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The International Fund for Agricultural Development

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REPUBLIC OF INDIA

STATUS OF HIV/AIDS

Asia and the Pacific Division
Programme Management Department

CONFIDENTIAL
REPORT No.1442-IN

October 2003

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REPUBLIC OF INDIA

STATUS OF HIV/AIDS

Table of Contents

Executive Summary
Acronyms

I. Introduction.......................................1
II. HIV Estimates and Geographical Spread.......................................3
III. Hot-Spots.......................................4
IV. Controversy over Estimates.......................................8
V. Major Causes and Determinants.......................................9
VI. Response : Prevention and Control Strategies.......................................10
VII. Present Trends of Impact of Prevention and Control Strategies.......................................18
VIII. Impact Of HIV/AIDS On Morbidity/Mortality.......................................20
IX. Conclusions and Major Issues for Donor Agencies.......................................23

APPENDICES

1. Assumptions of NACO's HIV Estimates.
2. State-wise HIV Prevalence Levels, 1998-2002.
3. List of High Prevalence Districts, 2001.
4. State-wise Distribution of HIV/AIDS cases, January 2000
4B. State-wise Distribution of AIDS cases, September 2003
5. Ashok Das's report: The Hindustan Times/28 October 2003
6. Salient Features of APAC Project, Tamil Nadu, 2001
7. Peter Godwin's Interview with Satya.
8. Sara Yang's report: UC Berkeley News/19 June 2003
9. John Lancaster's report: The Washington Post/11 June 2003
10. Amy Waldman's report: The New York Times/11 November 2002

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Acknowledgement

This report was written for IFAD by Mr.Priyadarshi Thakur, IFAD Consultant as a background paper for the Country Strategy and Opportunities Paper (COSOP) for India.

The opinions expressed in this report do not necessarily represent the view of IFAD or its member governments.

Status of HIV/AIDS

Executive Summary

The seroprevalence estimates of National Aids Control Organization (NACO) indicate that in 2002 there was 4.58 million people living with HIV/AIDS of whom about 25% are estimated to be women. On account of the huge population of over 1 billion the seroprevalence rate is only 0.8%. Being less than 1% it is termed as low but that cannot be a cause for complacency because even 0.1% upward increase in India would mean half-a-million more HIV/AIDS cases. All international agencies like UNAIDS, USAID, CIDA, UNDP who are providing assistance for fighting HIV/AIDS as well as the GOI itself are of the view that if effective steps are not taken urgently to contain its spread, the country might get into a crisis situation in the next decade.

The epidemic has already resulted in approximately 95000 (January, 2000) reported cases of HIV and over 55000 cases of AIDS (September, 2003), but these numbers may be deceptive as there is a general tendency to hide HIV-positive status both as a condition and as a cause of death because of fear of social stigma and ostracisation. Reluctance to get tested for HIV, non-declaration HIV-positive status, inadequate testing facilities etc. have resulted in the HIV epidemic leaving deceptively low statistical foot-prints and in controversies about the intensity of the epidemic, estimates of HIV prevalence etc. There were differences on this score in the 1990s but now both UNAIDS and NACO agree on the estimate of 4.58 million in 2002 yielding a seroprevalence percentage of 0.8%.

There are 6 major States and one small State in the Indian Union which are categorized as high prevalence States on the basis of the parameters adopted by NACO in consultation with UNAIDS and WHO experts and epidemiologists. These States are Andhra Pradesh, Tamil Nadu and Karnataka in the southern part, Maharashtra and Goa in the western part and Manipur and Nagaland in the northeastern part of the country. Two western States, Rajasthan and Gujarat are categorized as medium prevalence states while the remaining States of the country are categorized as low prevalence, though vulnerability of the latter is high because of high levels of illiteracy, poverty and their contribution to the migrant labour market in other parts of the country as well as to urban areas within their own boundaries. Mumbai, Delhi, Kolkata and Chennai and other smaller cities, their red-light districts and slums are some of the main breeding grounds of the HIV infection. So are the highway networks with the truckers being on the road for months on end and indulging in unprotected sex with multiple partners.

The main cause and route of infection is unprotected heterosexual and homosexual relations between multiple partners, with Sexually Transmitted Diseases playing a catalytic role, and account for almost 85% HIV cases. The other major factors are unsafe blood transfusions (4%) and Injecting Drug Use/Syringe sharing (8%). Unsafe sexual contact with prostitutes, men having sex with men (MSM) and promiscuity are the biggest factors driving the epidemic, followed by injecting drug use which is the major factor in the north-eastern states. What is really worrying the government and HIV experts in India and abroad is that the epidemic, earlier localized in high-risk behaviour groups is showing signs of breaking out of the confines of such groups in urban areas and is beginning to affect general population groups which are at risk because of lack of awareness or low social status, e.g. rural women getting infected by their husbands coming back from work in urban areas. Until January, 2000 approximately 3622095 samples had been screened and 94966 HIV and 10857 AIDS cases had been reported in the country. The reported cases of AIDS were 55764 as on 30 September, 2003. However, the actual number of cases may be much higher because very few people/families like to admit having HIV infection because of social stigma.

NACO has identified 49 districts in the country on the basis of annual Sentinel Survey of 2002 as high prevalence districts. A number of other districts/places mentioned in section III of the report and all truckers-joints on the highways and red-light districts in urban areas also need to be seen as potential hotspots for targeted preventive and remedial interventions.

Rural hinterlands which send millions of seasonal and migrant labourers to urban/semi urban areas are highly vulnerable on account of lack of awareness, illiteracy and low status of women, thousands of whom might be getting infected by their husbands. Such States even through categorized as low-prevalence at present need to be brought into the focus of preventive interventions, particularly PPTCT.

NACO is implementing a diversified campaign against HIV/AIDS under NACP Phase II 1999-2004, described in detail in section VI of the report. The campaign has gathered greater momentum since the adoption of National AIDS Prevention and Control Policy and National Blood Policy in 2002 and sanction of a much larger package of financial assistance by the World Bank and other donor agencies in the late 1990s, but most observers and experts are of the view that much more needs to be done to prevent India following in the footsteps of sub-Saharan Africa.

No reliable statistics of morbidity and mortality are available because most people tend to hide their seropositive status for fear of severe social stigma and ostracisation (See Annexes 5 and 7 in particular). No firm estimates of economic impact of HIV/AIDS in India are available either, but some studies cited in the report and the experience of African countries quoted in the National AIDS Policy document, suggest crippling and calamitous implications for the economy and developmental programmes if the anti HIV campaign is not raised to 'war-footing' with immediate effect. Major issues, which international donor agencies need to keep in view, are listed in section IX of this report.

Abbreviations used in the paper

AIIMS	-All India Institute of Medical Science
AIDS	-Acquired Immune Deficiency Syndrome
ANC	Antenatal Clinic
APAC	-AIDS Prevention and Control Project, Tamil Nadu
BSS	-Behavioural Surveillance Survey 2002
CBO	-Community Based Organization
CSW	-Commercial Sex Worker
FHI	-Family Health International
FSW	-Female Sex Workers
GOI	-Government of India
HIV	- Human Immunodeficiency Virus
IEC	-Information Education & Communication
ICMR	-Indian Council of Medical Research
IDU	-Injecting Drug Use/Users
MSM	-Men who have sex with men
NACO	-National AIDS Control Organization, India
NAPC	-National AIDS Control Programme
NGO	-Non-Government Organization
PTCT	-Parent to Child Transmission
PPTCT	-Prevention of PTCT
PLHA	-People Living with HIV/AIDS
SACS	-State AIDS Control Society
STD	-Sexually Transmitted Disease
STI	-Sexually Transmitted Infection
UNAIDS	-Joint UN Programme on HIV/AIDS Control
USAID	-United States Agency for International Development
VCCT	-Voluntary Confidential Counselling and Testing
VHS	-Voluntary Health Services, Chennai
WHO	-World Health Organization

I. Introduction

According to the latest estimates of National Aids Control Organization (NACO), the nodal agency of Govt. of India (GOI) which coordinates and spearheads the fight against AIDS, approximately 4.58 million men, women and children were living with HIV/AIDS in the country at the end of the year 2002 at an adult (15-49 years) prevalence rate of about 0.8%. India accounted for 10% of the global HIV burden and a staggering 65% of the prevalence estimate of South and South East Asia. Its estimated population of 4.58 million persons infected by HIV/AIDS is second only to South Africa, which has an estimated 5.00 million people suffering from HIV/AIDS.[1]

2. The UNAIDS Report on the Global HIV/AIDS epidemic, released in July 2002, noted that an estimated 3.97 million people were living with HIV/AIDS (PLHAs) in India at the end of 2001, and though the overall prevalence rate was under 1%, the country was 'experiencing serious, localized epidemics', leaving little room for complacency in dealing with the situation. The UNAIDS Report added that there were more PLHAs in India than any other country besides South Africa. The epidemic was spreading among general population and beyond groups with high-risk behaviour.2 In May 2003, commenting on the HIV/AIDS scenario in India Peter Piot, UNAIDS chief stated that if steps being taken by government were not effective, India might soon overtake South Africa in absolute figures though not in relative terms,3 implying obviously that the alarm bells tended to get somewhat muted by the relatively low statistic of prevalence in percentage terms because of the gigantic population size of India.

3. More recently, in October' 2003 Richard Holbrooke, Former US Ambassador to the UN and President and CEO of the Global Business Coalition (GBC) on AIDS warned that India needed to focus on prevention of AIDS immediately in order to avoid a crisis in the future, and that experience of countries like Thailand, Uganda and Senegal showed that effective action could indeed stem and reverse the growth rate of HIV prevalence. He added that though the overall prevalence rate in India had not touched 1% yet, enormous effort would be necessary to keep it below that level in the years to come.4

4. Also, in October 2003 Bill and Melinda Gates Foundation made an announcement doubling their grant for fighting AIDS in India from $100 million to $200 million and released $ 67.5 million to 5 organizations in India. There is reason to believe that the Foundation took a well-considered decision looking to the seriousness of the HIV/AIDS scenario in India.5

5. According to NACO the estimated numbers of PLHAs in India in the last five years since 1998 do not indicate any dramatic upsurge, as these have risen from 3.5 million in 1998 to 3.71 million in 1999, 3.86 million in 2000, 3.97 million in 2001 and 4.58 million in 2002.6 However, a number of socio-economic and infrastructure related factors would appear to lend greater credence to the warning of a 'crisis in the future' than suggested by low prevalence percentage, absence of sudden spurt in the numbers of PLHAs or the relatively small number (55764) of full-blown cases of AIDS reported so far in the country. The major factors complicating the scenario, which is potentially fraught with the seeds of an epidemic of enormous proportions, are as under:

[1] NACO : 'HIV Estimates in India' at http://www.naco.nic.in/indianscene/esthiv.htm
[2] UNAIDS Report on Global HIV/AIDS, 2002
[3] rediff.com: India second highest in AIDS cases/news/July/03/aids.htm
[4] Global Business Coalition on AIDS/Internet report
[5] The New York Times report on Gates Foundation announcement at http://www.saaaids.org/media/gatesCharity.html
[6] NACO : 'HIV Estimates in India' at http://www.naco.in/indianscene/esthiv.htm

- A huge segment of India's population, almost 450 million being illiterate, which is bound to inhibit the effectiveness of Information Education and Communication (IEC) initiatives in general, and IEC on HIV/AIDS in particular because of conservative social mores.
- A huge segment of population, an estimated 260 million, living below the Poverty Line of a dollar a day and a large part of it being constantly in the flux of inter-state and rural-to-urban area migration in search of employment; more often than not, without their families accompanying them.
- Low social status of women and gender bias against women, particularly in the population segments indicated above, making them easy, and often helpless prey of HIV infection.
- High degree of social stigma attaching to Sexually Transmitted Diseases (STDs)/HIV/AIDS which are often seen as 'just' retribution of Nature for loose, lecherous and immoral behaviour, and consequent aversion to talk about or have anything to do with STDs/HIV/AIDS.
- Social taboo and popular misconceptions about AIDS being a highly contagious disease, manifesting itself often in a less than professionally-informed approach even amongst a high percentage of medical personnel expected to deal with the menace.
- General social apathy including lack of adequate medical facilities towards Commercial Sex Workers (CSWs), transvestites, migrant labour and other high-risk behaviour groups.
- Tendency to hide STDs and consequent preference for private clinics, even quacks, over public health facilities.
- Less than adequate facilities/coverage for antenatal check of pregnant women.
- Less than adequate infrastructure/coverage for screening of blood donated to blood banks and lingering clandestine presence of professional blood donors despite the recent ban on professional donors imposed by the government.
- Less than adequate database/facilities/coverage for epidemiological studies.
- Rise in stress-levels in society leading to greater incidence of Injectable Drug Use (IDU).
- Manifold expansion of highway network and exponentially increasing volume of highway traffic.

6. On account of these factors, HIV/AIDS situation/statistics can easily get out of hand in no time if complacency arising out of low prevalence percentage statistic is allowed to determine the attitude of those engaged in dealing with the situation. Given the socio-economic environment of urban and rural life in India, the HIV/AIDS scenario in India has to be recognized as potentially grave, which makes it imperative for the government agencies and non-government organizations (NGOs) engaged in anti-AIDS campaign, and indeed the community at large, to take immediate note of the warning sounded by the UNAIDS Report and GBC on AIDS.

7. It may not, however, be out of place to briefly mention at the outset that NACO does indeed recognize the gravity of the situation and has formulated, and obtained the approval of the GOI on a comprehensive National Blood Policy, 2002 as well as National AIDS Preventions and Control Policy, 2002 besides giving concrete shape to a number of initiatives on the ground to effectively fight and contain the menace of HIV/AIDS. It is intended to cover the substance of these initiatives in section VI of this Report.

II. HIV Estimates and Geographical Spread

8. Estimates of HIV/AIDS prevalence in the country are based on annual rounds of Sentinel Surveillance Survey conducted in all the States and Union Territories of the Indian Union. These Sentinel Surveys are conducted in accordance with the guidelines of NACO, formulated on certain assumptions evolved in consultation with a group of experts which includes eminent epidemiologists, bio-statisticians and representatives of WHO and UNAIDS. These annual exercises which have been conducted regularly since 1998 through 2002 at selected sites, spread all over the country, include STD clinics (STD) Ante-Natal clinics (ANC) Injectable Drug Users clinics (IDU) and sites for Men having sex with Men (MSM). In order to broad base the sample-size, the number of such sites has been progressively increased from 180 in 1998 and 1999 to 232 in 2000, to 320 sites in 2001 and to 384 sites in 2002.[7]

9. The annual round of HIV Sentinel Survey was conducted during August-October, 2001 at 320 sites, which included 135 STDs, 170 ANCs, 13 IUDs, and 2 sites for MSM. According to NACO's 'HIV Estimates in India,' working on the basis of assumptions made during 1998-2000 and following a consistent methodology, a similar worksheet was developed using the 2001 HIV Sentinel data. This worksheet was then examined and discussed by a group of experts and later by a Task Force on Surveillance, which included international experts from WHO and UNAIDS. The assumptions for HIV data of 2001 were also updated in line with recommendations of this expert group. This formed the basis of a point estimate for the year 2001 of 3.31 million HIV infections in adult population (15-49 years) in the country, and allowing for a variability of 20% to take care of the unaccounted numbers of IDUs, MSMs etc. a working estimate of 3.97 million HIV infections was prepared.[8]

10. The assumptions which formed the basis for the estimates as indicated above (including the justification for urban: rural and male-female gradients) are appended as Annex-1 to this report.[9]

11. On the basis of these assumptions, States of the Union have been divided into 3 categories: (i) High Prevalence States (ii) Moderate Prevalence States, and (iii) Low Prevalence States, defined as under:

- High Prevalence States – More than 1% HIV prevalence in Antenatal women.
- Moderate Prevalence - Less than 1% HIV prevalence States in Antenatal women with 5% or more HIV prevalence in STD & other high-risk groups.
- Low Prevalence States -Less than 1% HIV prevalence in Antenatal women and less than 5% HIV prevalence in STD and other high-risk groups.

