Background Study for the Swedish Country Strategy for India 2003–2007

# HIV/AIDS and Development in India

#### **Foreword**

Twenty years after the first case of the acquired immunodeficiency syndrome was reported, HIV/AIDS has developed into a devastating global epidemic. At the end of 2001, an estimated 40 million people worldwide were living with HIV. Sweden was among the first countries to acknowledge the crucial need to address the issue of HIV/AIDS and remains committed to the global effort to reduce its spread and effects.

The rapid spread of HIV/AIDS in India is a cause for great and increasing concern. As of 2001, according to official sources, the cumulative number of HIV-infections and AIDS-cases reached 4.0 million and 24,000 respectively. However, such figures hide wide regional variations in prevalence and alternative sources suggest considerably higher infection rates.

The Swedish International Development Cooperation Agency (Sida) is currently preparing a new Country Strategy for the development co-operation between Sweden and India. In order to provide Sida with information on the HIV/AIDS situation in India we asked a team of consultants to:

- Review and analyse the current HIV/AIDS situation in India,
- Elaborate on the likely scenario by year 2010,
- Elaborate on the possible impact of HIV/AIDS on the overall development in India during 2002– 2010, and
- Make recommendations to Sida on priorities, principles and possible areas for future Swedish support.

We are pleased to share with you their findings and recommendations.

Embassy of Sweden, New Delhi, October 2002

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The views and opinions presented in this report are solely those of the named authors and do not necessarily reflect the policy of the Swedish International Development Cooperation Agency (Sida).

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### **Executive Summary**

The HIV/AIDS epidemic in India is now about fifteen years old; however, the incidence of HIV continues to give cause for alarm, as the virus continues to spread into new areas as well as new low-risk population groups. India has seen commendable responses to combat the epidemic, from the government, non-government as well as international agencies. What roles have donors and other organisations played in this country response? How effective has this collective response been? How can Sida make a greater difference to controlling the magnitude and impact of the epidemic? This report addresses these issues by focusing first on the most important aspect of the epidemic: its developmental nature. The report begins by arguing that underdevelopment and poverty are the main reasons why a significant proportion of the population is vulnerable to the epidemic in the first place. In turn, the epidemic widens and deepens poverty by its serious economic impact on individuals, households and different sectors of the economy. Finally, poverty is the reason why messages of prevention and control do not make an impact on a vast majority of the vulnerable population. Thus, understanding and incorporating these linkages and mainstreaming responses should form the cornerstone of any package of intervention.

The analysis then goes on to look at the current epidemiological scenario and at the current responses of the government, donors and NGOs. It brings out some of the areas of response, which can be improved upon and are applicable to all donors, and then specifically makes a few recommendations on strategic focus for Sida.

Epidemiologically, despite commendable efforts, the number of people living with HIV in South and South-East Asia is dominated by India; in 2001, 63 percent of the Asia-Pacific total estimate of 6.1 million People Living with HIV (PLWH) were in India alone. Surveillance data indicate that risk practices are getting diffused and infection rates continue to rise among low-risk groups like pregnant mothers. The considerable underreporting of AIDS cases hide the fact that management and care of infected and affected individuals will pose a grave challenge to the resources and capacity of the country. This scenario indicates that prevention and control efforts as well as care and support programmes need to be stepped up, and complacency can have devastating effects.

HIV infections are estimated to rise for a while to come, with the burden of disease as measured by DALYs rising till 2010. Studies on economic impact of the epidemic in India indicate that individuals and households will increasingly find it difficult to cope with the economic hardships associated with increased treatment costs and reduced income due to illness and loss in productivity. Impact would also be felt severely by the health sector and the government, with government health subsidies rising rapidly as a result of a rapidly spreading epidemic. Finally, with antiretroviral therapy becoming more accessible due to price reductions especially by Indian firms, there will be increasing pressure on central and state governments and other agencies to look at the possibility of subsidizing these drugs, though questions of equity as well financial feasibility will continue to remain important issues despite price reductions.

Some of the gaps identified in the current response are in the following areas: (a) inadequate understanding of barriers to scaling up, including lack of documentation and of evidence on what works; (b) prevention priorities yet to effectively include low risk population, bridge population, pediatric population, girls in prostitution, adolescents and youth; (c) operational research in issues of care and support for a better understanding of the epidemic, as well as innovative ways of involving and building capacity among PLWHA in research as well as interventions; (d) operational research on links between poverty, development, governance and HIV/AIDS; (e) focus on areas that have hitherto received less attention, especially states that see a lot of in- as well as out-migration; (f) greater emphasis on monitoring and evaluation.

Keeping in mind these areas that may need more attention in the collective response to HIV/AIDS in the country, the following specific recommendations have been made for Sida's consideration.

- Document Sida's successful interventions in the form of a best practice document, so that Sida as well as other donors can replicate it.
- Re-strategise the thrust of current interventions that have proven operationally difficult.
- Lay greater emphasis on mainstreaming intervention efforts.
- Focus on states/regions that are relatively weak programmatically as well as in interventions. Assam
  in the North-East and Bihar in the rest of India need urgent focus.
- Focus on youth and women, migrants, bridge population.
- Promote and support research in strategic areas.
- Lend support to, and encourage formation, of PLWHA groups.
- Incorporate/support monitoring and evaluation aspects in its own/other organisations' programmes.

It is also suggested that to carry out some or all of these recommendations, Sida may have to take another look at its own organisational situation. There may be a need to expand administrative as well as technical personnel so that programmes are sustainable, as well as are of the highest quality. Finally, Sida may want to explore to a greater extent partnerships and co-financing with other donors, including the government.

# 1. Country Strategy Preparations: Analytical Framework

#### 1.1 Background

This analysis was commissioned by the Swedish International Development Cooperation Agency (Sida) to a team of three independent consultants: Dr. Indrani Gupta – a health economist, Dr. Samiran Panda – an epidemiologist, and Ms. Renuka Motihar – a social development professional. The main aim of this consultancy was to prepare a Background Document (for Country Strategy Preparation), highlighting the critical issues in the context of HIV/AIDS, the future implications of the epidemic, the kind of response that has emerged over the years from all the sectors, the areas where response can be added or improved, and Sida's possible role in the next five years (2003–2007) in helping India combat better with the HIV/AIDS epidemic.

The consultancy was done over a period of three months, and involved intensive data gathering as well as meetings with key stakeholders, mainly in Delhi, to understand the extent of the response. While research was done on the epidemiological as well as socioeconomic impact of the epidemic, opinions of policymakers – both within and outside the government – were sought. The rich experience of the three consultants ensured that the views of other constituencies like people living with HIV/AIDS were also incorporated wherever relevant. The report was finalized only after inputs of experts in Sida were incorporated.

#### 1.2 Development, Poverty and HIV/AIDS<sup>1</sup>

Development experts and economists have studied poverty for a long time now. Very recently, Chen and Ravallion have provided new estimates for absolute and relative consumption poverty for the period 1987–1998 for the world. The results indicated that there was a net decrease in the overall incidence of consumption poverty over 1987–98, but it was not enough to reduce the total number of poor, which was about 1.2 billion people (Table 1)

Table 1: Population living below \$1.08 per day at 1993 PPP<sup>2</sup>

Region	Incidence and number of poor (millions)			
	Incidence	of poverty	Number of	poor
	1990	1998	1990	<b>1998</b> (prelim.)
East Asia	27.58	15.32	452.45	278.32
(excluding China)	18.51	11.26	91.98	65.15
Eastern Europe & Central Asia	1.56	5.14	7.14	23.98
Latin America & Caribbean	16.80	15.57	73.76	78.16
Middle East & North Africa	2.39	1.95	5.66	5.55
South Asia	44.01	39.99	495.11	522.00
Sub-Saharan Africa	47.67	46.30	242.31	290.87
Total	28.95	23.96	1276.41	1198.88
(excluding China)	28.05	26.18	915.94	985.71

Chen and Ravallion (2001)

<sup>&</sup>lt;sup>1</sup> This section of the document is reproduced from the paper presented by Indrani Gupta at the plenary session on poverty and the socioeconomic determinants of HIV/AIDS, 6<sup>th</sup> ICAAP, Melbourne, 5–10 October 2001.

<sup>&</sup>lt;sup>2</sup> PPP is Purchasing Power Parity.

From the tables it can be seen that the highest poverty incidence relative to the \$1 per day line is in Sub-Saharan Africa, followed closely by South Asia. While the proportion of people poor fell in both South Asia and Sub-Saharan Africa, it was not enough to prevent an increase in the number of poor in the two regions. Together, these two regions accounted for 68percent of those living below \$1 per day in 1998, up from 58percent in 1987. The only exception in this group is China, which has made remarkable progress in lowering poverty.

Talking only about consumption poverty hides the fact that there is a very high correlation between consumption poverty on the one hand and a whole host of socio-economic variables on the other, including health. At the micro level, inadequate income goes hand in hand with poor health, greater illiteracy, low levels of education, lower status of women etc. Data reveal that countries with low per capita income and low growth are also often countries that have poor indicators of health and education, as well as high levels of poverty.

While there has been recognition that poverty and the HIV epidemic are closely related, the above discussion clearly points out that poverty is a much broader concept encompassing developmental issues beyond income or consumption. Thus it is imperative to see the epidemic through this prism of development-poverty link.

UNAIDS estimates indicate that 5–7 million people are living with HIV/AIDS in the Asia – Pacific region. Different countries of the region are at different stages of the epidemic, depending on how it all began and how it continues to spread. Countries with high prevalence are Cambodia, Myanmar, and Thailand. These aggregate numbers hide more than they reveal. Firstly, for populous countries, a small prevalence rate will translate into large absolute numbers. For example, India and People's Republic of China account for most of Asia's infected cases due to their large populations.

Secondly, while overall prevalence may be low, many of these countries have nascent epidemics in specific group, where infection rates are very high.

Further, if one looks at the principal modes of transmission in the region, the infection is spreading mainly through sexual transmission, especially heterosexual transmission, injecting drug use, unclean blood supply, and now from mother to child. All these modes are closely correlated with poverty and underdevelopment. Poverty is the reason why many women are forced into prostitution and remain there, why many women cannot ensure safe sexual behaviour of their partners, why many youths and adults take to drugs and then cannot come out of it, why individuals cannot access the more costly but safe blood, why individuals and households migrate from rural to urban areas or across borders even though their status in the areas of destination is little more than that of slum dwellers. Poverty also makes people more vulnerable to discrimination — whether based on caste, gender, sexual preference, or religious beliefs. Further, socioeconomic impact is felt most by the poor and the almost-poor, sending many individuals and households into fresh or further poverty. Finally, poverty defined in this broad sense, is also the reason why messages of prevention and control do not make their impact on a large majority of vulnerable individuals.

#### 1.3 Poverty trends in India

The Planning Commission's National Human Development Report (Planning Commission, March 2002) indicates that at the national level, the incidence of poverty on the Head Count Ratio declined from 44.48 percent in 1983 to 26.10 percent in 1999–2000. It was a decline of nearly 8.5 percentage points in the ten years period between 1983 and 1993–94 followed by a further decline of nearly 10 percentage points in the period between 1993–94 and 1999–2000. In absolute terms, the number of

poor declined from about 323 million in 1983 to 260 million in 1999–2000. The decline has not been uniform either across states or across rural and urban areas. While the proportion of poor in the rural areas declined from about 45.65 percent in 1983 to 27.09 percent in 1999–2000, the decline in the urban areas has been from 40.79 percent to 23.62 percent during this period.

At state level, among the major states, Orissa, Bihar, West Bengal and Tamil Nadu had more than 50 percent of their population below the poverty line in 1983. By 1999–2000, while Tamil Nadu and West Bengal had reduced their poverty ratios by nearly half, Orissa and Bihar continued to be the poorest states with poverty ratios of 47 and 43 percent respectively. These poor states are also doing poorly in terms of demographic and health indicators such as life expectancy at birth, infant mortality and maternal mortality. Similarly, the poorer states also show a poor record of educational attainment like literacy rates and school enrollment rates. Finally, the northeastern region as a whole – but Manipur and Arunachal Pradesh in particular continue to be poor and underdeveloped.

