, but in the twenty-first century, the pandemic is clearly reaching further. A September 2000 National Intelligence Council (NIC) report on the HIV/AIDS pandemic predicted that 50–75 million people in five of the world's most populous states—India, China, Russia, Ethiopia, and Nigeria—will be HIV-positive by 2010.

In other words, HIV/AIDS now threatens to bring the devastation it has brought to sub-Saharan Africa to these "second-wave" countries. The disease certainly varies considerably from country to country in its transmission rates, demographic distribution, and societal impact; each affected country has differing public and private capacities, financial resources, and relevant research and health care infrastructures to deal with the pandemic.[3] Some

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countries, however, particularly India, China, and Russia, share similar social and economic patterns, such as their sizable populations (in which not only high-risk groups but also middle-class families are now being affected), significant human capital, and an existing (though far from adequate) health care infrastructure, let alone their immense geopolitical importance. All these countries confront the prospect of sharp increases in HIV-positive citizens, and none has a viable strategy or adequate resources for wide-scale treatment. India's success or failure in stemming the tide against the epidemic will have important repercussions for these other second-wave countries locked in similar battles.

One Country, Different Epidemics

India's citizens may share one time zone, but they live in vast regions separated by immense distances and customs. They speak various languages (India has 22 officially recognized languages, in addition to English and Hindi), practice different religions and customs, and face diverse AIDS crises.[4] Distinct locations have different modes of diffusion. For instance, virus transmission by heterosexuals accounts for 85 percent of the country's HIV infections, but intravenous drug use also drives the spread, particularly in northeastern states such as Manipur. Some cities have gone further in preventing the spread than others. Workers in the sex trade in Kolkata (formerly Calcutta) have formed a union to promote condom use, which has kept the prevalence rates well below the 50 percent rates in cities such as Pune and Mumbai (formerly Bombay).

The HIV virus has spread to all of India's states and territories since it was first discovered in the country, but six out of 28 states in particular—Andhra Pradesh, Karnataka, Maharashtra, Tamil Nadu, Manipur, and Nagaland—are considered high-prevalence states, where more than 1 percent of prenatal mothers test positive for HIV. In effect, the epidemic has spread beyond high-risk groups to the general population in these localities. Three additional states—Gujarat, Goa, and Pondicherry—have concentrated epidemics, with a prevalence rate of 5 percent or higher among high-risk groups. Most of India's states have populations the size of relatively large countries; 10 states have a population of more than 50 million. If even one of these states reaches South Africa's nationwide 20 percent prevalence rate among adults, 10 million people will have contracted the disease in that state alone.

Forecasting such consequences and predicting future trends are difficult. India has massive poverty, illiteracy, and socioeconomic disparities between men and women, all of which make the fight against AIDS par-

ticularly daunting. The 2000 NIC report drew sharp criticism from Indian authorities with its dire prediction that 25 million Indians (5 percent of the adult population) could be infected with HIV by 2010—roughly equal to the total number of adults infected in all of sub-Saharan Africa today.[5]

Questions about the accuracy of such estimates arise mainly because researchers gather data from "surveillance" sites in major cities, which sample high-risk groups such as pregnant women, sex workers, and drug users. Whether this means that the numbers are overestimated or underestimated is a contentious issue. Because the surveillance sites are disproportionately located in the states that are known to have a significant epidemic, many observers believe that new outbreaks of the disease in low-prevalence states will go unnoticed. The country lacks a national information system to collect HIV testing information from the private sector, which provides 80 percent of the country's health care. The weakness in the surveillance system, bias in targeting groups for testing, and lack of available testing services in several parts of the country leads many AIDS clinicians to suspect that the country has a far bigger crisis than has been reported and to fear that several presently "low-risk" states could have a potential AIDS crisis hidden from public view.[6]

The epidemic has spread beyond high-risk groups to the general population in some areas.

Beyond difficulties in estimating the disease's spread, consequences are difficult to estimate. Besides the tragic human costs, for example, the emerging AIDS crisis in India also has grave implications for the country's economy, which has been on a strong growth trajectory since 2003. Because AIDS afflicts individuals in their most productive years, India will lose some of its most prized assets: cheap, skilled labor. Even though no studies have been conducted to put a dollar figure on the danger in India, a July 2003 World Bank study indicated that, if AIDS were to continue unchecked in a developing country such as South Africa, the epidemic could socioeconomically wreck a society in three generations.[7]

A similar study in 2003 on the AIDS challenge in Southeast Asia estimates that, globally, HIV/AIDS reverses annual economic growth by as many as two percentage points in the worst-affected countries.[8] Even if the precise ramifications for India's economy cannot be predicted, particularly in light of difficulties in tracking the pandemic's growth, it is safe to say that, as the prevalence of the disease increases, its impact on the country's economic growth will worsen significantly.

