



Antiretroviral drugs for all?

Obstacles in accessing treatment
Lessons from India



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Photographs

Front cover (Top): Civil society activists in Delhi campaign against the US company Gilead's patent application for tenofovir, an AIDS drug which is preferred because it leads to fewer side effects. If Gilead is granted this patent, the drug will become unaffordable in India.

PHOTO COURTESY, DELHI NETWORK OF POSITIVE PEOPLE.

(Lower): Antiretroviral drugs. © GARY HAMPTON

Back cover: Pharmacists dispensing ART drugs. © GARY HAMPTON

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Design

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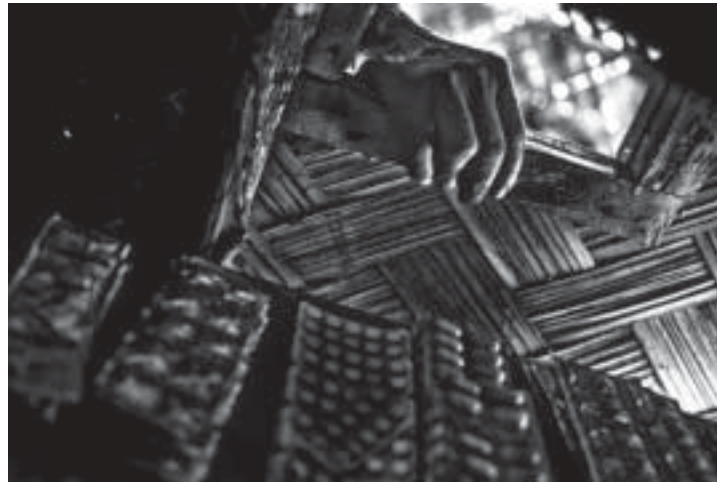
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ACRONYMS

ACT: Access to Care and Treatment	MSM: Men who have sex with men
AHF: AIDS Healthcare Foundation	NACO: National AIDS Control Organisation
AIDS: Acquired Immune Deficiency Syndrome	NACP: National AIDS Control Programme
AP: Andhra Pradesh	NCP+: Network for Chennai Positive People
APSACS: Andhra Pradesh State AIDS Control Society	NFHS: National Family Health Survey
ARV: Antiretroviral (drugs)	NGO: Non Government Organisation
ART: Antiretroviral Therapy	NIMHANS: National Institute of Mental health and Neural Sciences
BSS: Behaviour Surveillance Survey	NNP+: Nagaland Network of Positive People
BEST: Brihan Mumbai Electric Supply and Transport Undertaking	NPP+: Network of Positive People, Secunderabad
BHU: Benaras Hindu University	OI: Opportunistic Infections
BNP+: Bengal Network of Positive People	OPD: Out Patient Department
CAHA: Children Affected by HIV or AIDS	PEPFAR: President's Emergency Plan for AIDS Relief
CARES: Cutting-Edge Medicine and Advocacy Regardless of the Ability to pay	PFI: Population Foundation of India
CHC: Community Health Centre	PGIMER: Post Graduate Institute of Medical Education and Research (Chandigarh)
CII : Confederation of Indian Industry	PHC: Primary Health Centre
CINI : Child in Need Institute	PPTCT: Prevention of Parent to Child Transmission
CNP+: Chandigarh Network of Positive People	PRAMS: Physicians Responsible for AIDS Management
DAPCU: District AIDS Prevention Control Unit	PSACS: Punjab State AIDS Control Society
DOTS: Directly Observed Treatment, Short Course	PWN: Positive Women's Network
FXB: Association Francois-Xavier Bagnoud	RIMS: Regional Institute of Medical Sciences (Imphal)
GICA: Greater Involvement of Children Living with AIDS	SAATHI: Solidarity and Action Against the HIV Infection in India
GIPA: Greater Involvement of People Living with AIDS	SASO: Social Awareness Service Organisation
GMC: Goa Medical College	SIAAP: South India AIDS Action Programme
GSACS: Goa State AIDS Control Society	SEEDS: Social Economical and Educational Development Society
HIV: Human Immunodeficiency Virus	STD: Sexually Transmitted Disease
HPSACS: Himachal Pradesh State AIDS Control Society	STM: School of Tropical Medicine (Calcutta)
ICAP: India-Canada Collaborative HIV and AIDS Project	SVYM: Swami Vivekananda Youth Movement
ICTCs: Integrated Counselling and Treatment Centres	TAI: Tamil Nadu AIDS Initiative
IDUs: Intravenous Drug Users	TB: Tuberculosis
IEC: Information, Education and Communication	TI: Targetted Intervention
INP+: Indian Network of Positive People	TNMSC: Tamil Nadu Medical Services Corporation
GFATM: Global Fund to Fight AIDS, Tuberculosis and Malaria	TNP+: Telugu Network of Positive People
GSNP+: Gujarat State Network of Positive People	TNSACS: Tamil Nadu State AIDS Control Society
KGMC: King George Medical College (Lucknow)	TRIPS: Trade-Related Aspects of Intellectual Property Rights
KHPT: Karnataka Health Promotion Trust	UNAIDS: United Nations Programme on HIV and AIDS
KIMS: Karnataka Institute of Medical Sciences	UNICEF: United Nations Children's Fund
KNP: Kolkata Network of Positive People	UNGASS: United Nations General Assembly Special Session on AIDS
KNP+: Karnataka Network of Positive People	UP: Uttar Pradesh
KSACS: Karnataka State AIDS Control Society	UPNP+: Uttar Pradesh Network of People Living with HIV and AIDS
MACS: Manipur State AIDS Control Society	UPSACS: Uttar Pradesh State AIDS Control Society
MDSACS: Maharashtra District AIDS Control Society	VAMP: Vaishya Anyaya Mukti Parishad
MLA: Member of Legislative Assembly	VCTC: Voluntary Counselling and Testing Centre
MNP+: Manipur Network of Positive People	WBSACS: West Bengal State AIDS Control Society
MPT: Mumbai Port Trust	WHO: World Health Organisation
MSDR: Maharashtra State Development Report	
MSF: Medecins Sans Frontieres	

INTRODUCTION

“The microbe is nothing, the terrain everything.”