#### 1.4 Governance and civil society issues

In addition to well-being measures that quantify underdevelopment and poverty, there are certain key features of a society and economy that determine how efficacious development policies — whether to reduce poverty or to reduce vulnerability to diseases — will be. Two such factors are degree of governance and the presence of a functional civil society. Good governance is a key to development and therefore to the success of policies which are essentially addressing developmental issues, like the HIV/AIDS epidemic. Whether or not there is good governance will of course depend to a large extent on the political stability of a country, state or region. In addition, however, the participation of civil society also determines the extent to which governance will be effective. Thus, the formation as well as the continuous participation of civil society in key policy issues is also an important factor that determine the success of such development efforts, including public health problems like HIV/AIDS.

The factors described in the preceding section are significant in the context of the epidemic: it has implications for the future spread of the virus, its detection, the impact as well as containment. Thus, this framework should be used to guide the priority setting of Sida's country strategy preparation.

### 2. Current Scenario of HIV/AIDS in India: An Analysis

#### 2.1 HIV/AIDS in India

As of March 2001, India has reported a cumulative total of 20304<sup>3</sup> cases of AIDS (15563 males and 4741 females); no single state or union territory is free from HIV. In eighty three percent of these AIDS cases, HIV infection was acquired through the sexual route, four percent through sharing of injection equipment, and another four percent through transfusion of contaminated blood and blood products. Peri-natal transmission accounted for 2 percent of the total AIDS cases. For the rest of the AIDS cases, the route was unknown.

While males between 15–29 year (6022/15563) and 30–44 year (7621/15563) age brackets constitute 49 percent and 39 percent of the total male AIDS cases respectively in India, the proportion contributed by females in female AIDS cases had a reverse distribution. Fifty percent of the total female AIDS cases were in 15–29 year (2360/4741) and 37 percent (1692/4741) in 30–44 year age group. Of all the reported AIDS cases for 15–44 year old individuals, women constituted a significantly higher percentage of AIDS cases – compared to males – in the age range of 15–29 years. This is an important indicator of the likely impact of the epidemic on households and communities, especially children.

It is worth noting here that some studies from the states with generalized epidemic such as Tamil Nadu – indicated that marriage itself is a risk factor for many Indian women for contracting HIV; for example a study reported a HIV prevalence of 4 percent among housewives in rural setting<sup>4</sup>. It is of major concern to see similar phenomenon reported from a state like West Bengal, which is still considered a low epidemic state, where couple concordance rate reported by the School of Tropical Medicine was as high as 68 percent<sup>5</sup>.

Common opportunistic infections (OIs) associated with the reported cases of AIDS in India have been tuberculosis, fungal infection of the mouth (oral candidiasis), *Cryptosporidia* (causing diarrhea), *Pnuemocystis carineii* (causing pneumonia) and Herpes Zoster (causing shingles). While a detailed account of the economic burden of treating different episodes of these OIs at the family level and in hospital settings are yet to be worked out, it has been documented that satellite epidemics<sup>6</sup> of OIs are happening in different parts of the country. Managing the dual epidemic of tuberculosis and HIV/AIDS is currently posing a great challenge to the public health practitioners. HIV prevalence ranging from 10–20 percent has been recorded among samples of urban TB patients in India, and it is projected that 20–25 percent of the increase in TB cases over the next five years could be directly attributable to co-infection<sup>7</sup>. In addition to the impact of increased case load of newly diagnosed TB cases on the TB Control Program, urgent attention also needs to be paid to monitoring of drug resistance in TB treatment.

NACO, Combating HIV/AIDS in India, 2000–2001. Ministry of Health and Family Welfare. National AIDS Control Organization, Government of India.

<sup>&</sup>lt;sup>4</sup> Solomon S, Kumarasamy N, Ganesh AK and Amalraj RE. Prevalence and risk factors in HIV-1 and HIV-2 Infection in urban and rural areas in Tamilnadu, India. International J STD and AIDS 1998; 9: 98.

<sup>&</sup>lt;sup>5</sup> Guha, S.K: Profile of HIV/AIDS in West Bengal: An Appraisal from a Teaching Hospital in Kolkata. Third International Conference on AIDS INDIA, Chennai, India, December 1–5, 2001.

<sup>&</sup>lt;sup>6</sup> Panda S, Sarkar S, Mandal BK, Singh BK Th, Singh KL, Mitra DK, Sarkar K, Tripathy SP, Deb BC. 1994. Epidemic of Herpes zoster following HIV epidemic in Manipur, India. J of Infection. 28 (2).

Global Tuberculosis Program (GTB)/UNAIDS. Managing the dual epidemic of Tuberculosis and HIV/AIDS: a review of challenge and response in five countries; Brazil, India, Indonesia, Kenya and Thailand. March 1998.

#### 2.2 HIV infection across states and the character of different sub-epidemics

Indian states and union territories are at different stages of development of the HIV epidemic; they can be broadly classified into three groups as follows:

#### a) States with generalised HIV epidemic

In this category are included Maharashtra, Tamil Nadu, Karnataka, Andhra Pradesh, Manipur and Nagaland where HIV prevalence has reached 1 percent in antenatal clinic attending women representing female general population. While the first outbreak of HIV infection happened among injection heroin users in the northeastern states of Manipur and Nagaland which have common borders with Myanmar, the other states in this category had seen the epidemic taking off first among female sex workers. However, all the states subsequently saw a significant progress of HIV in general population. HIV care and management-needs are pressing issues now in these states on top of prevention, as increasing numbers of AIDS deaths, young widows and AIDS orphans on the one hand and increased hospital bed occupancy for HIV disease on the other, are being recorded.

#### b) Concentrated HIV epidemic States

HIV has infected more than 5 percent of the population groups observing high-risk behavior in these states but the prevalence in female general population has remained below 1 percent. Gujarat, Goa, Pondicherry, Mizoram and West Bengal fall in this category. The epidemic is making in-roads in bridge population such as migrant labourers and clients of female sex workers in these states. It is still not clear what are the best ways to intervene in these populations, essentially due to lack of evidence on best practices.

It is important to note that although HIV epidemic took off at the same time in IDUs in three north-eastern states (Manipur, Mizoram and Nagaland), the subsequent course taken by the virus was different, as reflected by the current sentinel surveillance data. While Manipur and Nagaland have seen a rise in HIV in IDUs followed by a rise in HIV prevalence in antenatal clinic attending women, Mizoram saw a plateauing of HIV epidemic among IDUs around 5 percent, and HIV prevalence among heterosexuals went up. It is important to identify the determinants of this heterogeneity in different northeastern states for effective future interventions.

#### c) Low HIV epidemic

Remaining states and union territories fall in this category where the population groups observing high-risk behavior is yet to attain a 5 percent prevalence of HIV. While these could be seen as states having windows of opportunity for preventing an intense HIV epidemic, one needs to also examine whether the required coverage is being met under the sentinel surveillance. For example, the National AIDS Control Organization (NACO) sees strengthening of sentinel surveillance in Assam, Bihar and Orissa as an issue of urgent importance, since in many rounds of sentinel surveillance the requisite number of samples tested (denominator) could not be collected. Although Tripura – the smallest northeastern state of India - which has common border with Bangladesh, has reported low HIV and limited injection drug use, anecdotal data reveals an established route for cross border smuggling of injection tidigesic (buprenorphine) ampoules from India to Bangladesh. On the other hand, Meghalaya has reported mostly oral dextropropoxyphene, diazepam and nitrazepam use and limited heroin smoking and still lower injecting practices among local youths as well as students coming from other northeastern states to Shillong (the capital of Meghalaya) for pursuing higher studies. A regional approach to designing innovative interventions is therefore required where AusAID and Sida have taken some important initiatives. However, there are states in northeast India such as Arunachal Pradesh, Tripura and Assam that are yet to get adequate attention from donor agencies for designing of intervention low

prevalence setting. Similarly, diffusion of injection drug use occurring in other metropolitan cities of India outside the northeast, require urgent attention too.

#### 2.3 Possible scenario a decade later?

While socioeconomic impact is directly linked to the magnitude of the epidemic, the extent of devastation caused by it can be gleaned from a very early study done by Bloom and Glied (UNDP 1993). This study estimated that there will be a total of 1 million AIDS cases by the year 2000, yielding a total of \$11 billion (1991 US\$) in direct and indirect costs. Direct costs include medical costs whereas indirect costs comprise value of income foregone because of AIDS-related morbidity and mortality. The AIDS surveillance system in India is in a nascent stage compared to the HIV surveillance system, and thus the reported cumulative AIDS cases of 20,304 (NACO 2001) greatly understates the real number of AIDS cases in India, and therefore will also understate the macro costs of the epidemic. Evidence indicates that at least 40 percent of the patients reporting for the first time in OPDs in apex hospitals<sup>8</sup>, are in advanced stages of AIDS, and are being missed out at the district levels. Thus, the figure of 1 million AIDS cases in 2000 may be much closer to the actual load of AIDS cases in the country.

A more recent study is the one by Murray and Lopez<sup>9</sup> (1996) of the Burden Of Disease in India, the World Bank<sup>10</sup>, where they have calculated the trends in Disability Adjusted Life Years (DALYs) lost due to selected diseases in four States (Andhra Pradesh, Karnataka, Punjab and West Bengal) of India (Chart 1). The study indicates that communicable diseases still predominate in terms of disease burden, especially in the young age groups. A projection till 2020 based on alternative assumptions indicate that DALYs lost due to HIV infections in India are expected to rise significantly up to the year 2010 and decline thereafter (World Bank 1997).

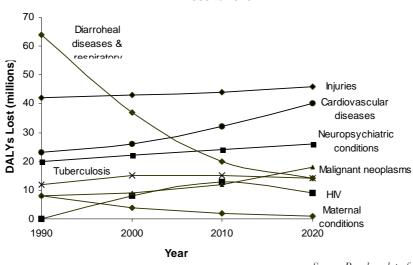


Chart 1: Trends in DALYs lost due to seclected diseases in India 1999 to 2020

Source: Based on data from Murray & Lopez, 1996.

<sup>&</sup>lt;sup>8</sup> Guha, S.K: Profile of HIV/AIDS in West Bengal: An Appraisal from a Teaching Hospital in Kolkata. Third International Conference on AIDS INDIA, Chennai, India, December 1–5, 2001.

<sup>&</sup>lt;sup>9</sup> CJL Murray and Lopez AD, Eds 1996. Global Burden of Disease Health. Harvard University Press.

World Bank. 1997. India: New Directions in Health Sector Development at the State level: An operational perspective. Report No. 15753-IN.

The impact of the epidemic is likely to be felt on all sectors – households, communities, industry, agriculture, health as well as the government. A study that looked at the economic impact on individuals who were HIV positive (Gupta 1998<sup>11</sup>) indicated that the group on an average spent between 10 to 30 percent of their annual incomes on HIV-related health expenditures, with the bulk of expenditures being on drugs and medicines. As expected, individuals with lower income as well as with at least one child had a greater probability of a more severe impact than others did. The immediate implication of this is that economic impact will be most severely felt by households that are relatively less well off and have a greater number of dependents.

The 1997 World Bank report on Confronting AIDS states that if India maintains its current level of health care subsidies, a severe AIDS epidemic would increase government expenditure by about \$2 billion per year by 2010. If subsidies are increased to the 50 percent level, the same size epidemic would increase annual government health expenditure by an additional \$30 billion (World Bank 1997)<sup>12</sup>.