12. The annual Sentinel Survey, 2002 witnessed a rise in the number of sites to 384 with the inclusion of 64 new sites. These consisted of 166 STDs, 200 ANCs, 13 IDUs, and 3 sites for MSM and 2 sites for CSWs. During the 2001 survey, a number of high prevalence districts were also identified on the basis of consistently high figures of prevalence during the last 3 rounds of annual surveillance, for focused and intensive programme action.

13. A comparative table of sites surveyed during 1998-2002 indicating the State-wise HIV prevalence findings and State-wise list of high prevalence districts identified in 2001 are appended as Annex-2 and Annex-3, respectively. Annex-4 and Annex-4B contain the State-wise distribution of the number

[7] NACO : 'HIV Estimates in India' at http://www.naco.in/indianscene/esthiv.htm
[8] *ibid*
[9] *ibid*

of HIV and AIDS cases reported until 31 January, 2000 and reported AIDS cases as on 30 September, 2003, respectively.

14. According to information available at NACO's website, in addition to consistency of assumptions and methodology being maintained while analyzing the data of 2002 survey, a number of other decisions were also taken in order to make for a more objective and broad-based set of findings through professional peer review and impartial scrutiny. These were:

- The Indian Council of Medical Research (ICMR) was invited to participate in the exercise.
- A core group of experts was set up. It included eminent epidemiologist, bio-statisticians and representatives of WHO and UNAIDS. The ICMR and NACO convened a meeting of the expert group to review the procedures and data used for estimation.
- A decision was taken to adopt a prevalence range instead of a point estimate, as the former was considered more scientific and realistic.

15. In line with the recommendations and advice of the expert group, the HIV estimates for the year 2002 worked out to be 3.82 million HIV infections (15-49 years), which yielded an upper range figure of 4.58 million with a 20% variability factor adopted in 2001 too. This increase of approximately 0.6 million from 2001 to 2002 is attributable mainly to ANC sites in Karnataka, Rajasthan, West Bengal and STDCs in Andhra Pradesh, Tamil Nadu, Gujarat, Bihar, Madhya Pradesh and Rajasthan.[10]

III. Hot-Spots

16. It would be seen from the prevalence statistics of various categories of sites in different states as revealed in the sentinel surveys during years 1998-2002 [Annex-2] read together with the definitions of high, moderate and low prevalence States (para 11), that the following are categorized as high prevalence States and moderate prevalence States:

High Prevalence States

S.No.	Name of State	Number of sites 2002	HIV Prevalence (%) 2002
1	Andhra Pradesh	STD 8 ANC 14	30.40 1.25
2	Goa	STD 2 ANC 2 CSW 1	11.29 1.38 24.00
3	Karnataka	STD 7 ANC 10 IDU 1	13.60 1.75 2.26

[10] *ibid*

4.	Maharashtra	STD 9 ANC 14	7.60 1.25
5	Manipur	IDU 3 STD 2 ANC 10	39.06 9.60 1.12
6.	Nagaland	IDU 3 STD 1 ANC 4	10.28 2.42 1.25
7.	Tamil Nadu	STD 11 ANC 10 IDU 1 MSM 2	14.7 0.88 (1.13 in '01) 33.80 2.40

Medium Prevalence States

S.No.	Name of State	Number of sites 2002	HIV Prevalence (%)
1.	Gujarat	STD 8 ANC 8	6.17 0.38
2.	Rajasthan	STD 7 ANC 6	6.00 0.50

17. In terms of number of high prevalence districts identified in 2001 survey, Maharashtra tops the list with 14 districts, followed by Karnataka (10), Andhra Pradesh and Tamil Nadu (7 each), Gujarat and Nagaland (3 each) and Goa (1). [List of Districts: Annex-3].[11] Amongst the Metro-cities, Mumbai finds special mention in the Sentinel Survey listing of NACO with the following results in 2001 and 2002:

No. of sites	HIV Prevalence (%) 2001	HIV Prevalence (%) 2002
STD 3	21.06	14.84
ANC 6	2.25	0.75
IDU 1	41.37	39.42
MSM 1	23.60	16.80
CSW 1	52.26	54.50

18. It would appear from the table above that: (a) in Mumbai (Bombay), which was described sometime ago as the 'AIDS capital of India', the percentages have registered a downward trend except in the case of CSW, and (b) prevalence percentage in ANCs in Tamil Nadu has decreased from 1.13% in 2001 to 0.88% in 2002.

19. The 49 districts, most of which are located in the high-prevalence States, and Mumbai, which finds special mention as above could be termed as 'hot-spots' of HIV/AIDS infection for the country as a whole. These, however, do not exclude the very probable existence of many smaller clusters of intense HIV infestation and future breeding ground of AIDS. India has an increasingly expanding network of 58312 kms of National and 128000 kms of State highways besides about half-a-million kms. of major district roads. Transportation of commercial goods by trucks has been growing by leaps and bounds with the growth of commercial activities in the wake of liberalization of the economy. Both these factors together have resulted in hundreds of smaller 'hot-spots' of HIV infections developing along the arterial corridor of highways. Roads and road-transport have also opened up

[11] *ibid*

remote tribal areas and have made it possible for truckers and certain other urban segments to have greater opportunities of casual sex in such areas because of a combination of factors like poverty, innocence and permissive social mores of the local populace. Most experts on HIV/AIDS in India agree that given the overall Indian socio-economic scenario, there have to be hundreds of such HIV 'hot-spots' along highways and areas inhabited by tribal people with relatively relaxed sexual mores.

20. Another reason, which has resulted in manifold increase in the number of smaller clusters of HIV 'hot-spots', is the unprecedented growth of urban slums because of domestic migration to urban areas as well as influx of refugees from neighbouring countries. Eminent epidemiologists like L.M. Nath believe that given the hygienic, nutritional and sexual parameters of life obtaining in these slums, these are ideal breeding grounds for STDs/HIV and finally AIDS.[12]

21. Although among the major Indian cities only Mumbai is included separately in the survey listing of NACO, all major cities like Delhi, Kolkata, Chennai and even smaller ones like Hyderabad, Bangalore etc. and their surrounding semi-urban areas having their own red-light districts, substantial population of open and clandestine CSWs and huge slums with sizeable percentage of migrants living without their families, have to be seen as 'hot-spots' of HIV/AIDS for purposes of investigative surveillance, IEC, and remedial measures. As a matter of fact Kolkata's red-light district Sonargachi was the site selected some years ago for a project on universal condom use and was the subject of a micro-study on AIDS awareness.

22. A number of such examples have been referred to in some detail by Gracious Thomas of Indira Gandhi National Open University[13]:

- Bhawani Shankar, a social worker in Rajasthan reported that 'Rajnat' and four other tribes were spread over 144 sex centers in the state. In its eastern part where the study was conducted, there were at least 20000 'Rajnat' women known to be involved in sex- trade and about 2000 of them were estimated to be suffering from HIV/AIDS; majority of men in Nandlalpura were unemployed, except for ferrying customers in jeeps from the highway. Highways in the State served the sexual appetites of truck drivers and men from towns close by. (p.90-91)
- According to a NACO report, Baina in Vasco-de-Gama (Goa) has over 2000 commercial sex-workers. A small district-sized state like Goa had as many as 2490 HIV and 19 AIDS cases (Jan.2000). WHO and NACO have selected Baina for special targeted intervention (P.91).
- As many as 1400 of the 21862 Devadasis in Karnataka concentrated in Belgaum, Bijapur and Raichur districts, suffered from HIV, as reported in Jan 1993. (p.107)
- A study conducted by Tata Institute of Social Sciences (TISS), Bombay has estimated that there are approximately 2 million brothel- based prostitutes in India residing in about 817 red-light districts with more than 5 million children labelled as illegitimate. Obviously the number of 2 million does not include call-girls or non-brothel based CSWs. Most of these sex workers live and work in abominable conditions of nutrition, health and hygiene, conducive for contracting STI and HIV infection and spreading it through their customers. Since this study by TISS is over 13 years old, the numbers could be much higher now. (p.102)

The above is only an illustrative mention and could indeed be the proverbial tip of the iceberg.

23. Contents of paras 19 to 22 above may appear to be generalizations without sufficient supporting data pinpointing the HIV 'hot-spots'. It is true that at this stage of epidemiological studies and

[12] Dr. L.M. Nath, former Director of AIIMS, New Delhi and an eminent epidemiologist: 'The Epidemic in India: An Overview' in 'The Looming Epidemic – The Impact of HIV and AIDS in India' Ed. Peter Godwin/MosaicBooks, New Delhi/1998.

[13] 'HIV: Education and Prevention – Looking Beyond the Present' by Prof. Gracious Thomas, 2001

because of the sample size of annual Sentinel Surveys in India, it is difficult for any organization to furnish precise data on each of the mushrooming 'hot-spots'. Even the overall estimation of HIV/AIDS infection has been the subject of some debate and a degree of disagreement (mainly because of insufficiency or irregularity of epidemiological data). However, as testified by a plethora of micro-studies conducted in India and abroad, such as the ones cited in publications like 'The Looming Epidemic: The Impact of HIV and AIDS in India' [14], any attempt to understand the nature of growth of HIV/AIDS infection in India must, in order to succeed, take into account not only what is established and accepted officially on the basis of data but also facts which are seen as the ground reality at the micro-level by people having an insight in the overall socio-economic and developmental scenario of the country. This is necessary so as to allow for a mindset which recognizes the problem as being larger than can be proven by official statistics, and the consequent need for flexibility and delegation of authority for micro-level solutions by NGOs acting in concert with Civil Society and local self government authorities. The validity of such a perception of mushrooming HIV 'hot-spots' is substantiated by the basket of IEC and other activities selected by SACS and NGOs as described in section V and the activities selected by VHS for APAC in Tamil Nadu. Responsible media reports appended as annexes and available at the websites under Reference at the end of this report also indicate in a similar direction.

24. The latest status reports received from high prevalence States on their HIV prevention and control activities indicate that the following districts/places may be regarded as an illustrative list of 'hot-spots' of HIV/AIDS in these States:

Andhra Pradesh

1. Hyderabad City
2. Nizamabad
3. Karimnagar
4. Medak
5. Warangal
6. Rangareddy
7. Nalgonda
8. Guntur
9. Ananthpur
10. Cuddapah
11. Chittoor
12. Nellore
13. Prakasam
14. Krishna
15. West Godavari
16. East Godavari
17. Vizianagarm

Karnataka

1. Bangalore City
2. Mysore
3. Dharwad
4. Bellary
5. Belgaum
6. Gulbarga
7. Dakshin Kannada
8. Udipi
9. Bijapur
10. Shyamraj Nagar

Maharashtra

1. Greater Mumbai (Bombay)*
2. Thane*
3. Nasik
4. Pune*
5. Satara
6. Solapur
7. Kolhapur*
8. Sangli*
9. Aurangabad
10. Latur
11. Chandrapur
12. Nagpur*

(*Particularly serious localized epidemics)

Manipur

[14] 'The Looming Epidemic: The Impact of HIV and AIDS in India'/Ed. Peter Godwin New Delhi, 1998

1. Imphal
2. Shalom
3. Bishnupur
4. Churachandpur
5. Senapati
6. Ukhrul

Nagaland

1.	Kohima	Peren, Jalukie
2.	Dimapur	Medziphema, Chumukidema
3.	Mokokchung	Tuli, Changtongya, Merangkong
4.	Tuensand	Noklak, Panso, Chare, Shamator, Longkhim, Kiphere, Longleng
5.	Mon	Naganimore, Tizit, Abhoi, Tobu
6.	Zunheboto	Aguloto
7.	Phek	Pfutsero, Chazouba, Meluri
8.	Wokha	Bhandari, Sanis, Baghty

(Districtwise list of localised epidemics)

Tamil Nadu

1. Chennai City
2. Madurai
3. Trichy
4. Salem
5. Coimbatore
6. Namakkal
7. Tirunelveli

IV. Controversy over Estimates

25. As stated earlier in section III of this report, the estimates of HIV prevalence in India have been a subject matter of some debate and difference of opinion since the mid-1990s when endorsing the prediction of WHO's Global Programme on AIDS (GPA), UNAIDS declared that India would soon have the dubious distinction of being the epicenter of the HIV/AIDS pandemic in the world.[15] In the years between 1995 to 1997 several divergent estimates of HIV prevalence emanated from (a) NACO working with GPA, (b) NACO itself, (c) South East Asia Regional Office of WHO (SEARO/WHO) and (d) Prof. T. Jacob John of Vellore. While the GPA-NACO estimate was of 1.75 million[16], NACO by itself pegged this figure at 1.5 million at the end of 1995[17]. On the other hand, SEARO/WHO estimated it to be 2.5 million (March'97)[18] Around the same time, Prof. T. Jacob John raised the pitch of divergence sharply by coming up with an estimate of 4.48 million.[19]

26. However, the divergence of views regarding HIV-prevalence statistics between UN bodies and NACO now seems to have been reconciled over the years by involving experts from UNAIDS and WHO in the processing of Sentinel Survey data and agreement to allow 20% margin of variance, as indicated above. This is reflected in the fact that UNAIDS Report on the Global HIV/AIDS epidemic (July, 2002) also adopted the NACO estimate of 3.97 million HIV infections.[20]

27. 27. While on the subject of controversies regarding estimates, it may be mentioned that in 2000 some critical observations also appeared in the media alleging manipulation of data with regard to

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[15] Peter Piot: UNAIDS, MAP, Vancouver
[16] Burton A, Thierry E. M. and Shiv Lal: 'Estimation of Adult HIV Prevalence as of the end of 1994 in India', Ind. Jn. Public Health, 39:79-85, 1995
[17] NACO, Country Scenario Update, MOHFW India, Dec. 1995
[18] SEARO/WHO: AIDS Update, March 1997
[19] T. Jacob John: 'Estimating the Burden of HIV infection in India' – Round Table on HIV/AIDS Surveillance in India, Network for Child Devlopment and Association for Health, New Delhi/1996.
[20] UNAIDS Report on Global HIV/AIDS Epidemic, p.30

Manipur state which was shown as having recorded an improvement from 177 HIV positive people per thousand to just 20 per thousand in only two years.[21] However, NACO's comparative figures of Manipur in Annex-2 do not exhibit any evidence of such a sharp drop between 1998 to 2000.

28. NACO on its part maintains that annual Sentinel Survey is the most scientific of the available alternatives for estimating HIV prevalence rates and the data collected in the Survey and processing thereof is a transparent procedure completely in the public domain. While no one can possibly guarantee complete accuracy of estimates based on Sentinel Survey, yet there is no way that these can be rigged at will by manipulating survey data. Fluctuations in data can be caused by a wide variety factors and circumstances, and that by itself cannot be proof of manipulation.[22]

29. Protagonists of action-oriented approach towards fighting HIV/AIDS do not put much store by the controversy about statistics and estimates, and believe that exact figure is largely an academic issue, and given the unanimously admitted gaps in epidemiological data and procedural delays, accurate figures at any point of time might well be a desirable but unachievable ideal with little 'programmatic implication'. L.M. Nath sums it up nicely: 'The interventions required to be put in place will not change whether the actual number turns out to be one million or five millions; once we are dealing with such very large numbers, we have a very serious problem. No matter where the true figure lies, there is no contesting the fact that there are a lot of HIV positive persons in India and it is essential that health decision-makers take immediate steps to minimize the spread of HIV today.[23]

30. While reliable statistics do indeed make for more effective implementation of programmes, one would tend to agree with L.M. Nath's view that looking to the unique socio-economic, sociological and psychological factors and misapprehensions which surround the phenomenon of HIV/AIDS in a highly conservative country like India, expending too much time or energy on accuracy of estimates might indeed prove to be an expensive diversion.