– Louis Pasteur, 1850

SANDHYA SRINIVASAN and T.K.RAJALAKSHMI

The overall scenario – policy and perspective

More than two decades after the detection of the first AIDS case in India, the disease is now regarded as a “development” problem and not just a public health issue. Government policy has also moved forward, from AIDS denial to practical acceptance. **The estimated number of Positive People¹ in the country has gone up from 3.5 million in 1998 to over 5.206 million in 2005, accounting for one eighth of HIV infections in the world. The virus has moved from a few epicentres in the southern and north-eastern states to 163 districts in 20 Indian states, though the overall prevalence remains low in the general population (0.9%). It is also acknowledged that women and young people are becoming increasingly vulnerable to the infection. The 2005 sentinel surveillance showed 38.4% of infected persons in the country were women.²**

In the second phase of the national programme being implemented till early 2007, the government stepped up its advocacy, prevention, care, support and treatment programmes. Political advocacy as an activity gained importance. The government recognised that the ‘ABC’ – or Abstinence, Behavioural change and Condom use – approach is of little effect, given the varied risk factors for infection.

The NACO policy document states, “Behaviour change will not occur without a significant change in the social and political environment,” This includes problems of gender inequality, taboos in open communication on sexual health, and stigma and discrimination at all levels. The government also realises the limitations of adopting a “moral” approach to the problem. In the second phase of the programme, condoms, earlier advocated as a safe method of population control, re-emerged as a non-controversial, effective method to prevent HIV transmission. Innovative promotion schemes and social marketing approaches were employed to increase the use of condoms. The number of targeted intervention (TI) programmes among “most-at risk” groups such as sex workers, drug users, men who have sex with men (MSM), transgenders, street children, truck drivers and migrant workers increased from 199 in September 1999 to 1033 by 2006. The number of voluntary counselling and testing centres (VCTC) increased from 79 in 1998 to 2815 integrated counselling and testing centres (ICTC) by March 2006.³ The number of prevention of parent to child transmission (PPCT) centres was expanded from 11 hospitals in five states to 1882 centres across the country (this number includes 502 stand alone centres and 1380 ICTCs which offer PPTCT services). Six hundred and seventy nine sexually transmitted diseases (STD) clinics were also set up at the district level. Another 922 STD clinics were scaled up. Though treatment was not a component of the second phase of the programme, the government initiated antiretroviral treatment (ART) in six most affected states in 2004.⁴

Indeed, while the efforts have seemingly been successful, as in HIV incidence reduction of more than a third in 2000-04 in women attending antenatal clinics in some selected states of India⁵, the most marginalised continue to be acutely vulnerable to HIV and AIDS.

- 1 People Living with HIV and AIDS are referred to as Positive People in this document.
- 2 *Strategy and Implementation Plan, Phase III (2006-2011)*, National AIDS Control Programme, Government of India, November 30, 2006.
- 3 VCTCs and PPTCT centres are now re-modelled as Integrated Counselling and Testing Centres. All counselling services will now be converged at one centre, the ICTC. The ICTC will provide entry points for men and women requiring different services such as STD clinics, TB treatment and women attending antenatal clinics.
- 4 http://data.unaids.org/pub/Report/2006/2006_country_progress_report_india_en.pdf, *Strategy and Implementation Plan, National AIDS Control Programme, Phase III (2006-2011)*, National AIDS Control Programme, Government of India, November 30, 2006.
- 5 Kumar R. *et al*, Trends in HIV-1 in young adults in South India from 2000-2004: a prevalence study, *The Lancet*, Vol.367, No. 3517, April 8, 2006.

In a scenario of low spending by the government on public health in general and increased spending on vertical programmes like AIDS, a new initiative by the government, to increase access to antiretrovirals (ARV) through the public health system has become the subject of a major debate in India.

The 2005 annual sentinel surveillance shows HIV prevalence among sex workers is increasing in Delhi, Assam, Chandigarh, West Bengal and Kerala.⁶ The government recognizes that though condom promotion and procurement registered an improvement, condom use still remained below target.⁷ Findings of the third National Family Health Survey (NFHS-III), 2006 show that while there has been an improvement in the general awareness levels on HIV and AIDS among women (57% in NFHS-III as compared to 40% in NFHS-II), the awareness level on modes of prevention remained low. Only 34.7% women knew that consistent condom use can reduce the chances of HIV and AIDS.⁸ NACO's Behaviour Surveillance Survey (BSS) 2001 found that 30% of street-based sex workers did not know that condoms prevent HIV infection. And in some states such as Haryana, fewer than half of sex workers (brothel-and-street based) knew that condoms prevent HIV.⁹

The strategy implementation plan for the third phase of the National AIDS Control Programme (NACP), which is to be launched in 2007, recognises that the HIV epidemic in India is heterogeneous and states cannot just be clubbed together as high or low prevalence states. A key lesson learnt from the second phase of the programme is that marginalised groups like out-of-school youth, married adolescents and rural populations do not get any attention. The plan, therefore, classifies 611 districts in four categories based on their prevalence and emphasises focusing on districts based on their vulnerability. To increase outreach to rural populations, District AIDS Prevention and Control Units (DAPCU) would be set up in the third phase.