Another study (Gupta 2000<sup>13</sup>) which looked at the health and treatment costs for 1999 calculated that Rs. 2,045 crores would have been spent in 1999 in India, which translates into about \$95 million in current prices. This was the minimum expenditures or costs that would have taken place in one year if only 2.8 percent of the individuals are on antiretroviral treatment and only half of the new infections in 1999 display any opportunistic infection. Clearly, this kind of expenditure is untenable for a country like India, irrespective of who spends the money.

The above analysis indicates that socioeconomic impact will be felt at both the individual and household level, but also at the macro and sectoral level. The two sectors that are most severely going to be affected are the health and the government sectors. The health sector will increasingly see a rise in demand for health care, and given the current health sector scenario, pressures on existing government hospitals will rise; there is already evidence of this from states like Tamil Nadu and Manipur. This is bound to have impact on individuals accessing health care for other diseases as AIDS care can crowd out not-AIDS care.

The government will also need to think strategically about its policy on newer treatments like antiretroviral therapy (ART), which are now seen as being central to the treatment of HIV positive patients. The issue around ART has become even more critical since the prices of these drugs have been falling, indicting a possibility of subsidizing these drugs. The fact that most of the major drug companies manufacturing these drugs are Indian has made this issue even more sensitive in India. Given India's low per capita income, as well as competing needs outside health sector – and within the health sector – it is not clear to what extent the government can subsidize ART. At the same time, greater access to ART will clearly reduce health expenditures and reduce economic impact at all levels, by keeping individuals healthy and productive. This is an area, which has yet to see much policy-oriented analysis.

#### 2.4 Is India going the African way?

While most of the public health experts and social scientists in the country believe that HIV is not going to take a course similar to the one that happened in Africa, the epidemiological evidence obtained

<sup>&</sup>lt;sup>11</sup> Gupta, Indrani "Socio-economic impact of HIV/AIDS on Individuals: A Planning Perspective from India". In "The Looming Epidemic: the Impact of HIV and AIDS in India", ed. Peter Godwin, Mosaic, 1998.

<sup>&</sup>lt;sup>12</sup> Confronting AIDS: Public Priorities in a Global Epidemic. World Bank, 1997.

<sup>&</sup>lt;sup>13</sup> Gupta, Indrani 2000. Paper presented at the Meeting of the UNAIDS Reference Group on Economics, Cuernavaca, Mexico, February 2001

so far does ring an alarm of concern. The virus in India has taken different courses in different states since its first detection in 1986 in Chennai, and has contributed to the heterogeneous picture of the epidemic within the country. Of course, this heterogeneity has been influenced by varied sexual and injection behavior patterns among network population groups as well as 'bridge population' linking different networks. Genesis and extent of response to the epidemic differed across states, and played their role in shaping the epidemic differently in different states. It is important to note that the number of people living with HIV in South and South-East Asia is dominated by India; in 2001, 63 percent of the Asia-Pacific total estimate of 6.1 million People Living with HIV (PLWH) were in this country alone<sup>14</sup>.

The estimated number of people living with HIV in the country<sup>15</sup> was 3.5 million, 3.7 million, 3.86 million and 3.97 million respectively in 1998, 1999, 2000 and 2001. These estimates have used HIV sentinel surveillance data collected from antenatal clinic attending women, STD clinic attendees, injecting drug users and men having sex with men. Altogether 237 select sites were used for this purpose from all over the country, of which 109 were STD clinics, 110 clinics for pregnant women, 11 sites for injecting drug users (IDUs) and only 2 for men having sex with men (MSM). AIDS cases were not included at the time of calculating the estimates using sentinel surveillance data, and the age range in focus was 15 to 49 years. Also, sex workers are not currently being included as a sentinel group in the surveillance. Lack of adequate representation of all the risk groups (including those not traditionally regarded as high-risk groups) as well as lack of proper geographic spread – including proper representation from rural areas – in sentinel surveillance, clearly highlight the need for involving these subpopulations and non-government organizations having active contact with some of the 'hard to reach population' such as IDUs and MSMs in surveillance activities.

#### 2.5 Diffusion of different risk practices and other emerging issues

#### a. Injection drug use

During the initial phase of HIV epidemic in India, injection drug use related HIV was identified from the North-Eastern States of Manipur, Mizoram and Nagaland, which had a common international border with Myanmar; the drug of choice for injecting was heroin. The HIV prevalence in local IDUs in Manipur, Mizoram and Nagaland subsequently stabilized at 80 percent, 5 percent and 50 percent respectively.

Although the present scenario of drug use in the country has changed considerably, the State AIDS Prevention and Control Societies in the states other than the North-East are yet to support outreach and harm reduction activities. Recent data from the 'Rapid Situation Assessment' reveal that a diffusion of injection drug use has taken place in major metropolitan cities of Kolkata, Delhi, Chennai and Mumbai, as well as in other parts of India over the last ten years<sup>16</sup>. The drug of choice for injecting in IDUs in these cities is Buprenorphine, and it is frequently cocktailed with sedative and anti-histaminic injections leading to venous thrombosis and abscess formation; the HIV prevalence varies from 1 percent in IDUs of Kolkata<sup>17</sup> to 31 percent in Chennai<sup>18</sup>. The reported high needle syringe sharing rate

<sup>&</sup>lt;sup>14</sup> UNAIDS/WHO. AIDS Epidemic update December 2001.

<sup>&</sup>lt;sup>15</sup> National AIDS Control Organization (Government of India), Ministry of Health and Family Welfare: Combating HIV/AIDS in India 2000–2001

<sup>&</sup>lt;sup>16</sup> Reid G, Costigan G. Revisiting 'The Hidden Epidemic': A Situation Assessment of Drug Use in Asia in the context of HIV/AIDS: The Centre for Harm Reduction, The Burnet Institute, Australia, January 2002.

<sup>&</sup>lt;sup>17</sup> Panda S, Chatterjee A, Bhattacharjee S, Ray B, Saha M.K and Bhattacharya S.K 1998. HIV, hepatitis B and sexual practice in the street-recruited injecting drug users of Calcutta: risk perception versus observed risks. Int. J STD & AIDS. April, 9(4): 214–218.

among IDUs and observed switching of large number of heroin smokers to injection drug use during heroin-drought in these cities, indicate the need for large scale intervention. Research should also be conducted to identify the factors responsible for heterogeneity in HIV prevalence among IDUs in these cities so that appropriate intervention could be designed and national response to HIV in IDUs could be augmented.

#### b. Sex work

A countrywide surveillance for HIV was initiated in 1985 by the apex research institute ICMR<sup>19</sup>. This generated the first evidence for presence of HIV from a group of female sex workers in Chennai in 1986. Subsequently HIV prevalence in sex workers in Mumbai went up from 0 percent in 1987 to 20 percent within a period of three years<sup>20</sup>.

All these early cross-sectional findings prompted launching of targeted interventions in brothel based sex workers in different parts of India, especially since evidence from successful AIDS control projects around the world showed targeted intervention approach to be able to stop the transmission of infection within and from the 'core transmitters'.

However, adequate knowledge of the vulnerability of certain population groups such as unorganized sector of sex workers (street and cabin- restaurant based sex workers as opposed to those in brothels) to HIV and STD is still lacking. Thus, it is not clear how exactly to reduce risks in these hard-to-reach populations, and what would comprise effective intervention for these groups.

#### c. HIV epidemic in pediatric population

The latest sentinel surveillance data from ante-natal clinics in 7 metro cities<sup>21</sup> in the country reveal that HIV infection has crossed 2 percent in Mumbai, is more than 1 percent in Hyderabad, Bangalore, Chennai and below 1 percent in Kolkata, Ahmedabad and Delhi. This clearly indicates that the cities with 1 percent or more HIV prevalence among pregnant women have already fallen under the grip of HIV epidemic in pediatric population as well. It *has* also been recorded that Manipur – which had the earliest explosive HIV epidemic among IDUs – has started seeing the impact of the disease in the form of many AIDS orphans<sup>22</sup>, a phenomenon which needs a very different set of interventions not yet witnessed on a large scale.

Government of India has taken commendable steps in launching hospital-based prevention of HIV transmission from pregnant mothers to children through administration of short course AZT in 11 centers located in the worst hit States. However it is worth noting that two third or more of the deliveries take place at husbands' or parents' homes of the pregnant women (National Family Health Survey-2). Moreover, stigma and discrimination often come in the way of positive women accessing health care, especially in government facilities.

A national feasibility study of administering short-term AZT intervention among HIV-infected mothers to prevent mother-to-child transmission of HIV was conducted between April 2000 and July 2001. The

<sup>&</sup>lt;sup>18</sup>Kumar MS, Mudaliar S Thayagarajan SP, Kumar S, Selvanayagam A, 2002. Rapid assessment and response to injecting drug use in Madras, South India. Int, J of Drug Policy. 11, 1–2: pp 83–98.

<sup>19</sup> Indian Council of Medical Research (ICMR) 1988, Changing trends in serosurveillance for HIV infection, ICMR Bulletin 18: 39.

<sup>&</sup>lt;sup>20</sup> World Health Organization (WHO), 1993, The HIV/AIDS Pandemic, 1993 Overview, Geneva, WHO, 1993.

<sup>&</sup>lt;sup>21</sup> National AIDS Control Organization (Government of India), Ministry of Health and Family Welfare: Combating HIV/AIDS in India 2000–2001

 $<sup>^{\</sup>rm 22}$  UNICEF/UNAIDS, South Asia: The HIV/AIDS Epidemic. 2001.

study was conducted from 11 medical institutes in five States (Maharashtra, Tamil Nadu, Andhra Pradesh, Karnataka and Manipur) in India. It was observed that a total of 192474 women were offered HIV counseling and testing services during the study period, of which 171471 (89 percent) received the services. There was a further decline in HIV test uptake. 103681 among 171471 (60 percent) undertook HIV test of which 1724 (1.7 percent) were HIV positive. Despite best possible efforts of health care providers – backed up by counseling services in the medical institutes – some of the HIV positive women in the study never came back for the test results and only 44 percent (751/1724) took AZT prophylaxis which was to be received from the study centers. Willingness to deliver at the institutes was another inclusion criterion in the study that did not allow many women to enroll in the study, as they wanted to go to their parents' home in third trimester and deliver there. This further emphasizes the need for innovative community based approach for prevention of third wave of the epidemic in the pediatric population in the country. Future program planning should look for alternate ways of reaching out to 'mothers-inneed', especially through involvement of non-government and community based organizations.

#### d. Migration and HIV: in-country and cross-border

Migration has added another dimension to the epidemic in India. The country has seen – and continues to see – significant migration, both between states, and between the country and other neighboring countries. Nepal and Bangladesh have extremely porous international borders with India. While Bangladesh still has a low HIV epidemic, the HIV prevalence among sex workers in Nepal has reached 16 percent and among IDUs 50 percent<sup>23</sup>.

Some of the destination states of India also happen to be those registering high HIV prevalence. These include the more industrialized States of Maharashtra, Gujarat and Andhra Pradesh. These States attract male and female laborers from all over the country, but particularly from those States with lower income levels such as Uttar Pradesh, Bihar, Rajashthan and Madhya Pradesh. While these latter states have relatively low levels of reported HIV infection, labor migration to high prevalence states may soon change the scenario. Indeed many of the migrating men leave their wives and families behind, thus increasing the likelihood that they will visit sex workers during their stays away from home<sup>24</sup>.

Migration due to various factors such as eviction of tribal people from forests to be owned by government in Rajasthan<sup>25</sup> or fatal ethnic clash in Manipur<sup>26</sup> have also been documented as reasons why women are forced to take up prostitution as alternate means of living.

#### e. Care and support: an urgent need

Historically in India, more emphasis has been given to HIV prevention. Time is however ripe that HIV/AIDS care is also discussed along with prevention. Those already infected and in advanced stages of HIV disease are in substantial number in the country; without effective case management approach with currently available antiretroviral therapy, neither prevention nor care needs will be addressed.

