



Commitment for Action:

*Assessing Leadership for Confronting
the HIV/AIDS Epidemic Across Asia*

Focus on India

January 2005



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The POLICY Project is funded by the U.S. Agency for International Development (USAID) under Contract No. HRN-C-00-00-00006-00, beginning July 7, 2000. The project is implemented by the Futures Group in collaboration with the Centre for Development and Population Activities (CEDPA) and Research Triangle Institute (RTI). To learn more about the POLICY Project, please visit <http://www.policyproject.com>.

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By

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● ACKNOWLEDGMENTS

This report is an assessment study of national political commitment and leadership for confronting the HIV/AIDS epidemic in India. The study was conducted by the POLICY Project on behalf of the Asia and Near East (ANE) Bureau of the U.S. Agency for International Development (USAID). The POLICY Project also conducted similar country studies in Bangladesh, Nepal, and Viet Nam.

The authors extend their thanks to all the respondents who generously gave their valuable time and insights to enrich this study. We would like to acknowledge the guidance, technical input, and review provided by USAID technical staff, including Mai Hijazi, Rose McCullough, Billy Pick, Elizabeth Schoenecker, and the USAID/India Mission. The views presented here do not necessarily reflect those of USAID.

● ABBREVIATIONS

ABC	abstinence, be faithful, use condoms
AIDS	acquired immune deficiency syndrome
ANE	Asia and the Near East
ARV	antiretroviral
CCM	Country Coordinating Mechanism (of GFATM)
CII	Chamber of Indian Industries
CMIS	computerized management information system
DFID	Department for International Development (United Kingdom)
FICCI	Federation of Indian Chambers of Commerce and Industries
FP	family planning
GDP	gross domestic product
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
GIPA	Greater Involvement of People Living with HIV/AIDS
HAART	highly active antiretroviral treatment
HIV	human immunodeficiency virus
ICMR	Indian Council for Medical Research
IDA	international development agency
IDU	injection drug user
IEC	information, education, and communication
INP+	Indian Network for People Living with HIV/AIDS
INR	Indian rupee
MIS	management information system
MSM	males who have sex with males
NACO	National AIDS Control Organization
NACP	National AIDS Control Program
NGO	nongovernmental organization
NHRC	National Human Rights Commission
NSP	national strategic plan
PIL	public interest litigation
PLHA	person living with HIV or AIDS
PPTCT	prevention of parent-to-child transmission
RCH	reproductive and child health
SACS	State AIDS Control Society (Societies)

STI	sexually transmitted infection
TRG	Technical Resource Group
UNAIDS	Joint United Nations Program on HIV/AIDS
UNGASS	United Nations General Assembly Special Session on HIV/AIDS
USAID	United States Agency for International Development
VCT	voluntary counseling and testing

● EXECUTIVE SUMMARY

HIV/AIDS is not only a biomedical phenomenon but also a social reality. Despite the fact that the Indian government recognized the potentially far-reaching impacts of the disease as early as 1985, respondents in this study concluded that India's level of political commitment for dealing with the epidemic remains low and sporadic. Top national leaders have made statements on several occasions but, until recently, have failed to translate those statements into a pragmatic policy or initiative.

India has a well-documented, comprehensive HIV/AIDS policy that covers the full range of responses needed for program implementation, including a policy for blood safety and a policy for vaccine trials. However, policy dissemination has not effectively taken place. The country's set of human rights guidelines is not specific to HIV/AIDS, and India has yet to adopt an HIV/AIDS law that prohibits discrimination, though the Lawyers Collective has begun preparing a draft law. The establishment of the Parliamentary Forum for HIV/AIDS and the organization of the first-ever National Convention for Elected Representatives on political leadership in combating HIV/AIDS are two noteworthy achievements.

India has not committed a significant amount of its own budget for HIV/AIDS and, to a considerable extent, continues to pursue external support. Multiminsty involvement in the planning process for HIV/AIDS is encouraged on paper but, with the exception of two or three ministries, other ministries have not earmarked funds for HIV/AIDS activities. Yet, one positive step is that the Tenth Five-Year Plan mentions the crosscutting nature of HIV/AIDS and has asked other ministries to earmark a separate budget and plan to help combat the disease. In 2004, the Group of Ministers on HIV/AIDS also agreed to develop a plan of action and meet at regular intervals to improve collaboration.

Nongovernmental organizations (NGOs) have been involved to a large extent in addressing HIV/AIDS, especially with respect to care and support programs and targeted intervention programs for vulnerable groups. However, the role of faith-based and women's groups, according to respondents, is minimal. The government should assume responsibility for sensitization of faith-based groups and women's groups for facilitating better support to the programs.

India's surveillance system, though in place, is not effective and not representative of the entire country. The national program includes voluntary counseling and testing (VCT) and prevention of parent-to-child transmission (PPTCT), and efforts began in 2004 to provide free antiretroviral (ARV) drugs. However, logistics remains a concern, and a respondent noted that counselor positions in VCT centers were vacant.

While a few top leaders have evidenced a change in attitude in recent years, their contributions toward reduction of stigma have been minimal, and the level of political commitment for addressing the issue of stigma and discrimination is low. Stigma has been cited as one of the greatest barriers to averting further infections, providing adequate care and support, and enabling HIV-positive people to lead productive lives.

In terms of strengthening political commitment, and thereby improving the country's national response, stakeholders from across Indian government and society should now work to:

- Further sensitize national and local leaders to the importance of addressing HIV/AIDS now and conduct advocacy to help leaders from all sectors understand their role as opinion leaders who can help confront stigma and discrimination;
- Foster an enabling policy environment, including implementing and enforcing human rights-based approaches;
- Establish mechanisms that will help translate policies and public statements into action, with special attention to mobilizing internal and external resources, effectively allocating human and material resources, and strengthening human capacity development within government and civil society;
- Strengthen multisectoral collaboration within government institutions and encourage meaningful involvement of civil society groups and members of affected communities; and
- Facilitate the collection, analysis, and dissemination of high-quality, accurate information regarding the epidemic, including not only HIV sentinel surveillance but also behavioral studies, information about affected groups, and data highlighting the social and economic impacts of the epidemic.

INTRODUCTION

● INTRODUCTION

In the 1950s, India became one of the first countries in the world to adopt an official national family planning program. In view of the country's rapid rate of population growth, the government recognized the need to address the problem by introducing an official family planning program and public health measures for improving health conditions, especially for people in rural areas. Such an effort could not have been possible without political will and commitment, as reflected in budget allocations since the first five-year plans. Many studies have documented the conscious efforts by the political apparatus, and the findings clearly illustrate concrete actions and events that characterize political commitment and an enabling environment for implementing the programs. Most of these changes took place when a one-party majority ruled the country at both the national and state levels, barring one or two states. However, the situation in the last decade has shifted such that a multiparty coalition holds office at the national level, with many regional parties in power in the states. Accordingly, the development of a national consensus on various issues poses a significant challenge.

The Indian government recognized the potentially far-reaching impacts of HIV/AIDS in 1985, when the first few HIV/AIDS cases were reported among sex workers in Mumbai and Chennai and among injection drug users (IDUs) in the northeastern state of Manipur. By that time, HIV/AIDS had already attained epidemic status in Africa and was spreading rapidly in many countries. The Government of India, realizing the seriousness of the problem, took a series of important measures to tackle the epidemic. In 1986, it convened a high-powered National AIDS Committee under the chairmanship of the Union Ministry of Health and Family Welfare with representation from various sectors. In the following year, the National AIDS Control Organization (NACO) was created to manage and implement the HIV/AIDS program.

Since initiation of the national program, 35 State AIDS Control Societies (SACS), 10 Regional HIV Reference Centers, 499 clinics for the treatment of sexually transmitted infections (STIs), and 232 sentinel sites have been set up to serve the entire country. The HIV sentinel surveillance system is the country's best mechanism for monitoring trends in HIV infection among groups that practice high-risk behaviors and among low-risk groups. Individuals representing various population groups at selected sentinel sites are screened for HIV prevalence, with trends monitored over time. An epidemiological analysis based on 2000 data estimated that there were 3.86 million people living with HIV or AIDS (PLHAs). The number increased to 3.97 million the following year (based on 2001 data). Further, 45 districts, mostly in high-prevalence states, had shown a high prevalence of HIV among STI and antenatal cases in 2000; by 2001, the number had increased to 49 districts. NACO estimates that, by the end of 2003, India was home to 5.1 million PLHAs (NACO, 2004). The predominant mode of transmission of infection was heterosexual contact (80.86%), followed by blood transfusion (5.52%), injection drug use (5.30%), perinatal transmission (0.72%), and other modes (7.60%). UNAIDS estimates that 1.9 million (or 37%) of India's PLHAs are women (UNAIDS, 2004). The low status of women and girls, unequal power within relationships, and limited economic opportunities for women place women and girls at increasing vulnerability for HIV infection as the epidemic matures in India.

To prevent the further spread of HIV among vulnerable groups and the general population and to provide care, support, and treatment for those already affected, India must design and implement a comprehensive response to the epidemic. Many of the significant features of a strong response—including multisectoral engagement, protection of human rights, civil society participation, meaningful involvement of PLHAs, well-financed programs and well-trained staff, and monitoring and evaluation systems that allow for

developing lessons learned—are directly and indirectly influenced by an enabling policy environment and strong national political commitment. Until now, however, few attempts have been made to identify key characteristics of or ways to measure strong political commitment for addressing HIV/AIDS, particularly in the context of low HIV prevalence countries. Against such a backdrop, this assessment of national political commitment for confronting the HIV/AIDS epidemic in India not only provides a mechanism for improving in-country responses, but also contributes to the international community’s understanding of political commitment and leadership and their impact on strategies for addressing HIV/AIDS worldwide.

● Purpose and Methodology

This case study of India is part of a larger, multicountry assessment designed to analyze national political commitment and leadership for confronting HIV/AIDS in low HIV prevalence countries in Asia as well as to develop indicators for measuring national political commitment. It is based on the assumption that while experience shows that political commitment can help catalyze a strong response before an epidemic spreads to the general population, political commitment is a term that is often used without a clear sense of what it means, how it affects programs, and how it can be strengthened by advocates and policymakers.

The study was conducted during mid-2003 in four countries with low seroprevalence in Asia by the POLICY Project for the Asia/Near East Bureau of the U.S. Agency for International Development (USAID).¹ The study expands and builds on POLICY’s past efforts in the development of methodologies to measure political commitment for confronting the HIV/AIDS epidemic.² The study’s methodology involved two phases:

- **Literature review and assessment guide development.** POLICY Project researchers conducted a review of the literature on political commitment for addressing HIV/AIDS and other relevant health issues, such as reproductive health. The review, coupled with the project’s own experiences in assessing and building political commitment, informed the development of a qualitative research tool for measuring 13 aspects of national political commitment (see Appendix A). Local consultants and counterparts also reviewed relevant country-specific materials relating to the country’s national response and political commitment. The materials included national HIV/AIDS plans; UNAIDS reports; applications to the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM); and other relevant documents.
- **Identification of key stakeholders and in-depth interviews.** POLICY staff identified key HIV/AIDS stakeholders from the public sector and civil society as interview subjects who could discuss their views on current levels of political commitment evident in the various sectors of Indian society. Face-to-face interviews were conducted with 13 persons, including a politician and representatives from donor agencies, an international implementing agency, NGOs, groups representing PLHAs, a journalist, a faith-based leader, and an academician. The respondents formed a diverse group of individuals directly or indirectly involved with the HIV/AIDS program. The study was conducted between mid-June and the end of July 2003. The respondents were cooperative and expressed themselves with authority for most of the components. However, in some instances, the respondent honestly admitted ignorance of a few areas addressed by the

¹ The four countries in the study are Bangladesh, India, Nepal, and Viet Nam.

² See *HIV/AIDS Toolkit: Building Political Commitment for Effective HIV/AIDS Policies and Programs* (POLICY Project, 2000), available at <http://www.policyproject.com/pubs/toolkit.cfm>. Also see “Measuring the Level of Effort in the National and International Response to HIV/AIDS: The AIDS Programme Effort Index (API)” (UNAIDS, USAID, and POLICY Project, 2001), available at <http://www.policyproject.com/pubs/Monographs/APIreport.pdf>.

study. It is also necessary to mention that most respondents come from outside the government sector and that a more complete perspective on the important areas of the study would depend on the participation of NACO officials. Despite our attempts to gain their participation, NACO officials were not available for the study, requiring project staff to analyze government documents.