Social Taboos

Thus far, the common characteristics uniting the variety of India's experiences with HIV/AIDS have been denial and missed opportunity. Since the 1986 discovery of the first cases among female sex workers, infection rates have increased significantly, a development that shows the progression of the disease as well as improvements in reporting AIDS cases. Traditionally, most Indian health officials and the health care establishment viewed HIV as a "foreign" disease or an "imported" infection, confined to people returning from foreign countries or port cities and to marginalized groups such as sex workers and drug users and unlikely to spread to the general population.

Combating social taboos will require political leaders to speak out in public forums.

Politicians initially regarded the spread of HIV/AIDS as a law and order problem, that is, they believed that the spread of the disease could be managed by controlling certain high-risk groups, thus preventing the virus from spreading to the general population. Among other measures considered in the early 1990s were incarcerating infected sex workers, deporting HIV-positive foreign nationals, and mandatory testing of foreign students coming from AIDS-infected countries. Each measure carried the same hidden message: AIDS affects "them," not "us." As a result, infected people are ostracized while vulnerable groups—women and members of 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.

Stigma and misconceptions, coupled with complicated social norms and conservative attitudes toward sex, make it difficult for politicians and policymakers to get beyond taboos when responding to the epidemic. For example, prostitution is illegal yet widespread. Contrary to the belief of many Indians, homosexuality is quite common, even though it is also illegal. In fact, according to studies by the Naz Foundation, a New Delhi–based nongovernmental organization (NGO), sex between men is widespread in all South Asian countries.[9] More importantly, those involved often do not consider that some common instances of sex between men are homosexual acts. In a society where dating and sexual relations before prearranged marriages are generally not allowed, such acts include teenage males' sexual experimentation with other boys before marriage and sexual encounters between truckers and their young assistants.

The low status of women is also accelerating the spread of the disease. Despite an impressive array of female leaders in government and civil society, most ordinary Indian women have very little say in the daily affairs of their households. The proportion of women in the population is one of the lowest in the world: 933 women to every 1,000 men.[10] According to the 2003 UN Human Development Index, the literacy rate for females aged 15 and above stood at 46 percent, well below the 69 percent rate for males.[11] In a society in which women feel vulnerable and lack a strong voice even in matters of their own health, they are less likely to protect themselves from infected husbands who contract the disease from sex workers because insisting on prophylactics often results in accusations of infidelity or in physical abuse.

Moreover, fear of retribution by their families and friends prevents many afflicted with the disease from coming forward for testing and treatment. Discussions about sex remain off-limits in most Indian households and even in elite private schools in large cities such as New Delhi. AIDS is often seen as a disease restricted to a marginal, morally suspect population, people who "brought it on themselves," making it difficult for India to respond effectively through strong public awareness messages because they are deemed too controversial.

An Emerging Political Response

Combating such social taboos will require political leaders to speak out against these beliefs in public forums. On this front, there is good news. Atal Bihari Vajpayee, India's former prime minister from the Bharatiya Janata Party, and Sonia Gandhi, leader of the Congress Party, have each spoken about the epidemic and the urgency of uniting the country to battle the disease and its devastating consequences. Elites throughout the country now recognize that the epidemic is a major threat to the health of India's citizens and to its economy. As in China, where Premier Wen Jiabao took a stab against the stigma associated with the disease when he publicly shook hands with three AIDS patients in December 2003, the strong commitment to combating the pandemic that India's political leaders have begun to show is also encouraging.

Sushma Swaraj, the former health minister, caught the attention of the local press in September 2003 when she publicly embraced two HIV-infected children who had been refused admission to a school in the state of Kerala. The high level of publicity that the Indian media gave to this incident was a significant step toward removing the stigma associated with people suffering from the disease. Indeed, a rare common commitment across In-

dian political lines has emerged to tackle the HIV/AIDS issue. Manmohan Singh, the newly elected premier of the Congress Party, has expressed a similarly strong commitment to slowing the spread of the disease, and his government is expected to continue steps already taken by the previous administration toward combating the disease. The new government, however, will have to increase health spending and investments in the public health infrastructure significantly if it wants to demonstrate that it is serious about this effort.