V. Major Causes and Determinants

31. HIV/AIDS epidemic in India, as in most other countries of Africa, South Asia and South-East Asia is driven predominantly by infection through the heterosexual and homosexual route with about 85% of the infection occurring on account of casual unprotected sex with multiple partners. The other lesser contributing factors are infection through/in the course of blood transfusion (4%) and through injecting drug use/needle sharing (8%). Sexually Transmitted Diseases (STDs) have a strong co-relation with HIV/AIDS and are in a large number of cases, the starting-point of HIV infection. About 90% of the reported HIV/AIDS cases are seen to have occurred in the sexually active and economically productive age group of 15-49 years, and one in every 4 cases (approximately 25%) is a woman. Once a woman is carrying HIV infection or a pregnant woman becomes infected, there is a 25-30% chance of the child inheriting the infection and becoming a case of paediatric infection, also referred to as Parent to Child Transmission (PTCT).[24]

32. As indicated in section I of this report, a number of socio-economic factors have been contributing to and are capable of further fuelling the spread of HIV/AIDS infection in India. From the reports published by NACO, the nodal agency of GOI and various international agencies like WHO, UNAIDS, USAID as well as research on HIV/AIDS in India, it is abundantly clear that major determinants of HIV/AIDS situation in the country are of a socio-economic and cultural nature. The National HIV/AIDS Prevention and Control Policy, 2002 also recognizes the fact that rather than being a mere public health issue, HIV/AIDS is a developmental concern for the country as a whole because it derives sustenance from behavioural risk dictated by poverty, illiteracy, social customs etc.

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[21] http://www.aegis.com/news/ips/2000/IP 001103.html
[22] http://www.aegis.com/news/ips/2000/IP 001103.html
[23] Dr. L.M. Nath: 'The Epidemic in India: An Overview' in 'The Looming Epidemic: The Impact of HIV Aids in India' Ed. Peter Godwin
[24] National AIDS Prevention and Control Policy'2002 document

33. Survey undertaken in two of the high prevalence States under AIDS Prevention and Control (APAC) Project supported by USAID and NACO by Voluntary Health Services, Chennai (an NGO) in respect of Tamil Nadu[25] and Behavioural Surveillance Survey in Maharashtra[26] conducted by Family Health International, also funded by USAID/NACO, have confirmed that HIV/AIDS is largely confined to the underprivileged and arise out of high-risk behaviour of marginalized segments of urban and semi-urban communities living in varying degrees of poverty and having ample opportunities/compulsion for casual and unprotected sex with multiple partners. They can be broadly categorized as under:

i. Brothel-based CSWs.
ii. Other 'home-based' or 'temple-based' sex workers like in Tamil Nadu and Karnataka or call girls in urban areas.
iii. Truck drivers/helpers spending months on the highways and their sexual partners (CSWs/Men).
iv. Migrant labour/transport operators living in urban slums without their families.
v. Slum-dwelling youth, both heterosexual and homosexual, indulging in risky behavior.
vi. Injectable Drug Users who get exposed to HIV/AIDS infection through needle sharing. This is believed to be the major driving factor of the epidemic in the high HIV prevalence States of Manipur and Nagaland.
vii. Professional Blood-donors, a high percentage of whom get infected, causing blood-borne transmission and spread of the infection. Although professional donation has been legally banned now as a part of the National Blood Policy, the phenomenon of professional blood donation cannot have disappeared altogether so soon.

34. Categories ii to iv above are rightly regarded as the factors driving the epidemic towards its second phase, i.e. transmission from urban pockets and from high-risk behaviour groups to rural areas and passive recipients in low or non-risk behaviour general groups. Home–based CSWs, truckers and their helpers, migrant labour etc. who contract STIs/HIV infection during their high-risk behaviour phase in urban and semi-urban areas become carriers of the infection to their unsuspecting families based in rural areas, thus spreading the scourge directly as well as through PTCT mode. On account of gender bias, low status of women, illiteracy and ignorance, wives of such infected persons are easy prey for HIV infection. In any case women in India, particularly in rural and semi-urban setting, are rarely in a position to insist on any preventive measure like use of condoms.

35. Another major determinant of HIV/AIDS epidemic, which has helped it to break out surreptitiously from the high-risk behaviour groups and spread silently into the general population, is the extremely high level of stigma and social ostracisation associated with this dreaded disease. In the highly conservative Indian society HIV/AIDS is seen as a dirty disease arising out of lust and immorality and is often mistaken for a highly contagious disease which can be contracted by simple contacts like shaking hands, the same mosquito biting someone close on heels after an infected person etc. As a result, even the mere suspicion of HIV infection can cause a person to become a social outcaste overnight and shatter his personal life, as may be seen from the pathetic case of Syed Basheer reported on 28 October, 2003 in The Hindustan Times, a leading national daily published from New Delhi (Annex-5). It is only to be expected, therefore, that even if a person becomes aware of his HIV-positive status, he would, more often than not, want to keep it under cover, perhaps a secret from even his own family. This, in turn, results in facilitating the silent spread of the virus and makes its detection and containment an extremely difficult task. It also results in deceptively low statistical footprints and the consequent sense of complacency.

VI. Response : Prevention and Control Strategies

36. The first case of HIV was reported from Chennai in 1986. Recognising the potential threat and seriousness of an infection without cure so far, the GOI responded with alacrity and set up a high-

[25] Aids Prevention - It Works': published by Voluntary Health Services, Chennai on APAC - Tamil Nadu /2002
[26] 'Preparatory Study : BSS in Maharashtra', Family Health International/USAID, 2001

powered committee in the Ministry of Health & Family Welfare to study the situation, and soon after, a National AIDS Control Programme (NACP) was launched in 1987. Initially the programme activities consisted of surveillance, screening of blood and blood products and health education. By 1990 HIV prevalence rates were observed to have reached alarmingly high level of over 5% in high-risk behaviour groups like CSWs and STD patients in Maharashtra and IDUs in Manipur. From 1987 to 1990 the AIDS Control Programme, however, remained confined largely to research-based activities and development of sentinel surveillance set-up at 55 centres in the 3 most affected States. Programme activities during this period were in hands of the State governments and did not have strong central guidance.

37. The Government of India set up the National Aids Control Organisation (NACO) in 1992 and launched a re-structured 5-Year Strategic Plan for prevention and control of HIV/AIDS under the National AIDS Control Programme (NACP). Since 1992 NACO has been the spearhead nodal body at the national level for all matters relating to HIV/AIDS including formulation of policy, prevention and control programmes. NACO has been mandated to 'lead and catalyse an expanded response to the HIV/AIDS epidemic in order to contain the spread of infection, reduce people's vulnerability to HIV and promote care within an enabling environment'.[27]

NACP Phase I, 1992-1999

38. The approach during the first phase remained primarily medical, with HIV seen largely as a health issue. The programme, however, helped set up administrative and technical framework for programme implementation; State AIDS bodies in 25 States and 7 UTs of the Indian Union; and 135 centres and 180 sentinel sites across the country to monitor HIV trends and geographical spread of HIV among general population and at-risk groups.

39. The major achievements and key-lessons of Phase I of NACP may be summarised as under:

- Multi-sectoral involvement was gradually built up.
- Project activities were integrated optimally with the existing health-care system. Efforts to target vulnerable and at-risk groups were intensified.
- An increase of approx. 50% was achieved in the volume of condom distribution through social marketing.
- In select major States the awareness of HIV prevention reached a range of 54% to 78%.
- Screening of donated blood became almost universal and professional donation of blood was banned by law.
- Concept of syndromic management of STD was developed.
- Surveillance capacity was increased to 135 centres and 180 sentinel sites.

Key lessons learnt

- After the initial phase, the responsibility of programme implementation ought to be decentralized to States and municipal bodies in order to elicit stronger local responses and to accommodate the responses required for varying epidemiological patterns. This would necessitate decentralization of IEC and service providing activities, executive authority and funds.
- It is essential to have a multi-pronged approach in planning and prioritization of programme interventions.
- Target interventions need to have a high level of coverage and saturation in order to be effective.
- The creation of an enabling environment is essential for facilitation of behaviour change.

[27] Report on Round Table Conferences Series-No.6, April 2000 – Ranbaxy Science Foundation, New Delhi/ p.29

- Reform in the Blood Banking System is a necessary prerequisite of addressing blood safety issues.
- Dependable and up-to-date epidemiological and management information is an essential requirement for effective implementation.
- Standardization of performance levels of States has to be a focus area.
- Monitoring should be made an integral part of programme implementation for better inflow and utilization of feedback.
- Porous boundaries of the country call for enhanced regional perception and mutual cooperation.

NACP Phase II, 1999-2004

40. Despite the efforts made during NACP Phase I, in the last four years the epidemic has broadened across the southern and western States and has resulted in a concentration of injecting drug users in the Northeastern states particularly Manipur and Nagaland. In the most affected state of Maharashtra HIV has reached 60% in the CSWs of Mumbai (Bombay), 14-16% in sentinel STD clinics and over 2% among women attending Ante-Natal Clinics. The prevalence rate in women in ANCs can be taken as an indicator for the general population, which makes the situation in greater Bombay quite alarming. ANC prevalence rate has reached 6.5% in Namakkal in Tamil Nadu and 5.3% in Churachandpur in Manipur and gives credence to the UNAIDS report's claim of 'serious localized epidemics'. The sharp increases in Andhra Pradesh and Karnataka have resulted in these two states having overtaken Tamil Nadu. Three states (Maharashtra, Tamil Nadu and Manipur) account for 75% of the country's estimated HIV cases. While it is true that in other parts of the country, the overall levels are still estimated to be low, with some areas reporting no cases at all, the burden of AIDS cases is beginning to be felt in states affected early. AVERT, an internationally funded NGO is of the view that 'weaknesses in sero-surveillance system, bias in targeting groups in testing and lack of availability of testing services in several parts of the country suggests a significant element of underreporting. Given India's large population, a mere 0.1 percent increase in the prevalence rate would increase the number of adults living with HIV/AIDS by over half a million people'.[28] As stated earlier in section I, the situation has to be viewed as potentially grave on account of a number of socio-economic factors.

41. Taking note of this, in 2001 Prime Minister of India urged the Chief Ministers of States to intensify AIDS control and prevention activities. In April, 2002 GOI adopted the National Aids Prevention and Control Policy as well as the National Blood Policy. These documents stipulate an approach to HIV/AIDS that is more comprehensive and holistic and regards AIDS not merely as a public health issue, but as a developmental problem. Such an approach is in line with the view taken in the UNAIDS Report on Global HIV/AIDS, 2002.[29]

42. On the basis of the National AIDS Control Policy, NACO on behalf of the GOI is now implementing NACP Phase-II throughout the country aimed at reducing the spread of HIV infection, reducing the vulnerability of people in the hitherto less affected areas, dealing with HIV/AIDS patients with full regard to their human rights and strengthening the capacity of States/local self government bodies as well as NGOs/Private Sector to respond to challenge of HIV/AIDS on a sustained basis. The salient features and strategies Phase II of the NACP are summarized[30] below in three segments:

- Strategies for Prevention
- Reform, Expansion & Streamlining of Service Delivery System
- An Expanded and Comprehensive Response

[28] 'HIV/AIDS in India : The Situation Now' at http://www.avert.org/aidsindia.htm
[29] UNAIDS Report on Global HIV/AIDS Epidemic, 2002, p.177
[30] Summary of NACO's response/activities based on information available on NACO's website at http://www.naco.nic.in/nacp/Phase2.htm

Strategies for Prevention

Information, Education and Communication (IEC)

43. Since neither a cure nor a vaccine for HIV has been developed yet, creation of awareness through an effective IEC programme continues to be the major plank of prevention and control objective. Although awareness by itself may not suffice to bring about behavioural change in high-risk groups, it certainly has to be regarded as the logical first step in that direction. The IEC strategy of NACP II is operationalized at two levels. At the national level, NACO frames guidelines for IEC activities countrywide and undertakes multimedia campaign coupled with political and media advocacy. NACO emphasizes on publicizing all four routes of transmission as well as the ways in which, contrary to some widespread notions and apprehensions, it does not spread. This has been found useful in educating people against the stigma and discriminatory attitudes toward the disease. The current World AIDS Day campaign of UNAIDS also focuses on fighting stigma and discrimination with the slogan 'Live and Let Live'.

ABC Approach

44. Emphasis is also placed on ABC approach to AIDS prevention. A, Abstinence stands for efforts to delay sexual initiation in youth; B for Being faithful to one's partner in life; and C for condom use to ensure protected and safe sex. Going by the feedback NACO has received, the ABC approach seems to have struck a receptive cord among adolescents and young adults, a group which his highly vulnerable in both rural and urban settings.

Advocacy

45. Advocacy efforts are on at the highest level, with the Prime Minister addressing Chief Ministers of States and other high functionaries of Central/State Governments exclusively on the issue of HIV/AIDS. World AIDS Day (December 1) And Voluntary Blood Donation Day (October 1) are also utilized as occasions for creation of awareness through sponsored activities at the national and state levels. As part of the IEC campaign, a National Convention of Parliamentary Forum on HIV/AIDS was recently organized. The Convention was inaugurated by the PM and was attended by high dignitaries of state like the Speaker of Lok Sabha (Lower House of the Indian Parliament), Leader of the Opposition in the Lok Sabha, Dy. Chairperson of the Rajya Sabha (Upper House of the Parliament) besides a large number of Members of Parliament. The Convention adopted a declaration of commitment in the fight against AIDS, which has been endorsed by all major political parties.

Prevention of HIV amongst young people

46. In order to ensure that young people acquire necessary knowledge and skill to protect their sexual and reproductive health a comprehensive 'School AIDS Education Programme' is being implemented and will cover all secondary schools in a phased manner over the next 2-3 years. For college/university students 'University Talk AIDS Programme' is being implemented in collaboration with Nation Service Scheme of Ministry of Human Resource Development. For the coverage of out-of-school youth, a 'Village Talk AIDS Programme' is being implemented by involving community-based organizations (CBOs) like the Nehru Yuva Kendra Sangathan. The combined outreach of these interventions is likely to ensure that the desired message of AIDS prevention will get across to all sections of youth population.

Training

47. Capacity building of health care providers through training at regional/state/sub-state levels is one of the key focus areas of NACP Phase II. Training is one of the most crucial inputs towards enabling various institutions including NGOs in dealing effectively with HIV/AIDS control activities, besides helping in dispelling the exaggerated fears/apprehensions of the medical service providers about

HIV/AIDS and creating a more enabling environment which is necessary for prevention, control and care being offered to HIV patients without treading upon their dignity and human rights. NACO organizes training programme for Trainers, who can then replicate it through a series of cascading training courses at the State level. Over 95% of the training programmes at the State level are reported to be organized by State AIDS Control Societies (SACS) themselves with the help of key-personnel trained by NACO. NACO's capacity-building training courses are tailored and structured to suit the skills required by a wide variety of functionaries like:

- Specialist doctors of Medical Colleges
- General Duty Medical Officers
- Nurses
- IEC personnel
- Counsellors
- NGOs
- Lab Technicians
- Blood Bankers
- District nodal officers, etc.