Whether this strategy results in success remains to be seen. Despite a decentralised focus and emphasis on greater participation and involvement of Positive People and other vulnerable groups in prevention and control efforts, certain issues remain unresolved. While NACO seems to recognise the need for a holistic, multi-sectoral approach to the problem, it is still working on ways to translate this perspective into action. The AIDS prevention and control programme is still largely within the Ministry of Health. Though links have been established with other ministries like social justice and empowerment and women and child development, they need to be strengthened. Further, rigid guidelines on implementing intervention programmes make it difficult for programme managers to meet the varying needs of vulnerable groups.

The programme's problems are further illustrated by its targeted intervention strategy, which continues to be the mainstay of its third phase. The targeted intervention component has the highest allocation (19.6%) of the total funding in the third phase also. This calls for targeting vulnerable groups like sex workers, truck drivers, migrant workers and drug users, among others. Unfortunately, this strategy still does not meet needs like immunising the children of sex workers and providing alternate employment opportunities. In analysing policy and implementation, one cannot afford to ignore the fact that AIDS does not constitute the leading cause of mortality and morbidity in the country.¹⁰

Perhaps this is why public health experts argue that increased funding for a vertical AIDS prevention programme is no solution; spending that money for a holistic concept of public health and public good will help alter the landscape of morbidity and mortality, including that caused by HIV, in the country. So, the question remains as to why should the population living below poverty line – with needs other than AIDS and at risk of ill-health in several other ways – neglected by the government and kept out of policy-making, take HIV and AIDS campaigns seriously?

Though the present government has increased allocations to the health sector by 21.9% to Rs 15291¹¹ crores in the union budget for 2007-2008, it still remains below the World Health Organisation standard for public health expenditure, which is 5% of GDP. Moreover, majority of the amount is to be spent in vertical programmes like polio prevention and HIV and AIDS control. Critics say, India's

6 *HIV/AIDS Epidemiological Surveillance & Estimation Report for the Year 2005*, National AIDS Control Organisation, Ministry of Health & Family Welfare, Government of India, April 2006.

7 *Strategy and Implementation Plan, National AIDS Control Programme, Phase III (2006-2011)*, National AIDS Control Programme, Government of India, November 30, 2006

8 National Family Health Survey (NFHS-III), Government of India, 2005-2006. <http://www.nfhsindia.org/pdf/IN.pdf>

9 *National Baseline General Population Behavioural Surveillance Survey*, National AIDS Control Organisation, Government of India, 2001

10 [http://cbhidghs.nic.in/CBHI%20Book chapter4.pdf](http://cbhidghs.nic.in/CBHI%20Book%20chapter4.pdf)

11 USD 347 million (1 USD=Indian Rs. 44)

health took a knock in the 1990s – the era of economic liberalization, when stagnant public health budgets and decreasing government expenditure in public health facilities were worsened by the introduction of charges at various levels in the public health sector.

In this scenario of low spending by the government on public health in general and increased spending on vertical programmes like AIDS, a new initiative by the government, to increase access to antiretrovirals (ARV) through the public health system has become the subject of a major debate in India.

The battle for access to medicines

The story of affordable antiretroviral drugs goes back some years, as new drugs changed the prognosis for people with AIDS. These patented drugs were out of the reach of most people even in the developed world. So, health activists and networks of Positive People launched an international campaign to force governments and international organisations to recognise their right to treatment and care¹¹. Indian drug companies were, at that time, manufacturing and exporting cheaper generic versions of the branded drugs to Africa and Asia. Multinational drug companies fought the ‘threat’ of cheap generics and the challenge to their patent rights.

In February 2001, the Indian pharmaceutical company Cipla Ltd. check-mated the multinationals by offering to sell the three-drug ‘cocktail’ of first-line ARV drugs to international voluntary organisations at \$350 per person per year – a small fraction of the US price of \$10,000-\$15,000 per year. Other Indian companies followed Cipla’s lead, bringing down prices even further.

In response to global advocacy efforts, the UN convened a special session on HIV and AIDS (UNGASS) in 2001, calling for additional funding for ART. Two years later, WHO and UNAIDS declared the lack of access to therapy a “global health emergency” and launched the ‘3 by 5’ initiative to ensure that three million people living in resource-limited settings were treated for HIV infection by the end of 2005. Massive funding increases made this goal potentially feasible. The US President’s Emergency Plan for AIDS Relief (PEPFAR) promised US\$ 15 billion over five years for AIDS prevention, care and treatment. The World Bank has already disbursed an additional US\$ 1 billion towards the effort, and the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) has doled out US\$ 3 billion in the past two years for the prevention and treatment of these three devastating diseases.

The final report on the ‘3 by 5’ initiative released in March 2006 states that the basic objective of the project was not met on time. It revealed that though around 1.3 million people in low- and middle-income countries were receiving ART at the end of 2005, this was just 40% of the intended target. Nevertheless, the effort to expand access to antiretroviral therapy set up structures for treatment implementation. In two years, the number of people receiving antiretroviral therapy in low- and middle-income countries has more than tripled.¹³ The ‘3 by 5’ target has now changed into “Universal access by 2010”. In July 2005, leaders of the Group of Eight (G8) countries pledged to try their utmost to achieve universal access to ART worldwide by 2010. This promise was reaffirmed by world leaders at the UN High-level Meeting on AIDS in June 2006.