● Characteristics of Political Commitment

Strong political commitment for confronting the epidemic is an essential component of a comprehensive and effective strategy for addressing HIV/AIDS at the local, national, regional, and international levels (UNAIDS, 2000; USAID, 2000). The POLICY Project defines political commitment as:

[T]he decision of leaders to use their power, influence, and personal involvement to ensure that HIV/AIDS programs receive the visibility, leadership, resources, and ongoing political support that is required to support effective action to limit the spread of HIV and mitigate the impacts of the epidemic (POLICY Project, 2000).

A sizeable body of literature exists on political commitment, in general, and on political commitment for HIV/AIDS, in particular (e.g., Patterson, 2000; POLICY Project, 2000). The review of the literature suggests several concrete actions and events that characterize political commitment. Examples include:

- **Formulating a national HIV/AIDS plan.** The Declaration of Commitment of the United Nations General Assembly Special Session on HIV/AIDS (UNGASS), for example, sets as a goal that all countries should have national strategic plans in place by 2003.
- **Strengthening the public health infrastructure.** Scaling up an HIV/AIDS response requires the development of and investment in necessary infrastructure, including health facilities, related systems, and human capacity. For example, the ability of a country, such as Thailand, to conduct vaccine trials serves as an important indicator of political commitment because clinical trials cannot be conducted without first developing basic utilities and laboratory facilities, training staff, ensuring supply lines and transportation, and so on.
- **Passing public health legislation.** Legislation can take many forms. One example is legislation that identifies HIV/AIDS as a communicable disease and outlines the role of the state in prevention, care, and mitigation. Another example is legislation that makes HIV/AIDS a national priority, such as the Philippines AIDS Law of 1998, which mandated education about HIV-related risks and safer practices and behaviors as well as screening, counseling, and the provision of health services (Stephenson, 2001). A third example is laws that prohibit discrimination against PLHAs.
- **Mobilizing and allocating resources.** Sufficient, cost-effective, and strategic budget allocations are necessary for the successful implementation of all prevention, treatment, and care programs.

Political commitment is the decision of leaders to use their power, influence, and personal involvement to ensure that HIV/AIDS programs receive the visibility, leadership, resources, and ongoing political support that is required to support effective action to limit the spread of HIV and mitigate the impacts of the epidemic (POLICY Project, 2000).

- ***Encouraging civil society participation.*** NGOs should be encouraged to act locally to reduce risk behaviors, slow the spread of the epidemic, and participate broadly in a country's planning and policymaking processes (Parkhurst, 2000).
- ***Promoting human rights.*** Commitment to international conventions and compliance with international standards, such as the "International Guidelines on HIV/AIDS and Human Rights" (Watchirs, 2000), is essential for creating an enabling policy environment for HIV/AIDS programs and for reducing stigma and discrimination.
- ***Serving as an "AIDS policy champion."*** Some top-level political leaders have used their status and personal dedication to keep HIV/AIDS high on the agenda in their own countries. Examples include President Yoweri Museveni of Uganda, former President Kenneth Kaunda of Zambia, former President Nelson Mandela of South Africa, and Senator Mechai Viravaidya of Thailand.

Patterson (2000) identifies a number of indicators of political commitment drawn from successful national programs, including:

- Key ministries having their own HIV/AIDS plans and budgets, as in the case of Thailand (Sittitrai, 2001);
- Provincial governors playing a lead role in the HIV/AIDS program of their respective provinces, as in the case of Thailand (Sittitrai, 2001);
- Encouraging multisectoral engagement and including businesses, PLHAs, faith-based organizations, and other community leaders in policy dialogue and resource mobilization, as in the case of Thailand (Sittitrai, 2001);
- Government publicly acknowledging the HIV/AIDS epidemic as a national priority and creating a highly placed national HIV/AIDS commission early on, as in the case of Uganda;
- Enabling and promoting NGO involvement in HIV/AIDS activities, as in the case of Senegal;
- Including HIV/AIDS-related topics in health and sex education for school-aged children, as in the case of Senegal;
- Integrating detection and treatment for STIs into primary health services, as in the case of Senegal; and
- Providing antiretroviral (ARV) drugs and/or adopting a government policy of universal access, as in the case of Brazil.

The next chapter explores the extent to which India's national response to HIV/AIDS has demonstrated strong political commitment for confronting the epidemic.

SALIENT FINDINGS

This section presents the key findings from the in-depth interviews regarding respondents' attitudes and opinions toward several aspects of national political commitment. The major topics covered are:

- *Understanding of Political Commitment*
- *Top Leadership*
- *Government Response*
- *Role of NGOs and Civil Society*
- *Research, Monitoring, and Evaluation*
- *Stigma and Discrimination*

Where appropriate, and primarily for providing additional background information, respondents' views are supplemented with information from the literature review of relevant policies, budgets, and strategic plans.

● UNDERSTANDING OF POLITICAL COMMITMENT

Respondents were asked to express their perception of what they meant by political commitment, how would they measure it, and how would they know it. Respondents generally agreed on some common elements of political commitment, such as dedication and consistent support; translation of policies and statements into action; allocation of adequate human and financial resources for program implementation; inclusion of HIV/AIDS in a political party's manifesto; multiministry involvement; local and community participation; and viewing HIV/AIDS as a development, not simply a health, issue.

● Government

In terms of the government's response to the epidemic, a respondent from Parliament stated that:

[H]ealth as such has always taken a back seat in politics, as politicians are busy with other activities and chores. The prioritization that was required for HIV/AIDS did not exist and we as a group [underestimated the] problem in the country. Though the National AIDS Committee was formed, it met infrequently and couldn't provide proper direction. In other words, there was lack of political will and commitment and majority of Parliamentarians were unaware about the pandemic nature of the disease. However, of late, there is a realization of the importance of action and hence all the political parties got together and [the Parliamentary Forum on HIV/AIDS] came into existence. This is something that can be termed as political commitment with consensus.

For this respondent, political commitment should not end here but should be considered part of the government's day-to-day activities or an ongoing process; after all, health is a major aspect of India's overall development effort. Some examples of political commitment include personal involvement, public speaking, working to reduce stigma and discrimination, and providing subsidies for the production of medicines at affordable prices.

● NGOs and Human Rights Groups

For respondents representing NGOs and human rights groups, political commitment means responding to an issue with dedication, total support, perseverance, and proper vision. Political commitment is a responsibility that should extend to addressing issues from a national perspective and not involve advocacy of personal views. Further, respondents noted that political statements should not be arbitrary but should emulate a process for constructive political action. In addition, respondents stressed that HIV/AIDS should not be considered a stand-alone program and should form part of the political parties' political manifesto calling for greater involvement in program implementation and monitoring. In other words, political commitment should work to bridge the gap between policy and implementation in terms of passing legislative amendments/enactments and ensuring a human rights-based approach for PLHAs. The perceptible changes attributable to political commitment will result not only in destigmatization but also in overall changes in various development sectors, such as education, the economy, social justice, and empowerment and social welfare. Further, the extent to which HIV/AIDS policies are implemented,

the changes brought about in anti-discrimination laws, and increased financial commitments will express quantifiable changes in political commitment.

The respondent from an international NGO explained that political commitment is a willingness to follow through with the formulation and implementation of policies and programs by sufficiently allocating funds and developing the necessary coordination mechanism. In other words, political vision and commitment are important for creating an enabling environment that will facilitate coordinated program implementation. However, to ensure realization of an enabling environment, policymakers must be updated on various issues that impede program implementation. Further, policymakers must learn about the developments and experiences of other countries. The dialogue between policymakers and implementers is a prerequisite for the emergence of political commitment.

● Coalitions for People Living with HIV/AIDS

Respondents from PLHA groups felt that expressions of political commitment must take the form of sustained mutual support between politicians and civil society, a willingness to learn among leaders at all levels (including local self-government), and an adequate response to challenges by not treating HIV/AIDS as a “problem” but as a public health issue. In addition, they noted that national and community leaders must act according to their public statements and not contribute to fear and stigma. As advocates of change, PLHA representatives stressed the need for sensitization of politicians.

● International Donor Agencies

The donor agencies stated that political commitment means continued and committed—rather than sporadic—support. They felt that HIV/AIDS should form part of a party’s political manifesto and should be considered a development issue. Politicians should take the lead in promoting ownership of the HIV/AIDS program by translating political statements into action. Actions that express political commitment include increased budgetary allocations; monitoring the HIV/AIDS program through an apex decisionmaking body chaired by the Prime Minister after sensitization; and multiministry involvement in addressing crosscutting issues. The donor agencies pointed to the following as a few means of measuring the change in political commitment: incorporation of HIV/AIDS into political parties’ mandates, more political discussions in Parliament, improved coverage of HIV/AIDS issues in press reports, increased allocation and more efficient utilization of resources and Parliamentary development funds, and greater involvement of state societies.

● Other Sectors

The journalist viewed political commitment as a response to an issue of national and regional importance as not only reflected in public statements but also addressed through a continuous process of interaction with various stakeholders throughout society. One major aspect of political commitment calls for gathering information and then acting on it. For the faith-based leader, political commitment means the proper vision and willingness to pursue such commitment with dedication, total support, and perseverance. Political commitment expresses a sense of urgency and seriousness and can be measured through public statements and through legislative amendments that address human rights. The academician noted the importance of “personal willingness” on the part of leaders to pursue HIV/AIDS programs. Facilitating the implementation of programs, particularly through financial and other resources, is an essential aspect of political commitment.

In light of the above observations and views of respondents, it can be inferred that political commitment has inherent strengths that can facilitate creation of an enabling environment. Political commitment does not mean the occasional public statement but rather involves follow-up with concrete actions that will help foster a human rights-based approach. Strong political commitment can pave the way for destigmatization of PLHAs through the amendment and implementation of laws. Further, political commitment can ensure coordinated efforts within and between various government departments as HIV/AIDS is a crosscutting issue and should not be treated in a stand-alone program.

KEY FINDINGS: UNDERSTANDING OF POLITICAL COMMITMENT IN INDIA

- According to respondents, some characteristics of strong political commitment to address HIV/AIDS include dedication and consistent support among top leaders; multisectoral engagement across ministries; recognition that HIV/AIDS is a development issue and not simply a health issue; local and community participation in developing and implementing the HIV/AIDS program; allocation of appropriate human and financial resources to HIV/AIDS programs; promotion of attitudes that destigmatize HIV/AIDS; and a human rights-based approach.
- National and community leaders can demonstrate their political commitment by delivering speeches and public statements; incorporating HIV/AIDS issues into party manifestos; allocating resources to HIV/AIDS programs; and formulating and adopting policies, strategic plans, and legislation.
- A major concern, as noted by respondents, is to ensure that political commitment goes beyond mere statements of support and is translated into support for the implementation of policies and programs.

● TOP LEADERSHIP

While respondents felt that political commitment among India's top leaders is growing, the respondents representing Parliament, PLHAs, NGOs, donor organizations, international NGOs, human rights groups, and others (e.g., journalist, faith-based leader, and academician) believed that India's commitment to HIV/AIDS was sporadic. They also noted that efforts to address HIV/AIDS tended to be spearheaded by certain individuals rather than based on broad consensus and commitment throughout the government. Some of the individuals mentioned as taking a lead include President Abdul Kalam, then Prime Minister Atal Bihari Vajpayee, and Congress Party leader Mrs. Sonia Gandhi—though, again, respondents often felt that these individuals' support was sporadic or tied to specific events and occasions. In contrast to the finding that national leadership is limited to individuals, respondents observed that, in high-prevalence states, leadership has grown more broad-based as states have gained first-hand experience in tackling issues related to prevention and care and support.