Some important issues under care and support are women-headed and children-headed households, orphans and the elderly. There is no national structure for care and support, and in the absence of social security, insurance or other safety nets, the issue takes on an even more urgent tone. A few organizations such as the HIV/AIDS Alliance and Naz India are filling this gap in three states of

<sup>&</sup>lt;sup>23</sup> National Center for STD and AIDS Control, Nepal. 2000. Report

<sup>&</sup>lt;sup>24</sup> MAP: The status and trends of HIV/AIDS/STI epidemics in Asia and the Pacific. October 4 2001, Melbourne, Australia.

<sup>&</sup>lt;sup>25</sup> Jain K. Tribal sex seller women and HIV/AIDS infection in India. Xth International conference on AIDS. Yokohama, Japan. 1994. Abstract PD 0126

<sup>&</sup>lt;sup>26</sup> Panda S, Bijaya L, Devi NS et al. Interface between drug use and sex work in Manipur. Nat Med J India. Vol 14: No 4, 2001

Andhra Pradesh, Tamil Nadu and Delhi through their network of implementing partner organizations. The needs include medical support, counseling, livelihood, educational support and working with the families and communities to reduce stigma and discrimination. It is being increasingly realized that care can be given at home and not necessarily in an institutional setting. It is now necessary to focus attention on innovative ways of extending support to those affected, without injecting elements of inequity across socioeconomic classes or across disease categories. Replicable and feasible models of care and support need to be developed. One important lacuna so far in the care and support efforts have been a lack of legal framework, which ensures the rights of PLWHA, especially in the areas of workplace and health care settings.

#### f. Blood safety: re-emerging issue

The cornerstone of programs to reduce HIV transmission by transfusion of blood/blood product is the testing of all blood donations for HIV antibody. Although the situation has improved in India after the Supreme Court verdict in this direction, 100 percent safe blood/blood product transfusion is yet to be achieved in India. The main issue is of supply; demand always exceeds supply and currently only 60 percent of the demand is being met through official sources<sup>27</sup>, which has serious implications for HIV transmission in the country. States with relatively less developed rural areas and difficult hilly terrain with inadequate health care delivery services have this as a problem, but also in states such as Mumbai<sup>28</sup> and West Bengal, concerns<sup>29</sup> have been raised in this regard. As centralized blood transfusion services would be difficult in as vast a country as India where these are operated by government, voluntary and commercial establishments, and development of standardized processes and centralized quality assurance programs have been recommended. Additional inputs that could boost up the whole prevention program in the country in this field are training of health care providers on 'rational use of blood transfusion', 'component therapy instead of whole blood transfusion' and innovative donor deferral criteria (based on a history of genital ulcer or sexually transmitted disease) in conjunction with blood screening.

While the issues discussed above may seem diverse, needing completely separate sets of interventions, there are some fundamental commonalties underlying the spread of the virus, which call out for a developmental approach to interventions. These common features can be brought out by first asking the following two questions:

- what are the factors that facilitate the spread of the virus
- where will the impact of the epidemic be felt the most

In India the major route of transmission is sexual, followed by infected blood and blood products. Taking the sexual route of transmission first, given the age structure of the population, a large majority of India's population is in the sexually active age group (49.5 percent in the age group 15–49 as reported in NFHS-2). This figure is about 6 percentage points higher in the urban areas than in the rural areas, indicating possibly migration<sup>30</sup>. Another point to note is that all of India has an adverse sex ratio, which deteriorated further by 2001; thus there are fewer females per 1,000 males. Secondly, a slightly lower proportion of female aged 6 and above have never married compared to males<sup>31</sup>. Finally, women

<sup>&</sup>lt;sup>27</sup> Salunke SR, Shaukat M, Hira SK, Jagtap MR, 1998. HIV/AIDS in India: A country responds to a challenge, AIDS; 12 (Suppl B).

<sup>&</sup>lt;sup>28</sup> Mudur M. 1995, August 19 India hit by contaminated blood scandal. BMJ.

<sup>&</sup>lt;sup>29</sup> Times of India (Kolkata) 5 March, 2002. State orders HIV infection enquiry at blood banks.

<sup>&</sup>lt;sup>30</sup> NFHS-2 also indicates that rural –urban migration has been dominated by males in India.

<sup>&</sup>lt;sup>31</sup> NFHS-2 reports that 49.4% males in the urban areas have never married compared to 38.2% females. These numbers are 46.8 and 35.1 percentages respectively.

in India marry at much younger ages than men, and both men and women marry at younger ages in rural than in urban areas. To really understand the extent of risky behavior of individuals, one also needs some estimates of pre-marital, extra-marital as well as sexual behavior of never-married individuals. While these figures are not easily available, it can only be conjectured that these practices exist just like anywhere else in India as well.

In any case, these demographic facts do indicate the wide prevalence of marriage as well as the vulnerability of women in India, two facts that are very important in the context of the HIV/AIDS epidemic. It also implies that it is *possible* for this sub-population of sexually active individuals to acquire the infection, though the *probability* will depend on their specific risk behaviors. While there exists now a large amount of literature on who, why and how risky sex behavior occurs, the simple fact is that risky sex can occur only in one of two ways: deliberately (with correct knowledge) or non-deliberately. While no statistics exist on the proportion of each, it may be safe to conclude that most individuals have a long time horizon and will not willfully engage in behavior that may jeopardize his/her life. However, there are some factors that may increase even this kind of behavior, and these factors have to do with a much shorter time horizon (i.e. they do not care too much about the future) emanating from a variety of reasons, or a lifestyle that has little to offer by way of a peaceful and stable existence. But, a majority of risk behavior is undertaken with lack of knowledge about the implications of such behavior. Thus we need to answer two additional questions in turn:

- Who are least likely to be informed?
- Who are most likely to have a shorter time horizon?

It is our contention that there are a number of factors that need to be considered to address these questions, and these are the commonalties that cut across risk groups and behavior and these are indicated below:

- Poverty: one of the main reasons for poverty is unemployment and/or underemployment. In addition, the poor will also include seasonally employed, a large section of the informal sector workers, beggars, street children, sex workers, slum dwellers
- Illiterate, uneducated and less educated
- Marginalized and disempowered populations: the poor, the uneducated, women, minorities, refugees, street children, beggars, sexual minorities
- Those with interrupted family lives either by lifestyle choice or by force of circumstances: migrants, frequent long-distance travelers, armed forces, refugees, slum dwellers
- Women, especially those who are poor, uneducated, unemployed and generally disempowered due to the cultural and patriarchal structures of Indian society
- The youth and the elderly, especially those belonging to any of the vulnerable groups mentioned

Many of these factors go into making a large majority of India's population *potentially* vulnerable to HIV via the sexual route of transmission.

In addition to the sexual transmission, there are still a significant number of individuals who continue to get infected through contaminated blood. If one examines the list above, it becomes clear that these are mostly the same individuals who are likely to receive infected blood at illegal and unlicensed blood banks. In fact, we can add another factor to the list above, which will complete the vulnerability scenario.

 Inadequate, inaccessible and unaffordable health services of adequate quality for a large proportion of the population

While the above description brings out the vulnerability factors in India that make for a potential pool of "at-risk" population, it should also be emphasized that state-wide variation in all these are tremendous. Thus for instance, the status of women is low in many northern states, literacy is lowest in Bihar and Rajasthan, unemployment and poverty is marked in Orissa, Bihar and some north-eastern states, etc. The HIV/AIDS surveillance system is not designed to catch these vulnerability factors, which play out only in the medium and long run. Therefore, it is somewhat dangerous to base all interventions on results from the surveillance system; even behavioral surveillance data often cannot capture fully all the socio-economic and demographic determinants of vulnerability, which is essential to for effective interventions.

## 3. Current Response to the Epidemic in India: An Analysis

#### 3.1 Government Response: the National AIDS Control Program

The Government of India responded to the epidemic by setting up the National AIDS Control Program, which was implemented between 1992 and 1999. The immediacy of the problem prompted a reaction in India, which largely mirrored the practices followed by other countries in prevention and control of HIV/AIDS. The National AIDS Control Organization (NACO) responded by putting in place a the National AIDS Control Program (NACP) – a fully Centrally- sponsored scheme – which comprised Surveillance, Program Management, Information, Education and Communication (IEC), Blood Safety, Condom Promotion, Control of STDs, and Clinical Management. Needless to say, much less was known about the determinants and outcome of HIV/AIDS at that point than is known now. This first phase (1992–1999) of the project was mainly to be financed by a Government of India contribution of \$14.1 million, an IDA credit of \$84 million and a WHO co-financing grant of \$1.5 million. It should be noted that the GOI contribution was actually much higher than the original estimate and came to \$27.5 million. In addition, there were two important additional sources of financing: USAID and DFID. Now, in Phase 2 of the NACP, the objectives of NACO continue to be similar; these are:

- To reduce spread of HIV infection
- To strengthen India's capacity to respond to HIV/AIDS on a long-term basis.

The targets envisaged in the NACP-2 are the following:

- Reduce blood-borne transmission of HIV to less than 1 percent of total transmissions
- To introduce Hepatitis C as the fifth mandatory test for blood screening
- To set up new and upgrade existing blood banks as well blood component separation units
- To attain awareness level of at least 90 percent among youth and those in reproductive ages
- Training of NGOs for targeted intervention programs among high risk groups, to in turn promote condom use to at least 90 percent in these groups
- Conduct annual Family Health Awareness Campaigns among general population; provision of drugs for control of STDs and RTIs.
- Promotion of voluntary testing facilities so that every district in the country will have at least one voluntary testing facility
- Use of interactive awareness campaigns like folk arts and street theatre.
- Cover all the schools and universities under awareness programs
- Promote organizations of PLWHA and give then financial support to form self-help groups

The above are firm targets that the NACP-II hopes to achieve by the end of 2004. Further, the major components of NACP-II under which these targets would be achieved are:

 Priority targeted interventions for high risk population: this has to be done mainly through NGOs/ CBOs/Public sector

- Preventive interventions for the general population: this has to be done through IEC, awareness
  campaigns, voluntary testing and counseling (VTC), reduction of transmission by infected blood
  and blood products and prevention of occupational exposure
- Low cost care for people living with HIV/AIDS: financial and technical assistance to be provided to states/UTs for home-based and community-based care
- Institutional strengthening, including strengthening surveillance activities and research and development.
- Inter-sectoral collaboration: coordination within the Ministry of Health and Family Welfare, as well
  as other central ministries.

The above description indicates that the main emphasis on NACP-II is on clean and adequate supply of blood, IEC and targeted interventions among high-risk groups. The achievements of the first phase however lie in responding swiftly, building program capacity, efforts to tone up the surveillance system, getting the blood banks to supply cleaner blood and raising awareness. A major innovation in Phase I of NACP was the replacement of the earlier structure of State AIDS Cell by State AIDS Control Society. This step was taken to ensure easier disbursement of funds, lack of delays and more decentralization in decision-making. The other has been to move from developing and disseminating IEC materials to actually translating these into action by using the targeted intervention approach.

Table 2 below gives a break-up of the Phase II outlay by major areas of focus. As the table indicates, prevention among low-risk groups is to receive the highest allocation (33.7 percent), followed by institutional strengthening and prevention among high-risk groups (24.8 percent and 23 percent respectively).