Political efforts transcend India's executive branch. A private group, the Lawyers' Collective,[12] a dedicated group of Indian legislators from a wide range of parties, has established a parliamentary committee, the Indian Parliamentary Forum on AIDS, to discuss and create legislation to deal with HIV/AIDS. Unfortunately, the parliamentary forum primarily consists of congressional lawmakers from Rajya Sabha (the upper house of Parliament), who have considerably less legislative power than their Lok Sabha (lower house) counterparts. Because of the lack of support among members of the Lok Sabha, no legislation dealing with discrimination against HIV/AIDS patients has thus far been introduced in Parliament. Understanding how Indian politicians deal with the politics of AIDS would be useful for U.S. policymakers as they develop a strategy to fight the epidemic globally and roll out President George W. Bush's Emergency Plan for AIDS Relief (PEPFAR), a five-year, $15 billion initiative.

Addressing the HIV/AIDS Crisis

Whether India will be able to contain the epidemic will depend on how aggressively the new Congress government pursues and expands existing programs. At present, India's strategy to deal with HIV/AIDS focuses first and foremost on prevention. Most resources have been poured into mother-to-child HIV transmission prevention and activities such as surveillance, blood and blood products screening, and health education. Treatment programs have been a low priority. The operational objective is to contain the prevalence of the virus at a level of 3 percent or below in the six states with a generalized epidemic and 1 percent in the rest of the country. The plan also aims to increase HIV/AIDS awareness to a level of 90 percent among teenagers and other vulnerable segments of the population and to increase condom use to a level of 90 percent among high-risk groups.[13]

For this strategy to work, however, more resources will be needed. The Indian government's health budget is roughly $160 million per year, but only a small portion of this amount is earmarked to combat HIV/AIDS.[14] International funding has provided the largest share of financial backing for

India's HIV/AIDS program. Estimates of the five-year commitments of India's international donors run as high as $850 million.[15] Even if all the domestic and international commitments were disbursed on schedule, however, this would represent a rather modest investment in AIDS prevention and treatment in India, about $0.17 per person. By way of comparison, estimated per capita spending on AIDS in Uganda is $1.85 and $0.55 in Thailand.

India's AIDS programs are implemented through the National AIDS Control Organization (NACO), a semiautonomous organization within the Ministry of Health set up in 1992 with financial assistance from the World Bank. NACO's special status was intended to prevent the bureaucratic delays that normally plague India's decisionmaking process. NACO's state offices have a great deal of autonomy and make most of the decisions. NACO also works closely with NGOs and is allowed to accept money from international donors as well as private funding, a significant change from standard government regulations.[16]

The level of awareness of the pandemic varies widely among India's cities and states.

In addition to national and state AIDS control programs, the Indian government works toward HIV/AIDS prevention and treatment through a number of health care programs established for government employees. Indian Railways, a company that operates the largest health care system in the country, as well as the military and the Central Government Health Scheme, all provide testing and counseling as well as treatment. Health officials estimate that, as of early 2004, 15,000 people were receiving antiretroviral (ARV) drugs through these plans, some in government hospitals and others through referrals to private hospitals.[17]

In April 2004, India's Health Ministry began an ambitious plan to provide ARV therapy to new parents (in practice, primarily mothers) who are HIV-positive, infected children under the age of 15, and patients being treated in government hospitals in the six high-risk states. Significantly, the program offers at no cost a standard cocktail of ARV drugs produced by Indian generic drug manufacturers. Previously, the government program provided ARV drugs only to pregnant women to prevent transmission to their newborn children and to medical personnel who were exposed while in the line of duty.

Under the new plan, the government intends to provide ARV drugs to 100,000 patients in the first year, starting in the major tertiary public hospitals and eventually moving to less specialized facilities, effectively expanding access to ARV drugs at least sixfold. Just how this ambitious plan will be

funded, however, remains unclear. The hope is that the Ministry of Finance will be able to provide the budgetary support required as, thus far, the cost of ARV drugs has put them out of reach for most Indians, even at prices normally charged by generic drug manufacturers.

Although it is still too early to predict the success of the ARV program, significant obstacles beyond acquiring needed funding must be overcome. For example, few hospitals and clinics are equipped to handle such ambitious programs. Experts worry particularly about the cost of monitoring patients under treatment, which requires measuring their levels of CD-4 white blood cells, a key indicator of the body's immune function, and the amount of HIV in their blood. Counting CD-4 cells requires a flow cytometer, an expensive machine that only the largest hospitals and research laboratories in the wealthiest cities possess.