Prime Minister Vajpayee (in office at the time of this study) mentioned HIV/AIDS during his Independence Day address to the nation on August 15, 2000—it was the first time any Prime Minister's Independence Day address mentioned HIV/AIDS. In addition, when he opened the Business Coalition Meeting in December 2001, Prime Minister Vajpayee spoke about HIV/AIDS and emphasized the importance of developing a workplace policy for PLHAs. As Chairperson of the State Chief Ministers Committee, he convened a meeting of six high-prevalence states in May 2002 and requested the states to become more involved and take a lead in the program. In December 2004, new Prime Minister Manmohan Singh asked NACO to develop a road map for the next three years to control HIV/AIDS. The goal of the ambitious road map would be to reach a target of a zero rate of new HIV infections by 2007. In addresses to the United Nations General Assembly in September 2004 and to the National Students and Youth Parliament Special Session on HIV/AIDS in India in November 2004, Prime Minister Singh also mentioned the importance of confronting HIV/AIDS.

Respondents noted that, as leader of the Congress Party, Mrs. Sonia Gandhi represented India at the UNGASS in 2001. Following the special session, she has personally taken initiative to write letters to all the State Congress Committees urging them to play an active role in reducing HIV/AIDS in India and requesting the Chief Ministers to lead the efforts to curtail the epidemic in locations where the party holds power. In addition, in 2004, Mrs. Gandhi spoke at the closing session of the XV International AIDS Conference in Bangkok, along with world leaders such as Nelson Mandela.

In a Parliamentary meeting on May 11, 2002, Prime Minister Vajpayee launched the Parliamentary Forum on HIV/AIDS. He discussed the challenges ahead and urged new and innovative approaches for developing effective vaccines, diagnostics, and drugs by using, among other things, the modern tools of biotechnology. He made his plea in the context of ARV drugs that are currently available but too costly for the poor, despite the elimination of all excise duties. The Prime Minister commended the efforts of high-prevalence states, the business community, and NACO. He said that much remains to be done, particularly with respect to reaching out to the illiterate and to people most vulnerable to HIV.

Building on the momentum of growing political commitment for confronting HIV/AIDS, Parliamentary Forums formed in Andhra Pradesh, Assam, Bihar, Delhi, Karnataka, Manipur, Nagaland, and West Bengal by mid-2004.

Despite progress, many respondents observed that leaders deliver statements under duress but that such statements do not add up to commitment. The statements are event-oriented and often end with the event itself. Nonetheless, respondents largely agreed that leaders have taken a stronger position with respect to addressing the epidemic by setting up the Parliamentary Forum. A respondent from a human rights group felt that the leaders would like to be perceived as leading the effort but that they continue to face challenges associated with social and cultural taboos within the political establishment. Added to this, the academician explained, frequent changes in the Health Ministry at both the ministerial and bureaucratic levels have undermined progress.

Although some top leaders have exhibited a change in attitude, their contribution to the reduction of stigma has been minimal. One major concern that came out of the interviews with five respondents—those representing an NGO, PLHA network, human rights group, faith-based organization, and the media—was that rather than reducing stigma, India’s top leaders sometimes contribute to stigma. Another three respondents reported that the top leadership has done nothing to help reduce stigma and discrimination. While top leaders had started to make some efforts in this direction, such as visiting people affected by HIV/AIDS, they also contribute to stigma by viewing the disease as a “foreign” or “Western” and therefore not part of Indian society and culture. In some cases, their answers to community concerns have even promoted stigma. For example, in Kerala, when parents did not want HIV-positive children attending schools, the government mandated that the children were to be taught within their own homes and did not reinforce their right to attend school. While the state government may have believed that it was upholding the children’s right to education, it did so by isolating the children from others in the community.

When considering the greatest successes in India’s response to HIV/AIDS, respondents noted the creation of NACO, formulation of the national policy and blood safety policy, and creation of the Parliamentary Forum. Respondents agree that the policies are well articulated and cover the entire gamut of areas important for program implementation. Respondents stated that these successes are attributable to the former Project Director of NACO, various NGOs, and ministerial support. In addition, respondents considered the shift from prevention to targeted interventions and support for vaccine trials as partial successes. In regard to shortcomings, respondents pointed to gaps between what is stated in policy and national law and what is implemented in practice; a lack of vision and commitment; failure to recognize the connection between health and development; and stagnation and lack of follow-up for concrete action.

First National Convention of Elected Representatives on HIV/AIDS

Following the launch of the Parliamentary Forum on HIV/AIDS in May 2002, political advocacy reached new heights when leaders of all three tiers of the Indian government gathered in New Delhi at India’s first National Convention of Elected Representatives on HIV/AIDS. Prime Minister Vajpayee opened the convention, which was held on July 26–27, 2003. Over 1,000 political leaders from across the country attended, including national and state ministers, parliamentarians, legislators, mayors, and panchayat representatives. The forum was the largest gathering ever of Indian decisionmakers to discuss the fight against HIV/AIDS, and it was the largest effort on such a level anywhere in the world. Participants unanimously adopted a “Declaration on Political Leadership in Combating HIV/AIDS,” which reaffirmed the political parties’ collective commitment to mobilize communities, involve civil society, and create the enabling environment necessary to fight HIV/AIDS (Joint UNAIDS/Parliamentary Forum on HIV/AIDS press release; UNAIDS, 2003a, 2003b). The commitment statement is available online at <http://www.nacoonline.org/speech-press/Parliamentary.pdf>.

KEY FINDINGS: TOP LEADERSHIP IN INDIA

- India's top political leaders have recently taken steps indicating a growing political commitment to addressing HIV/AIDS. For example, for the first time ever, a Prime Minister mentioned HIV/AIDS in an Independence Day address; the leader of the Congress Party wrote to state party committees to encourage their support for HIV/AIDS programs; and the Parliament established a Parliamentary Forum on HIV/AIDS. In addition, a large-scale national convention of elected officials from all levels of government highlighting HIV/AIDS was held in July 2003.
- According to respondents, political commitment for confronting HIV/AIDS has been sporadic and has been led mainly by a few individuals, such as NACO's former project director. Too often, public statements of support are made at special events and fail to translate into long-term, consistent support.
- A central concern raised by respondents was that the words and actions of top political leaders sometimes contribute to the stigma and discrimination faced by people affected by the disease. HIV/AIDS is often treated as a "foreign" or "Western" disease that is not part of Indian society or culture.

● GOVERNMENT RESPONSE

This section explores respondents' assessment of specific aspects of the government's response, including policy formulation, national legislature, and regulatory environment; resources; organizational structure and multiministry involvement; program components; foreign technical assistance and foreign experience; and public information and education. Respondents were not necessarily familiar with all the areas mentioned and, depending on their expertise and experience, answered only those questions pertaining to their areas of expertise.

● Policy Formulation, National Legislature, and Regulatory Environment

Policy Formulation. The draft of the National HIV/AIDS Policy was first formulated in 1998. NACO held a series of deliberations with health care professionals, scientists, social workers, NGOs, and other eminent personalities working in the field of HIV/AIDS prevention and control. Technical Working Groups, specially constituted to address various aspects of HIV/AIDS prevention and control strategies, provided valuable input. Subsequently, NACO drafted the policy, and the National AIDS Committee held further deliberations on the policy guidelines before submission to the government for approval. In April 2002, the government approved the National HIV/AIDS Policy, which subsequently took effect (NACO, 2002a).

The main strategies identified in the policy relate to prevention, creation of an enabling environment, and provision of health care during illness related to HIV/AIDS. In particular, the policy outlines a multisectoral approach and spells out guidelines on program management; advocacy and social mobilization; participation of NGOs and community-based organizations; control of STIs; use of condoms as a preventive measure; HIV testing; counseling; care of and support for PLHAs; surveillance; injection drug use; blood safety; research and development of medications; the need for providing antiretroviral treatment; provision of indigenous systems of medicine; and international cooperation with bilateral and other governments (Lawyers Collective, 2002b).

Respondents, including the Parliamentarian and representatives from NGOs, PLHAs, human rights groups, international NGOs, donors, and other sectors, agreed that the Government of India has a well-documented, comprehensive National HIV/AIDS Policy that covers all basic program components. The two human rights group respondents reported that, on the whole, the policy takes a human rights-based approach. While some respondents reported that the policy was developed in a participatory manner that included NGOs, PLHAs, and donor groups, a nearly equal number felt that participation was lacking or took the form of a token gesture.

One theme that emerged throughout the interviews was that a policy, however well documented, will be effective only when widely disseminated and supported by implementation plans and infrastructure. The dissemination of the policy has not taken place effectively; in fact, many people seem to be unaware of it. The policy assigns a high priority to voluntary counseling and testing (VCT), but many VCT centers lack counselors and, once a patient tests positive for HIV, no mechanism is in place for follow-up. A policy on blood safety also exists, yet testing facilities in many districts have yet to launch operations. Partner

notification and mandatory testing are among the controversial topics still subject to debate. Many respondents also felt that the policy does not adequately address the role of civil society groups. Finally, respondents noted that the national strategy emphasizes care and support, yet the national policy does not adequately address associated programs.

The government has prepared national strategic plans that are available for public access on the NACO website. The National AIDS Control Program (NACP-I [1992–1999]) focused mainly on prevention and covered strengthening management capacity for HIV/AIDS control, promoting public awareness and community support, improving blood safety and rational use of products, controlling STIs, and building surveillance and clinical management capacity. Many respondents felt that the first plan, unlike the policy formulation process, did not follow a consultative, participatory approach. It was centralized and inflexible—state organizations did not have discretion to adapt the strategies to local conditions. Further, the information, education, and communication (IEC) component was poorly implemented, messages were not properly pretested, and the management information system (MIS) was not made fully operational—resulting in inaccurate estimates of national prevalence and incidence. The plans did not prioritize strategies, resulting in delays in the planning, authorization, and implementation of projects such that only about one-fourth of the allotted budget was spent under NACP-I. This apart, NACO has itself outlined key lessons learned from NACP-I wherein it has identified the shortcomings related to institutional and technical issues.

NACP-II became operational as of November 1999. Plan formulation followed a participatory process and involved state and municipal corporations. NACO's technical liaison officers, in collaboration with State AIDS Control Program officers, conducted state planning workshops in all the states and in the cities of Ahmedabad, Chennai, and Mumbai. Each two-day workshop brought together all stakeholders, including senior officials of government departments, district officers, and representatives of NGOs, the private sector, and the medical community. Besides facilitating strategy formulation, the workshops provided a major advocacy opportunity (NACO, 2000a).

According to respondents, the second plan did not focus on the general population (including women and adolescents) or how to involve communities/grassroots leaders. Respondents felt that the plan lacked balance between prevention and care and support. In particular, they noted that NACP-II could not achieve its desired goal of increasing communities' awareness of HIV/AIDS, especially in rural areas. Although documentation available on NACO's website suggests that the NACP-II was participatory, respondents disagreed. They felt that the NACP-II state-level exercise was a formality in low-prevalence states where the program was yet to become active. Due to the inexperience of state-level stakeholders, NACO ultimately had to assume responsibility for outlining action plans. The action plans were not shared and inputs provided by certain NGOs were not considered. According to respondents, the process involved only token representation by NGOs to endorse predetermined strategies.

With respect to meaningful participation of PLHAs in policy develop and implementation, respondents noted that few networks of HIV-positive people are involved. Commitment to the Greater Involvement of People Living with HIV or AIDS (GIPA) is mentioned in the policy document, which devotes a section to PLHAs. However, some respondents, including representatives of NGO, PLHA, and human rights organizations, felt that GIPA has remained merely a concept that has not been operationalized. A few respondents felt that the more inclusive activities are underway. For example, one NGO respondent noted that the recent Country Coordinating Mechanism (CCM) proposal process included PLHAs. Respondents commented that the situation differs from state to state. In high-prevalence states such as Tamil Nadu and Maharashtra, networks of HIV-positive persons have been closely and directly involved through representation on state committees and as participants in projects related to care and support. In June 2004, the Indian Network for People Living with HIV/AIDS (INP+) prepared a strategy paper for NACO on increasing PLHA involvement in the national response to the epidemic.

The national policy does not directly mention human rights, although a section focuses on stigma and discrimination. According to respondents, the government has not taken concrete steps to address stigma and discrimination, though it authorized a project to review existing laws. In the words of one respondent, “As long as stigma exists, positive people will not disclose their identity and unless stigma is addressed, GIPA cannot be effective.”