Table 2: Allocation of funds for NACP-II

Components	Outlay (Rs. Crores)	Percentage
Prevention among high-risk groups	265.6	23.0
Prevention among low-risk groups	389.1	33.7
Care of HIV/AIDS	163.3	14.1
Institutional strengthening	286.5	24.8
Intersectoral collaboration	50.6	4.4
Total	1155.1	100.0
USAID – AVERT project	166	-
DFID	104	-

It must be noted that out of the total Rs. 1155.1 crores in the NACP- II, World Bank has provided Rs. 959.1 crores; the remaining Rs. 196 crores is to be provided by the Government of India. In other words, the World Bank is to provide 83 percent of the proposed outlay for NACP-II. In addition to these two sources of funding, the two other major sources of funding are USAID and DFID. The USAID has extended support of Rs. 166 crores, to the Government of Maharashtra for implementation of AVERT project, based on the earlier success of the still on-going APAC project in Tamil Nadu. DFID has given assistance of Rs. 104 crores, for Sexual Health projects in the states of Andhra Pradesh, Gujarat, Kerala and Orissa

While there are other bilaterals and international NGOs (INGOs) who are contributing to the spread and impact of the HIV/AIDS, the four key players as far as the National AIDS Control Program is concerned are the four mentioned above.

The main conclusion that emerges from the above description of the NACP-II is that the overall focus of the NACP is towards prevention and control: about 60 percent of its funds are allocated to prevent the transmission of HIV. Also, the other major partners – DFID and USAID – are also heavily involved in prevention. Care and support receive a much smaller allocation – 14 percent – in the program. In fact, the number of Targeted Interventions (TI) projects in India are 475, with the highest numbers being carried out in Tamil Nadu, followed by Maharashtra. DFID and USAID as mentioned above fund many of these. It is interesting to note that there are no NACP-funded TI projects in the following states and UTs: Andaman & Nicobar Islands, Bihar, Dadra and Nagar Haveli, Daman and Diu, Delhi, Jammu and Kashmir, Lakshwadeep, Meghalaya, Pondicherry, Sikkim and Uttar Pradesh<sup>32</sup>. However, it is also true that there are instances of non-governmental organizations running targeted interventions in different states; for example, there is an EU-funded 5-city oral sublingual buprenorphine substitution program for IDUs, which includes Delhi.

#### 3.2 UN Initiatives and Major Donor Interventions

Organisations involved in both prevention and control programs as well as care and support can be divided into four categories: the UN agencies, bilaterals, international NGOs (INGOs) and domestic NGOs/CBOs. The role of each of these and lessons learned will be discussed in brief below.

#### a. UN organizations

At the time of writing of this report, plans are under way for the workplan of UN organizations for the current year. Thus in this section, we present an overview of the workplan for 1999–2001, and supplement it with new information gathered from other sources (Table A1 in Annexure)

As is well known, UNAIDS does the facilitating among key UN players and lends technical support wherever necessary. Each of the UN organization has been leading on with activities in their specialized areas. These organizations have been working closely with NACO and the states, and also several international and national NGOs. The table indicates that UNAIDS has been able to lead on many fronts, especially in the area of prevention and control. The development approach of UNDP has been a very useful framework to adopt. The only drawback of the joint UN program has been a lack of focus on care and support.

#### b. Bilaterals, Private Foundations and international NGOs

The major bilateral players are USAID, DFID, CIDA, Sida and AusAID. European Union (EU) has also emerged as an important player. Besides these, there are other international Foundations and NGOs (INGOs) like the Ford Foundation, MacArthur Foundation, Population Council, Family Health International (FHI), HIV/AIDS Alliance etc. that have added significance to the overall activities around HIV/AIDS in India. In Table A2 in Annexure, we present an overview of the main players and their current and planned activities. The information has been gathered from desk review of documents from NACO, UNAIDS and discussions with UNAIDS, select bilaterals and international agencies, given the limited time period available.

Most of the donor interventions are in the areas of prevention through targeted interventions and awareness campaigns, and primarily focussed in the states of Maharashtra, Andhra Pradesh, Tamil Nadu, Manipur, West Bengal, Kerala and Gujarat. One of the few international agencies working on HIV/AIDS care and support in India is Oxfam in Manipur and India HIV/AIDS Alliance in the states of Andhra Pradesh, Tamil Nadu and Delhi. The states with limited donor HIV/AIDS interven-

<sup>&</sup>lt;sup>32</sup> Source: Response to Rajya Sabha starred question no. 58, reported in Indiastat.com.

tions are Bihar, Rajasthan, Karnataka, Orissa, Assam, Arunachal Pradesh and Tripura. Many of these states are also underdeveloped with high levels of poverty, as discussed in the first section.

Some of the other international organizations that are working on HIV/AIDS in India are CARE India who are in the process of negotiating a US \$ 15–20 million grant (from USAID) to work in 7 low prevalent states across the country. Their focus will be on prevention and awareness building amongst vulnerable groups. BBC World Service Trust is working on communication for the northern states of Uttar Pradesh, Rajasthan and Delhi. Catholic Relief Services, Plan International, Action AID, World Vision are other international organizations also working on HIV/AIDS who are beginning to support more prevention as well as care and support programs in the high prevalent states. CEDPA will be working on HIV/AIDS and youth as a part of the USAID funded IFPS project in Uttar Pradesh. Some of the other Foundations funding in India are Bill and Melinda Gates Foundation (for whom India and HIV/AIDS are becoming a key focus area), Packard Foundation (focus on Bihar and Jharkhand for reproductive health and sexuality), Francois Xavier Bagnoud (FXB), Elton John Foundation, Richard Gere Foundation etc.

#### c. National NGOs

In addition to these organizations mentioned above, India has seen an emergence of several competent NGOs who have often filled in the gaps left by other players, especially in working with vulnerable groups. While it is difficult to list all the NGOs working in India on HIV/AIDS and related issues, some of the more notable ones are Y.R.G. Care (Chennai), Indian Network of Positive People (INP+), Naz Foundation India Trust (Delhi), Sahara (Delhi), Sharan (Delhi), SPARSHA (Society for Positive Atmosphere and Related Support to HIV/AIDS, Kolkata), Freedom Foundation (Bangalore, Hyderabad), SOS Medical Foundation (Nasik), Prayas (Pune), Sangram (Sangli), CASA (Mumbai), Prepare (Chennai), Lawyers Collective (Mumbai and Delhi), Durbar Mahila Samanvaya Committee (DMSC, Kolkata) etc. In addition to these, India has seen the emergence of several NGO conglomerations such as FINGODAP, working on drug and AIDS, and India Network of NGOs (INN).

The rich NGO experience unfortunately has not been adequately analysed, evaluated and documented, including showcasing of best practices. This has meant that this resource has been both non-scalable as well as underutilised. This remains an important area where donors can step in to facilitate a wider dissemination and utilisation of knowledge, experience and best practices emanating from the NGO/CBO sector. Also, the NGOs often lack technical as well as administrative capacities, and have very little knowledge or understanding of research. The donors can help by lending technical support as well as research support to these organisations.

#### 3.3 A few lessons learnt from donor agency supported HIV interventions in India

#### **Swedish International Development Cooperation Agency - Sida**

The overall objective of Sida in India is to fight poverty and strengthen the rights of marginalised groups in society. Health and education are two major areas of focus for Sida. In the recent past, given the urgent need for prevention and control, HIV/AIDS has been given a critical priority in Sida's health program in the country. In Manipur, apart from ICMR-WHO collaborative projects, Sida was the first donor to support NGO programs, based on the philosophy of harm minimisation. Three NGOs in Imphal, Manipur – Centre for Social Development (CSD), Institute for Social Disease (ISD) and Lifeline Foundation (LLF) have been receiving Sida support since 1993. The main goals of the projects are (a) to reach out to the injecting drug users (IDUs) and their sexual partners and facilitate them to reduce sharing of unclean injecting equipment and practice safer sexual behaviours; (b) to provide psycho-social support and health care to people with HIV/AIDS; (c) to sen-

sitise policy makers and mobilise the community and other NGOs; and (d) to facilitate formation of self help groups. A North-East Network on HIV/AIDS has recently (2001) been initiated by the Sida-supported NGOs with the objective of a consistent regional sharing of experiences, advocacy and capacity building. Important emerging issues to be addressed by this network are women, youth and vulnerability.

#### The following outcomes have emerged from Sida interventions.

Policy Level	Project Level		
- IDUs are no more shot at nor kept in lock ups	<ul> <li>NGOs have reached out to more than 4000 IDUs</li> </ul>		
<ul> <li>Advocated for state policy on harm minimisation</li> </ul>	<ul> <li>Group of trainers developed in each NGO</li> </ul>		
- Through community participation programs gained commu-	<ul> <li>Women drug users identified and their issues addressed</li> </ul>		
nity acceptance	<ul> <li>Women Self Help Groups formed</li> </ul>		
<ul> <li>Neighbouring states influenced and gained learning from experiences</li> </ul>	<ul> <li>Drop in centres established and needle syringe exchange program started</li> </ul>		

Source: Sida

#### India HIV/AIDS Alliance

The *India HIV/AIDS Alliance* has been primarily focussing on care and support programmes in the states of Andhra Pradesh, Tamil Nadu and Delhi. The purpose has been to provide people living with HIV/AIDS (PLHA), children affected by AIDS (CAA) and their families with appropriate and adequate support in their clinical and psychosocial needs through the delivery of integrated home and community care by NGOs/CBOs; and to strengthen communities in their response to the epidemic and the mitigation of its impact. The major lessons learned from the implementation experience have been that integrated community development organisations are more flexible and innovative in identifying and planning community based care and support activities, and also address stigma and discrimination, in comparison to those that have existing institutional services or are involved in prevention through targeted interventions. These organisations also address sustainability issues early on in project development. Participatory Community Assessment (PCA) and use of participatory tools is also a good start up activity for implementation of HIV/AIDS care and support projects.

#### **Project Concern International (PCI)**

PCI – an international private organisation – has been working on HIV/AIDS in India for the last few years. The major focus of their HIV/AIDS interventions has been behaviour change through counselling and education, condom promotion, STI treatment and counselling (syndromic management of STIs), training on STIs, HIV/AIDS and sex and sexuality. The special groups for focus are truckers, street and working children, PLHA and their families, sex workers, injecting drug users, adolescents and devadasis. Their HIV/AIDS care and support interventions have included home based care and support for PLHA through medical and psychosocial care, training and orientation of PLHA, their families and community members. This experience has indicated that PCI has provided a forum for NGOs to come together for discussions and experience sharing that has been beneficial for cross fertilisation of ideas and innovative intervention development. Also, implementation of Management Information Systems (MIS) for the partner NGOs as also financial systems that are capable of capturing information on local donation, cost recovery mechanisms, income-generating projects and community contributions have greatly enhanced the effective functioning of these NGOs.

#### APAC/VHS/USAID

AIDS Prevention and Control (APAC) project is administered by Voluntary Health Services (VHS), Chennai, with financial assistance from USAID, under a bilateral agreement with the Government of India. APAC initiated HIV/AIDS prevention in Tamil Nadu in the year 1996 with the overall goal of reducing the sexual transmission of HIV in the state. The project supports NGO partners to implement thematic intervention projects reaching "Truckers and Helpers", "Women in Prostitution", "People Living in Slums" and tourists. It also conducts HIV Behaviour Surveillance Survey (BSS) to capture the intervention efforts, and to inform the intervention programme. Altogether five rounds of BSS have been completed by now. APAC is the only project in India that has attempted to systematically look into the changes in risk behaviour of different population groups since 1996 through 2000, and has used the behaviour surveillance data for informing interventions. The experience of APAC for tripartite collaboration and documented behaviour change are certainly worth emulating after adapting to different local conditions.