Science's Significant Role

Unlike the majority of countries hit hard by the AIDS pandemic, India is fortunate to have a vibrant domestic pharmaceutical industry that can play a crucial role in the fight against the pandemic by providing ARV drugs at low cost to the government. Several Indian pharmaceutical companies manufacture generic drugs at competitive prices. Cipla, Ranbaxy Laboratories, Matrix Laboratories, and Hetero Drugs recently announced an agreement with the Clinton Foundation to provide drugs to four African and nine Caribbean countries at a per capita cost of about $0.37 per day. India's Ministry of Health, which is still negotiating a final price with the generic drug manufacturers, hopes to obtain the drugs for India at a price even lower than that.

In addition to a thriving pharmaceutical industry, India also has first-rate scientists and biomedical researchers who can be tapped to improve the epidemiological studies. Since the 1950s, the country has established high-quality institutions to conduct research in various scientific disciplines. The National AIDS Research Institute (NARI) is one such organization. Based in the industrial city of Pune on India's west coast, NARI has a staff of 60 and enjoys modern laboratories that are funded in part by collaborative agreements with partners in the United States, such as the Johns Hopkins University and National Institutes of Health. NARI has a repository of the different HIV strains peculiar to India and conducts various epidemiological studies; it soon plans to work with the International AIDS Vaccine Initiative to launch a study of the first AIDS vaccine to be tested in India. NARI, however, like the government's promising ARV drug plan, also has a shortcoming: the lack of resources and manpower. Most of its studies are based in Pune. The challenge for NARI researchers is to broaden the scope of their

work to other parts of India and to include more social and behavioral research into its biomedical projects.

The Next Steps

Even more fundamental to combating the emerging HIV/AIDS pandemic in India than drug treatment plans and funding is to create a sense of national urgency about the pandemic. India must urgently ramp up its communication campaign to make its citizens aware of the disease as well as the dangers they face from the virus. Awareness has grown substantially in the last two to three years, but the level of awareness varies widely among cities and states. Few AIDS awareness posters can be seen in New Delhi, whereas in the city of Hyderabad and in the state of Andhra Pradesh, they are everywhere. The press and television networks have not yet been mobilized in the HIV/AIDS campaign. Messages about AIDS prevention must come from a multiplicity of sources and reach a tremendously diverse audience in India if the government wants to spread the message to all levels of society.

The press and television have not yet been mobilized in the HIV/AIDS campaign.

One important lesson that emerges from India's experience with HIV/AIDS is that, without effective social leadership, it is difficult to spread any message to the masses. In addition to political figures, afflicted countries such as India and China need a personality like former U.S. professional basketball player Magic Johnson who can serve as a role model and speak out against discrimination against those afflicted with the disease. One survey indicates that more than 60 percent of Indians still mistakenly believe that they can contract AIDS by mosquito bites, sharing a meal, or shaking hands with an HIV-infected person.[18]

India's film industry has done little more to raise awareness of the disease than give it mandatory lip service on World AIDS Day, and no Indian entertainment personality has taken up the HIV/AIDS cause seriously. In the United States, Rock Hudson's death in 1985 made AIDS a household word and helped to remove the "gay plague" tag from the virus in a way that has yet to happen in India or the other second-wave countries. Public understanding of specific ways to prevent infection, though rising, remains very low among the general population. Even the best medical facilities have refused to admit HIV-positive patients out of fear that they might infect the staff. The emphasis on biomedical measures for fighting HIV/AIDS has tended to remove attention from the equally necessary task of fighting the social stigma attached to the disease.

India's private sector must also step forward to play its part in raising awareness and providing badly needed funding. India's financial requirements for its HIV/AIDS programs could be resolved to a great extent with support from domestic private industries. So far, only a handful of Indian companies have done anything other than express sympathy; these companies need to turn their words into action. The national and state governments are both urging India's businesses to set up workplace clinics that provide voluntary counseling and testing. Some companies, such as the Bajaj conglomerate, have taken first steps in this direction. What are now rare efforts need to become the norm. Members of the business community have also committed to help the government procure flow cytometers for testing CD-4 levels. If the offer materializes, it would go a long way toward reducing the government's financial burden and reliance on foreign assistance to combat HIV/AIDS.