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12 Jesani Amar *et al*: Government-funded anti-retroviral therapy of HIV/AIDS: new ethical challenges. *Indian Journal of Medical Ethics*, July-September 2004. <http://www.issuesinmedicalethics.org/123ed070.html>

13 http://www.who.int/hiv/fullreport_en_highres.pdf

Despite the fact that India is a major producer of cheap generic HIV and AIDS drugs, treatment reaches just 20 per cent of those who need it.

ART roll-out in India: A dramatic announcement

On November 30, 2003, the Government of India announced a plan to provide ART through public hospitals in the country, from April 1, 2004. The programme was initially to cover HIV-positive pregnant women who had access to government antenatal clinics, children under the age of 15, and adults with AIDS who went to government hospitals for treatment. The programme would offer a fixed-dose combination of first-line drugs. The drugs would be provided by the three large generic drug manufacturers in India. The aim was to treat 100,000 people free of charge through the public sector by 2005 end.

The initial start to the '3 by 5' initiative in India was slow.¹⁴ As of July 2005, just 10,255 people were on the programme in 25 hospitals across the country. Another 9,000 people were on ART, through schemes for government employees and workers in the organised sector.¹⁵ The number of patients using antiretrovirals increased to a little over 18,000 by December 2005, but accelerated implementation has taken place in the early months of 2006 (see box). By December 2006, approximately 95,000 people were receiving antiretroviral treatment including people enrolled through private facilities. This means that despite the fact that India is a major producer of cheap generic HIV and AIDS drugs, treatment reaches just 20 per cent of those who need it.¹⁶

14 <http://www.whoindia.org/CDS/CD/HIV/Tech-Asst/hiv-tech-asst-main.htm>

15 Lok Sabha unstarred question No. 454 to be answered on July 27, 2005.

16 *Towards universal access—scaling up priority HIV and AIDS interventions in the health sector: progress report*, WHO, UNICEF, UNAIDS, April 2007.

17 Sir JJ Hospital, Mumbai, Maharashtra; Institute of Thoracic Medicine and Chest diseases, Tambaram, Chennai, Tamil Nadu; Regional Institute of Medical Sciences, Imphal, Manipur; Bangalore Medical College Hospital, Bangalore, Karnataka; Osmania Medical College Hospital, Hyderabad, Andhra Pradesh; Ram Manohar Lohia Hospital, New Delhi; LNJP Hospital, New Delhi; District Naga Hospital, Kohima, Nagaland

18 *Anti-retroviral treatment: a new initiative*, National AIDS Control Organisation. http://www.nacoonline.org/directory_arv.htm

ART Roll-out through the Public Health Sector in India

- | | |
|-------------------------------------|--|
| April 1, 2004: | ART starts through eight hospitals in the six high prevalence states of Maharashtra, Tamil Nadu, Karnataka, Manipur, Andhra Pradesh and Nagaland, and two in Delhi. ¹⁷ |
| December 2004, January 2005: | ART treatment expands to a total of 25 hospitals in Tamil Nadu, Manipur, Karnataka, Andhra Pradesh and in the low- (or moderate-) prevalence states of Gujarat, Goa, Punjab, West Bengal, Rajasthan, Uttar Pradesh and in the union territory of Chandigarh. ¹⁸ |
| December 2005: | ART treatment centres expand to 54 centres in high and low-prevalence states. |
| September 2006: | ART expands to a total of 91 centres in high, moderate and low-prevalence states. |
| December 2006: | Paediatric ART initiated at all ART centres. Paediatric referral centres (centre of excellence) to be established in each region of the country. Fees on CD4 count tests waived. |



A look at the ART programme in 14 states: some insights, some questions...

In this collection of articles, journalists from 14 states and union territories describe the Indian government's scheme to provide ART, which started in April 2004. They report from six high-prevalence states (Tamil Nadu, Andhra Pradesh, Karnataka, Maharashtra, Manipur and Nagaland), two medium-prevalence states (Goa and Gujarat), low-prevalence but highly vulnerable states like Punjab, West Bengal, and Uttar Pradesh and low-prevalence, but vulnerable states (Himachal Pradesh, Union Territory of Chandigarh and Haryana). They look at what it means to get ART from the government programme and outside the government's scheme.

These articles are a mix of insiders' views and journalistic insights. They contain the voices of Positive People, vulnerable groups, health professionals, public health experts, government officials, industry representatives and others involved with the programme. The report begins with Maharashtra, a high prevalence state, which highlights all issues of concern. These concerns are accentuated by voices of key stakeholders in other states. The report ends with Tamil Nadu, another high prevalence state, that shows ways of overcoming some of the obstacles.

These interviews were conducted between December 2004 and January 2005 when the programme was initiated. The reports were updated through interviews and desk reviews in December 2005, June 2006 and February 2006. To a large extent they reflect the situation, more than two years after the programme was initiated in April 2004. With every passing day the figures of those accessing treatment and responses change and this report is cognisant of that. We therefore cite dates for which the figures provided are applicable. However, the broad challenges have not changed and will require concerted efforts by all stakeholders. As can be seen from

ABOVE

A woman collects medicines from an ART centre in India. Though figures on ART in India are still low, significant progress is being made due to activism by Positive People, international commitments and increased donor support.