National Legislature and Regulatory Environment. One achievement of the national legislature reported by respondents (and discussed earlier) was the establishment of the Parliamentary Forum for HIV/AIDS, which recently held a sensitization workshop for public officials. In terms of laws and legislation, India has not enacted an HIV/AIDS law or related anti-discrimination law. Two respondents working in the area of human and legal rights stated that Article 14 of the Indian Constitution mandates equity and equality for every citizen of the republic. If this article is fully enforced, then all the human rights issues and approaches would be addressed, despite stigma and discrimination. At the time of the study, the Lawyers Collective was reviewing laws and working on plausible amendments—along with the NACO and Indian Council for Medical Research (ICMR), a premier medical research institute of the government. The legislation reviewed by the collective relates to discriminatory practices, denial of health services, the Narcotic and Psychotropic Substances Act, Immoral Traffic Prevention Act, Section 377 of the Indian Penal Code, impact of trade policies on access to medicines and treatment, partner notification, divorce laws, and gender and vulnerability of women to HIV/AIDS (Lawyers Collective, 2002a). In 2004, the Lawyers Collective took the initiative in drafting and discussing a national law on HIV/AIDS.

In addition to the above efforts, the National Human Rights Commission (NHRC) has prepared a set of human rights guidelines, though not specific to HIV/AIDS. NGOs, along with the Lawyers Collective, have filed a series of public interest litigations (PILs) on behalf of PLHAs in health service and workplace discrimination cases, leading to some judicial pronouncements by courts in support of PLHAs. The Chamber of Indian Industries (CII) and the Federation of Indian Chambers of Commerce (FICCI) have developed some guidelines for improving workplace policies, although the guidelines are not legally binding and can be challenged in court. A few industrial houses, such as Tata’s and Reliance, have started to implement the guidelines. The Mumbai police force announced a nondiscrimination policy for HIV-positive employees—the first nondiscrimination initiative by a government agency.

● Resources

More than three-fourths of respondents were of the opinion that India does not commit a substantial amount of its own budget to the HIV/AIDS program, reflecting an insufficient level of political commitment to addressing the epidemic. Almost all respondents felt that the country depends, to a large extent, on donor funding and soft loans. In mid-2004, the newly elected United Progressive Alliance government pledged to increase spending on health to 2–3 percent of the gross domestic product (GDP) over the next five years, to boost public investment in programs to control communicable diseases, and to provide leadership to the national AIDS control effort. President Kalam affirmed the government’s commitment in his address to the first session of both houses of Parliament after the election of the 14th Lok Sabha. The Minister for Health and Family Welfare, Dr. Anbumani Ramadoss, has requested an audit of NACO to determine if government resources are used to maximum effect.

NACP-II received funding from three sources: the International Development Agency (IDA)/World Bank, the United States Agency for International Development (USAID), and the Department for International Development, UK (DFID). The IDA/World Bank soft loan totaled US\$191 million, with the government’s contribution at \$38.8 million; the total outlay for NACP-II summed to \$229.8 million, or

Rs. 11,550 million. USAID extended its assistance to the government of Maharashtra for implementation of the AVERT Project based on earlier experience in working in the state of Tamil Nadu in the APAC Project; the assistance totaled Rs. 1,660 million (US\$38.1 million). DFID extended its assistance for implementation of sexual health projects in the states of Andhra Pradesh, Gujarat, Kerala, and Orissa in continuation of earlier projects in West Bengal, for a total outlay of Rs. 1,040 million (\$23.9 million). The total outlay for NACP-II from the above sources reached Rs. 14,250 million (\$327.5 million). Table 1 presents the approved year-wise phasing of expenditures.

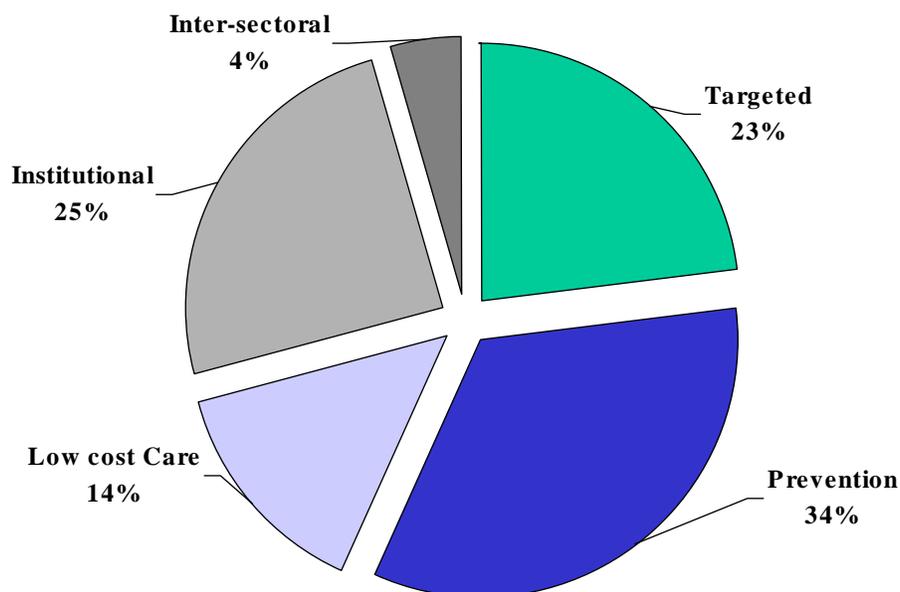
Table 1: Approved Year-Wise Phasing of Expenditures in Millions, INR (and US\$)

Year	World Bank Project	USAID	DFID	Total
1999–2000	1,545 INR (\$35.5)	436 INR (\$10)	126 INR (\$2.9)	2,017 INR (\$46.3)
2000–2001	2,701 INR (\$62)	285 INR (\$6.5)	187 INR (\$4.3)	3,173 INR (\$72.9)
2001–2002	2,579 INR (\$59)	285 INR (\$6.5)	222 INR (\$5.1)	3,086 INR (\$70.9)
2002–2003	1,931 INR (\$44)	285 INR (\$6.5)	222 INR (\$5.1)	2,448 INR (\$56.2)
2003–2004	1,980 INR \$45.5	251 INR (\$5.7)	283 INR (\$6.5)	2,514 INR (\$57.8)
2004–2005	814 INR \$18.7	118 INR (\$2.7)	--	932 INR (\$21.4)
Total	11,550 INR (\$265.4)	1,660 INR (\$38.1)	1,040 INR (\$23.9)	14,250 INR (\$327.4)

Source: Program Financing, NACP-II.

The component-specific allocation to NACP-II through the World Bank Project (see Figure 1) is Rs. 3,891 million (US\$89.4 million) for prevention interventions for the general community, Rs. 2,865 million (\$65.8 million) for institutional strengthening, Rs. 2,656 million (\$61 million) for targeted interventions for vulnerable groups, Rs. 1,633 million (\$37.5 million) for low-cost AIDS care, and the remaining Rs. 505 million (\$11.6 million) for intersectoral collaboration. Besides these major donors, the Canadian International Development Agency and United Nations Development Program are providing about Rs. 462 million (\$10.6 million) (NACO, 2000a).

Figure 1: Component-wise Allocation of World Bank and Government of India Funds in NACP-II



Since its inception, NACO has involved other ministries, such as Railways, Social Justice and Empowerment, and Labour and Employment, in the initiation of certain project activities. More than three-fourths of respondents were not sure if the various ministries have a separate budget earmark for HIV/AIDS. However, a few mentioned that the Ministry of Social Justice and Empowerment funds rehabilitation programs for HIV-positive IDUs. The Ministry of Information and Broadcasting has not allocated funds but provides free air-time for broadcasting HIV/AIDS messages. The Ministry of Health and Family Welfare supports the condom promotion program by supplying free condoms.

Most respondents agreed that the government budget is transparent. The government publishes and posts on its website an annual fiscal report. However, it also centralizes the allocation and disbursement of funds to the extent that states have little say in budgetary matters, except in the case of states with active SACS. It should be noted that, in India, health is a state matter funded out of state budgets while reproductive and child health (RCH) and family planning (FP) are funded by the national government. Funding of HIV/AIDS services follows the RCH and FP pattern.

More than half of respondents were of the opinion that the available funding has not been fully and effectively spent. As an example, one respondent reported that the government often releases funds during the last quarter of the fiscal year, largely hindering field activities even in the states with efficiently functioning SACS. In absolute terms, government funding has increased, but the proportion of the government's budget devoted to HIV/AIDS has more or less remained the same.

Apart from NACP-II, India submitted a GFATM proposal largely intended to support the gaps identified in the plan. The proposal mentions that when NACP-II was developed, the prevention of parent-to-child transmission (PPTCT) and provision of ARVs had not yet emerged as strategic priorities. Scientific, technical, and pricing breakthroughs have, however, made PPTCT and ARV program components more feasible such that India should integrate them into its national program. Similarly, with the advent of

rapid HIV tests, provision of VCT services at the subdistrict level is feasible and can complement tuberculosis-related efforts to reduce HIV/AIDS morbidity and mortality.

Respondents representing international donor groups felt that government funding is inadequate. They mentioned that the Planning Commission has established a limit on donor assistance for all departments, including the Ministry of Health and Family Welfare. Some respondents, especially those from donor agencies, feared that the limit on donor assistance could pose an impediment to future external funding. As for resource availability, the response was mixed—respondents felt that if medication and treatment are considered, then resources are insufficient; others felt that resources would be sufficient if activities were more efficiently prioritized. The former opinion is in accord with the justification for the GFATM proposal. As an indication of low political commitment, many respondents noted that the government still does not consider HIV/AIDS a priority relative to other debt relief funds and that, in terms of resource allocation, the nation has failed to strike an appropriate balance between prevention and care and support.

● Organizational Structure

The national HIV/AIDS program was launched in 1987. An apex committee was formed with a view to bringing together various ministries, NGOs, and private institutions to coordinate program implementation, provide policy direction, and forge multisectoral collaboration. The apex committee consists of 24 members, including the Union Minister of Health and Family Welfare (Chairperson); Union Minister of State for Health and Family Welfare (Vice Chairperson); health ministers of a few states; Union Secretaries from the Departments of Health and Family Welfare, Indian System of Medicine and Homeopathy, Biotechnology, Tourism, Social Justice and Empowerment, Information and Broadcasting, Women and Child Development, National Commission for Women, Human Resources, Labour and Employment, and Railways; Additional Secretary and Project Director of NACO; technical persons from the Armed Forces and ICMR; and Director General of Health Services. The committee also includes nonofficial members from the All-India Motor Transport Congress, CII, FICCI, the Associated Chamber of Commerce and Industry of India, Salvation Army, and Indian Medical Academy.

While the apex committee provides direction and guidance to the HIV/AIDS program, NACO as the implementing organization is responsible for managing the program. Chaired by the Minister of Health and Family Welfare who functions as Secretary, NACO includes 11 members. A senior officer from the administrative cadre (bureaucrat) in the rank of additional secretary serves as NACO's project director and regularly reports to the Secretary (Health). Below the project director are one additional project director and four joint directors who oversee blood safety, training, IEC, and technical programs. Other program officers and administrative and finance staff members include a deputy director, two assistant directors, two undersecretaries, a finance officer, a section officer, and a statistical assistant (NACO, 2000b).

While a clear-cut structure exists at the national level, NACO's structure at the state level takes the form of a society called the State AIDS Control Society (SACS). The project director, usually a bureaucrat from administrative services, heads the SACS and is assisted with program implementation by program officers. The SACS Committee, like NACO, includes NGOs and PLHA representatives, among others. The SACS is supposed to execute its activities through the public health system. The HIV/AIDS program amalgamates or converges at the district level only, which, according to many respondents, seemed to be one of the structure's major weaknesses. Respondents felt that the convergence would work if intersectoral coordination were in place at higher levels.

Respondents agreed about the importance of a national body responsible for program coordination and policy direction. Most respondents also reported that NACP is multisectoral, with representation from various ministries and civil society. Some respondents noted, however, that they could not be certain about the degree to which representatives participate in NACP activities and whether their views are considered. One respondent stated that some ministries are not committed to addressing HIV/AIDS while another raised the concern that ministry representatives to NACP are not necessarily knowledgeable about HIV/AIDS. NACO, according to many respondents, is understaffed and technically ill-equipped to handle all the components of the HIV/AIDS program. As a result, one respondent stated that NACO must rely on consultants to address various technical areas. As an example of a program strength, the respondents noted that NACO has laid out specific goals and objectives that are monitored regularly through either a computerized management information system (CMIS) or periodic behavioral surveys and annual sentinel surveys. Some respondents questioned the sentinel survey's methodology out of concern that it covered only public health institutions. As for weaknesses of NACP, many respondents pointed to an inflexible, highly centralized, and bureaucratic structure and a national body that meets only infrequently.