Targeted Interventions

48. These are directed toward most vulnerable and marginalized segments of population, most likely to become sources/carriers of HIV infection on account of high-risk behaviour. The efficacy of such targeted interventions when implemented in a focused and holistic manner for groups like CSWs, IDUs, MSM, truckers, migrant labourers, street children etc. is universally acknowledged. Such groups are approached with the help of NGOs and CBOs who are able to develop a more flexible approach and better rapport with target groups. Interventions include (i) behaviour change counselling on a one to one basis (ii) delivering health-care and support services particularly for Sexually Transmitted Infections (STIs) (iii) condom promotion and (iv) creating an enabling environment conducive for behaviour change. At present 820 targeted intervention projects are under implementation through NGOs in different States/UTs.

Counselling

49. Being diagnosed as having HIV/AIDS, even the mere likelihood of such a diagnosis, has profound emotional, social, behavioural and medical consequences, and causes immense psychological and emotional stress to the infected person and others who live with him/her as it seriously jeopardizes his dignity, independence, privacy and social status. Professional counselling helps reduce such psychological stress and equips the person to adjust to and deal with his circumstances with greater understanding and equanimity and to acquire self-help skills and ability to draw support from family/community. Counselling is also an essential input of Voluntary Confidential Counselling Testing (VCCT) and Prevention of Parent to Child Transmission (PPTCT). Though maintaining confidentiality and dignity of the infected person is basic to the concept of VCCT, the counsellor is expected to encourage him to involve the spouse and family for achieving long-term social support and limiting the transmission multiplier to the minimum. Involvement of the family, however, is subject entirely to voluntary consent of the infected person.

Family Health Awareness campaign

50. Conducted over a fortnight once a year, this innovative campaign comprises of house-to-house contact and interaction with target population in 15-49 age group and massive social mobilization involving NGOs and community representatives at the grass roots level for discussing ways and means to prevent HIV/AIDS and STDs.

Condom promotion

51. Abstaining from sex, mutual monogamy between uninfected sexual partners and correct and consistent condom use are the only existing options for avoiding HIV infection through sexual route. Evidence suggests that consistent condom use has been the most successful and cost-effective prevention method in high-risk groups worldwide. It also has the added advantage, in an overpopulated country, of being a contraceptive device. NACO is, therefore, committed to promoting condom use by improving availability and ensuring quality at an affordable cost. NACO collaborates with the Department of Family Welfare in free distribution of condoms all over the country, particularly at STD clinics and among target groups of CSWs, MSM etc. Social Marketing of condoms at highly subsidized rates at kiosks and small outlets near vulnerable/project sites, with State AIDS Control Society/ Private marketing agencies playing the role of distributor has also been tried with considerable success alongside free distribution of condoms.

Vaccine & Microbiocide

52. The Govt. of India's Ministry of Health & Family Welfare and Indian Council of Medical Research (ICMR) have signed a Memorandum of Understanding with the International AIDS Vaccine Initiative (IAVI) to promote and accelerate efforts to develop an indigenous AIDS vaccine specially geared to address the strains of HIV-1 subtype C predominant in India. Meanwhile, Modified Vaccine Ankara is reportedly innumerable complex and complicated steps away from the stage of clinical trials, though work on it is continuing in two ICMR institutes namely, National AIDS Research Institute (NARI), Pune and National Institute of Cholera and Enteric Diseases, Kolkata. It must, however, be conceded that nothing substantially positive looks like materializing on the vaccine front within the country in the near future. However, a microbiocide being developed at NARI, Pune with the assistance of NACO is reported to have reached phase 2 of clinical trials and it is anticipated that a microbiocide called Praneem might enter the market in a couple of years and enable women to partially protect themselves in high-risk situation, though the exact extent of protection it is likely to make available is yet to be established.

Reform Expansion and Streamlining of Service Delivery System

Blood Screening and Safety

53. The Blood Safety Programme drawn up in line with the National Blood Policy, 2002 assists in ensuring the adequacy and safety of blood supplied for medical purposes in the country. Unlicensed Blood Banks and commercial donation of blood have been legally banned. It has been made mandatory to screen all donated blood for HIV besides testing it for Hepatitis B, Hepatitis C, Syphilis and Malaria. The GOI have strengthened/modernized Blood Banks down to the district level and have established 81 Blood Component Separation Units. In order to ease the situation of shortage of blood availability in rural areas and smaller hospitals, where it is not feasible to operate Blood Banks, it has been decided to establish storage centers which can provide tested blood obtained from District Blood Banks for life-threatening emergencies. A comprehensive action plan has been drawn up to improve the quality of blood transfusion services in the country. It focuses on establishing an accreditation system, rational use of blood and promotion of voluntary blood donation.

Treatment of Sexually Transmitted Infections (STIs)

54. Sexually Transmitted Infections and HIV are behaviourally and epidemioligically linked. Not only is similar behaviour largely responsible for spreading both, the probability of contracting HIV infection is greatly increased in the presence of STIs, particularly those characterized by genital ulcers and discharge. Hence, control of STIs helps reduce the incidence of HIV. STD treatment also provides an opportunity for providing preventive education and counselling to an individual/couple at risk of HIV. Quality STI treatment and associated condom use are usually the most effective entry-point for organizing prevention programmes for vulnerable communities like CSW and MSM groups. However, less than 25% of those suffering from STIs seek treatment through public health services. Perceived lack of confidentiality and the likelihood of stigmatization drive most of them to seek help from private health sector or from unqualified practitioners. The National STD Control Programme, which predated NACO and has been integrated with the latter since 1992, is fully funded for

personnel, laboratory modernization and drug support by NACO. Effective control of STD is accorded a high priority by NACO, which plans to expand the present network of 687 district-level STD centres to at least one in every district in the country.

Prevention of Parent-to-child Transmission (PPTCT)

55. According to NACO estimates, Parent-to-child Transmission (PTCT) of HIV accounts for approximately 2.14 % of the total infection load in the country. PTCT of HIV is known to occur during pregnancy/delivery or through breast-feeding. Approximately 25-30 % children of HIV infected women become pediatric cases of HIV. It is estimated that over 7 million women, including about 92000 HIV-infected women have babies every year in India. The number of HIV-positive women is increasing, and with that the likely number of pediatric HIV cases too. Fortunately, PTCT in most cases can be prevented by a combination of reasonably priced short-term preventive drugs like AZT/Nevirapine, safe delivery practices, infant-feeding methods and counselling support. PPTCT feasibility studies using drugs like AZT (Zidovindine) and Nevirapine have been going on in 11 medical colleges since March 2000 with the help of pregnant women volunteers willing for screening, and prophylactic treatment if found HIV positive. In order to reduce the instance of PTCT, NACO is currently following a multi-sectoral, decentralized, phased and incremental approach towards PPTCT. The plan is to first cover the medical colleges of high prevalence States, followed by all high prevalence districts of these States. The project is now under expansion to the medical colleges of low prevalence States. At present 224 PPTCT centers are providing services with trained counsellors and NACO is in the process of streamlining procurement of drugs and rapid HIV tests, with the ultimate goal of integrating PPTCT into the reproductive health services system. In January 2003, the Global Fund to Fight AIDS, TB and Malaria approved a grant of US$ 100 million for strengthening of PPTCT services, which would greatly help NACO to expand and enhance the quality of these services.

Voluntary Confidential Counselling and Testing (VCCT)

56. As already stated, in the absence of a vaccine or cure for HIV infection, VCCT is regarded as a key strategy to reduce the incidence of transmission of HIV in the community. The aim of VCCT is to enhance people's access to knowledge and understanding of HIV status and its implications on a voluntary basis, thereby facilitating early and easy access to services available for prevention, care and support. VCCT Centres also provide social and psychological support to those already affected by HIV, besides prevention of transmission. Counselling is totally non-coercive and confidential and has been found to be an effective strategy for behaviour change in at-risk groups. It is professionally designed for various stages like pre-HIV test, post-HIV test and follow up, and referrals, where necessary, to PPTCT, DOTS, STI clinics etc. The VCCT Centres have been found to be so useful an intervention that NACO has expanded the network of such Centres from 62 in 1997 to 540 at present, with every district of the 6 high prevalence States, Tamil Nadu, Andhra Pradesh, Karnataka, Maharashtra, Manipur and Nagaland having been covered.

Care and Support

57. People Living with HIV/AIDS experience a variety of health and social support needs as their illness progresses and opportunistic infections begin to take their toll. For the management of care of such cases NACO has taken the following initiatives:

- Initiation of a set of comprehensive, multi-layered training programmes for medical and paramedical personnel in the country.
- Provision of drugs for treatment of opportunistic infections in all public sector hospitals through Sate AIDS Control Society.
- Collaboration with Revised National Tuberculosis Control Programme for early diagnoses and treatment of HIV-TB co- infection.
- Prevention of infection amongst health-care workers by providing for post-exposure prophylaxis.

- Provision of funds to State AIDS Control Society to supply anti-retroviral drugs and post-exposure prophylaxis to health care workers in the event of any infection contracted while providing care to HIV/AIDS patients. As a part of the care and support infrastructure, 47 HIV/AIDS care centers have been established in the NGO sectors supported by SACS.

Anti-retroviral Therapy

58. At present there are 11 anti-retroviral drugs available in the country. In order to make these drugs affordable, customs and excise duties exemption has been allowed and the State Governments have also been requested for exemption from sales tax and other taxes. Organizations like Employees State Insurance Corporation, Railways, Steel Authority of India, health organisations under the Ministry of Defence besides GOI itself through Central Government Health Scheme have started providing anti-retroviral treatment to regular employees/dependents suffering from HIV/AIDS. It is well-known that anti-retroviral treatment is at present quite expensive and government have not been able to take a decision so far to provide anti-retroviral treatment to citizens at large at government cost, on account of resources constraints. However, a number of 'Drop-in-Centres' are being set up in high prevalence States. These would be run by NGOs, CBOs and networks of people living with HIV/AIDS. The objectives of these centres are (i) to promote positive-living and improving the quality of life of PLHAs, ii) to build the capacity and skills of PLHAs to cope with infections, iii) to create an enabling environment for PLHAs, iv) to establish linkages of PLHAs with the existing health services, NGOs, CBOs and other welfare organizations and, v) to protect and promote the rights of PLHAs.

An Expanded and Comprehensive Response

Convergence

59. As stipulated by the National AIDS Prevention and Control Policy, 2002, one of the specific objectives of the Programme is to generate a feeling of ownership (for the NACP) among all participants both in the government and non-government sectors, like the Ministries and Agencies of the Government of India, State Governments, municipal bodies, industrial undertakings in public and private sectors, Panchayat institutions and NGOs in order to make the anti-HIV/AIDS campaign a truly national effort. NACO has been therefore, mandated to promote the integration of HIV/AIDS prevention and care into the ongoing governmental programmes of all other Ministries having a socio-economic role or having a large work force like the Ministries of Health and Family Welfare, Human Resource Development, Labour, Social Justice and Empowerment, Youth Affairs, Defence, Railways, Steel etc. with a view to optimizing India's response to HIV/AIDS and enhancing its effectiveness and sustainability.

Research and Development

60. NACO on behalf of the government is vigorously pursuing research and development activities for female condoms and micro biocides as these are likely to empower women and enable them to protect themselves, reducing the incidence of transmission amongst women and children. As already mentioned, a tripartite agreement between NACO, ICMR and IAVI has also been signed for developing a safe, effective and affordable vaccine for HIV/AIDS infection.

Management Information System

61. A computerized Management Information System has been put in place for the effective monitoring of the implementation of NACP Phase-II at the national and State levels. Monitoring and Evaluation officers of SACSs have been trained in operation of the system and all information/data from the States has been flowing to NACO electronically since January 2002.

Financial Resources

62. The National AIDS Control Programme coverage extends to all States and Union Territories in the country under the guidance and programme coordination by NACO at the Centre. At the same

time, the approach is fully decentralized to allow flexibility in implementation of the programme through State/Union Territories AIDS Control Society. Financial resources for NACP Phase-II flow from Government, World Bank Assistance and financial support of some bilateral agencies.

The total outlay for NACP Phase-II (1999-2004) is as under: -

		(Rupees in Million)
i	World Bank-assisted Project	9500.04
ii	GOI contribution	1960.00
ii	USAIDS AVERT Project in Maharashtra	1660.00
iv	DFID's partnership for Sexual Health Project	1040.00
	Total	14250.00
v	Canadian International Development Agencies	378.10
vi	UNDP assisted HIV/AIDS Project	64.70
	Grand Total	**14692.80**

Computerized Project Finance Management System

63. The agreement with the World Bank stipulates that the GOI would advance the funds for implementation to the State/Union Territory AIDS Control Society as well as other agencies and claim reimbursement from the World Bank on the basis of actual expenditure. A Computerized Project Financial Management System (CPFMS) for NACP-II has been developed. It facilitates maintenance/ preparation of all accounting records/documents on computer, including reimbursement claims and project management reports in accordance with Loan Administrative Change Initiative (LACI) procedures and compliance of audit requirements in terms of the agreement with the World Bank. The CPFMS assists projects to perform better by reducing delays and financial bottlenecks, speeding up disbursement down the line and facilitating project monitoring and control. LACI is a useful project monitoring system as it links expenditure with actual physical achievements. Similar CPFMS systems are being installed in all the SACS and inter-sectoral collaborating organizations, 25 of which are already operational.

VII. Present Trends of Impact of Prevention and Control Strategies.

64. As pointed out in earlier sections of this report, inadequacy of accurate epidemiological data has been a constraint in estimating the exact extent of seroprevalence accurately. Similarly, the absence of authentic countrywide baseline surveys regarding patterns of sexual behaviour use of condom by various high-risk groups like CSWs and their clients, MSMs etc. prior to the national Baseline BSS, 2002 makes it difficult to be specific and categorical while commenting on the subject. This fact is recognized by the National Aids Prevention and Control Policy document which refers to the national Baseline BSS, 2002 findings briefly but rather than compare them with any previous statistics, it starts by stating that the awareness levels were 'almost insignificant' at the beginning of the epidemic.[31]

65. However, on account of the countrywide HIV prevention & control measures initiated and implemented under NACP Phase I and Phase II by NACO since its inception in 1992 a number of achievements have been made. These appear to be impressive even on a stand-alone basis, particularly when these are seen in the background of socio-economic and literacy indices of the country. The following may be enumerated as significant indicators of the impact of prevention and control strategies developed and pursued by NACO:

[31] National AIDS Prevention and Control Policy document

- The findings of national Baseline BSS, 2002 indicate that a substantially high level of awareness has been created about HIV/AIDS. In some high prevalence States like Andhra Pradesh and Manipur the awareness levels were found to be as high as 94-96%. About 71% of the respondents were aware of the predominant transmission route of HIV/AIDS i.e. sexual contact. As many as 77.6% males and 64.9% females were aware of the possibility of HIV transmission through sharing of needles for IDU and 72.5 were aware of similar risk through blood transfusion. In most States awareness about condom was also found to be high (94.7% male/86.2 female) Although the awareness levels were found to be distressingly low among women in Bihar (21.5%), Gujarat (25%), Uttar Pradesh (27.6%), Madhya Pradesh (32.30%) and West Bengal (38.6%), the overall awareness level in key indicators does indicate a measure of success of the IEC strategies of NACO and SACS and NGOs collaborating with them.[32]