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- 19 Affordable Medicines and Treatment Campaign. A response to the Government of India's antiretroviral treatment (ART) plan. *ACCESS* 1-4, May 2004.
- 20 Interview with K.K. Abraham, President of the Indian Network for People living with HIV/AIDS, AIDS-Care-Watch Campaign, October 6, 2005. <http://eforums.healthdev.org/read/messages?id=8153>
- 21 Chakrapani V. *et al*, *Missing the Target, a Report on HIV/AIDS Treatment Access in India*, Indian Network of Positive People, International Treatment Preparedness Coalition (ITPC), India, November 28, 2005.
- 22 http://www.hivcollaborativefund.org/fileadmin/HIVCDocs/India_Country_Report.ppt
- 23 http://www.tehelka.com/story_main24.asp?filename=Sp122306Drug_supply_p15.asp
- 24 *Strategy and Implementation Plan, Phase III (2001-2011)*, National AIDS Control Organisation, Government of India, November 30, 2006.
- 25 CD4 is a type of T cell involved in protecting against viral, fungal, and protozoal infections and are HIV's preferred targets. Destruction of CD4+ cells is the major cause of the immuno-deficiency observed in AIDS. Measurement of the CD4 count is critical for determining the clinical stage of HIV infection, for deciding when to start ART, evaluating the efficacy of treatment and changing medications if necessary.
- 26 As told by Dr.B.B. Rewari, Consultant, ART, NACO in January 2007.

the set of articles that follow, the key issues emerging in different states on the free ARV roll-out largely remain the same, irrespective of the prevalence and the preparedness of the health system.

Indeed, it is worth noting that the issues raised in an early critique of the programme¹⁹ are quite similar to those in a commentary 18 months later²⁰, a report in November 2005²¹, a presentation in March 2006²², an interview with the project director of NACO in December 2006²³ and e-group discussions in January 2007. The concerns expressed in the interviews in this collection of articles are reinforced through these critiques, as well as references to official statements, press reports and study findings.

ART roll-out: Two years later

Positive developments

Two years after the ART launch in India, there seems to be a significant shift in the attitude of the government to provide antiretroviral treatment. While treatment was not a component in Phase II of NACP, 12.5% of the total funds will be spent on ART (11.5% on adult ART and 1.0% on paediatric ART) in the third phase. This makes funding for treatment, the fourth largest allocation in NACP-III after targeted interventions (19.7%), condom usage (17.3%) and providing a package of services such as STD treatment and counselling to "most-at-risk groups" (12.0%). The plan of NACP-III also emphasises that first-line drugs will be made available to Positive People referred from targeted interventions, seropositive women particularly those who have participated in the PPTCT programme, infected children and those below the poverty line. NACO recognises that to reach a target of 300,000 by the end of 2011, 250 ART centres need to be set up. NACP-III envisages building public-private partnerships, free of cost to prioritised sub-populations.²⁴

When the programme was announced in 2003, NACO had stated that children would be a priority for ART. Yet, for two years, ARV was only available in adult doses for children under nine, leading to problems in physically administering drugs to children and fears of drug resistance. To fill this gap, NACO launched the National Paediatric HIV and AIDS Initiative that – for the first time in the country – allowed children under the age of 18 months to be diagnosed and provided free child-specific dosages of ARV. Under the initiative, 36 ART centres will provide free medicines to children. Additionally, seven registered paediatric centres will offer free CD4 count monitoring and testing for HIV and AIDS until the age of 15.

A major criterion for enrolment under the ART programme is the CD4²⁵ count (NACO guidelines state that those with a CD4 count below 200 should be enrolled for treatment). Though ART itself is free, people had to spend an amount ranging from Rs. 500 to Rs.1500 to get a CD4 test done. To reduce the cost of treatment, NACO sent an order to all states in January 2007 to waive fees for CD4 tests at government centres.²⁶

Some more positive changes can be discerned. The most obvious is that the numbers on treatment have increased. There are increased public-private partnerships, which has helped scale up treatment and improve the quality of service. For example, to improve the quality of counselling and to provide treatment literacy, NACO is implementing a project on "Access to Care and Treatment (ACT)" in partnership with the Population Foundation of India (PFI) in six high prevalence states: Tamil Nadu, Andhra Pradesh, Karnataka, Maharashtra, Manipur and Nagaland. The Global Fund is supporting the project. In states like Assam, ART roll-out is totally managed by an NGO, AIDS Healthcare Foundation (AHF) which works closely with NACO in providing treatment. Additionally, corporates like Reliance and ACC Ltd. (a cement manufacturing company) have set up state-of-the-art ART centres in Surat, Gujarat and Karnataka.

Management systems are being streamlined as well. When the programme started in 2004, there was just one ART consultant in NACO. The year 2006 saw ART consultants being appointed to manage the roll-out in all states. Currently, each high prevalence state has an ART consultant, while a group of three or four low or medium-prevalence states share one ART consultant, depending on the number of centres.

The participation of Positive People in programme implementation has increased considerably though their voices are still not really heard in planning fora. ART roll-out has also helped in strengthening some positive groups. In 2004, participation of positive groups was limited to Tamil Nadu. Today, positive groups across the country are involved in patient referrals and follow-up. Movements of Positive People in states like Chandigarh, which were in a fledgling stage in 2004, are much stronger today. For example, in 2004, Positive People were reluctant to come out and form groups in places like Chandigarh. In 2006, a group was formed and provided consultation on expanding access to vulnerable groups.