● **Multiministry Involvement**

Almost all respondents named ministries such as Labor and Employment, Women and Child Development, Education, Social Justice and Empowerment, Defense, Information and Broadcasting, and Youth Affairs as part of NACO's management board. However, many respondents believed that the ministries' political commitment exists primarily on paper—with the exception of the ministries of Social Justice and Empowerment, Education, and Women and Child Development, whose budgets have earmarks for the HIV/AIDS program. Some multiministerial involvement is evolving with NACO's authorization of a few projects for the Railways, Labor and Employment, and Law ministries. In addition, the Planning Commission has talked about treating HIV/AIDS as a development issue and, in the Tenth Five-Year Plan document, asked the other ministries to earmark a budget and programs for addressing the epidemic. On the whole, most respondents believed that the involvement of the ministries, particularly in terms of implementation, is not visible. Due to the vertical nature of programs at both the national and state levels, linkages among ministries are not forthcoming, leaving a wide gap between commitment and actual implementation.

In October 2004, the Group of Ministers on HIV/AIDS met and agreed on the need for a national action plan to address HIV/AIDS. Representatives of the ministries of Health and Family Welfare, Information and Broadcasting, Rural Development, Labor and Employment, Social Justice and Empowerment, and Human Resource Development attended the meeting, during which participants pledged to outline a draft plan by December 2004, as well as meet regularly to improve coordination across ministries.

● **Program Components**

Two of the major program components of India's HIV/AIDS program are VCT and PPTCT. In general, according to respondents, VCT service coverage is poor. By 2004, more than 700 VCT centers had been established covering all 593 districts in the country, but one respondent noted that many counselor positions were vacant. At the time of the study, the national program did not include the provision of highly active antiretroviral treatment (HAART), though GFATM was under consideration as the mechanism for its inclusion. In April 2004, the government launched a program for the provision of free ARVs, which, by December 2004, covered 2,500 people. In June 2004, GFATM awarded India US\$165 million to provide ARVs over a five-year period. In 2004–2005, the number of centers providing ARVs will increase from eight to 25 in the six high-prevalence states and Delhi (NACO, 2004).

NACP-I focused to a large extent on prevention while, according to most respondents, NACP-II provides care and support and focuses on targeted interventions for vulnerable populations along with prevention. The program envisages a comprehensive and integrated approach and consists of specific prevention and care programs that include behavior change communications, counseling, health care support, treatment of STIs, and creation of an enabling environment that will facilitate behavior change among groups such as sex workers, truckers, MSM, IDUs, migrant workers, and street children. In all, one donor representative reported there were 735 targeted intervention projects across the country in 2000–2001. Of these projects, 157 targeted sex workers, 162 targeted truckers, 26 targeted MSM, 41 targeted IDUs, 260 targeted migrants, 34 targeted street children, and 55 targeted prisons. Most projects focused on the southern states of Andhra Pradesh, Tamil Nadu, and Kerala. NACO, as part of NACP-II, has fully empowered the SACS to select the NGOs and provide funding support for implementing targeted interventions. Every state society is, therefore, expected to appoint an NGO advisor, who is a professional in the field of social work, to manage and guide the targeted intervention. NACO, for its part, has already conducted two rounds of intensive training programs for the state officers. With support of UNAIDS, NACO is developing a training module for NGOs.

● Foreign Technical Assistance and Foreign Experience

Nearly all respondents reported that, while the Government of India sends delegates to visit other countries to learn about their responses to HIV/AIDS, it has not demonstrated a commitment to analyzing or building on these experiences in a meaningful way. One problem is that there is no clear-cut scope of work and no accountability for delegates returning from trips. All but one respondent agreed that India does not use its foreign technical assistance to its maximum capacity. Hence, the country needs to develop a strong commitment to making effective use of the findings from visits to other countries and channeling foreign technical assistance in the most productive manner possible. Program areas where India could benefit from the experiences of other countries, as identified by respondents, include VCT, PPTCT, HAART, monitoring and evaluation, and programs for vulnerable groups, such as women, youth, MSM, sex workers, and IDUs.

● Public Information and Education

Communication continues to be an important strategy in the fight against HIV/AIDS. The national government uses different media channels to address HIV/AIDS—television, radio, newspapers, posters, hoardings, marches, and rallies—and carries out family health awareness drives across the country. In addition, it provides tele-counseling services. Despite a concerted public education effort, only two respondents believed that the information provided by the government is accurate and comprehensive.

One concern was that the government does not integrate messages regarding HIV/AIDS with other health messages. The stand-alone HIV/AIDS messages have focused on prevention and sometimes have even created further confusion, especially in regard to condom use. One respondent stated that the scare tactics used in the message about safe sex have had an adverse impact. The respondent further added that messages are not pretested and not well packaged. While acknowledging the need to encourage correct and consistent condom use, four respondents believed that India's prevention education programs have been condom-centric and need to promote abstinence and fidelity. At the same time, respondents from NGOs and human rights groups reported that public education campaigns do not openly address issues

surrounding sex and sexuality and often tend to contribute to the fear and stigmatization surrounding HIV/AIDS. To a large extent, local media channels have been overlooked, and the VCT campaign is still in its infancy.

The findings from the study are in line with NACO's views. In NACP-II, NACO is assigning top priority to an effective and sustained strategy to bring about changes in behavior to prevent further infection. NACO instituted a review of studies that revealed the following:

- Most individuals do not have accurate and complete information;
- The link between STIs and AIDS is not clear;
- STIs are not taken seriously by some members of the public because they are curable; and
- Many believe that HIV transmission and AIDS affects only certain groups, such as foreigners, MSM, sex workers, and IDUs (NACO, 2000c).

The new communication package is expected to address all the aforementioned issues.

The national social marketing campaign has finally evolved, and many organizations are involved in its promotion. Life skills education has been incorporated into the school curricula in classes IX and XI, covering general health, personal hygiene, adolescent health, reproductive health, and HIV/AIDS. However, since education is a concurrent subject (central and state), providing life skills education ultimately depends on whether or not the states want to include the course. One respondent noted that the University Talk AIDS Program has developed a module on HIV/AIDS. The government network of Nehru Yuvak Kendras (Youth Clubs) in villages is being trained on HIV/AIDS, and the Indira Gandhi Open University offers a Diploma and a Certificate Program on HIV/AIDS.

KEY FINDINGS: GOVERNMENT RESPONSE IN INDIA

- India adopted a National AIDS Policy in 2002. Respondents representing NGOs, PLHAs, human rights groups, international NGOs, donors, and other sectors agreed that the Government of India has a well-documented, comprehensive policy that covers all the basic components of the nation's HIV/AIDS program. The policy takes a human rights-based approach, and mentions a commitment to GIPA. Some civil society groups were involved in the policy's formulation through technical working groups. While Article 14 of India's Constitution guarantees the equality of all citizens, no specific law prohibits discrimination on the basis of HIV status (or perceived status). The Lawyers Collective is leading an effort to prepare a draft HIV/AIDS law.
- Many respondents believed that the Government of India does not contribute enough of its own resources to HIV/AIDS programs and services. The nation is largely dependent on external sources of funding, though the Planning Commission has established a limit on funds received from external donors. The government does seek resources to fill gaps in program funding—for example, for provision of ARVs—through GFATM. While respondents agreed that India's budget is transparent, funding is centralized and states have little input into how funds should be used. In mid-2004, the newly elected United Progressive Alliance government pledged to increase spending on health by 2 to 3 percent of the gross domestic product over the next five years.
- India has developed a clear-cut structure for addressing HIV/AIDS. NACP is managed by NACO, under which SACS operate. Respondents believed that the NACP structure will support program coordination and provide program direction. However, they also felt that NACO could do more to strengthen multiministry collaboration, promote meaningful civil society and PLHA involvement, and allow for greater flexibility at the state level given that different states are facing different stages of the epidemic. Developments in 2004 include a pledge by the Group of Ministers on HIV/AIDS to improve collaboration and develop a national action plan for HIV/AIDS. INP+ also prepared a strategy document for increasing PLHA involvement in the national response.
- The major components of the HIV/AIDS program are VCT and PPTCT. As of April 2004, the government also launched an ARV program that covered about 2,500 people by the end of the year. According to respondents, NACP, especially right after its formation, largely focused on prevention. Targeted interventions are increasingly undergoing development for groups that practice high-risk behaviors. Implementation of various components of the program has been a challenge, however. According to respondents, many ministries do not have budgets earmarked for HIV/AIDS programs, and NACO and NACP lack sufficient personnel with technical expertise in HIV/AIDS issues.

● ROLE OF NGOS AND CIVIL SOCIETY

Respondents were asked about the extent of NGO involvement in planning and implementation of the HIV/AIDS program, NGOs' role in addressing stigma and discrimination, the extent of political parties' support for HIV/AIDS activities and the commitment of various different groups, such as faith-based organizations, PLHA networks, academia, health care professionals, women's and human rights groups, and business establishments.

In terms of India's NGO and civil society sector, several NGOs specialize in various development activities. In the health sector, however, few NGOs command specialized skills and, even if such NGOs exist, they often operate in India's more developed states. According to respondents, most NGOs working in HIV/AIDS are concentrated largely in the urban areas, with limited networking among organizations. The funding mechanism for NGOs varies from one organization to another, depending on an organization's expertise and credibility. Some NGOs depend solely on the government for funding. Other NGOs receive funding directly from international donor agencies and foundations and it is the prerogative of these organizations to seek government funds or not. Still other NGOs depend on both government and international donor funds.

That being said, respondents noted that NGOs have played a prominent role in implementing various components of India's HIV/AIDS program. In fact, according to some respondents, the program's current dimensions reflect the activism of NGOs. In various forums, NGOs have spoken out about various aspects of the epidemic, generating sufficient pressure that the government has reacted with appropriate measures. They have even demonstrated how to approach the area of care and support. Most NGOs specialize in different aspects of the HIV/AIDS responses (e.g., prevention, care and support, stigma reduction) and have continued to develop expertise in these areas. In particular, since the inception of the NACP, NGOs have taken a leading role in implementing targeted intervention programs among vulnerable populations. By December 2003, more than 900 targeted interventions programs were in place.

The government has involved NGOs either directly in the national program or through SACS. NGOs represent various committees of NACO or SACS. For instance, NACO has convened Technical Resource Groups (popularly known as TRGs) that provide technical support and direction to the program in terms of planning and implementation. At the time of preparing the action plan for NACP-II, there were about 11 TRGs, each representing important areas of the program. NGOs, based on their expertise and experience, were represented within these groups. In addition, as part of GFATM, it is mandatory to involve NGOs and PLHA networks in the CCM. The selection of NGOs to the CCM, however, is solely at the discretion of government authorities. In 2004, NACO announced plans to formulate a National Partnership on AIDS to strengthen multisectoral collaboration that will include partners from all sectors, including government, parliamentarians, NGOs, and the private sector.

During the course of the interviews, many respondents opined that the selection process for involvement of NGOs in the national program has lacked transparency. NGOs that enjoy good rapport with NACO officials and agree with the officials' approach are represented on NACO committees—leading to the unanimous passage of decisions without critical review. Four respondents representing NGOs and PLHAs contended that, even if NGOs offer suggestions, the organizations represented on the NACO committees are not sure whether their suggestions have been considered or incorporated into the final

document. In this context, the respondents felt that the government involves only those NGOs that endorse the government's position. Given that many international funding mechanisms require the representation of various stakeholders, NGOs are involved for their name only or as a token gesture. The respondents questioned the credibility of NGOs represented on various NACO committees. To an extent, they blamed the international community for instituting guidelines that do not reflect reality. Thus, on paper, NACO's participatory process appears to promote the involvement of NGOs when, in fact, such involvement may be limited.