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Foreign assistance can also play an important role. In June 2004, the U.S. government selected Vietnam to receive funds as the 15th "focus country" under Bush's emergency plan—the only non-African or non-Caribbean country thus far. PEPFAR currently directs funding to 12 African nations—Botswana, Ethiopia, Côte d'Ivoire, Kenya, Mozambique, Namibia, Nigeria, Rwanda, South Africa, Tanzania, Uganda, and Zambia—as well as Haiti and Guyana in the Caribbean to combat HIV/AIDS, tuberculosis, and malaria through bilateral programs. Choosing India as a focus country or at least increasing support for its HIV/AIDS program would reinforce India's efforts, signal that it was on the right track, and encourage Indians to take on more of the financial burden. In addition, professional relationships among Indian and U.S. scientists, NGOs, and government officials should be strengthened so that India can benefit from the scientific expertise and experience of U.S. NGOs.

Lessons for the Second Wave

India also has important lessons for other second-wave countries, who are confronting similar challenges and can learn from India's successes or failures.[19] Four lessons seem especially important:

- *Reconciling scale with diversity.* India's enormous population includes countless regional and social microzones, each with its own dynamics.

The country has to move from targeted awareness and successful interventions among high-risk groups to developing a strategy that is valid for the whole country but tailored to local characteristics. The experience of the ARV treatment program will demonstrate what it takes to operate on a large scale. At the same time, some of India's most effective programs, especially those run by NGOs, are small and cannot be scaled upward readily. The experience of meshing a huge state or national structure with small programs, which may need to be adapted to local circumstances rather than simply expanded, will undoubtedly provide lessons for dealing with the epidemic elsewhere.

- *Integrating social and biomedical responses.* Research on the social issues that are so critical to the HIV/AIDS epidemic in the country, especially gender and stigma, require special emphasis from Indian scientists and researchers. The trend so far has been to focus too much on the scientific aspects of the epidemic itself and not enough on the social implications. How India's biomedical researchers balance the two goals while designing their epidemiological studies, for example, is an important lesson for biomedical professionals in other second-wave countries.

- *Addressing caste, gender, and class differences.* Issues of social stratification are common in many countries, but in India, the clear hierarchy along wealth and social lines make it particularly difficult for government polices to overcome practices and customs observed for centuries.

- *Fighting AIDS in a democracy.* Democratic politics in India have complicated the fight against HIV/AIDS in the past because issues of sexual behavior and the marginalized populations that figure so prominently in the epidemic are not easy topics for public discussion. Yet, this picture is changing. There are signs that AIDS is becoming a political issue in India, at least in selected areas. Although access to primary health care has not been a major campaign issue in Indian politics in the past, the HIV/AIDS epidemic could change that, especially in areas that include seriously affected constituencies. How Indian politicians handle a sensitive subject such as AIDS in India's conservative society will offer clear guidelines to politicians in other second-wave countries.

Cautious Optimism

An accelerating HIV/AIDS epidemic presents India with a daunting task in coming years. Although the situation is better now than it was two years ago

and political awareness has increased, great challenges persist in preventing HIV/AIDS from becoming a national emergency. AIDS was not an issue in the most recent parliamentary elections, and health care is still considered a low priority in the political hierarchy. The health minister, for example, is not a high-ranking official in the cabinet, and social taboos often delay necessary policy decisions. The Vajpayee government's aversion to advertising condoms is just one such example. The stigma attached to anything related to AIDS remains immense, especially for women whose poverty, low status, and relative powerlessness makes it difficult for them to protect themselves and stop the spread of the disease. Prime Minister Singh and his government must prioritize battling the HIV/AIDS epidemic and use his personal appeal to mobilize support from lawmakers from other political parties. The Congress government must boost its spending on public health infrastructure and launch a massive public awareness program, especially in rural areas.

There are signs that AIDS is becoming a political issue in India.

AIDS is one of the greatest threats facing India's future. It will not take a 20 percent AIDS infection rate—the rate in many African countries—for the disease to become a human tragedy. The challenge for India is to harness its immense pool of scientists, scientific institutions, pharmaceutical manufacturers, and private businesses to tackle the pandemic. The disease has caused the greatest damage in the most prosperous parts of the country, where it has affected groups hitherto considered low risk, such as teenagers. Were it to spread to the country's general population, as it has in many parts of Africa, the world would face a crisis of unimaginable horror, and the disease would simultaneously extinguish the promise of a world-class economy as well as destroy the foundations of the world's largest democracy.

Notes

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