- More specifically, Part 1 of the national Baseline BSS, 2002 which focused on Female Sex Workers (FSW) and their clients, unanimously acknowledged as core HIV breeders and carriers, revealed that as many as 75% of the FSWs were intermittently using condom with paying clients and 81% of them usually insisted on their clients using a condom. Awareness of HIV/AIDS (94%) and STDs (83%) was also found to be quite high. As many as 96% of the clients of FSWs were broadly aware of HIV/AIDS and 85% of them were reported to be specifically aware of the efficacy of condom-use for safe sex.[33] Such awareness levels are pointers towards the impact of IEC measures moving in the right direction.
- The IEC and advocacy of anti-HIV/AIDS programme were also responsible largely, if not solely, for the legal decree prohibiting unregistered Blood Banks, the ban against professional donation of blood and other blood bank reforms including compulsory screening of blood for HIV/AIDS. Although much of the streamlining in this sector may still be in the process of stabilizing, NACO claims that the percentage of HIV infections through blood transfusion has reduced from 8% in 1994 to 3-4% in 2001. This must indeed be rated as a substantial gain.
- As a result of the activities of first 10 years of the anti-HIV/AIDS programme, the NGO sector and international donor agencies as well as other sectors in the government itself are firmly on board the campaign. This is borne out by the substantial assistance of the World Bank, UNDP, CIDA etc. for NACP Phase II, very strong and enthusiastic NGO sector support for the programme and the National AIDS Prevention & Control Policy clearly recognizing and stating that HIV/AIDS is not merely a health issue, it is a multi-sectoral 'developmental problem'.[34]
- The strength of NGO support for the HIV/AIDS prevention and control programme can be gauged by the fact that targeted interventions for high-risk group are on at as many as 820 sites. Some of the major success-stories noted by the National Policy document are the CSW project in Sonargachi red-light district of Kolkata, MSM project in Chennai and projects on IDUs in Manipur.[35]
- Another example of the high-quality NGO support to the programme is that of APAC Project being implemented with USAID assistance by Voluntary Health Services, a Chennai based NGO in collaboration with 36 smaller NGOs for targeted interventions all over Tamil Nadu amongst truckers, women in prostitution, slum residents, sex workers catering to tourists, clinical intervention for better treatment facilities for STI (Annex-6). VHS claims to be catalyzing through its condom promotion campaign the marketing of 30 million condoms annually, and an increase in condom use by the target group of CSWs from 56% to 86%. It is reported that the functioning and achievements of APAC Project

[32] National Baseline BSS Survey 2001, NACO
[33] National BSS Survey (Pt.1), 2001, NACO
[34]) National AIDS Prevention and Control Policy document, 2002, paras 2.2/2.5
[35] ibid

Phase-I (1995-2001) were evaluated by USAID in 2001, on the basis of which an extension of five years has been recommended beyond 2002-03.[36]

- As stated in para 17 above, the percentages of prevalence in Greater Mumbai region and Tamil Nadu seem to have registered a downward trend in 2002. This is no mean achievement in two of the worst affected areas of the first wave of the epidemic.
- As noted in section VI of this report, one of the major thrust areas of the NACP Ph.II is the expansion, upgradation and streamlining of the treatment facilities for STI down to the district level all over the country, and already 460 districts have been provided with this input. Although it is early days yet to expect any authentic data of cases treated by these upgraded centres or to find evidence of their relatively better functioning, the initiative itself has to be seen as a useful one.
- Similarly the streamlining of the network of sentinel surveillance sites and increase in their number from 185 in the 1990s to 384 in 2002 (proposed to be further increased to 455 in 2003) has now provided NACP a much improved infrastructure for a more representative, diversified and dependable measurement of seroprevalence in different regions/states as well as the effectiveness of prevention and control measures in future.

VIII. Impact Of HIV/AIDS On Morbidity/Mortality

66. While the World Development Report of the World Bank published in 1993 ranked HIV/AIDS first and fourth largest cause of morbidity and mortality respectively, curiously enough, in the World Health Report of WHO two years later (1995) HIV/AIDS was not mentioned as major cause of morbidity/mortality. On analysis, the reason for this discordance, particularly in the context of developing countries including India would appear to be that the WHO report was based mainly on the de jure position of the causes of mortality on record whereas the World Bank report took note of the de facto causes of morbidity/mortality hosted and facilitated by the fast spreading epidemics of HIV/AIDS across the globe, particularly in the under-developed countries of Africa, South Asia, and South-east Asia. It has been argued that most PLHAs living with HIV/AIDS in these countries, particularly India, are either not aware of their sero-positive status or want to hide it on account of the stigma and social ostracisation, and when the end comes through an opportunistic infection like TB, diarrhoea, or one of a variety of communicable diseases (of which there is no dearth in most such countries), the opportunistic infection rather than HIV/AIDS gets to be recorded as the cause of death. In an overwhelmingly large percentage of cases it is not known even after death that morbidity experienced for several years before was on account of HIV infection or that the main cause of mortality was AIDS.

67. In India widespread ignorance of sero-positive status is quite openly admitted and attributed to both lack of adequate testing facilities and reluctance to get tested because of the fear of social stigma. That is why only 94966 cases of HIV and only 10857 of AIDS had been reported until January, 2000 despite the fact that there is general consensus on as high a seroprevalence estimate as 4.58 million. Even until 30 September, 2003 the total number of AIDS cases reported in the country was only 55764, although that is a five-fold increase over the January, 2000 figure. Clearly, the number of deaths reported on account of HIV/AIDS, and concomitantly the morbidity figures, if available, are likely to be highly unreliable. The reasons for the widespread tendency to hide the HIV-positive status by patients and their immediate families as well as the socio-economic impact of prime-age death on account of HIV/AIDS come through graphically in a research interview conducted by epidemiologist and HIV expert on India, Peter Godwin with an HIV-positive respondent Satya,[37] which is being appended to this report as Annex-7.

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[36] 'Aids Prevention - It Works' – VHS, Chennai/USAID on APAC/2002

[37] Peter Godwin : 'The Making of an Epidemic' in the 'The Looming Epidemic: The Impact of HIV and AIDS in India', New Delhi/1998 - p.26

68. In a published research paper on the possible economic impact of HIV epidemic in India it has been estimated that the total annual mortality on account HIV/AIDS over the next 70 years (with 1991 baseline) is likely to be 572000.[38] In another similar research paper based on the EPIMODEL developed by Chin & Lwanga of WHO, assuming 3 million infections as the baseline, the likely annual mortality of HIV/AIDS in India has been calculated in the range of 204470 and 321786 per annum from 1999 to 2001.[39] Dr. S.R. Salunke using the EPIMODEL has suggested that by the end of 1996 in Maharashtra alone 341623 people would have died of AIDS.[40] The World Bank in the course of considering financial assistance had estimated that its support for the interventions planned through NACO had the potential of averting 300000 deaths. Experts argue that since no programme can be totally effective, if 300000 deaths were to be prevented, the actual deaths, which could take place, would have to be much higher.

69. It is clear, therefore, that on account of the reasons stated in the foregoing paragraphs of this section, no consistent and reliable data or estimate are available for mortality on account of HIV/AIDS. Neither are any reliable State-specific statistics available for morbidity on account of HIV prevalence except Maharashtra which has reported an estimated increase of occupancy level of HIV related cases in hospitals from 725000 in 2001 to 936000 in 2002. However, if we look at NACO's seroprevalence growth figures from 1999 to 2002, the net addition to the number of infected persons estimated for these years are approximately 200000 in 1999, 186000 in 2000, 110000 in 2001 and 600000 in 2002. Working backwards, it would appear reasonable to assume a seroprevalence estimate between 3 to 4 million in 1991. That figure is fairly close to the basis on which the estimate of 572000 deaths per annum of the first study cited above has been arrived at. Even if the more conservative figures of the second study cited above are taken as being closer to the mark, considering that these are mortality figures, in any given year morbidity on account of advanced stage of HIV infection affecting the health status of PLHAs could be expected to be at least 3 times that number. It could, therefore, be argued that the number of PLHA currently suffering morbidity in India cannot be less than about a million. EPIMODEL based estimation even on a very conservative HIV-infection figure of 1 million 1992 would give a result of 300000 annual cases of full-blown AIDS by 2000 AD. Thus, the figure of about a million PLHAs in different stages of morbidity appears to be a reasonable estimate.

70. It may be mentioned that Subhash Hira, professor of infectious diseases at the University of Texas who heads the AIDS Research and Control Centre in Mumbai, is also reported to have arrived at a figure of approximately 1 million PLHAs needing health-care, which according to him, might require government spending of the order of $ 1.5 billion per annum.[41]

71. Since the predominant transmission mode of HIV/AIDS is sexual contact (85%), it follows that the brunt of morbidity/mortality would be borne by the prime-of-life and productive age group of 15 to 49 years. The morbidity/mortality rate of an incurable and terminal variety in this group is likely to have wide-ranging implications of an adverse nature for the families as well as the economy as whole. Though the mortality rate of children below 5 and adults between 60-64 years in India ranges between 22-23%, it is surprisingly low at 2.6% for the age-group 20-24 yrs., as a result of life expectancy of 15-30 year-olds having improved by almost 50% between 1941 to 1970. Even a small upward change in the number of deaths clustered in the young adult age group could therefore significantly change the death rate in that age group.[42]

72. The experiences of Africa and some South-East Asian countries, already well into the second phase of their epidemics, would show that the Indian epidemic might also head towards taking heavy

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[38] Dr. L.M. Nath : 'The Epidemic in India: An Overview'

[39] Dr. Indrani Gupta : 'Planning for Socio-economic Impact of the Epidemic'

[40] 'The Looming Epidemic: The Impact of HIV and AIDS in India

[41] Siddharth D. Shanghvi: 'Quiet Assasin: Aids in India'/San Francisco Chronicle/8 August 2002 at http: www.saaaids/org/media/quiet_assasin.html

[42] Peter Godwin : 'The Making of an Epidemic' – op.cit.p.12

toll on the availability of industrial labour and skilled workers particularly in the transport and construction sectors besides causing tremendous pressures on the existing health-care infrastructure and extreme economic hardships to the affected families. It is well recognized that in India, as in Africa and South-East Asia, HIV/AIDS is developing as a poor man's disease, spreading mostly among the less-informed and economically less-fortunate and marginalized segments of the social hierarchy; with no cure in sight and anti-retroviral therapy being well out of the reach of such population segments, affected families are bound to face extreme hardship and the need for frequent hospitalization and medication during the morbidity phase is likely to drive them to destitution. The World Bank's report on HIV/AIDS in South Asia Region (SAR) – India refers to WHO estimates which reveal that while in 1998 AIDS was responsible for only 2% deaths caused by infectious disease-related deaths, assuming the annual addition of 330000 AIDS cases, by 2033 AIDS is likely to account for about 17% of total deaths and 40% of disease-related deaths.[43] Obviously the economic impact of such a galloping death rate on account of HIV/AIDS would be absorbed mostly by the poor, and being prime-age deaths after long years of morbidity, its results on economically weaker sections would be quite devastating.

73. Another disturbing facet of the nexus between poverty and HIV/AIDS is that the ever-increasing number of migrant labour living periodically in urban slums may result in large numbers of rural women succumbing irresistibly to the infection and spreading it further through PTCT. Unless a very strong and effective PPTCT programme is implemented, the increasing number of pediatric cases of HIV would continue to add further dimensions to the emotional and economic misery of the already infected families. Although somewhat dated, the research papers contained and cited in the book edited by Peter Godwin referred to in this section provide illuminating insights into the disruptions likely to be caused in developmental interventions in the event of a run-away HIV/AIDS epidemic.

74. When estimating the impact of HIV/AIDS on developmental interventions, with particular reference to economically weaker sections, the following have to be kept in mind as factors which specially intensify such impact:

- The likelihood of multiple cases of HIV/AIDS within a household.
- Death being preceded by a fairly long period of illness.
- The long incubation period between infection and the appearance of first opportunistic infection.
- Clustering of morbidity/mortality in prime-age group adults in their productive years.
- The disease being associated with high levels of discrimination and stigmatization.

75. The fact that policy-makers in the Indian governmental system are aware of the multifaceted deleterious effect on developmental interventions and indices that a run-away HIV/AIDS epidemic might have, is evidenced by the specific inclusion of the following passage (as a highlighted box-item) in the National AIDS Prevention & Control Policy document itself:

Economic Impact

76. The effects of the epidemic radiate from the household across the society. In cote d'Ivoire, urban households that have lost at least one family member to AIDS have seen their income drop by 52-67%, while their expenditure soared fourfold. To cope, they have to cut their food consumption by 41% rural households facing similar predicaments in Thailand are seeing their agricultural output shrinking by half. In 15% of the cases, children are removed from schools to take care of family members who are ill and to regain lost income.

[43] South Asia Region (SAR) – India on HIV/AIDS website of the World Bank

77. Some companies in Africa have already felt the impact of HIV on their bottom-lines. Managers at one sugar estate in Kenya said they could count the cost of HIV infection in a number of ways: absenteeism, lower productivity (a 50% drop in the ratio of processed sugar recovered from raw cane between 1993 and 1997) and higher overtime costs for workers obliged to work longer hours to fill in for sick colleagues. Direct cash costs related to HIV infection have risen dramatically in the same company: spending on funerals have risen five-fold between 1989 and 1997, while health costs rocketed up by more than ten-fold over the same period, reaching Ksh. 19.4 million ($ 325000) in 1997. The company estimated that at least three-quarters of all illness is related to HIV infection. Indeed, illness and death have jumped from last to first place in the list of reasons for people leaving a company, while old-age retirement slipped from the leading cause of employee drop-out in 1980 to just 2% in 1997.'[44]

78. It would be noticed that while making the above reference to economic impact of HIV/AIDS the authors of the Policy document have relied only on instances/statistics of African countries and Thailand making no mention of similar statistics of any high prevalence State of the country itself. This would appear to indicate that statistics in this regard are yet to be collected/compiled in India. According to a responsible media report, a health-based productivity model has been used by USAID to estimate that minus AIDS, India could experience upto 80% increase in GNP per working age person over the next 25 years. However, Chairman of American Red Cross David Mclaughlin is of the view that 'in an intermediate HIV/AIDS epidemic, this same GNP would be no higher in 2025 than it is today'.[45]

IX. Conclusions and Major Issues for Donor Agencies.

79. As has been brought out in the preceding sections of this report, though the estimated seroprevalence percentage may not appear to be high and only six of 25 States of the Indian Union are categorized as high prevalence States, the situation is potentially far more alarming than meets the eye on the basis of official statistics and estimates. The total numbers of HIV and full blown AIDS cases reported so far are almost universally regarded as a case of underreporting because of a variety of reasons discussed in earlier sections. The Indian scenario and response are seriously handicapped by high levels of poverty, illiteracy, migration of rural poor and landless labour and their intermittent exposure to sleazy conditions of urban slums, lack of evenly efficient testing facilities/health services and statistics-gathering all over the country, and above all, the stigma that the highly conservative Indian society attaches to open discussion about sexuality in general and pre-marital/extramarital sex, MSM, HIV/AIDS etc. in particular.

80. Although the anti-HIV/AIDS campaign has undoubtedly acquired greater focus and momentum since the inception of NACO in 1992, particularly after approval of substantial international funding in the late 1990s and adoption of National AIDS Control Policy and National Blood Policy in 1992, efforts are urgently required to identify and measure the problems arising out of the socio-economic background of high-risk behaviour and other vulnerable groups and to address them by specific strategies. Government and international agencies as well as the Policy document recognize the fact the HIV infection is beginning to transcend the barriers of high-risk groups and make inroads into general population. In the Indian socio-economic conditions such a development has to be seen as being one, which is fraught with frightening possibilities of an epidemic of enormous proportions. Poorer states like Bihar, Uttar Pradesh, Rajasthan send out millions of skilled and unskilled workers, agricultural and construction labourers, watch and ward and transport staff and others to areas like Punjab, Haryana, Delhi, Maharashtra, Andhra Pradesh etc. They live there for months every year, away from their families in slums infested with prostitution and homosexuality and return home regularly to visit their families. How many such men might be infecting their wives everyday, it is difficult to say, or to find out even if efforts are made. Similarly in the southern states, it is difficult to be sure how many women working as 'home based' sex workers or FSW under the 'Devadasi system'

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[44] National AIDS Prevention and Control Policy document, 2002

[45] India Takes Note of AIDS' Impact on Domestic Workforce/The Financial Express/9 January 2003

or how many HIV infected truckers all over the country might be spreading the infection to their spouses. However, those who know their India well will not take long to understand that as usual the numbers could be mind-boggling. Copies of some recently published reports suggest a fast deteriorating scene in this regard and are being appended as Annexes-8-10 of this report. More such reports can be seen at the websites listed in the section under References at the end of this report. These would appear to indicate that it is a 'now or never' situation for India.