Concerning NGOs' involvement in addressing stigma, all respondents involved in dealing with the issue, particularly as related to care and support, mentioned that not a day passes without one of their clients facing stigmatization. Hence, respondents are compelled to take up issues surrounding stigma at appropriate places. One recent event tells the story. In Kerala, one of India's most socially advanced states, two HIV-positive children were removed from school when the local community protested and parents refused to send their own children to the school. Eventually, the state government intervened by sending teachers to instruct the two children at home. In the view of one respondent, in suggesting such an extreme remedy, the state itself is promoting stigmatization.

NGOs organize protest marches, demonstrations, and rallies; conduct advocacy and sensitization workshops to enhance the knowledge of various groups, including some government officials and health care providers; and file PILs in court. For instance, the recent verdict regarding a PIL filed by the Voluntary Health Association of Punjab on the denial of health services to HIV-positive people stated, "AIDS patients were given no treatment at any of the government hospitals and were simply let to die." The Supreme Court (India's highest court) issued notices to the center, all the states, and union territories as well as to NACO to file their replies within four weeks (*Times of India*, 2003). PILs filed by NGOs in various courts have generated pressure, and the verdicts, whether favorable or not, have created a sense of awareness at least among the educated.

In regard to the commitment of political parties, most respondents stated that the parties have neither supported nor opposed the HIV/AIDS program. However, a few respondents mentioned that Mrs. Sonia Gandhi took the initiative of writing to the state Congress leaders. Many respondents saw the formation of the Parliamentary Forum for HIV/AIDS as a positive step but, at the same time, remarked that not one of the political parties has addressed HIV/AIDS in its political manifesto. Though the involvement of political parties in addressing the issue was limited, the support provided by the government to carry out the HIV vaccine trials in the country should be noted.

Concerning the commitment of various groups, most respondents were of the common view that:

- Missionaries funded by Christian organizations were committed to the HIV/AIDS program and exhibit considerable dedication. The other faith-based groups lagged behind, but both NACO and UNAIDS have made efforts to sensitize religious leaders. Workshops have been held and projects with religious leaders authorized in a few states.
- Concerning PLHA groups, they are committed but lack resources. However, networks such as INP+ and Positive Life are working actively in care and support. The view expressed by PLHA respondents was that the deteriorating health of an active HIV-positive person many a times hinders activism and may result in a leadership vacuum. It is, therefore, essential to build capacity and disseminate lessons learned within the PLHA community so that others in the network are educated to take up the cause.
- Despite the fact that women are becoming increasingly vulnerable to HIV infection as the epidemic matures in India, women's groups have not yet demonstrated a strong commitment to

addressing HIV/AIDS, according to respondents. Human rights groups, including the NHRC, have taken up various issues related to stigma and discrimination and are pursuing human rights-based approaches for HIV-positive people.

- A few business federations such as CII and FICCI have taken the lead in developing HIV/AIDS-related workplace policies. Some industrial companies, such as the Tata group of industries, have also developed policies. However, the adoption and implementation of workplace policies has not been widespread.
- Other groups, such as academia and health care professionals, have not demonstrated much commitment; support from these sectors often comes from individuals rather than from a broad base.
- The government has encouraged publicity through television and other media channels, and the Information and Broadcasting Ministry has provided free air-time. However, the value of air-time is questionable because the time allotted does not include prime-time hours. Further, with only a few local celebrities, the government must rely on national celebrities. A few respondents believed that celebrities are involved only in special events rather than on a continuing basis.

On the whole, respondents felt that, over the years, civil society has become more aware, vocal, and empowered in addressing HIV/AIDS. Civil society groups have come to terms with the fact that HIV/AIDS is here to stay and that India must develop ways of addressing the disease. Respondents felt that the growth and strength of civil society involvement in HIV/AIDS programs is more evident in the high-prevalence states, but cannot be generalized to the entire nation or to rural areas.

KEY FINDINGS: ROLE OF NGOs AND CIVIL SOCIETY IN INDIA

- Many respondents credited NGOs with taking a lead role in the country's response to HIV/AIDS. In particular, NGOs have been involved in providing care and support, addressing stigma, and implementing targeted intervention programs among vulnerable populations.
- Though many international funding mechanisms require NGO involvement (e.g., the CCMs of GFATM), respondents reported that government efforts to work with NGOs often take the form of token gestures. The government tends to select for involvement those NGOs whose philosophy supports the government's ideas and approaches; when NGOs provide criticism or feedback, it is not clear to what degree the government incorporates suggested changes into final policies, plans, and proposals.
- Some NGOs and civil society and private sector groups are beginning to demonstrate their commitment to addressing HIV/AIDS. Human rights groups have been active in filing litigation in discrimination cases. Business groups, such as the Tata group of industries and CII and FICCI, have developed workplace policies. Christian faith-based groups have also been involved in providing care and support. More needs to be done in other sectors, however, including women's groups and health care professionals.

● RESEARCH, MONITORING, AND EVALUATION

Research, monitoring, and evaluation are important components of any program, and India's national program has included it as an integral part of the program strategy for continuously assessing the status of implementation and performance at the national and state levels. As part of the study, respondents were asked about their views of the effectiveness of the HIV surveillance system, flow of information, and methods for establishing priorities.

India's HIV surveillance system, put in place by the Indian Council for Medical Research (ICMR), dates back to 1985, with the sentinel surveillance component initiated in 1994. In 1990, the responsibility for surveillance was transferred from ICMR to the Director General of Health Services. According to one respondent, the government erred in taking over responsibility for surveillance from an autonomous institution. While some respondents believed that the surveillance system is well designed, many stated that it is not effective in practice. Owing to wide variation in the estimates of HIV/AIDS cases reported by different sources and the states, a few respondents were concerned that the incidence rate as declared by India is debatable. About three-fourths of respondents questioned the sentinel survey's estimation methodology, noting that the sentinel surveys cover only the public sector. In addition, according to respondents, approaches such as "assuming certain groups to be high-risk and considering them as targets for HIV surveillance" and "confining [surveillance] to only antenatal screening and not community screening" have resulted in gross underestimates of both incidence and prevalence rates.

Moreover, respondents noted that the indicators do not undergo regular monitoring and that the monitoring system itself is not standardized. Almost all respondents agreed that information dissemination takes place from the national to state level but not beyond to the local level. In terms of priority issues, most respondents felt that the government does not establish clear priorities and instead relies on whatever information is available. Nonetheless, the ongoing experience of implementing and monitoring the HIV/AIDS program has led to improvement in the monitoring and evaluation system. The government now monitors the benchmarks and goals for each of the main program components and regularly conducts program reviews. Regarding the evaluation of programs, respondents noted that independent agencies and experts periodically undertake annual behavioral surveillance surveys and surveys of health care providers on STI case management. The surveys have provided both NACO and donor agencies with insights into risk behaviors and help track the knowledge of health care providers for mid-course corrections. As the monitoring system has started to evolve, it has clearly improved, with further room for improvement with the inclusion of care and support. (See the box below to learn more about how NACO proposes to improve the monitoring and evaluation system.)

Recently, the government started to promote steps for better identifying groups vulnerable to HIV. By mid-2004, 30 states and union territories had completed extensive mapping of vulnerable populations, with the goal of identifying and prioritizing areas in need of targeted interventions. NACO reported that the effort was being conducted by external agencies that are "now on to address the needs of scattered high-risk core groups, wherever identified (NACO, 2004, p. 22).

NACO Seeks to Improve Monitoring and Evaluation System

NACO, too, realized the flaws in the monitoring and evaluation component of the national program under NACP-I. Under NACP-II, NACO is attempting to address the earlier shortcomings. An extremely important feature is the concurrent system for monitoring and evaluating program activities with the help of the Computerized Management Information System (CMIS). CMIS will provide critical information about the course of the HIV/AIDS epidemic in India and help guide decisions about where and how to intervene effectively. The concurrent evaluation of the ongoing program will supplement CMIS. The information generated by CMIS will indicate how well the program is being implemented and whether it is making a difference as envisaged under NACO-II. The new monitoring and evaluation system is expected to provide SACS with greater autonomy in implementing activities while strengthening the states' capacity to monitor and evaluate programs (NACO, 2000d). Apart from measuring effective implementation of various activities, the new system will provide information on aspects of program management related to:

- Priority targeted interventions among poor and marginalized populations;
- STI control through provision of appropriate treatment of STIs;
- Condom promotion among high-risk populations and within the general community;
- Information, education, and communication;
- Voluntary counseling and testing;
- Blood safety;
- Epidemiological surveillance;
- Institutional capacity building;
- Low-cost community-based care; and
- Multisectoral responses.

NACP-II will phase in the new monitoring and evaluation system, in addition to continuing with routine tracking. The new system is expected to provide a better understanding of the status of the HIV/AIDS epidemic in India.

KEY FINDINGS: RESEARCH, MONITORING, AND EVALUATION IN INDIA

- India operates an HIV surveillance system that dates back to 1985, although sentinel surveillance did not begin until 1994. The government uses behavioral surveillance surveys and other studies to provide periodic information on relevant trends, behaviors, and program impact. The government has established specific goals and benchmarks for each component of the HIV/AIDS program.
- Respondents raised the concern that current HIV sentinel surveillance methods fail to cover the entire country. With surveillance limited to public sector sites, much of the population is excluded, leading to underestimates of prevalence and incidence.
- Respondents felt that India must do a better job in terms of strategic planning and priority setting. While the government does try to use whatever information is available, it often carries out priority setting in an ad hoc, reactive manner.

● STIGMA AND DISCRIMINATION

This section deals with respondents' views on stigma, the extent of stigma, its root causes, and the measures taken to address stigma and discrimination in India.

All respondents were of the opinion that the level of HIV/AIDS-related stigma prevalent in India is particularly high. It is important to note that Indian society and culture have gone through an evolution of caste-related stigma that has changed since independence. However, sporadic events of stigmatization based on caste still occur in various parts of the country. Caste-related stigma exists not only in social settings, but also intertwines with economic and health issues, particularly in the case of various communicable diseases such as tuberculosis, leprosy, and HIV/AIDS, to mention a few.

Respondents attributed HIV/AIDS-related stigma to various causes, such as fear that the disease is new, deadly, contagious, and life-threatening. Further, they stated that HIV/AIDS is seen as the result of immoral behavior (e.g., promiscuity or deviant sex) that deserves to be punished. One respondent noted that views regarding unprotected sex and injection drug use are influenced by “moral judgment, taboos on sex and sexuality, [and] religious or moral beliefs that it [HIV infection] is an outcome of moral fault, punishment for immoral behavior. . . .” One respondent even pointed out that one of India's laws directly contributes to stigma. Homosexuality, for instance, is considered a criminal offense punishable under the penal law; therefore, MSM cannot access services, such as counseling and health care, due to the fear that they may be arrested and criminally charged. Other sources of stigma include myths and misconceptions associated with the disease, lack of awareness and ignorance about modes of transmission, illiteracy, and political unwillingness to fight the epidemic. Stigmatization translates into fear of family rejection; fear of denigration by the community; fear of criminalization; fear of treatment as an outcast; fear of marital conflicts and violence; denial of jobs; problems in receiving inheritance; and denial of health care, among others.

Several instances of stigma and discrimination were cited by respondents. An HIV-positive woman was stoned to death in Andhra Pradesh. One of the respondents pointed out that the stigma even continues after the death of the infected person. The respondent described an incident from one of the villages in Pondicherry District where the villagers refused to allow cremation of the body of an HIV-positive person out of fear that the disease would spread even after death. In another example, in Kerala, a mob burned an ambulance that transported the dead body of an infected individual. In some cases, actions taken by program planners and implementers have contributed to stigma. For example, as one respondent noted, the message of equating “HIV=AIDS=DEATH” has added to the fear and stigma surrounding the disease. The medical fraternity also adds to stigma and discrimination. In Muzzarfurpur District in Bihar, a doctor denied treatment to his patient because the patient tested HIV-positive.

Most respondents felt that stigma was one of the greatest barriers to averting further infection, expanding care and support, and enabling PLHAs to lead productive lives. Even though the national policy document has addressed stigma, the level of political commitment for addressing the issue remains low, according to respondents. To date, efforts to deal with stigma have been sporadic and inadequate—political leaders and policymakers rarely conduct campaigns, make speeches, or visit people affected by the disease. Multiminsty involvement should have tackled the stigma issue; in particular, the Ministry of Health and Family Welfare and Ministry of Justice should have lobbied for an anti-discrimination amendment. With the increasing involvement of the Parliamentary Forum, however, the review and

drafting of laws pertaining to human and legal rights—spearheaded by NACO and the Lawyers Collective—must be accelerated with the involvement of NHRC. Further, according to respondents, as part of a national movement, all policymakers and health care providers must be educated with complete information about HIV/AIDS—concurrently with community awareness efforts. If this happens, then there would be a perceptible change in the attitudes of the Indian people.