#### **Department for International Development (DFID-India)**

DFID has been implementing the Sexual Health Project in West Bengal with the focus of HIV/AIDS control programmes and developing IEC techniques. DFID has also supported a national Healthy Highways Project with the truckers' community. The pilot project has been integrated into the NACP-II. In addition, DFID has formulated "partnership for sexual health" projects for the prevention and control of HIV/AIDS and other sexually transmitted infections in the states of Andhra Pradesh, Gujarat, Kerala and Orissa. The objectives of the project are: a) To ensure better sexual health for people vulnerable to sexually transmitted diseases (STDs) and HIV, especially the poor; and b) lowering incidence of sexually transmitted infections in the four states. The components of the project are: 1) surveillance, 2) condom programming by ensuring that quality condoms are made available and acceptable to those who are vulnerable to STDs/HIV through effective social marketing, 3) strengthening service providers to respond to clients needs through targeted interventions for vulnerable groups, such as sex workers and their clients, men having sex with men, migrant workers and prison inmates. Some of the lessons learned are: political will is the essence of success of HIV/AIDS prevention programs; establishing and maintaining decision making systems needs full co-operation from the government; planning for HIV/AIDS prevention programmes at the state level needs greater co-ordination between GO-NGO; having a Management Agency makes co-ordination feasible; collating the strengths of each organisation is the key to success; build capacities of the states to sustain the programme which includes developing local expertise in HIV/AIDS prevention.

#### 3.4 Private sector – a brief overview

In addition to the government and national and international donors and NGOs, the private sector in India has also made its presence felt in HIV prevention activities, especially around issues like workplace interventions, community programs and support to NGOs. The Confederation of Indian Industry (CII) has supported over 1700 companies in establishing workplace programs and has provided income generation opportunities for people living with HIV/AIDS.

B Muthuraman, the managing director of TATA Steel, in his statement on the HIV(+) and AIDS Policy on 1<sup>st</sup> October, 2001 mentioned that TATA Steel would take measures to prevent the incidence and spread of HIV and AIDS in the society. In case of need, the company would arrange to provide counseling and medical guidance to these patients and their families. AIDS awareness and treatment of drug dependence are two other related issues that TATA has been concerned for quite some time now. Since mid-'90s TATA Steel has been providing infrastructure support for running drug detoxification center in Barandi, Bihar where its collaborating partner organization 'The Calcutta Samaritans' is

in-charge of the technical inputs as well as service provision. The changing scenario of drug use from heroin smoking to synthetic pharmaceutical injecting among the local youths including a few industrial workers in and around Jamshedpur called for such an action and the present status of this collaboration exemplifies a successful networking between private corporate sector and NGO, many of which kind should take place within the country in order to achieve a significant public health impact on HIV/AIDS prevention and care.

Other examples of such activities include Tata Tea's collaboration with tea plantation workers in Kerala. Similar collaboration and business coalitions against HIV/AIDS are being set up in different states, and CII has also set up the Indian Business Trust for HIV/AIDS.

In another example of donors collaborating with the private sector, the ILO in consultation with its Indian tripartite constituents and NACO has developed a three-phased program, aimed at establishing a sustainable national action on HIV/AIDS prevention, care and support in the world of work. The notable features of the ILO project include: guidance to the project by a high-level project management team, mobilization of partners through stakeholders meetings and consultations/seminars etc in an attempt to put HIV/AIDS on the agenda, research based advocacy, documentation of corporate responses to HIV/AIDS, compilation and dissemination of existing research studies on HIV/AIDS in the world of work, initiation of action research projects and capacity building.

# 4. Evidence-based Interventions: Need of the Day

#### 4.1 Strengths and weaknesses of current collective response

From the point of view of the national response, the main strengths of NACP in India have been the following:

- swiftness of response
- setting up a fairly strong organization like the NACO
- ability to procure in two stages a high level of funding commitment from a major organization like the World Bank
- ability to build up state level capacities
- ability to attract additional donors and their funding
- successful collaboration with major bilaterals and INGOs
- ability to work with Indian NGOs

Gaps, however, remain even today in the NACP as well as in the non-government response. Most of these gaps have been recognized, but there has been an inability to deal effectively with these, mainly because of an imperfect understanding of how to move forward. Below we list some of the continued problems despite over a decade-long response

- Inability to integrate HIV/AIDS into the mainstream of public health activities
- Inability to reduce stigma and discrimination
- Inadequate focus on vulnerability factors, especially poverty, illiteracy and disempowerment
- Inadequate geographic and population coverage in terms of targeted interventions
- Inadequate focus on care and support
- Inadequate attention paid to the issues around antiretroviral treatment
- Lack of focus on generating evidence, especially around risk practices and treatment-seeking behavior among bridge population and core transmitters.
- Almost complete neglect of monitoring and evaluation of programs

Of these, the most damaging have been the first and the last one. It is our contention that by making HIV/AIDS a stand-alone and vertical program, which is not integrated into an overall public health framework, we may have added to the stigma and discrimination surrounding it. The high-profile activities and funding have also brought out in sharp focus the possible inequities that such programs might inject into both national health policy as well as overall welfare policies. This is because, it is not always clear why HIV/AIDS should merit greater attention than other infectious diseases, or why those who are infected should merit greater assistance than those who are not infected but fatally sick. This inadequate recognition given to equity issues has been instrumental in bringing criticism to the extent that some have questioned the very need for such a high-funded project for AIDS.

In addition to not adequately recognizing the need for integration into other health programs right at the outset, or even midway into the first phase, the problem was compounded by messages of IEC that made HIV and AIDS stand out like some frightening and severe malady, which happens only to those who ask for it by behaving in manners not consistent with Indian morals.

To a great extent, this high profiling of the epidemic was also due to the multiplicity of players, especially the international donor communities, which poured funding into prevention and control activities.

A related and equally important point is that while much of the NACO core funds as well as co-financing went into prevention and control, almost no mechanism was put in place to evaluate these prevention activities. A prime example is IEC, which has often been implemented through targeted interventions aimed at high-risk population. There is no allocation made in the NACP budget for monitoring and evaluation. While additional funding is always welcome in a cash-strapped country, funding does not seem to be the problem in India. It is an imperfect and inadequate understanding of what works, which can come only if evaluation procedures are put in place before activities are being planned. Evaluation is a scientific process and cannot generally be done well in an ex-post fashion. Another example is the proposed scaling up of the MTCT program, which has been put in place before any evaluation of the current program, has been done.

Unfortunately, the other donors have also not insisted in scientific evaluations, though it is being recognized now that there is a need to know whether good money is being thrown after bad programs.

As for care and support, it is clear that no single organization or even the government can shoulder the care responsibilities of AIDS patients; it is neither feasible nor is it equitable in terms of other diseases. However, it is possible to remove the constraints in care-seeking and patient-management with careful planning, and helping groups to help themselves in planning for the future. This would, of course, require a completely new and truly developmental approach to the epidemic, requiring integration of poverty reduction and other welfare programs into HIV/AIDS activities. This is again not something that has been attempted in any serious fashion.

As for the national NGOs, while there are many that are doing commendable work, there is a lot going on that is not being evaluated either. If national and large donor-driven programs are not evaluated, this is even truer of NGO activities in India. There is no monitoring and evaluation at all, especially outcome evaluation. While figures are not easily available, it is probably true that much of the funding continues to flow into behavior change and IEC activities – an area where it is easy to put in money, but which is difficult to evaluate in terms of outcome.

On the other hand, national NGOs, including some international ones with branches in India are also filling in one important gap in response – care. There are now a few NGOs and INGOs like YRG Care, Naz Foundation – India Trust, HIV AIDS Alliance, ARCON etc that are catering to the needs of at least a small proportion of PLWHAs.

Finally, in all the programs – national or international – there has been a lack of research component, operational or otherwise. Except for some organizations like Voluntary Health Services (VHS), NGOs and INGOs have almost never undertaken serious research into areas of their interventions. One aspect of this omission has meant that there has been an imperfect understanding of the impact of the epidemic on different sectors. The one that should concern India immediately is the health sector. There is almost no research that looks into the impact that increased morbidity and mortality will have on the health sector in India. There are some studies however on the impact on individuals and households, though these results have not been put to much use. All this implies that policymakers have no channels of being informed about what is needed, where and how.

#### 4.2. Scaling up of intervention

While the prevalence of HIV in India may seem relatively low – 0.7 percent of the general adult population compared with rates of over 20 percent in South Africa, Zimbabwe and Botswana – the infection has now been detected in all the states and union territories. It is no longer confined to vulnerable groups such as sex workers and transport workers, or to urban areas<sup>33</sup>, and here lies the necessity for urgent scaled up responses for prevention of further spread of HIV. Pilot HIV intervention projects supported by different donor agencies during phase-I of the National AIDS Control Program (NACP) in India have identified a number of essential elements of intervention, which were incorporated in the second phase of program planning<sup>34</sup>.

However, it is important to understand that while there are some essential elements (involvement of communities, creation of enabling environment, peer-based behavior change intervention etc) that go into any intervention, each context and setting is different, and therefore scaling up should be done with great caution. In other words, exactly the same "best practice" – for example Sonagachi sex worker intervention – when put in another setting with all the essential elements in place may not yield the same outcomes.

There may be a number of reasons why scaling-up and replication has not happened — even for some of the best practices. While a few such practices have been documented, inadequate attention has been paid to producing a complete blue print of these interventions. To do so, attention will have to be paid to (a) context; for example, power brokers in a sex work setting, (b) capacity building of community members, (c) how community members can be engaged in planning, implementation and evaluation.

A final point that needs emphasis here is that there are several interventions carried out by a multiplicity of agencies and organizations all over India. However, there has been very little documentation of these interventions. Without mapping the universal set of interventions, it is not possible to take the next step of evaluating which of these actually work.

#### 4.3. Generation of evidence

Inadequate current response to HIV/AIDS in India stems from the fact that the knowledge base about the epidemic is far from perfect. There are some critical gaps in information with regard to:

- HIV/STD Surveillance in female sex workers, low risk male population groups and migrant laborers
- Countrywide mapping of HIV/AIDS interventions in prevention as well as care and support
- Treatment seeking behavior of vulnerable groups such as sex workers and IDUs
- Risk practices and treatment seeking behavior of bridge population
- Socio-economic impact on households, various sectors especially the health sector and the economy as a whole
- Cost-effectiveness of interventions

Ramasundaram S, Can India avoid being devastated by HIV. BM7 2002; 324: 182–183 (26 January).

<sup>&</sup>lt;sup>34</sup> Jana S, Bandyopadhyay N, Mukherjee S, Dutta N, Basu I, Saha A. STD/HIV intervention with sex workers in West Bengal, India. AIDS 1998, 12(suppl B):S101-S108.

For informed and effective policymaking, it is imperative to start generating evidence in these areas. The information can be generated by a wide variety of organizations and by using various methods, including operations research. It must be pointed out here that good research on the epidemic must always be based on the involvement of individuals affected by HIV.

### 5. Conclusions and Recommendations on Priorities

The above analysis indicates that India has been able to respond fairly quickly and comprehensively to the AIDS epidemic. However, there are still many areas where more focus and attention are required. The main lacunae in the current collective response has been that despite a recognition of the need to mainstream, strategies of poverty reduction and prevention & control and care & support have remained more or less parallel. Thus, the Planning Commission of the country has yet to take a serious note of the epidemic and the need for integrating responses with other developmental ones.

This lack of mainstreaming has also resulted in a paradoxical situation, where too much visibility accorded to HIV/AIDS has added to the stigma and discrimination by creating a mysterious world around the epidemic. This could be eliminated or at least reduced only by an approach which recognizes that for successful prevention and control it is essential to pay attention to vulnerability factors, especially poverty, illiteracy and disempowerment.

The other shortfall of the current response is the geographic gaps that exist in prevention and control measures; while some states and areas have received a lot of focus, others have received very little. Thus, for instance, some of the most underdeveloped states like Orissa and Bihar have very little happening there compared to states like Tamil Nadu and Maharashtra. The low prevalence in these states is absolutely misleading because of the many vulnerability factors that make them potentially susceptible to high rates of transmission.

Another feature of the current response is the almost complete omission of monitoring and evaluation of programs; there are very few interventions that have been accompanied by evaluation to see whether these work and to what extent. This is potentially a worrying situation since resources are scarce, and there is the danger that more resources will be spent on programs that do not work very well.