81. Keeping the above in mind, a number of issues which emerge for the international donor agencies can be listed as under:

- There is no time to be lost on any front on grounds of non-availability of reliable statistics about high prevalence and vulnerability. Measurement of the problem and studies connected thereto must form part of funded interventions and move simultaneously with remedial measures.
- Anti HIV/AIDS measures must be multi-pronged and funding assistance must flow for a wide variety of interventions both for high-risk-behaviour group/areas and vulnerable groups/areas because if the former is the core breeding ground, the latter is where the carriers go back and silently spread the virus of infection. For this reason also, the areas and States which are currently categorized as low-prevalence should not get excluded from the consideration and attention of donor agencies merely on account of apathy of local administrations and weak NGO structure resulting in poor capacity to utilize assistance. (This possibility seems to be reflected in the following statement in the World Bank's website on AIDS in India: 'In the slow performing States like Bihar, a tiny portion of available IDA funds were put to use for prevention activities. The mid-term review identified a general lack of concern and sense of ownership among local government officials, combined with weak NGOs, as part of the problem in mobilizing these funds'.)
- National HIV/AIDS Baseline BSS 2002 and other studies have shown that awareness of HIV/AIDS is very poor, particularly amongst women, in the States which are referred to in developmental literature on India as BIMARU (literally meaning 'prone to sickness' and including **B**ihar, **Ma**dhya Pradesh, **R**ajasthan and **U**ttar **P**radesh), the zone most densely populated but lowest in the country in indices like IMR, female literacy, per capita income etc. besides being the provider of the largest number of migrant labour to Metros and a number of high prevalence States like Maharashtra, Andhra Pradesh etc. These States are highly vulnerable and must be brought into the focus of IEC and preventive action, particularly PPTCT, funded by international assistance.
- All Metros and other cities and towns known to attract large migrant population, particularly their red-light districts and slums, need to be surveyed for high-risk groups for saturated coverage through targeted interventions under funded projects. Surveys should also include identification of concentrations of non-brothel based FSW, MSM and truckers-joints on a comprehensive basis for coverage under a massive targeted programme.
- As a part of the funding agreement international donors should make efforts to promote a greater degree of open-ness about the hard ground realities of prostitution, sexuality and homosexuality in order that problem of HIV/AIDS is understood and faced squarely. However, they will also have to ensure that this change is brought about through a greater degree community participation and respect for cultural sensitivities and democratic ideal of dissent; while this may appear to slow down progress of interventions, it is important that societal support for anti-AIDS campaign is not jeopardized by the antagonism generated by the desire to force its pace beyond a point.
- Each funded project document must clearly articulate a number of simple-to-understand indicators to adjudge performance and MIS must allow inclusion of

conventional reporting and feedback mechanisms as computerized MIS may not be feasible initially in some relatively backward States/pockets.

- Interventions must be designed in a State-specific way and be based on appropriate technology acceptable and effective among target groups, e.g. folk-media, chaupals etc. In rural areas it would be useful to involve Panchayati Raj institutions, NGOs and community leaders IEC as well as intermediation in service providing interventions.
- In keeping with the consensus that HIV/AIDS is a development problem, not a mere public health issue, all possible efforts need be made to achieve cost-effectiveness by generating inter-sectoral synergy and convergence by inclusion of HIV/AIDS related capsules and initiatives in other internationally funded projects for poverty alleviation, primary education, highway development etc.
- Effort should also be made for reinforcement, integration and convergence of existing programmes in the health sector with the campaign. Strengthening of basic existing healthcare infrastructure would be essential to ensure sustainability of project interventions after international funding has concluded.
- Training of medical and paramedical staff and all others connected with anti-AIDS campaign including NGO personnel in keeping with their expected roles and functions should be an integral and important element of internationally funded projects.
- International funding should be used to encourage and catalyze Research and Development activities towards invention of less expensive alternatives of the currently out-of-reach anti-retroviral medication as well as the hitherto elusive HIV vaccine. This search should be liberal enough to accept the scientifically tenable branches of alternative systems of medicine like Siddha, Ayurveda and herbal products that might be helpful in containing the infection by reducing its virulence.

82. A close bok at the structure and interventions of NACP Phase II reveals that its philosophy and range of activities are quite comprehensive and broadly in keeping with the approach advised for the international funding agencies above. What is needed is (a) allocation of adequate resources for saturation level coverage and (b) a more effective and result-oriented implementation through involvement of NGOs and community leaders at the grass roots.

Appendix-1

Assumptions of NACO's HIV Estimates

The following assumptions on different parameters for estimation of the size of the risk group populations have been recommended and taken for estimation.

1. The 2001 census figures and the projected figures for October 2001 will be the basis for calculating:
   a) Population (in the age group of 1-49 years)
   b) Urban population and rural population
   c) Male-Female ratio

2. STD prevalence rates in both urban and rural populations as follows:
   - STD prevalence in urban areas will be 10% in high prevalent States, 7% in medium prevalent States and 5% in low prevalent States. It will be the same for both males and females.
   - 5% prevalence in rural populations in all States/UTs, for both males and females.

3. For the purpose of HIV estimation in high-risk population, urban rural differential will be 3:1 in all the States. Similarly, for HIV prevalence in low risk population, the urban-rural differential will be 8:1 in all the States. As there are more infected males than females, the following ratio would be applied:

   - In high prevalence States, for every infected female there are 1.2 males, in moderate prevalence States, for every infected female there will be 3 males.
   - Similarly, for every male STD patient from highly prevalence States, it is assumed that there would be 0.83 females, for moderate prevalence States, there will be 0.5 females and for low prevalence States, there would be 0.33 female patients.
4. In respect of the HIV prevalence rates:
   - The average of median value of HIV prevalence from State specific and group specific Sentinel data for 2000 and 2001 has been applied.
   - For States where the HIV prevalence rate has been reported as, the arithmetic mean of the low prevalent States, as applied in 2000 estimates has been taken.

5. For estimation of HIV infection among IVDUs, the HIV prevalence rate will be applied to the estimated size of IVDUs population in the State.

6. The States will be categorized as high, moderate or low, based on following definition:
   - **High prevalent States**
     States where HIV prevalence in antenatal women is 1% or more.
   - **Moderate prevalent States**
     States where the HIV prevalence in antenatal women is less than 1% and prevalence in STD and other high-risk groups is 5% or more.
   - **Low prevalent States**
     States where the HIV prevalence in antenatal women is less than 1% and HIV prevalence between STD and other high-risk group is less than 5%.
7. The justification for urban-rural and male-female gradient is as follows:

   - It is assumed that HIV spreads from urban to rural area and this differential is maintained even at very high level of HIV prevalence.
   - It is assumed that higher percentage of males have risk behaviour as compared to females in India. In the beginning of the epidemic, males outnumber females and ratio gets closer to 1 with the progression of the epidemic in general population. In all the South-Asian

countries, males outnumber females and in a high prevalence country like Thailand and Cambodia, this ratio is between 1.6:2.

- It is also assumed that the infection shifts from high-risk population to general population over a period of time. Therefore, all the States go through a stage of low and then concentrated and finally generalized epidemic in the absence of effective interventions.

Source: NACO's 'HIV Estimates in India'

Appendix-2

State-wise HIV Prevalence Levels, 1998-2002

S.No.	Name of State/UT	Number of sites in 2002	HIV Prev. 1998 (%) (180 sites)	HIV Prev. 1999 (%) (180 sites)	HIV Prev. 2000 (%) (232 sites)	HIV Prev. 2001 (1%) (320 sites)	HIV Prev. 2002 (%) (384 sites)
1.	Andhra Pradesh	STD 8	24.90	29.50	30.00	26.60	30.40
		ANC 14	2.25	2.60	2.00	1.50	1.25
2.	Arunachal Pradesh	STD 4	0.00	0.00	0.10	0.00	0.00
		ANC 2	0.40	0.00	0.00	0.00	0.00
3.	Assam	STD 5	2.10	2.40	0.61	1.49	0.75
		ANC 4	0.00	0.00	0.00	0.00	0.00
4.	Bihar	STD 8	1.35	0.60	0.50	1.20	1.60
		ANC 7	0.00	0.00	0.10	0.13	0.25
5.	Chattisgarh	STD 3	-	-	-	1.40	0.80
		ANC 5				0.33	0.25
6.	Delhi	STD 4	1.60	0.80	3.26	4.65	3.23
		ANC 4	0.25	0.30	0.25	0.13	0.25
		IDU 1			5.00	2.40	7.20
7	Goa	STD 2	19.40	13.50	12.02	15.00	11.29
		ANC 2	1.20	0.80	1.17	0.50	1.38
		CSW 1			53.20	50.79	24.00
8.	Gujarat	STD 8	2.50	6.70	4.65	4.14	6.17
		ANC 8	0.00	0.40	0.50	0.50	0.38
9.	Haryana	STD 5	2.60	5.30	2.75	1.08	1.14
		ANC 4	0.00	0.00	0.00	0.41	0.38
10.	Himachal Pradesh	STD 5	2.00	0.40	0.40	0.26	0.40
		ANC 7	0.36	0.30	0.89	0.13	0.00
11.	Jammu & Kashmir	STD 2	1.83	1.20	0.40	0.80	0.95
		ANC 3	0.00	0.00	0.12	0.25	0.08
12.	Jharkhand	STD 3	-	-	-	0.25	0.13
		ANC 6				0.08	0.00
13.	Karnataka	STD 7	16.70	15.50	12.80	16.40	13.60
		ANC 10	1.75	1.00	1.68	1.13	1.75
		IDU 1	-	1.30	4.23	2.00	2.26
14.	Kerala	STD 4	2.60	3.20	5.20	6.42	2.45
		ANC 4	0.10	0.00	0.00	0.08	0.38
15.	Madhya Pradesh	STD 10	3.50	0.20	1.60	2.69	2.35
		ANC 13	0.00	0.30	0.12	0.25	0.00
16	Maharastra	STD 9	16.00	20.00	18.40	9.20	7.60
		ANC 14	2.00	2.10	1.12	1.38	1.25
17.	Mumbai	STD 3			33.33	21.06	14.84
		ANC 6			2.00	2.25	0.75
		IDU 1			23.68	41.37	39.42
		MSM 1			23.94	23.60	16.80
		CSW 1			58.67	52.26	54.50
18	Manipur	IDU 3	70.70	48.80	64.34	56.26	39.06

		STD 2	4.15	12.00	11.60	10.50	9.60
		ANC 10	0.75	2.30	0.75	1.75	1.12
19.	Meghalaya	IDU 1	0.00	0.00	1.41`	1.39	0.00
		STD 2	0.13	0.30	0.00	0.00	0.90
		ANC 2	0.00	0.00	0.00	0.00	0.00
20	Mizoram	IDU 1	1.00	1.50	9.61	2.00	1.60
		STD 2	1.49	0.76	2.00	2.20	2.60
		ANC 3	0.48	0.48	0.37	0.33	1.50
21.	Nagaland	IDU 3	13.20	7.60	7.03	5.50	10.28
		STD 1	11.10	4.40	6.90	7.40	2.42
		ANC 4	0.70	1.30	1.35	1.25	1.25
22.	Orissa	STD 8	2.86	1.20	2.60	0.80	0.80
		ANC 4	0.00	0.10	0.27	0.25	0.25
23.	Punjab	STD 3	0.00	2.00	0.80	1.61	1.60
		ANC 4	0.00	0.40	0.00	0.40	0.49
24.	Rajasthan	STD 7	5.20	3.20	2.84	4.00	6.00
		ANC 6	0.00	0.30	0.25	0.00	0.50
25.	Siikkim	STD 1	0.00	0.00	0.00	0.00	0.00
		ANC 2	0.13	0.10	0.00	0.00	0.13
26.	Tamil Nadu	STD 11	16.30	10.40	16.80	12.60	14.70
		ANC 10	1.00	1.00	1.00	1.13	0.88
		IDU 1			26.70	24.56	33.80
		MSM 2			4.00	2.40	2.40
27.	Tripura	STD 2	0.00	0.80	1.34	3.20	1.40
		ANC 1	-	-	-	0.25	0.00
28.	Uttar Pracdesh	STD 17	1.60	0.60	1.80	0.90	0.80
		ANC 17	0.24	0.00	0.12	0.00	0.25
29.	Uttranchal	STD 4			-	0.40	0.26
		ANC 3			-	0.00	0.23
30.	West Bengal	STD 8	0.40	1.40	1.96	0.60	0.47
		ANC 9	0.62	0.10	0.50	0.13	0.00
		IDU 1					1.50
31.	A&N Islands	STD 2	1.20	0.40	1.20	1.20	2.60
		ANC 3	0.00	0.00	0.25	0.16	0.00
32.	Chandigarh	STD 2	2.95	1.80	3.35	3.78	0.80
		ANC 1	0.47	0.80	0.00	0.00	0.25
33.	D&N Haveli	STD 0	0.00	0.00	-	-	-
		ANC 1	0.00	0.00	0.00	0.25	1.00
34.	Daman & Diu	STD 0	0.00	0.00	-	-	-
		ANC 2	0.13	0.00	0.00	0.25	0.22
35.	Lakshdweep	STD 1	0.00	0.00	0.00	-	0.00
		ANC 2	0.60	0.00	0.00	-	0.00
36.	Pondicherry	STD 3	7.20	5.80	4.10	2.0	2.02
		ANC 2	0.50	0.90	0.25	0.25	0.25

Note:

1. HIV Prevalence values in States with more than 3 sites are median values, while in States/Uts with 3 or less than 3 sites, the values are mean values.
2. Sites with 75% coverage of desired sample size (STD: 250 & ANC: 400) are included for analysis.(Source: NACO's 'HIV Estimates in India')

Appendix -3

List of High Prevalence Districts, 2001

(On the basis of STD, IDU and ANC Attendees)

S.No.	Name of State/UT	Name of District	
1	Andhra Pradesh (7)	Hyderabad Vishakhapatnam Guntur East Godavari	Chittoor Kurnool Warrngal
2	Goa(1)	South-Goa	
3	Gujarat (3)	Ahmedabad Surat	Baroda
4	Karnataka(10)	Bangalore Mysore Dharwad(Hubli) Bellary Belgaum Gulbarga	Dakshin Kannada (Mangalore) Udipi Bijapur Shyamraj Nagar (Kollegal
5	Mahrashtra (14)	Nagpur Sangli Pune Aurangabad Chandrapur Latur Ratnagiri	Kolhapur Nasik Satara Solapur Thane Mumbai Jalgaon
6	Manipur (4)	Imphal Churachandpur	Bishnupur Thoubal
7	Nagaland (3)	Kohima Tuensang	Mokok Chung
8	Tamil Nadu (7)	Madurai Trichy Salem Coimbatore	Namakkal Tirunelveli Chennai

Source: NACO's 'HIV Estimates in India'

Appendix-4

State-wise Distribution of the Reported Cases of HIV/AIDS

(As on 31st January 2000)