KEY FINDINGS: STIGMA AND DISCRIMINATION IN INDIA

- All respondents noted that the stigma surrounding HIV/AIDS remains high in India. Factors that contribute to stigma are the nature of the disease (e.g., that it is eventually life-threatening, that there is no cure) and attitudes regarding how HIV is transmitted (e.g., some believe that HIV is a punishment for what society deems immoral behavior).
- Throughout the interviews, respondents noted examples of messages and actions taken by governments, courts, or political leaders that contribute to stigma and discrimination.
- Respondents reported that the level of political commitment for addressing stigma is particularly low. Efforts to address stigma have been sporadic—political leaders and policymakers rarely conduct campaigns, make speeches, or visit people affected by the disease.

RECOMMENDATIONS AND CONCLUSIONS

● RECOMMENDATIONS AND CONCLUSIONS

In its 2000 update on the global HIV/AIDS epidemic, UNAIDS identified nine common features of effective national responses (see box). “Political will and leadership” was the first item on the list. What attests to the importance of national political commitment is the fact that it plays a critical role in promoting all of the other eight common features of effective responses. For example, strong political commitment from a country’s top leaders can help mobilize resources, facilitate buy-in across sectors, encourage community-based involvement, ensure the wherewithal to support a sustained response, and promote openness in terms of addressing HIV/AIDS and caring for those affected by the disease. Understanding and strengthening national political commitment is therefore essential for confronting the HIV/AIDS epidemic—particularly in low prevalence countries where there is still time to act before the epidemic spreads. These are the countries where political commitment early on can make a difference—but the time to act is now.

UNAIDS: Common Features of Effective National Responses

1. Political will and leadership
2. Societal openness and determination to fight against stigma
3. A strategic response
4. Multisectoral and multilevel action
5. Community-based responses
6. Social policy reform to reduce vulnerability
7. Longer-term and sustained response
8. Learning from experience
9. Adequate resources

Source: UNAIDS (2000)

● Recommendations

In light of the findings of the study and the views of respondents, the following recommendations are proposed:

Understanding of Political Commitment

- ❖ Raise awareness of HIV/AIDS issues among policymakers at all levels, from the national to panchayat (village/local) level. In particular, educate leaders about their role in reducing stigma and discrimination surrounding HIV/AIDS.
- ❖ Ensure that appropriate mechanisms will help translate policies and public statements into action, and monitor implementation to help build on lessons learned. Highlight the importance of resource allocation, human capacity development, monitoring and evaluation, and civil society engagement as essential aspects of political commitment.
- ❖ Adopt an approach—through the passage of laws and amendments to existing laws—that respects and promotes the human rights of PLHAs.
- ❖ Recognize that analysis and improved understanding of the socioeconomic impacts of the epidemic in India are critical for strengthening political commitment and will among the country’s leaders.

Top Leadership

- ❖ Sensitization of elected representatives is important. Educating government representatives with complete knowledge regarding HIV/AIDS can help them become a catalyst for change.
- ❖ The Parliamentary Forum should communicate and consult with NACO and various ministries to ensure multiminsty involvement.
- ❖ Laws should be based on the experience of other high-prevalence countries and inform the work of the Parliamentary Forum as well as that of NACO and the respective ministries.
- ❖ More state governments should be encouraged to set up legislative forums for HIV/AIDS, with top leaders serving as active members of the legislative societies.
- ❖ HIV/AIDS should be treated as a development issue rather than as strictly a health issue.

Policy Formulation

- ❖ NACO, with the participation of the Parliamentary Forum, should undertake dissemination of policies to the state and local levels and to relevant ministries.
- ❖ The HIV/AIDS program should be decentralized to the state level to address state-specific issues. At the same time, as is mentioned in NACP-II, NACO should facilitate the decentralization process and guide states that are in the early stages of the epidemic.
- ❖ Integration of HIV/AIDS within the public health system is essential and will help take the HIV/AIDS program to the grassroots level.
- ❖ Elements of the national policy related to stigmatization should be implemented, with all health personnel being appropriately oriented to the policy.
- ❖ The appropriate balance between prevention and care and support programs should be maintained, reflecting the fact that states are in different stages of the epidemic.
- ❖ Medicines for treatment should be made more accessible and affordable.
- ❖ Promotion of GIPA should be formalized, and PLHAs should be closely involved in the formulation of appropriate strategies and implementation designs.

National Legislature and Regulatory Environment

- ❖ The Parliamentary Forum should collaborate with NACO, NHRC, and the Lawyers Collective to facilitate formulation of an HIV/AIDS laws for ensuring a human rights-based approach to dealing with the epidemic.
- ❖ Some sectors and companies have formulated their own workplace guidelines, but the government needs to formulate and ratify a national policy covering PLHAs' rights in both the public and private sectors.
- ❖ Implementation of anti-discriminatory policies should be a priority.

Resources

- ❖ Capacity building of decision makers and ministry personnel is needed at both at the national and state levels.
- ❖ Budgeting of activities should be supported by proper research and should be need-based.
- ❖ Decentralization of financial systems with proper accountability mechanisms should be initiated.
- ❖ Donor assistance should be sought following a thorough review of gaps identified within program components.

Organizational Structure

- ❖ Involve the central command structure more closely in decision making and in monitoring program implementation.
- ❖ Facilitate multisectoral ownership and continuity of representatives.
- ❖ Improve accountability.
- ❖ Provide for flexibility in planning and decisionmaking.
- ❖ Make sure that roles and responsibilities of personnel match qualifications and experience.
- ❖ Recruit new personnel and build capacity where needed.
- ❖ Undertake orientation of members on a regular basis.
- ❖ Streamline the monitoring and evaluation system.

Multiministry Involvement

- ❖ The Parliamentary Forum for HIV/AIDS and the Group of Ministers on HIV/AIDS should help ensure the involvement of other ministries.
- ❖ The Ministry of Health and Family Welfare should take the lead and, based on the Tenth Plan document, develop plans along with other ministries.
- ❖ It is essential to mainstream HIV/AIDS into the plans of other ministries.
- ❖ State health units should adopt the national approach of involving other governmental sectors for better implementation of the HIV/AIDS program at state, district, and local levels.
- ❖ It is vital to disseminate the results of ongoing activities to all partners; NACO should provide technical support to the respective ministries as they adopt successful program activities.

Program Components

- ❖ Decentralize the planning process to the state level, allowing states to set their own priorities relative to prevention, treatment, and care and support and to allocate resources accordingly.
- ❖ Promote civil society and PLHA involvement in the planning and implementation of each component of the HIV/AIDS program.
- ❖ Strengthen political commitment for developing the mechanisms to fill the human and financial resource gaps that hinder full implementation of program components, including VCT, PPTCT, and ARVs.

Foreign Technical Assistance and Foreign Experience

- ❖ Foreign technical expertise is available, and NACO must avail itself of such resources to train staff at both the national and state levels.
- ❖ Accountability of foreign visits is important. The scope of work of delegations visiting various projects within and outside India need to be clearly specified. Upon their return, delegations should share their findings with all relevant groups.
- ❖ Training materials and good management practices must be developed and adopted through, if necessary, on-the-job training.

Public Information and Education

- ❖ Comprehensive, well-tested messages must be developed by professional agencies.
- ❖ Media plans, including behavioral change strategies, have to be formulated and implemented jointly with the appropriate ministries and stakeholders.
- ❖ Use of local media channels should be encouraged and piloted.
- ❖ Mandatory inclusion of life skills education in school curricula should be instituted.

Role of NGOs and Civil Society

- ❖ Government and NGOs should work together to strengthen the capacity of NGOs, particularly as they have been instrumental in implementing targeted interventions for vulnerable groups.
- ❖ NGOs need to increase and strengthen networking and information-sharing efforts.
- ❖ NGOs should scale up their activities in rural and high-risk areas after a thorough review of their projects.
- ❖ The government and NACO should collaborate with NGOs that have achieved sound results in implementing HIV/AIDS program activities and that participate on various technical committees, even when disagreements over approach may arise.
- ❖ Transparency in the selection of NGOs should be enforced.
- ❖ Dissemination workshops on NGO experiences should form part of the planning process.
- ❖ Faith-based and other civil society groups should be sensitized in order to mobilize better support for the HIV/AIDS program. Women's groups should be encouraged and supported to address HIV/AIDS issues, especially given that women will become increasingly vulnerable to HIV infection as the epidemic spreads to the general public.

Research, Monitoring, and Evaluation

- ❖ Review the present surveillance system and strengthen it to be more representative of the epidemic.
- ❖ Activate SACS and make them responsible for periodic performance monitoring and review.
- ❖ Develop mechanisms for integration of the HIV/AIDS program beyond the district and below levels with reproductive and child health programs.
- ❖ Ensure systematic analysis before setting priorities.
- ❖ Evolve systematic procedures for identification of target populations.
- ❖ Develop proper evaluation plans involving independent experts and researchers to better assess program impacts and develop recommendations; make the system transparent.
- ❖ Disseminate the findings of evaluation studies to enhance the program.

Stigma and Discrimination

- ❖ Top leadership should take adequate measures to address stigma and discrimination and accelerate legislative reforms.
- ❖ International human rights guidelines relating to HIV/AIDS, to which India is a signatory, should be enforced; persons violating the guidelines should be penalized.
- ❖ Local leaders, teachers, and influential persons should be oriented to HIV/AIDS.
- ❖ Community awareness campaigns should be integrated with other health and development programs, and health and specific messages on destigmatization should be developed.

● **Conclusions**

According to respondents, national political commitment for confronting HIV/AIDS in India has been low despite the fact that the nation initiated its HIV/AIDS program in 1985. The commitment of top leadership has been sporadic and unsystematic, though it has shown signs of improving over the past 18 months. The country prepared a well-documented national policy on HIV/AIDS and a policy on blood safety and initiated vaccine trials and ARV provision—all through the collective efforts of NACO, NGOs, PLHA networks, other groups, and government and political leaders. The establishment of the Parliamentary Forum on HIV/AIDS and the first national convention of elected representatives are positive developments also worth mentioning. In other words, the first evidence of political commitment

is emerging,, yet considerable effort is required to increase awareness levels of not only the top leaders but also of every individual in the country. The awareness campaigns should result in a mass movement. The question of how India's political commitment will translate into action depends on how quickly NACO can pioneer legislative amendments and set in motion the already evolved mechanisms as part of the HIV/AIDS program. With the Parliamentary Forum showing signs of activism, it is necessary for NACO to advocate for legislative reform and ensure better coordination and cooperation with various ministries.

Further, from a program perspective, it is important to strike the appropriate balance between prevention and care and support. As respondents noted, given that India's states are at different stages of the epidemic, capacity building of health personnel should be a priority while allocation of resources should be need-based. The technical support of various local and international agencies can be used to help this effort. Decentralization of planning and management should be carried out systematically and involve the top leaders at the state level. Respondents stressed that the selection of NGOs and other agencies to participate in policy planning and implementation must be transparent and that the government must treat NGOs and other agencies as equal partners in the response to the epidemic. The government and NACO should advocate for all states to include HIV/AIDS education in the school curricula and foster involvement of faith-based organizations, academia, industrial houses, and other groups for faster implementation of the HIV/AIDS program. All these activities can be implemented in an effective manner, provided that India's top leaders and all elected representatives make a strong commitment to the HIV/AIDS program. As advocates, they can facilitate the process of change in a holistic and strategic manner. Issues surrounding stigma and discrimination, which until now have been prevalent in society, will change for the better with strong political will and commitment. Nevertheless, along with political commitment, the commitment of the implementing organization is essential for providing the HIV/AIDS program with proper direction.

APPENDICES

● APPENDIX A: QUESTIONNAIRE

1. What Do You Understand Political Commitment to Mean?

- How would you measure it?
- How would you know it when you see it?