In general there has been a lack of focus on generating evidence, especially around risk practices and treatment-seeking behavior among bridge population and core transmitters. There is therefore the need to compile best practices in different types of interventions, from the point of view of scalability.

Based on these conclusions, we present the recommendations and priorities below. These are given under two headings below: in section 5.1, we present the overall country-specific policy needs based on the above analysis. In section 5.2, we present some specific recommendations for Sida, keeping in mind its past organizational features and past experience.

#### 5.1 General priorities

1) Emphasis on both prevention & control as well as care and support: the epidemic has been around for more than 15 years now in India. But infections continue to occur in new areas and new groups, clearly indicating the need for continued efforts on prevention. At the same time, the need for care and support of those affected has increased enormously. Therefore donors should still treat prevention as their primary focus. At the same time, it should increasingly try to find innovative ways of dealing with issues of care and support.

- 2) **Scaling up**: the following are essential components that need focus before scaling up.
  - mapping of interventions across the country
  - analysis and documentation of what works
  - estimation of size of vulnerable groups, especially overlooked groups like unorganized sex workers in cabin-restaurants
  - constraints faced in increasing coverage through scaled up responses
- 3) Priorities under prevention: these are some of the key issues that need to be considered
  - Low risk population: situational analysis, operational research and interventions for the following groups – clients of sex workers, spouse of IDUs, migrant labourers and slum population
  - Bridge population: determinants of risk-taking behavior and treatment seeking behavior of bridge populations like truck drivers. Innovative ways of reaching out to these groups.
  - Informal and unorganized sector workers: collaboration and cooperation with the private corporate sector to bring these hard-to-reach workers under the umbrella of prevention.
  - Third wave of HIV among pediatric population: design appropriate interventions based on evidence from feasibility study that indicates reasons why most of the mothers do not access institution based interventions.
  - Cross border: cross country collaboration to address vulnerability issues of migrant population and girls engaged in prostitution, between India and neighbouring countries like Nepal and Bangladesh.
  - Adolescents and youth: situation analysis, operational research and appropriate interventions for this group.
  - Capacity building for effective transfusion services: innovative blood donor deferral and training
    of health care providers for rational use of blood transfusion as well as component therapy, as
    opposed to whole blood transfusion.
- **4) Priorities under care and support**: very little is known about how best to carry out care and support programmes. Thus, the following are identified areas:
  - research on socioeconomic impact, especially for households and communities, including quality
    and accessibility of antiretroviral therapy, and exploring mechanisms like health insurance to
    support increased health expenditure.
  - how to foster involvement of people living with HIV/AIDS and their friends.
  - Models for best practices in care and support, including costing.

- **5) Research needs**: there is a need to document good research as well as support research for generating knowledge. Such research can be used by funding agencies including NACO to inform policy. Some of the areas of research are:
  - Links between poverty and other developmental factors on the one hand and HIV/AIDS on the
    other: this will enable answering questions like who needs what type of help, and how. The priority areas mentioned under prevention are also areas of research that can be focused upon.
    Impact of morbidity and mortality on the health sector
  - Implications for the dual epidemic of HIV and TB in India: monitoring of trend of resistance in isolates of mycobacterium tuberculosis.
- **6) Geographic focus:** focus on areas/states that have received little attention so far from government and other donors/NGOs.
  - Need to extend analysis and coverage of areas that see out-migration to high-prevalence states in India, for example Bihar and Orissa are prime examples of neglected but vulnerable states.
  - Diffusion of injection drug use in metropolitan cities of India and heterogeneity in HIV prevalence in IDUs.

#### 7) Monitoring and evaluation (M & E)

- Strengthen Sida's capacity for M & E of programs and projects
- Advocacy for M & E activities
- Training in-house as well as outside on M & E.
- Lend technical support on M & E to NACO as well as other donors
- **8) Capacity building:** stress should be placed on involving communities infected and affected by HIV/AIDS
  - Roadmap for peer outreach intervention
  - Training to build capacity for operational research
  - Enhancing research and analysis capacities of NGOs as well as private corporate sector.
  - Training, orientation and sensitization of personnel of concerned ministries and departments, such as health, home, education, labour, industry etc. This will also enhance inter-sectoral collaboration.

Before we turn to the next section on specific recommendations for the consideration of Sida, it may be useful to point out a few strategic considerations that Sida may want to focus on while drawing up the next round of future plans.

Sida is the best judge of the extent to which it can carry out these recommendations. It may want to take another look at the current capacity in its India programme on HIV/AIDS – technically and administratively – within the overall budget allocation for HIV/AIDS, to look at the feasibility of implementing some or all of the recommendations. In any case, some of these constraints can be relaxed by working alongside other donors; collaboration, cooperation and partnerships must form the fundamental cornerstone of Sida's approach to HIV/AIDS.

#### 5.2 Specific recommendations for Sida

- Documentation of best practice: based on its experience in the northeast among injecting drug users,
   Sida should bring out best practice strategy paper which documents the process, outcomes as well as the challenges that could then be used by Sida itself as well as other donors including the government, for replicating the experience in other parts of the country.
- Re-strategise thrust of current interventions that are operationally less successful: strategic funding (co-funding) or other technical support for comprehensive intervention in areas like those under the Mumbai Municipal Corporation for prevention among sex workers. This can be done in consultation with NACO, which can in turn identify NGOs who are successfully working with brothel based and street based sex workers respectively. Sida could support growth of sex workers collective that has formed recently.
- Greater emphasis on mainstreaming intervention efforts: Sida can incorporate in its interventions a direct
  developmental approach, including poverty alleviation strategies. It can also support from outside –
  financially or technically or through advocacy other non-Sida programmes that are trying to
  mainstream their responses.
- Focus on states/regions that are relatively weak in interventions as well as programmatically: Assam in the north-east and Bihar and Orissa in the rest of India are 3 states that have seen much less activity than other states. Sida can help government of these states to strengthen sentinel surveillance activity as well as designing of HIV/STD intervention.
- Focus on youth and women: develop and support interventions for youth and women after reviewing current interventions in this area in the country. The focus should be on information and services for both married and unmarried youth, in school and out of school, and interventions should be nested within programmes of reproductive health and sexuality.
- Promote research in strategic areas: Sida should encourage, support or undertake research on the determinants of risk behaviour among migrant workers, informal sector workers, adolescents. Sida can support other such on-going research activities as a co-funder or even primary donor.
- Support to PLWHA: Sida should support and facilitate development of more groups of people living
  with HIV/AIDS. The approach should be a holistic one, not merely from a psycho-social and emotional perspective, but from the perspective of improvements in quality of life including livelihood
  issues.
- Monitoring and evaluation: Sida should incorporate in all its on-going programmes a monitoring and
  evaluation component as well participate in advocacy and training in this area.

### References

CJL Murray and Lopez AD, Editors, 1996. Global Burden of Disease Health. Harvard University Press.

Global Tuberculosis Program (GTB)/UNAIDS. Managing the dual epidemic of Tuberculosis and HIV/AIDS: a review of challenge and response in five countries; Brazil, India, Indonesia, Kenya and Thailand. March 1998.

Guha, S.K: Profile of HIV/AIDS in West Bengal: An Appraisal from a Teaching Hospital in Kolkata. Third International Conference on AIDS INDIA, Chennai, India, December 1–5, 2001.

Gupta, Indrani. "Socio-economic impact of HIV/AIDS on Individuals: A Planning Perspective from India". In "The Looming Epidemic: the Impact of HIV and AIDS in India", ed. Peter Godwin, Mosaic, 1998.

Gupta, Indrani. "The AIDS Epidemic and the Economic Burden of Treatment in India". Presented at the Meeting of the UNAIDS Reference Group on Economics, Cuernavaca, Mexico, February 2001.

Gupta, Indrani. Paper presented at the plenary session on Poverty and the socioeconomic Determinants of HIV/AIDS, 6th ICAAP, Melbourne, October 5–10, 2001.

Indian Council of Medical Research (ICMR) 1988, Changing trends in sero-surveillance for HIV infection. ICMR Bulletin 18: 39.

Jain K. Tribal sex seller women and HIV/AIDS infection in India. *Xth International conference on AIDS*. Yokohama, Japan. 1994. Abstract PD 0126

Jana S, Bandyopadhyay N, Mukherjee S, Dutta N, Basu I, Saha A. SID/HIV intervention with sex workers in West Bengal, India. AIDS 1998, 12(suppl B):S101-S108.

Kumar MS, Mudaliar S Thayagarajan SP, Kumar S, Selvanayagam A, 2002. Rapid assessment and response to injecting drug use in Madras, South India. International Journal of Drug Policy. 11, 1–2: pp 83–98.

MAP: The status and trends of HIV/AIDS/STI epidemics in Asia and the Pacific. October 4 2001, Melbourne, Australia.

Mudur M. 1995, August 19 India hit by contaminated blood scandal. BMJ.

National AIDS Control Organisation. Combating HIV/AIDS in India, 2000–2001. Ministry of Health and Family Welfare. National AIDS Control Organization, Government of India.

National Center for STD and AIDS Control, Nepal. 2000. Report.

National Family Health Survey –2 (1998–1999). International Institute of Population Sciences. Mumbai.

Panda S, Bijaya L, Devi NS et al. Interface between drug use and sex work in Manipur. National Medical Journal of India. Vol 14: No 4, 2001

Panda S, Chatterjee A, Bhattacharjee S, Ray B, Saha M.K and Bhattacharya S.K 1998. HIV, hepatitis B and sexual practice in the street-recruited injecting drug users of Calcutta: risk perception versus observed risks. International Journal STD & AIDS. April, 9(4): 214–218.

Panda S, Sarkar S, Mandal BK, Singh BK Th, Singh KL, Mitra DK, Sarkar K, Tripathy SP, Deb BC. 1994. Epidemic of Herpes zoster following HIV epidemic in Manipur, India. Journal of Infection. 28 (2).

Planning Commission, March 2002. National Human Development Report.

Ramasundaram S, Can India avoid being devastated by HIV. British Medical Journal 2002; 324: 182–183 (26 January).

Reid G, Costigan G. Revisiting 'The Hidden Epidemic': A Situation Assessment of Drug Use in Asia in the context of HIV/AIDS: The Centre for Harm Reduction, The Burnet Institute, Australia, January 2002.

Salunke SR, Shaukat M, Hira SK, Jagtap MR, 1998. HIV/AIDS in India: A country responds to a challenge, AIDS; 12 (Suppl B).

Solomon S, Kumarasamy N, Ganesh AK and Amalraj RE. Prevalence and risk factors in HIV-1 and HIV-2 Infection in urban and rural areas in Tamilnadu, India. International Journal of STD and AIDS 1998; 9: 98.

Times of India (Kolkata) 5 March, 2002. State orders HIV infection enquiry at blood banks.

UNAIDS, Workplan- 1999–2001. A Strategic Response to the HIV epidemic by the government of India, the UN and its development partners in India.

UNAIDS/WHO. AIDS Epidemic Update December 2001

UNICEF/UNAIDS, South Asia: The HIV/AIDS Epidemic. 2001.

World Bank. Confronting AIDS: Public Priorities in a Global Epidemic. 1997.

World Bank. India: New Directions in Health Sector Development at the State level: An operational perspective. Report No. 15753-IN. 1997.

World Health Organization (WHO), 1993, The HIV/AIDS Pandemic, 1993 Overview, Geneva, WHO, 1993.