Basic infrastructure in some centres has improved. For example, in Sangli, the programme was started in 2004 without any NACO-deputed staff or equipment. The already overworked hospital staff had to do data entry, counsel and provide treatment. In the absence of a CD4 machine, they used total lymphocyte counts. There was not even an inkpad to take thumb impressions before obtaining informed consent from illiterate patients. So, the doctor coloured the person's thumb with a ball-point pen and pressed it to the form to obtain a thumb print. Two years later, the situation has improved. Now, there is a CD4 machine and trained staff deputed by NACO.

The gaps

However, huge gaps can be discerned in the perceptions of government officials, donors, non-government organisations and Positive People on ART in India.

From a look at the programme in 14 states over a period of two years it is clear that the ART programme is poorly conceived, implemented and monitored, raising questions as to the validity of the government's claim of a "96.1 per cent" treatment adherence. Shortage of drugs, equipment and personnel continue to be a reality. An unprepared public health system with no transparency is in no position to handle such an intensive programme. Communication and counselling are the weakest links in the programme. Access for vulnerable groups such as sex workers, men who have sex with men and transgenders as well as those living in rural areas is very limited. There is also limited involvement of those affected by HIV and AIDS especially in planning. Further, inadequate prevention services, stigma and discrimination are also hindering successful implementation.

Targets and realities: The government's target is limited to a small fraction of those who need treatment. Reports point to only 20 per cent of those who require treatment getting it. The first announcement spoke of treating 100,000 people by the end of 2005. Responding to a public interest litigation (PIL) filed by civic groups in the Supreme Court, NACO denied that the government had ever promised to give 100,000 HIV patients access to free ART by 2005 end and said "India's commitment to cover 1 lakh people with ART by the end of 2005 was an aspiration".²⁷

In reality, as of December 2006, 55,473 people were receiving antiretroviral therapy through the public sector at 111 centres. About 15,000 people were being treated at nine sites by nongovernmental and private centres. Moreover, it was estimated that 25,000 people were treated in the unorganised private sector. Overall, approximately 95,000 people were receiving antiretroviral therapy by the end of 2006, including people enrolled through private facilities. The number needing treatment is at least 508,200, which means there is still a gap of 413,200.²⁸

Two years after the ART launch in India, there seems to be a significant shift in the attitude of the government to provide antiretroviral treatment. While treatment was not a component in Phase II of NACP, 12.5% of the total funds will be spent on ART (11.5% on adult ART and 1.0% on paediatric ART) in the third phase. This makes funding for treatment the fourth largest allocation in NACP-III

27 http://www.infochangeindia.org/Health/top.jsp?section_idv=2

28 *Strategy and Implementation Plan, National AIDS Control Programme: Phase III (2006-2011)*, National AIDS Control Organisation, Government of India, November 30, 2006.

SCALE UP PLAN OF NACP – III (Based on spectrum projections)

Year	2006	2007	2008	2009	2010	2011
Total number of AIDS cases estimated	508,200	501,800	493,000	486,000	478,000	473,500
Target for ART in the public sector not including 40,000 children	31,234	100,000	125,000	150,000	184,000	300,000
Proportion of AIDS patients covered with ART	6.1%	20%	25%	31%	38.5%	63%

Source: Strategy and Implementation Plan, National AIDS Control Programme, Phase-III (2006-2011), November 30, 2006.

Counselling remains the weakest component in the ART programme. Several interviews with those on treatment point to treatment being started without proper counselling on side-effects, the possibility of drug resistance eventually requiring second-line treatment, and the need to take the drugs regularly for life.

Supportive infrastructure and services: There are several complaints about the availability of health personnel and equipment. Even where staff has been appointed, their payments are sometimes held up for months, forcing some to resign. Though fees on CD4 tests have been waived, the woes of Positive People continue. Reports point out that in many centres, the CD4 machines are either out of order or test reagents are out of stock. Despite this, the government ART centres do not recognise CD4 test reports from private centres, leading to delays in treatment.

Physical queues at centres are long. Patients complain of standing for four to five hours before seeing the doctor. This is probably why a key recommendation of a two-day state consultation on ART access in Chandigarh was, "the government should ensure adequate facilities such as drinking water, proper seating arrangements, sanitary facilities and shelters/waiting rooms at the ART centres."

ART centres and voluntary counselling and testing services, such as in Lok Nayak Jai Prakash Hospital, New Delhi are not integrated at the moment. Patients spend considerable time in moving between the two centres. The NACP-III Strategic Plan recognises this need and has proposed setting up of integrated centres where counselling and treatment services will be provided at the same facility.

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Most counselling centres have one counsellor who sees 30-35 patients on an average, in five hours. This not only affects the quality of counselling, but also exhausts the counsellors. In crowded centres, counselling is done in the open, leaving no room for confidentiality. Positive People also complain of the moralistic attitudes of counsellors at some centres. Though NACO's national training curriculum has a component on counselling patients on ART, this half-day module is extremely inadequate. Lack of stand-in staff makes it impossible for counsellors to attend training programmes. Improving the quality of counselling services in the

government system has not been spelt out in the strategic plan of NACP-III. The turnover of counsellors is also a problem, as many of them have contractual jobs. This further means not just the loss of trained manpower, but the re-development of a centre. Constant supervision and support of such staff to ensure quality of services is a necessity.