2. Top Leadership

- Does the president or prime minister regularly make strong statements in support of HIV/AIDS programs?
- Is the president or prime minister seen as leading the effort against HIV/AIDS? Why or why not?
- In what ways, if any, does the president or prime minister indicate concern or commitment?
- How has this changed over time, if at all?
- Are there any personal connections to the HIV/AIDS epidemic by top leadership? E.g., a family member is affected by the disease. If so, is this openly disclosed or discussed?
- Does the top leadership contribute toward reduction of stigma? If so, in what ways?
- What has been the biggest success in the battle against HIV/AIDS? Who would you credit for this success?
- What has been a failure or shortcoming in the leadership's actions (now or before)?
- Is there broad-based leadership for political commitment or is it largely driven by one or two individuals?

3. Policy Formulation

- Is there a national HIV/AIDS policy? Please describe. What are its strengths/weaknesses? Was it developed in a participatory manner? If so, how? Who participated?
- Is there a national HIV/AIDS law? Please describe. What are its strengths/weaknesses? Was it developed in a participatory manner? If so, how? Who participated?
- Is there a national HIV/AIDS strategic plan (NSP)? What are its strengths/weaknesses? Was it developed in a participatory manner? If so how? Who participated?
- Is there commitment to the GIPA (greater involvement of people living with HIV/AIDS) principle? E.g., People living with HIV/AIDS (PLHAs) are included in a meaningful way in the policy formulation processes of the country. Has this commitment been codified into national policies or law?
- Has the NSP been fully implemented?
- Has the NSP been costed?
- Are there policies/laws that focus upon human rights? Of PLHAs? Are these HIV specific or included in other laws/policies?
- Are there specific policies to address stigma and discrimination related to HIV/AIDS?

4. Resources

- Does the country commit a significant amount of its own budget to the national HIV/AIDS program? How about ministries other than the Ministry of Health? If so, which?
- Is the national HIV/AIDS budget transparent? Is it published and/or available for public review?

- If budget process is centralized, are funds allocated to the provincial budgets for HIV/AIDS?
- If budget process is decentralized, do provincial budgets allocate funds for HIV/AIDS activities?
- Do resources get from the national to the local level?
- Has there been a recent increase in government funding for HIV/AIDS?
- Has the country submitted an application to the Global Fund for AIDS, Tuberculosis and Malaria (GFATM)?
- Is the Country Coordinating Mechanism (CCM) multisectoral in nature? Does it include PLHAs and other affected populations?
- How do you think international donors view the adequacy of funding by the government for the HIV/AIDS program?
- Is the country pursuing donor support for HIV/AIDS? To what extent?
- Is the available funding actually spent?
- Is available funding used efficiently?
- Is AIDS a priority for debt relief funds?
- How would you characterize resource availability? Lots? Not enough? Okay?
- Is funding targeted to vulnerable groups most affected by the epidemic or to general population and/or low-risk populations?
- How are resources allocated according to prevention, treatment and care, and mitigation—is the allocation level balanced?

5. Organizational Structure/National AIDS Control Program

- Is there a central command structure or Steering Committee for the National AIDS Control Program (NACP)? If so:
 - How significant is it? Strengths? Weaknesses? Actions needed?
 - Is the head of the NACP highly placed within the government structure? Is he/she seen as having access to the top leadership of the country?
 - Are there sufficient personnel resources in the NACP?
 - Is the NACP multisectoral in focus? In its planning/prioritizing function or in program implementation?
 - Who are its members?
 - Are the members adequately trained and knowledgeable of the issues?
 - Does the HIV/AIDS program have a set of specific goals and targets?
 - Is there a specific mechanism to monitor the implementation of the NACP?

6. Multi-Ministry Involvement

- Which ministries, besides health, are significantly involved in the HIV/AIDS program? In what ways?
- Are implementation activities strongly supported by these ministries?
- Do ministries have their own dedicated HIV/AIDS budgets? Personnel?

7. Role of NGOs and Civil Society in Implementation

- To what extent are local NGOs involved in addressing the HIV/AIDS epidemic?
- Name the major NGOs that have HIV/AIDS programs.
- How are NGOs involved in the planning and implementation of the NACP?
- Do any organizations actively pursue issues related to stigma and discrimination? If so, which? How are they doing this?
- How supportive is each political party in addressing HIV/AIDS issues? What specific actions have they taken?

- Comment on the commitment of the following:
 - Faith-based groups?
 - PLHA groups?
 - Academia?
 - Health care professionals?
 - Women's groups and other human rights groups?
 - Business?
- Are there advocacy organizations made up of individuals from target groups? E.g., sex workers? Men who have sex with men (MSM)? Injection drug users (IDUs)?
- Are local celebrities and/or sports figures involved in open support of AIDS programs? Does the government encourage this?
- Has there been an increase in the number, size, and quality of roles played by civil society?

8. Foreign Technical Assistance and Foreign Experience

- Does the government analyze and study the experience of neighboring countries? E.g., Mekong region drawing on the experience of Thailand.
- Does the government send delegations to visit countries with effective HIV/AIDS programs?
- What specific programs/populations are of concern requiring increased technical assistance?

Programs	Populations
Voluntary counseling and testing (VCT)	IDUs
Prevention of parent-to-child transmission (PPTCT)	Sex workers
Access to highly active antiretroviral treatment (HAART)	MSM
Public information and education	Youth
Monitoring and evaluation	Women
Condom distribution	Heterosexual men
Other	Other

- Is available foreign technical assistance used to its maximum capacity?

9. Public Information/Education/Use of Media

- Does the government use the media to address the HIV/AIDS problem? In what ways? If not, what other mechanisms are used to address the HIV/AIDS problem and reach the public with information?
- Does the government give accurate information to the public about:
 - Preventing HIV?
 - ABC (Abstinence, Be Faithful, Use Condoms) campaign? Correct and consistent use of condoms?
 - VCT?
- How is this information distributed/disseminated? Is there a national social marketing campaign addressing these issues?
- Is life skills education incorporated into the school curricula? What does it include? At what school levels?

10. Legal/Regulatory Environment

- Is there a special HIV/AIDS committee in the legislature?

- Is anti-discrimination legislation in place and enforced? Describe (e.g., employment testing, access to insurance).
- Has there been an effort to improve laws pertaining to HIV? If so, how? If not, why not?
- Have any HIV/AIDS-related constitutional amendments been passed or considered?
- Are the country's HIV/AIDS laws in accordance with international human rights guidelines?
- Are there laws safeguarding the human rights of vulnerable populations?
- Do businesses have clear and mandatory requirements regarding their policies and services for employees living with HIV/AIDS?

11. Monitoring and Evaluation

- Is there an effective HIV surveillance system? Describe.
- Does information reach local-level policymakers or remain only among the highest-level policymakers?
- Are priorities established systematically and based on the best available information?
- Are there specific benchmarks/goals for each of the main components of the NACP?

12. Program Components as Indicators of Political Commitment

- Does the NACP program implementation include components on:
 - VCT
 - PPTCT
 - HAART
- If not, is the program working to include each one?
- Are there specific prevention and care programs focused on vulnerable populations (e.g., sex workers, truck drivers, migrant workers, MSM, IDUs, orphans)? Describe.
- Are these programs reviewed and evaluated regularly by independent experts?

13. Stigma and Discrimination

- Is there a high level of stigma? For example, are people afraid to get tested? Are people afraid to disclose their HIV status because of violence, job loss, and ostracism?
- In your opinion, what are the root causes of stigma in this country?
- Are policymakers doing anything to address stigma? If yes, please describe what specific actions are being taken.

● APPENDIX B: REFERENCES

- Lawyers Collective. 2002a. "HIV/AIDS: The Law and Ethics." New Delhi: Lawyers Collective HIV/AIDS Unit.
- Lawyers Collective. 2002b. "The National AIDS Prevention and Control Policy: A Comment." *Positive Dialogue*, No. 13. Mumbai: Lawyers Collective HIV/AIDS Unit.
- National AIDS Control Organization (NACO). 2000a. "National AIDS Control Program (1999–2004)." New Delhi: Ministry of Health and Family Welfare/NACO. Available at www.naco.in/nacp/phase2.htm.
- NACO. 2000b. "National AIDS Control Program (1999–2004)." New Delhi: Ministry of Health and Family Welfare/NACO. Available at www.naco.in/nacp/bkg.htm.
- NACO. 2000c. "National AIDS Control Program (1999–2004)." New Delhi: Ministry of Health and Family Welfare/NACO. Available at www.naco.in/nacp/program/prog4.htm.
- NACO. 2000d. "National AIDS Control Program (1999–2004)." New Delhi: Ministry of Health and Family Welfare/NACO. Available at www.naco.in/nacp/program/prog15.htm.
- NACO. 2001. "Estimation of HIV Infection among Adult Population." New Delhi: Ministry of Health and Family Welfare/NACO. Available at www.naco.nic.in/indianscene/esthiv.htm.
- NACO. 2002a. "National AIDS Policy." New Delhi: Ministry of Health and Family Welfare/NACO. Available at www.indianembassy.org/policy/AIDS.html.
- NACO. 2002b. "Speech of Prime Minister: Parliamentary Meet on HIV/AIDS, New Delhi, May 11, 2002." New Delhi: Ministry of Health and Family Welfare/NACO. Available at www.naco.nic.in/speeches/pm.htm.
- NACO. 2004. *Annual Report: 2002–2003, 2003–2004 (up to 31 July 2004)*. New Delhi: Ministry of Health and Family Welfare/NACO.
- Parkhurst, J. 2000. "HIV Prevention Policy in Uganda: Lessons for Africa and Beyond." Presented at the XIII International AIDS Conference in Durban, South Africa (Abstract No. TuPeD3502).
- Patterson, D. 2000. "Political Commitment, Governance, and AIDS: A Discussion Paper." Ottawa, Canada: Interagency Coalition on AIDS and Development. Available at http://www.icad-cisd.com/pdf/publications/e_politic.pdf.
- POLICY Project. 2000. *HIV/AIDS Toolkit: Building Political Commitment for Effective HIV/AIDS Policies and Programs*. Washington, DC: Futures Group International/POLICY Project. Available at <http://www.policyproject.com/pubs/toolkit.cfm>.

Sittitrai, W. 2001. "HIV Prevention Needs and Successes: A Tale of Three Countries—An Update on HIV Prevention Success in Senegal, Thailand, and Uganda." Geneva: UNAIDS. Available at <http://www.unaids.org/publications/documents/epidemiology/determinants/Jc535-hi.pdf>.

Stephenson, J. 2001. "Swift Action Needed to Prevent Explosive HIV/AIDS Epidemics in Asia." *Journal of the American Medical Association* 286 (16): 1,959–1,960.

Times of India. 2003. "Treat AIDS with Care: SC." *Times of India* (online edition), August 4, 2003.

UNAIDS. 2000. *Report on the Global HIV/AIDS Epidemic—June 2000*. Geneva: UNAIDS.

UNAIDS. 2002. "Global Fund Proposal—India CCM." Available at www.globalfundm.org/funding/proposals/india.html.

UNAIDS. 2003a. "First Ever National Parliamentary Convention on HIV/AIDS Underscores India's Political Commitment to AIDS, New Delhi, July 25, 2003." Available at www.unaids.org/whatsnew/press/eng/IndiaParlForum250703_en.html.

UNAIDS. 2003b. "Speech to the National Convention of the Indian Parliamentary Forum on HIV/AIDS, New Delhi, July 26, 2003." Available at www.unaids.org/whatsnew/speeches/eng/Piot_NewDelhi_260703_en.html.

UNAIDS. 2004. *2004 Report on the Global AIDS Epidemic*. Geneva: UNAIDS.

UNAIDS, USAID, and POLICY Project. 2001. "Measuring the Level of Effort in the National and International Response to HIV/AIDS: The AIDS Programme Effort Index (API)." Geneva: UNAIDS. Available at <http://www.policyproject.com/pubs/Monographs/APIreport.pdf>.

United States Agency for International Development (USAID). 2000. *Handbook of Indicators for HIV/AIDS/STI Programs*. Washington, DC: USAID.

Watchirs, H. 2000. "A Rights Analysis Instrument to Measure Compliance with the International Guidelines on HIV/AIDS and Human Rights." Canberra, Australia: Australian National Council on AIDS, Hepatitis C, and Related Diseases.

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