# Annex 1

Table A.1: UN activities and workplan<sup>35</sup> 1999–2001

	Organization	Strategic objective	Specific activities	Major geographic focus
1	UNDCP	Drug abuse and HIV/AIDS	Inter-agency cooperation, capacity building, advocacy, support to TRGs	North-East
2	UNDP	Development and HIV/AIDS	Support to states in planning process, cooperation and capacity building of NGOs, work with PLWHAs;Emphasis on trafficking – women and girl child	Tamil Nadu, Maharasthra, Rajasthan, Gujarat, Himachal Pradesh, Delhi
3	UNESCO	Adult literacy and HIV/AIDS	Teacher education program, IEC, training, peer education for youth	MP, Rajasthan, UP, Delhi
4	UNFPA	STD prevention and control within reproductive health	Strengthen RTI/.STD services, condom programming, family life education, research on population and reproductive health in the context of HIV/AIDS	MP, Kerala, Orissa, Rajasthan, Gujarat, Maharashtra
5	UNICEF	Children/young people and HIV/AIDS	Reduction in MTCT, prevention among children and young people, care and support for children and families, support to school-based HIV/AIDS education, training of especially youth organizations, capacity building, mobilization of government & civil society for HIV/AIDS prevention and care, research	Selected districts of UP, Bihar, MP, Rajasthan
6	UNIFEM	Gender and HIV/AIDS	Build national capacities of women's organizations, develop resource knowledge base, develop gender strategy for the national program, advocacy	North-East, Maharasthra, West Bengal, Tamil Nadu, Delhi

7	WHO India Country Program	Surveillance system and HIV/AIDS	Prevention and control of STDs by capacity building of PHCs, Strengthen surveillance systems, strengthen capacities for safe blood and blood products, operations research
9	ILO	HIV and workplace	Promote the active involvement of its social partners – employers & unions – in tacking HIV in workplace & protecting rights of HIV employees
10	UNAIDS	Facilitate co-sponsors to lead on strategic areas and mainstream HIV into their ongoing activities	Coordination, support to TRGs, build state capacities, strengthen behavior change beyond high-risk groups, reduce stigma & discrimination, build state capacities, advocacy

Table A.2: Activities and workplans of major bilaterals and international NGOs

	Agency	Assistance (\$)	Major current thrust areas	Future priorities	States
1	Canadian International Development Agency (CIDA)(Source: NACO document)	\$10 million or Rs. 37.8 crores for 5 years, as part of NACP-II (1999-2004)	Models for prevention & capacity building. Focus on sex workers & migrant women	-	Karnataka Rajasthan
2	Netherlands Em- bassy and United Nations Foundation	\$2.9 million each to CHARCA (UNAIDS)Small fund to NGOs under Cul- tural Program for awareness	Capacity building & creation of awareness among vulnerable population, especially adolescent girls & young women	-	Karnataka, AP, UP, Rajasthan, Bihar, Mizoram (1 district each)
3	Norwegian Agency for Development (NORAD)	1.5 million SEK	Prevention (sex workers, peer educators, migrants) and Capacity Building	-	All India
4	MacArthur Foundation	15–20percent of annual budget	Earlier funded HIV/ AIDS programs di- rectly – prevention (counseling, aware- ness), capacity build- ing, networking, ad- vocacy. Now focus on Adolescent sexual- ity and reproductive health (linked with HIV/AIDS) and reduc- ing maternal morbid- ity and mortality	No direct funds for HIV/AIDS planned. Linkage with Sexual- ity and RH.	Rajasthan, Gujarat, Maharashtra, Goa, Karnataka, Delhi
5	European Union (EU)	US \$ 20-30 mill	Fund NGOs on care and support, re- search and rights issues	-	All India
6	Australian Agency for International Devel- opment (AusAID)	Australian \$ 1 million per year direct sup- port to NGOs (25per- cent on HIV/AIDS) Australian \$20 mil- lion (2002–2007) through NACO (still being discussed)	Focus on prevention and care and support	Prevention, Care and Support:MTCT, IDUs, Youth, migrants	Current: North-East, Sikkim, Himachal Pradesh and DelhiBilateral Program:Future:Mizoram, Meghalaya, Manipur and Delhi
7	Population CouncilHIV/STI Prevention and Care research project	\$ 1.5 million (2001– 2004)Funded by Eu- ropean Union	Focus on identifying, validating, developing intervention strategies on prevention and care and support	-	All India

8	Population Council, Horizon's project	Global \$40 million (funded by USAID)No specific allocation for IndiaNext phase: Global \$60 million (funded by USAID)	Focus on intervention research especially on prevention and care and support (community mobilization in sex workers, process documentation of HIV/AIDS intervention model, hospital based study, GIPA)	Next phase: Aug. 2002-July 2007. More emphasis build- ing on learning. Ad- vocacy and policy, MSM, youth, STIs	All India
9	Ford Foundation	No specific allocation for HIV/AIDS programs	Advocacy, peer education, counseling, training, community mobilization;	Sexuality and rights of vulnerable groups, especially women and PLWHA	Plans to focus on marginalized areas- North-East, Jharkhand, Uttaranchal, Chattisgarh.
10	Project Concern International (PCI)	\$300,000 (October 2001-September 2003)	Behavior change: counseling, educa- tion, condom promo- tion, STI (treatment & counseling, training). Care and support	Street and working children in Delhi; truckers in Rajasthan; PLWHA network; closely work with NGOs and CBOs for prevention; increasing care & support activities in Pune	Maharasthra, Delhi, Rajasthan, Tamil Nadu, West Bengal, Andhra Pradesh for prevention.Pune for care and support
11	USAID	Through NACO: APAC-\$ 15 million (5 yrs) AVERT-\$ 41 mil- lion (7 yrs) Field Sup- port: FHI, PSI	Focus on targeted interventions, prevention and Children Affected by AIDS, Research and Models development. New focus on Care and Support in APAC and AVERT	Focus on prevention and awareness in low prevalent states through CARE India, upscaling of CAA through FHI	All India Through NACO- Tamil Nadu and Maharashtra
12	DFID	Pounds 30 million currently to be ex- panded to 123 mil- lion for HIV/AIDS in India (under negotia- tion with GOI)	Prevention: HIV and STI among vulner- able populations in- cluding truckers, migrant workers, sex workers, MSM and prison inmates.	Prevention and sector support, Technical assistance and capacity building through a resource center (planned)	AP, Kerala, Gujarat, Orissa, West Bengal;
13	Family Health International (FHI)	Approx. \$ 1million per year to be in- creased to \$5 million per year	Children affected by AIDS (CAA); technical assistance to APAC and AVERT; technical assistance and re- search for DFID on the truckers' project; support to MSM and networks of positive people	Support to APAC and AVERT; upscale CAA; plans to work with IDUs, migrants and workplace interven- tion in the informal sector; collaborate with Horizons' project on operations research	High prevalence states

14	Population Services International (PSI)National Ports project	US \$ 15-18 million (funded by USAID)	Prevention, Condom promotion, social marketing, aware- ness, STD diagnosis and treatment	-	12 major ports of India
15	India HIV/AIDS Alli- ance	US \$3.5 million for 5 years (funded by Gates Foundation – Frontiers Prevention program)	Community based care and support through the mechanism of a lead partner and implementing partners in the states	Gates Foundation supported Frontiers Prevention project focussing on key populations in A.P and Delhi and Moni- toring and Evaluation	Tamil Nadu, AP, Delhi

## Annex 2

# Preparation of background document for country strategy paper on the current and future situation of HIV/AIDS in India and its possible impact on the future developments

#### **Background**

HIV/AIDS poses an increasing challenge to countries all over the world, both directly as health issues and indirectly through the challenge HIV/AIDS poses for development. The rapid rate of transmission of HIV calls for immediate action in the fields of prevention and care, as well as efforts to mitigate the epidemic's effects on individuals and communities. A wide range of actors and agencies are now involved in efforts to reduce HIV transmission and to mitigate the social and economic impact of the epidemic. Political commitment at all levels is vital in providing a supportive environment for effective and long-term HIV and AIDS-related activities and in ensuring that HIV/AIDS related concerns are integrated into overall planning for development. The Swedish government intends to take a more active role internationally to ensure that a concern for HIV/AIDS is made more central to development programming.

Currently, Sida supports non government organisations in the north-east of India working with injecting drug users and their sexual partners and also advocacy and capacity support to a network of agencies working with vulnerable groups and the community in the region.

#### **Objective of the Review**

Sida is in the process of developing a Country Strategy for development co-operation between Sweden and India for the period 2003-2007. The Country Analysis document will have a chapter on the current and future HIV/AIDS situation in India including an estimation of the scope of the epidemic by 2010 and an analysis of the possible impact of HIV/AIDS on the future developments in India. The Country Strategy document will contain suggestions for possible areas of Swedish support to combat the spread of HIV/AIDS in India.

This review shall provide the necessary information for inputs into the Country Analysis document (overall current and future situation) and the Country Strategy document (possible future interventions by Sida).

Given the time constraint, the review shall be based on information which is already available.

#### **Specific tasks**

The consultants shall

- review and analyse the current HIV/AIDS situation in India;
- elaborate on the likely HIV/AIDS situation in India by year 2010;
- elaborate on the possible future impact of HIV/AIDS on the overall developments in India during the period 2002-2010;
- derive implications for cost of the epidemic at the micro, sectoral and macro level; and
- make recommendations to Sida on priorities, principles and possible areas for Swedish support during 2003-2007.

#### Methodology

The consultants shall

- undertake a desk review of important published and unpublished material on HIV/AIDS in India;
- consult with experts and practitioners.

The entire exercise shall be undertaken in four weeks duration with the first two weeks spent on identification of sources for information and selecting priority data. During the next two weeks the data shall be analysed and a draft report prepared. The draft report shall be shared with a small group of relevant people for comments, following which the final analysis and report shall be submitted to the Development Co-operation Section (DCS) at the Embassy, New Delhi.

#### Reporting

A draft report shall be submitted to DCS no later than 15 April, 2002. The report shall not exceed a maximum of 40 pages and should include an Executive Summary and Conclusions and Recommendations. The consultants should quote the sources or attach excerpts from such sources whenever possible as well as list of people interviewed.

The finding shall also be verbally presented at a seminar organised by DCS.

Within two weeks after receiving comments on the draft report, a final version shall be submitted to the Embassy in five copies and on a diskette. The report should be written in Word 6 or in a compatible format.

#### **Team Composition**

A three member team comprising of experts from the field of social development, epidemiology and health economics shall be identified for the review.

#### **Time Plan**

The time frame for the assignment will be a total of 25 days spread over from February to April 2002.

# **List of Individuals Contacted**

- J.V.R. Prasada Rao, Director, National AIDS Control Organisation
- Nandini Kapoor Dhingra, Senior Project Officer (Development Assistance), AusAID
- Kathleen Kay, Country Director, Family Health International
- K.Pradeep, Strategic Planning Officer and Pernilla Berlin, UNAIDS
- Rajesh Singh, Assistant Country Director, Project Concern International
- Sanjay Kapur, Project Management Specialist, Office of Population, Health and Nutrition, USAID
- Frederika Mejer, Consultant-Gender and Development, Royal Netherlands Embassy
- M.K.Padma Kumar, Programme Officer, DFID India
- Tara Sharma, Program Officer, Royal Norwegian Embassy
- Parimal Bardhan, Team Leader-Health Sector, European Union
- Suneeta Dhar, UNIFEM
- Dipa Nag-Chowdhury, Program Manager, MacArthur Foundation
- Roshmi Goswami, Program Officer, Sexuality and Reproductive Health, Ford Foundation
- Dr.Swarup Sarkar, InterCountry Technical Advisor, Vidya Ganeshan and Anne Bergenstrom South Asia Regional Office, UNAIDS
- Vaishali Sharma Mahindra, Program Officer, Horizons Project, Population Council
- S.Suresh Kumar, Project Director, West Bengal State AIDS Prevention and Control Society
- Gurumurthy Rangayan, Project Director, Population Council
- Marta Levitt Dayal, Country Director, CEDPA India

Halving poverty by 2015 is one of the greatest challenges of our time, requiring cooperation and sustainability. The partner countries are responsible for their own development. Sida provides resources and develops knowledge and expertise, making the world a richer place.



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