S.No.	State/Union Territory	Screened	HIV Positive	AIDS
1.	Andhra Pradesh	74566	704	48
2.	Assam	17310	251	67
3.	Arunachal Pradesh	495	0	0
4.	Andaman & Nicobar Islands	12452	129	0
5.	Bihar	10194	41	3
6.	Chandigarh	56737	266	137
7.	Punjab	1523	65	100
8.	Delhi	335594	1545	219
9.	Daman & Diu (UT)	250	8	1
10.	Dadra & Nagar Haveli (UT)	160	1	0
11.	Goa	73463	2490	19
12.	Gujarat	454372	1767	137
13.	Haryana	171810	645	1
14.	Himachal Pradesh	5896	130	27
15.	Jammu & Kashmir	8981	40	2
16.	Karnataka	415976	5906	250
17.	Kerala	44547	215	106
18.	Lakshadweep (UT)	1211	8	0
19	Madhya Pradesh	112148	1022	354
20.	Maharashtra	442981	50556	3405
21.	Manipur	43124	6952	454
22.	Mizoram	44022	134	12
23.	Meghalaya	14250	60	8
24.	Nagaland	9156	469	37
25.	Orissa	93750	192	16
26.	Pondicherry (UT)	92896	3479	141
27.	Rajasthan	23044	554	106
28.	Sikkim	616	12	2
29.	Tamil Nadu	765531	15107	4914
30.	Tripura	5613	4	0
31.	Uttar Pradesh	122436	1565	234
32.	West Bengal	163991	649	57
	Total	**3622095**	**94966**	**10,857**

Source: 'HIV Education and Prevention: Looking Beyond the Present' by Gracious Thomas, 2001

Appendix-4B
STATEWISE DISTRIBUTION OF AIDS CASES
(As on 30 September 2003)

S.No.	State/UT	AIDS Cases
1	Andhra Pradesh	43.39
.2	Assam	171
3	Arunachal Pradesh	0
4	A&N Islands	32
5	Bihar	155
.6	Chandigarh (UT)	764
7	Delhi	836
8	Daman & Diu	1
9	Dadra & Nagar Haveli	0
10	Goa	326
11	Gujarat	3378
12	Haryana	313
13	Himachal Pradesh	144
14	Jammu & Kashmir	2
15	Karnataka	1809
16	Kerala	267
17	Lakshadweep	0
18	Madhya Pradesh	1024
19	Maharashtra	9234
20	Orissa	128
21	Nagaland	370
22	Manipur	1238
23	Mizoram	51
24	Meghalaya	8
25	Pondicherry	157
26	Punjab	248
27	Rajasthan	860
28	Sikkim	8
29	Tamilnadu	24667
30	Tripura	4
31	Uttar Pradesh	1125
32	West Bengal	930
33	Allahabad Municipal Corp.	267
34	Mumbai M.C	2908
	Total:	**55764**

Source: NACO

Appendix-5

Wrong HIV Report Ruins Man's Life

A year ago, Syed Basheer was a happy man with a steady job, a caring wife and two kids. Today, his life is in a shambles after a hospital wrongly diagnosed him as HIV positive.

His brother threw him out of the house, mother died of shock and his wife left him. He lost his job too. Two subsequent tests proved him negative but that did not help. Today, he can be seen begging at the Jame Osmania railway station.

The 32-year old is yet another victim of the casual way hospitals, both government and private, conduct AIDS/HIV tests. Basheer had approached the ESI Hospital at Nacharam with complaints of leg pain. After tests, doctors declared he was HIV positive.

But Basheer was not convinced he was HIV positive. He again underwent HIV-I and HIV-II tests at the Osmania Medical College Hospital on May5. The results showed he was HIV negative. Then, he approached the Indian Institute of Preventive Medicine (IPM) on June 17. The Department of Virology at IPM confirmed the Osmania report.

With negative reports from two reputed labs, he approached his former employer but no one was willing to give him a job. His family members did not believe him. The damage was already done.

(Source: Hindustan Times, New Delhi, 28 October, 2003)

Appendix 6

Salient Features of APAC Project, Tamil Nadu, 2001

AIDS Prevention and Control Project of Voluntary Health Services (Tamil Nadu) aims to reduce the sexual transmission of HIV/AIDS in Tamil Nadu by introducing and reinforcing HIV-preventive behaviour among high-risk behaviour populations. Through a network of affiliated NGOs, APAC focuses on four strategies for intervention:

- NGO support and technical assistance
- STD prevention and control
- Condom Promotion and Research
- Behavioural Change Communication
- Research

APAC targets its HIV/AIDS prevention programmes toward four high risks population groups: Long-distance Truck Drivers, Commercial Sex Workers, Tourists, and Youth in Urban Slum settlements. And within these groups also, APAC identified priority areas based on the following measures: population density, presence of major highways and industries, and presence of mobile population around religious centres and tourist sites.

APAC has developed five intervention programmes after a detailed assessment of priority populations:

- PATH — Prevention Along the Highways
- WIP — Women in Prostitution
- SIP — Slum Intervention Programme
- TWIP — Tourist and Women in Prostitution
- CLIP — Clinical Intervention Programme.

All programmes are implemented through a network of carefully selected NGOs who operate in geographical areas defined as priority areas by APAC. These NGOs were chosen by applying a transparent and consistent set of criteria, which included a proven track record and a demonstrable compliance with the objectives and technical strategies central to APAC.

APAC's efforts at prevention proceed through a systematic implementation of at least five clear strategies, mentioned below:

Peer Education, Condom Promotion, Entertainment-education through Theru Koothu (Street Plays), Information Exchange Communication and Promotion of Quality STD Care.
Every one of these strategies plays an important role in the five targeted interventions undertaken by APAC.

Source: 'AIDS Prevention – It works' (Published by APAC-VHS, Chennai

Appendix-7
Peter Godwin's Interview With Satya

PG: Satya, you have seen more and more friends, colleagues and contemporaries die as a result of HIV over the last two years. But have other community, family or society members noticed the increase in young people dying yet, do you think?

S: Most direct family members do notice that the deaths of individuals are due to the complications of HIV. Yet these family members, like People Living with HIV or AIDS (PLWHA), have had to remain anonymous, silent, fearing social reactions, fearing that the deceased's property may not be returned (there are incidents like this in Madras), and, worst of all, that the funeral may not be carried out if the death certificate states 'Died due to AIDS'. In fact, whenever, a person has died of AIDS, the family members request the physician not to mention this in the death certificate. The necessity to remain anonymous is an indication of the very real oppression, which the infected and affected people face – from the people. Peter, it's a vicious circle – until people can be easier about their family or community members who have died of AIDS, we will remain hidden and be 'others'.

PG: So you are saying that the denial of the implications and reality of HIV and AIDS at the personal level carries over to community and national level. No one wants to know about or accept this.

S: Yes. The deaths of young adults are not recognized or admitted as AIDS-related. Since PLWHAA die mainly of TB, or diarrhoeal disease, it goes in the record as TB or diarrhoea. Also, because of the long incubation of HIV disease, it makes it even more difficult for people to recognize that these deaths are due to HIV or AIDS.

PG: We all spend a lot of time talking about 'socio-economic impact'. In your experience, what effects do these deaths have?

S: In my personal experience, I would classify the impact as follows:

- Income: the loss of a PLWHA in his/her prime leads to increased poverty in the family. Since laws and customs restrict women's income-generating capacity, poverty in the family is exacerbated with the death of a male head.
- Women are unable to compensate for lost income by taking on the same or similar earning strategies.
- The funeral of the deceased family member: after exhausting all their resources before death, the people left behind have to really struggle for funeral expenses: anything from Rs.3,000/- to Rs.10,000/-. It is very difficult for people to borrow money for this, as most of them (the ones I have seen and spoken to) have already borrowed money from as many people as they can, and sold all their property, for treatment before death.
- Household management: things like paying rent, electricity bills, and other essential expenses.
- Food supply: the food supply, and so the nutrition of the family goes down. This is a very serious issue, for in most of the cases that I have seen the survivors are themselves positive. These PLWHA can no longer afford the proper quality of food, which means their health starts to deteriorate faster.
- Finally, the effect of the death of an adult on the children: this has not been very widely noticed as far as I know, but it is starting to happen. There are a few instances, which I have come across where the child or children have been removed from school, either to take care of someone at home, or to be sent into employment to support the family.

Please remember, this analysis should not be considered complete. It is purely my own personal experience and observation of people with HIV/AIDS over the past few years.

Source: 'The Looming Epidemic: The Impact of HIV and AIDS in India'/Ed. Peter Godwin, 1998

Appendix-8

"Researchers warn that AIDS in India could become as dire as in Africa"

By Sarah Yang, Media Relations 19 June 2003

BERKELEY – The epidemic of HIV/AIDS in India is following the same pattern as that of sub-Saharan Africa in the 1980s, and it could become just as devastating unless preventive action is taken now, according to researchers from the University of California, Berkeley, in a paper to be published Saturday (June 21) in the *British Medical Journal.*

"In hindsight, opportunities were missed to stem the explosive growth of AIDS in Africa," says Dr. Malcolm Potts, professor of population and family planning at UC Berkeley's School of Public Health and lead author of the paper. "It would be a tragedy if we don't apply the lessons learned from the failure to control the spread of HIV in Africa to the current situation in India. It is very painful to watch history repeating itself."

According to the Joint United Nations Programme on HIV/AIDS, 20 percent of people over 15 in some sub-Saharan African countries are HIV-positive, and 70 percent of them will eventually die from AIDS.

Recent estimates indicate the HIV prevalence rate in India, which has a population of 1 billion people, is less than 1 percent, but the low rate belies the looming pandemic on the horizon, according to the paper's authors.

Part of the change comes from the shifting demographics of India over the past few decades. Like in Africa, large numbers of men in rural areas are migrating to the cities for work and being exposed to changing cultural values, the researchers say.

"Certain sexual practices that were inhibited in a village suddenly become easier with the anonymity that comes with living in a large city," says Potts. "Men also start earning more money, so they have disposable income. And because the ratio of men to women is so low, the men spend their money on prostitutes, which contributes to the spread of HIV."

A report from the CIA's National Intelligence Council projects that the number of people infected with HIV in India will jump to 20-25 million by 2010. There is already evidence that, in some parts of India, HIV infection is moving from the core high-risk groups of prostitutes and intravenous drug users into the general population, the researchers say.

"In sub-Saharan Africa, not enough resources went towards effective prevention programs in these core high-risk groups," says Potts. "The situation in India today parallels that of Africa 15 years ago."

The authors are part of the Bay Area International Group (BIG), a family planning and reproductive health research group at UC Berkeley. Based upon an extensive literature review, original economic analyses and personal experience working in the fields of HIV prevention and international finance, the researchers concluded that current efforts to target high-risk groups in prevention programs fall far short of what is needed.

The paper notes that the public health expenditures for both India and sub-Saharan Africa fall below 6 percent of the gross domestic product. "Both India and Africa face similar challenges in that a large proportion of the population lives in poverty, and limited resources are available to help them," says Dr. Julia Walsh, UC Berkeley adjunct professor of maternal and child health, co-author of the paper, and a co-director of BIG. "In India, the government spends a total of $12 per year per person on health care. Per capita, you're lucky if get you get $1 per year spent on AIDS."

"Investment in AIDS prevention has been a story of too little, too late," says Potts. "The U.S. earmarked a mere $35 million globally for AIDS prevention in the mid-1980s. If we had had

$200 million dedicated to AIDS prevention in Africa in the 1980s, the region would not be in the shape it is in now."

With limited resources, it becomes even more important to use AIDS funds wisely, the researchers said. Yet, scarce funds are being wasted on a large number of small AIDS prevention pilot projects that cannot be scaled to the larger population and on large scientific meetings that have become "platforms for non-evidence based lobbying" rather than a forum for an exchange of ideas and collaborations, the authors say.

Moreover, funding for prevention efforts is in direct competition with funding for anti-retroviral (ARV) drugs. The researchers found that 60 percent of $378 million in grants from the Global Fund to Fight AIDS, Tuberculosis, and Malaria went towards HIV projects, and that 21 of 28 countries receiving those grants will use the money to purchase ARV drugs.

"With the exception of preventing mother-to-child transmission during birth, ARVs are difficult to use and are expensive in developing nations, even when drug companies greatly reduce the price," says Walsh. "The most compelling lobbyists for extending ARV treatment to poor countries are infected individuals in rich countries. But evidence shows that focusing efforts on prevention rather than drug treatment can avert more infections and deaths from AIDS in developing nations."

Another mistake made in the early years of the AIDS epidemic in Africa was the failure to act quickly on scientific evidence that sexually transmitted diseases (STDs) contribute to the spread of HIV by widely distributing condoms and subsidizing the use of antibiotics.

"We know these work, we just have to do it," says Walsh. "Developing programs that helped those at highest risk for HIV transmission means dealing with groups that are marginalized in society: the prostitutes, IV drug users and men who have sex with men. There is still a traditional culture in

India, but political leaders must be willing to acknowledge the need to commit more resources to these core groups if they are to slow the spread of HIV."

Evidence also has led the authors to recommend programs run by faith-based organizations, such as those in the Islamic, Christian and Hindu religions, that encourage sexual abstinence and a reduction in the number of sexual partners.

Another avenue of prevention advocated by the researchers is for HIV prevention programs to offer circumcision to Hindu men, who are generally not circumcised. This is based upon increasingly strong evidence that uncircumcised men are at significantly higher risk of becoming infected from an HIV-positive partner compared with circumcised men.

"We have a moral obligation to use the lessons learned from Africa to prevent a similarly catastrophic spread of HIV in India," says Walsh. "This involves coordinated efforts from national governments, large agencies and donor groups. To do anything less is unethical."

The Fred H. Bixby Endowment, the Bill and Melinda Gates Foundation and the William and Flora Hewlett Foundation provided funding for this research.

Source: http://www.berkeley.edu/news/media/releases/2003/06/19 india.shtml

Appendix -9

AIDS Begins to Widen Its Reach in India,

June 11, 2003

By John Lancaster

Peddapuram, India - On a packed-earth lane known as Bangaraman Temple Street, a resident leads a macabre house tour, ticking off the names of the dead and the doomed.

Here is the tiny concrete hovel where Beeraka, the tea seller, died of AIDS last Saturday, leaving behind an 8-year-old son and a wife who almost certainly is infected with the disease. Three doors down, on the opposite side, is Budavarthi, 40, a mother with HIV who lost her truck-driver husband to AIDS three years ago. Around the corner is Rekha, 28, who was infected by her late husband and transmitted the virus to her 6-year-old son.

And coming up an alley in the arms of her aunt is Devi, a solemn 3-year-old in a patterned cotton shirt. She lost both her parents to AIDS. Her mother died in April, and Devi is infected with the virus. Her aunt says the disease has prevented Devi from learning to walk.

“So many people are sick in any neighborhood,” said the tour guide, Bhavani Senapathi, 25, who works as a nurse in a nearby support center for HIV/AIDS victims. Her husband is bedridden with the disease, and she has HIV. “We have people dying every day.”

Such scenes are increasingly common in parts of India, signaling the start of the long-awaited breakout of the disease from traditional high-risk groups such as prostitutes and drug users into the general population. Infection rates still pale compared to those of sub-Saharan Africa. But HIV/AIDS experts say that is changing.

Blood-test data from pregnancy clinics, considered a reliable cross-section of society, show infection rates as high as 5 to 8 percent in some localities in southern India, according to state AIDS control agencies and independent researchers. A September 2002 report by the CIA's National Intelligence Council predicted 20 million to 25 million HIV/AIDS cases in India by 2010, more than any other country.