Drugs: shortages and delays

Drug shortages are a great cause for concern as they affect adherence and further chances of drug resistance. The original draft programme does not spell out procurement plans and journalists' reports point to many gaps in the procurement process. NACO officials admit that initially drug shortages were common, but claim the system is streamlined now. Drugs are centrally procured and given to the states based on their estimates. Reports from the states suggest that while in 2004 there were people waiting to be on drugs, today there are no queues for drugs. As soon as a patient is identified on the basis of NACO guidelines, he or she is enrolled in the treatment programme. However, as Dr. B.B. Rewari points out, "Sometimes our estimates are wrong and there is an overload of patients at the centre. This leads to drug shortages."

There were also specific complaints about the drugs available in the programme. Paediatric formulations were not available for two years after the scheme started, though NACO's guidelines specifically state that children will have priority for ART. Similarly, the drug combination with efavirenz, suitable for people with hepatitis B or concurrent TB treatment, was made available only several months after the programme started. Even so, there have been frequent shortages, apparently because of procurement issues. More recently, there were shortages of 40mg stavudine, which is used for patients with more than 60kgs of body weight.

Though NACO has started responding to the complaints on drug shortages, even today information about drug stocks and possible shortages are not in the public domain. Why is the government not negotiating rates with drug companies? What will happen when the current procurement efforts (apparently through WHO) come to an end? There seems to be no answer to the key question: what is the government doing to ensure the availability of second-line drugs under today's patent laws?

Second-line treatment: Second-line treatment is already becoming a concern in some parts of the country, where ART has been available for a longer period and patients have developed drug resistance. A YRG Care study found that 20 per cent of their drug-naïve patients were infected with resistant forms of the virus, requiring second-line treatment²⁹. Indian AIDS patients have been lobbying for the national programme to include second-line drugs, for which cheap, generic versions are not yet available. Koushalya, President, Positive Women's Network in Tamil Nadu says, "ART is very expensive. It is a challenge to sustain those who are on ART. Some medications are not available. The second-line therapy is very costly. The third-line therapy costs nearly Rs 8,000 a month." In response to the growing demand for free drugs for second-line treatment Sujatha Rao, Director, NACO recently announced that NACO will start providing second-line drugs free of cost once the number of patients who are availing first-line through the government hospitals reaches 100,000.³⁰

However, experts caution against scaling up the ART programme till monitoring systems are strengthened. Some experts feel that instead of providing second-line therapy the government should look into introducing expensive drugs like tenofovir in the first-line regimen currently unavailable through the public health system. The collection of articles too point towards a number of teething troubles in the current roll-out, which require a serious look before starting the second-line treatment.

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29 Babu G., 20 per cent HIV affected people in South India resistant to ARV drugs: study. Press report dated September 12, 2005, circulated on the SAATHI e-group on September 15, 2005. This seems to support informal reports from various parts of the country reporting resistance to first-line drugs.

30 <http://health.groups.yahoo.com/group/AIDS-INDIA/message/7166>

Training and monitoring: Though the initial five-day training for healthcare staff involved in the roll-out has been increased to 12 days, it is inadequate to implement and monitor a relatively complex drug regimen, which is new for many medical staff. There have been reports of patients dying in government ART centres because of doctors' inability to manage the drug induced reactions.³¹ Though all the drugs have toxic side-effects, the programme gives drug toxicity a go-by. Further, there are no refresher programmes for doctors as of now. More doctors also need to be trained on providing and managing ART. Training is currently limited to doctors in government hospitals providing ART.

There are fears that a poorly monitored treatment programme will also contribute to an increase in cases of drug-resistance. In most cases, follow-up of patients on ART is usually done through positive groups or NGOs. Considering that counselling is the weakest component in the programme, drug adherence is a major concern for those, like migrant workers, who enrol in government centres on their own. There are reports from Delhi about patients being enrolled in more than one ART centre, leading to fears of overutilisation of services and growing drug resistance. Although there are working guidelines to direct the course of ART management and practices, the programme falls short of ensuring effective monitoring mechanisms to identify and address gaps.

31 <http://health.groups.yahoo.com/group/AIDS-INDIA/messages/6961>

32 Sheikh K. *et al*, Urban private practitioners: potential partners in the care of patients with HIV/AIDS. *National Medical Journal of India*, 18: 32-6, 2005

Kielmann K. *et al*, Managing uncertainty around HIV/AIDS in an urban setting: Private medical providers and their patients in Pune, India. *Social Science and Medicine*, 61: 1540-1550, 2005

Sheikh K. *et al*, Private providers and HIV testing in Pune, India: challenges and opportunities, *AIDS Care*, 17: 757-66, 2005

Sheikh K., Proceedings of the XV International AIDS Conference, Bangkok 2004; Appendix: 4953:E710L6580.

Batura D. *et al*, Knowledge of HIV caregivers in Mumbai: an educational challenge. Presented at ASICON 2005, New Delhi, April 2005.

Batura D. *et al*, Assessing training needs of general practitioners in HIV management. Presented at the 3rd IAS conference on HIV pathogenesis and treatment, Rio de Janeiro, Brazil, July 2005.

NACO Project Director Sujatha Rao concedes that drug adherence is an important aspect, as the programme only provides first-line treatment. To strengthen adherence, NACO joined with Confederation of Indian Industry (CII) to introduce the 'Health Smart Card' for monitoring patients on ART, whereby patients can get treatment anywhere by showing the card. Currently, the project is being piloted at Ram Manohar Lohia Hospital and Lala Ram Swarup Institute of TB and Respiratory Diseases in Delhi.