“In some parts of India, particularly the states that are reporting the higher prevalence, the tipping point is long past,” Richard Feachem, Executive Director of the Global Fund to Fight AIDS, Tuberculosis and Malaria, said in a telephone interview from Geneva. “I think there is absolutely no doubt that the virus is moving into the general population.”

Despite efforts by private charities and some government health agencies, particularly at the state level, the national response to the disease has been spotty at best, according to HIV/AIDS specialists from international donors as well as Indian and foreign nonprofit groups. They cite, among other things, resource constraints, cultural barriers to HIV/AIDS prevention campaigns - including resistance to discussing condom use - and bureaucratic obstacles such as a federal budget rule that caps the amount foreign donors can contribute to fighting HIV/AIDS.

“There is a fairly widespread view among educated people and opinion leaders in India that HIV/AIDS is primarily an African problem and that Hindu and Muslim culture will protect India from the most serious consequences of the virus,” Feachem said.

“There has been a resort to the mythology of cultural immunity - it can't happen to us because we're different,” added Feachem, who toured the country this year on behalf of the fund, a quasi-U.N. agency that acts as a conduit for public and private funds.

"I found on my visit a persistent tendency to minimize the current scale of the epidemic and the potential future growth."

Officials from India's Health Ministry and the National AIDS Control Organization, which coordinates federal and state prevention efforts, did not respond to repeated telephone messages and faxes seeking comment for this article.

By most reckonings, the HIV/AIDS epidemic in India is still at a relatively early stage, with an overall infection rate among adults estimated at 0.9 to 1.4 percent; the adult infection rate in the southern African nation of Botswana, by comparison, is about 35 percent. HIV/AIDS experts warn, however, that unless more is done to arrest the spread of the disease, the window of opportunity could soon slam shut, creating a far bigger problem down the road.

The disease is already exacting a high toll. As always in India, the problem is sheer numbers: In a country with a billion people, even a 1 percent prevalence rate among adults translates into 4 million infected people, according to U.N. statistics, which means that India has more HIV/AIDS carriers than any country except South Africa. Many of those lives could be prolonged with antiretroviral drugs, which cost just $350 per year in India, far less than in the West. But even that is well beyond the reach of all but a tiny fraction of patients.

India can hardly be accused of turning a blind eye to the disease. Prime Minister Atal Bihari Vajpayee has delivered several speeches on the topic, and the government has orchestrated multiple ad campaigns promoting awareness and prevention. Here in the southeastern state of Andhra Pradesh, one of the hardest-hit areas, the state AIDS agency has been especially forthright, once inflating a giant condom outside the state legislature to dramatize its campaign.

In general, however, Indian officials have played down the threat.

For example, India's Planning Commission, a government body that sets spending priorities for the country, says in its 2002-2007 economic plan that the disease is likely to "plateau" in 2010 and has caused "only a small reduction in expected improvement in longevity." Government spending on HIV/AIDS has remained flat for the last several years. And government officials have reacted angrily to suggestions by outside experts that the disease is getting out of hand.

For example, Shatrughan Sinha, then India's Health Minister, denounced the CIA's National Intelligence Council prediction, as "completely inaccurate". He subsequently accused Microsoft Chairman Bill Gates of "spreading panic" when Gates warned during a trip to India last fall of the potential for an HIV/AIDS explosion in the country. Gates had traveled to India to announce a $100 million grant for fighting the disease.

As in any country, cultural attitudes have shaped the national response. Last December, India's Communications Minister, Sushma Swaraj - a senior leader of the Hindu-nationalist Bharatiya Janata Party that heads India's governing coalition - pulled the plug on a television campaign stressing the protective benefits of condoms; conservatives had complained that the ads encouraged promiscuity.

The ads have since been retooled to emphasize abstinence and faithfulness, in some cases avoiding any mention of condoms. One recent spot, for example, shows a village councilwoman warning other women about the dangers of HIV/AIDS and urging them to be faithful - but says nothing about how they should protect themselves if their husbands fail to follow the same advice. Swaraj, who is now India's Health Minister, told The Times of India this month that she favors a "holistic" approach to HIV/AIDS prevention.

One significant constraint on India's ability to marshal resources against the disease is bureaucratic.

For the most part, the government insists that money contributed by foreign donors flow through its coffers, rather than directly to private groups (it made an exception for Gates). The problem, according to officials with donor agencies, is that India's Planning Commission sets annual ceilings on the amount of money - government or otherwise - that can be spent on various programs, including those related to HIV/AIDS.

That puts India in the seemingly bizarre position of refusing some of the money that donors are eager to give.

"Donor commitment and available resources are greater than the plan ceilings allow," said Tim Martineau, a senior health advisor for Britain's foreign aid agency in New Delhi. "I believe that some states could absorb more resources and that ideally resource allocations should reflect the epidemiology of the disease."

Indian officials defend the system. They say it is up to them and not foreign donors to set the health care agenda in a country where HIV/AIDS is one of a number of chronic diseases - such as malaria and tuberculosis - that claim thousands of lives each year. "If the government gives free rope to one sector, then the other sectors will suffer," said N.N. Kaul, a Planning Commission spokesman. "What is the priority of the central government? What is the priority of the state government?"

HIV/AIDS is clearly a priority in Andhra Pradesh, a coastal state where the rate of infection among prostitutes in some cities approaches 50 percent, according to a 2001 study funded by the British government. Many prostitutes have passed on the disease to their clients, who infected their wives, who infected their children. By all accounts, the state has moved aggressively to combat the disease, both through public education and more practical initiatives such as distributing free condoms to prostitutes.

"I don't go anywhere without them," said Mani Devaradi, 25, pulling a foil package from her sari as she waited for customers at a busy intersection in the coastal city of Kakinada recently.

Kasaraneni Damayanthi, who directs the state program, said in a phone interview from the state capital, Hyderabad, that as a result of such efforts, infection rates have begun to stabilize in some areas. But she added: "We need much more than what we've been getting, because the problem is really massive. It has very much gone into the general population."

That much is clear from a visit to this sweltering farming town roughly 700 miles southeast of New Delhi.

Parvathi Vorra, a somber, slender woman in a blue sari, got the virus from her husband and then passed it on to her son, 3-year-old Sunil. She knows nothing of antiretroviral and couldn't afford them anyway. Now her husband is too ill to work, and she has taken over his job as a sweeper in a local cinema, despite fevers that sometimes last for days.

"I don't have any fear for myself," Vorra, 20, said during an interview at St. Paul's Trust, a local charity that provides her with food and medicine to treat secondary infections associated with the disease. "I only want my husband and child to be happy."

Source: http://www.saaaids.org/media/hivaids_articles.html

Appendix-10

As AIDS Spreads, India Struggles for a Workable Strategy

November 11, 2002
By Amy Waldman

Chennai, India - This is the sight of a wave, years in building, crashing onto shore. Women with HIV - plump women, skeletal women, always frightened women - fill two wards of the Tambaram tuberculosis sanitarium in the southern state of Tamil Nadu. With few exceptions, they are not the commercial sex workers who helped spread the epidemic in its early stages and who have since been taught that condoms can help curb it. Most of them are wives, or widows, infected years ago by their husbands, the only sexual partners they have ever known. Many have watched their spouses sicken, and die. Now their turn has come. Each month at this hospital, the Government Hospital for Thoracic Medicine and which has become the largest AIDS care facility in India, the number of patients with HIV or AIDS, especially women, seeking care is on the rise. The number of new outpatients with HIV, the virus that causes AIDS, has nearly doubled in the past year, rising to 1,151 last month from 613 in October 2001. From March 31 to August 31, the number of reported AIDS cases in the state rose to 22,826, from 16,677, by far the highest in the country. With no more empty beds, the hospital in Tambaram, a suburb of this city, has taken to offering patients straw mats on the floor. "We never expected this," said Dr. S. Rajasekaran, the deputy superintendent. Tamil Nadu, with a population of around 62 million, has been at the vanguard of the AIDS epidemic in India, the country with the world's second-highest number of HIV cases. The state had among the country's highest rates of HIV infections - but also led efforts to contain it through outreach to high-risk groups and other preventive means. Now, with both opportunistic infections from HIV and cases of full-blown AIDS climbing, Tamil Nadu faces a question that the country as a whole must confront: in a nation of limited resources, but where government is committed to providing basic medical care, what kind of investment can and should be made in caring for people who are already infected? There is no easy answer, given that most states lag dangerously behind Tamil Nadu even in prevention efforts. But in this lush state, many of those who have led the prevention campaign are now starting to talk about care. They are arguing that India also needs to develop a better health infrastructure for those already infected, and that even if it cannot provide antiretroviral therapy to the sick, it can help them live longer, more productive lives. The good news is that Tamil Nadu offers hope that with enough prevention, India, where the overall rate of infection is .8 percent among adults, can avoid an Africa-like pandemic. After a decade of focusing on high-risk populations like truck drivers and sex workers, Tamil Nadu's rate of antenatal infection, the most reliable way of tracking the epidemic's spread to the general population, appears to be stabilizing or even dropping. But without similar efforts at prevention in other states, many experts here and abroad fear the worst. India now has, by conservative estimates, four million people infected with HIV, and the United Nations warned this year that India could soon surpass South Africa, where nearly 5 million have HIV, in having the most cases in the world. A recent analysis by the United States National Intelligence Council predicted that India could have as many as 25 million by 2010. Recognizing that India's epidemic is at a pivotal point, on Monday the Bill and Melinda Gates Foundation will announce a $100 million commitment over 5 to 10 years to combat the spread of HIV and AIDS in India. As in Tamil Nadu, the foundation hopes to focus especially on prevention among mobile populations - sex workers, truckers, migrants - who carry the virus from state to state. But the long lines snaking inside the outpatient clinic at Tambaram, the forest of outstretched hands waiting for medicines that will help them stave off illness, the direly weak 25-year-old widow whose 9-year-old orphan-in-waiting sleeps on the cold floor at her side, all suggest that India will face a competing, and increasingly urgent, claim in its approach to AIDS. "I heard he doesn't want to give funding for care," said Dr. Suniti Solomon of Mr. Gates, who will announce the foundation grant in Delhi on Monday. Dr. Solomon, who runs the YRG Center for AIDS Research and Education in Chennai and diagnosed Tamil Nadu's first HIV case in 1986, added, "What I'm going to try to tell him is, unless you fund care, how is prevention going to work?" Dr. Solomon used to argue that prevention was all that mattered. She began rethinking her position as the price of antiretroviral drugs dropped, and as studies showed that over time, they save money by

reducing hospital visits and lost workdays. She has become such a strong believer in the notion that HIV is a disease that can be lived with that she has started helping couples safely conceive a child even though one or both has tested positive. There is also the fact that prevention efforts in Tamil Nadu are at a difficult juncture. The successes of the groups that tackled the AIDS epidemic, like the Tamil Nadu State AIDS Control Society and the AIDS Prevention and Control Project (APAC), which was financed by the United States Agency for International Development, were concentrated among high-risk populations. Spending about $6 million a year, they used peer educators and advertising, among other methods, to spread the word about safe sex and condom usage. The proportion of commercial sex workers using condoms increased to 88 percent in 2001 from 56 percent in 1996, according to an APAC study, and among truckers and their helpers to 78 percent from 44 percent. But the patients who are coming into the Government Hospital for Thoracic Medicine are members of populations that had been considered low-risk. At least a third of the new patients are women, most of them monogamous housewives. Seventy-two percent of new cases are from rural areas, once thought to be largely shielded from the epidemic. In 1996, the hospital had 10 cases of children with HIV; now it has 250. Reaching sex workers concentrated in a red-light district is one thing. Reaching, in a deeply conservative society, into not just diffuse villages, but the marital home, to teach infected men to start using condoms and their wives to demand that they do so, is quite another. Dr. Bimal Charles, the project director for APAC, said he was trying to figure out how to get condoms to rural areas so that husbands could discreetly buy them to use with their wives. Right now, "someone who goes to buy is a marked person," in a culture where the stigma of AIDS remains intense, Dr. Charles said. The biggest problem, Dr. Charles said, are "those who are positive and do not know it." Men who were not tested passed it on to their wives. Women not tested passed it to their babies. Most of the women in the wards were not tested even after it was clear their husbands were HIV-positive, but rather only when they became seriously ill. His organization now wants to encourage more voluntary testing. But even if testing becomes more widespread, what happens when a positive result comes back? Many private doctors and hospitals refuse outright to treat HIV/AIDS patients. One study of rural medical practitioners in Tamil Nadu found that of the 99, who said they had "treated" a HIV/AIDS case in the previous year, 80 percent had simply referred the patient to a government hospital and 9 percent had actually refused to treat the patient at all. And even many government hospitals, which in theory provide free care to everyone, are unwilling or unable to treat HIV/AIDS cases.

So most poor patients are sent to the Government Hospital for Thoracic Medicine in Tambaram, which began admitting HIV-positive patients in 1993. More than one-third of new HIV patients are coming from Andhra Pradesh, the neighboring state, where infections are spreading like wildfire. The Tambaram hospital feels like the backwater tuberculosis sanitarium it once was. Pigs roam freely through its run-down grounds and open-air wards. Over the summer, three HIV patients committed suicide by hanging themselves from the trees.

Most patients, some 300 a day, come for outpatient treatment, a monthly supply of Siddha - an indigenous form of medicine developed in Tamil Nadu whose efficacy in fighting HIV-related infection has yet to be clinically proved. The drugs are provided free to patients, at a cost of about $2 a month per person to the government. The hospital offers antiretroviral therapy only for staff members who may have been infected, and, for one or two months to patients on the brink of death - right now, about 50 to 60 out of 300. The cost is about $30 a month per patient.

The decision to spend money to give respite to the near dead reflects the struggles of caregivers overseeing a de facto hospice instead of a hospital. Asked what the point was of giving antiretroviral therapy for only a month or two, Dr. Rajasekaran, the deputy superintendent, replied, a touch defensively, "Saving a life is the point." In the future, Dr. Charles of APAC says more care will be "home-based," intended to give a "dignified end" to a terminal illness. "There's no way you can start care centers in every community," he said. But activists like Rama Pandian, who has been HIV-positive for a decade, see that as shirking responsibility for developing a public health system that can deal with AIDS. "Don't leave the burden on the community, on the family," he said, and allow doctors and hospitals to continue to avoid treating AIDS patients. For now, the burden is mostly on the

individual, particularly women whose husbands have already died. In a village of 300 families about 100 miles east of here, villagers say that the army man may have died of AIDS. The truck driver almost certainly did, and Shekhar the cow trader definitely did. That was why they insisted hospital workers dig up his body after he died and cremate it. Now some say the cow trader's wife, Shanthi, has HIV, too. In front of her neighbors, she denies it, blaming her weakness on a heart problem, her husband's death on his drinking. But in the privacy of her own barren, one-room hut, she breaks down. Her husband died of AIDS six years ago. She tested positive for HIV seven months ago, after she became sick. Her clothes are growing looser, her skin more lesioned. Her panic over her children's fate is mounting.

Her greatest concern is that no one in the village knows what is making her ill, even if they suspect. "If they know, they will isolate my children," she said. The main thrust of the counseling she received after testing positive was this: "If you want to stay in your village, don't tell anybody." She earns 300 rupees - about six dollars a month at a shoe factory, and is spending 60 of them on an ayurvedic "anti-infective therapy" prescribed by a private doctor. Similar drugs may be free at Tambaram, but she cannot travel there - although in all likelihood, as the disease progresses, that is where she will end up. For now, in the dimness of her thatched hut, she whispers the rest of what the counselor told her: Death is natural. It comes to everyone. Do not be afraid.

Source: http://www.saaaids.org/media/hivaids_articles.html

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