There are complaints that by limiting ART to those with a CD4 count of 200 or less, the government is effectively making people wait till they were ill enough to qualify for treatment. The Association of Physicians of India has recently suggested a cut-off point of 250 to account for test result errors and to reduce the risk of opportunistic infections as the CD4 count falls. Are the government's guidelines meant to guide decision-making at a programme level – or a form of rationing?

ART from NGOs and private doctors: It is believed that the majority of people on ART are on irrational treatment – inappropriate drug combinations or inadequate doses taken irregularly, without counselling and proper monitoring. While a number of writers point out that the programme is best administered by the public health services, despite all the flaws in private healthcare, the majority of people – even the poor – depend on private healthcare for treatment. Even with the expansion of ART roll-out, people depend entirely on an unregulated private sector because of fears of breach of confidentiality or in the hope of quality services. The private sector is known to be profit-driven, promoting expensive and sometimes irrational treatments. Private doctors routinely violate guidelines on testing and treatment. Studies in Mumbai and Pune show that though the majority have cared for Positive People, few are trained in the field. Many of them are uninformed and violate guidelines on counselling, testing and treatment. Poor patients get 'dumped'; they are sent to public hospitals.³² A state like Gujarat which has the advantage of a well-developed health care infrastructure loses out as a highly commercialised private sector dominates the health sector.

NACO has asked NGOs to submit tenders for providing ART, in a bid to scale up services. NACO says, all organisations which it supports will follow their guidelines and monitoring regime. However, reports from West Bengal raise serious concerns. In 2004, before ART was introduced in the state, NGOs were the main providers of ART. As their ART funding dwindled, the NGOs withdrew subsidised treatment without any warning, leaving people to raise the money on their own. In some

cases, they were forced to take alternative medicines supplied by the NGO. Questions are aplenty. How will NACO ensure the follow-up of patients receiving ART though NGOs in the likely event of funding being withdrawn abruptly? Is there a need for more stringent guidelines and regularisation? How does one ensure that the private sector follows guidelines and ethical practices?

Community involvement: Though NGOs and groups of Positive People are involved in referrals, follow-up and providing counselling, there is very limited involvement of the larger society in planning and designing the programme. It is a top down approach with NACO calling the shots.

NGOs and Positive People seem to be poorly represented in discussions with their involvement often confined to a token presence on committees. NGOs feel that the government uses them to project its own image, but does not take them into confidence. At the same time, some Positive People suggest that the leadership of some of their organisations is not always concerned with the needs of the poor and uneducated among them, who largely look to the networks for support. The better-off are able to take care of their needs without becoming part of an organisation.

Others suggest that they need to develop skills to voice their issues coherently and require training or access to information to make up for the lack of their technical and legal knowledge. Limited involvement also stems from the overwhelming stigma and discrimination faced by Positive People, as is best illustrated by the Northern states where fear of stigma forces them to stay hidden. Encouragement and support from programme managers and policy makers to meaningfully involve Positive People is equally important. In Andhra Pradesh, the appointment of a consultant to increase the involvement of Positive People has resulted in an increase in the number of support groups.

Need for Information: ART consultant in NACO, Dr. B. B. Rewari points out that, “we have drugs for one lakh patients but patients are not coming.” A major reason for this is a very weak communication campaign on ART. Though the government promised to step up the ART communication programme in August 2006, very little has been done in this regard. There are a few campaigns on television and in newspapers about ART and the centres; but these won't go too far in improving the access of marginalised communities. Material on treatment too is limited and dense. Further, there is no material specifically in local languages for Positive People on where ART is available, enrolment procedures, drugs, possible side-effects and the importance of treatment adherence. A study concluded in 2007 pointed out that 41% of respondents did not take ART because of lack of knowledge of ART. More than half of all public and private patients had not heard of CD4 (57%) or viral load testing (80%).³³

Information about drugs and different aspects of treatment needs to be simplified, with innovative communication approaches to explain the jargon to vulnerable groups with low literacy levels, like migrant workers, sex workers and housewives in rural areas. Community organisations, including groups of Positive People, need information on the programme, as they play a key role in publicising the programme, bringing people to centres and helping them adhere to treatment. However, as the reports point out, they often do not know about the programme. Marginalised groups are sometimes the last to know of ART – whether in the slums of a state capital, Bangalore or in rural Karnataka.

Questions are aplenty. How will NACO ensure the follow-up of patients receiving ART though NGOs in the likely event of funding being withdrawn abruptly? Is there a need for more stringent guidelines and regularisation? How does one ensure that the private sector follows guidelines and ethical practices?

33 <http://health.groups.yahoo.com/group/AIDS-INDIA/messages/7089>

RIGHT

Waiting outside a health clinic in remote Sunderbans, West Bengal. Women have less access to healthcare in general and more so with ART. The ART programme has to make special efforts to reach women and children.

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Panos-STOP TB Fellow, 2005



Does treatment reach the marginalised?

Access to vulnerable groups: The reports reveal that despite the scale up, ART is still beyond the reach of the marginalised. Though, in some states like Goa, sex workers and migrant workers report being treated as “any other patient” in other states like Tamil Nadu and Maharashtra, marginalised groups such as Men who have sex with men or commercial sex workers report avoiding public hospitals, having experienced discrimination. Further, as pointed out by Ricky Tombing and Mike Tonsing, associated with the Delhi Network of Positive People, some selection criteria for enrolment in the treatment roll-out effectively deny ART to those who need it the most. “They insist on proof of identity which is important for treatment and follow-up. But, as a result, migrant workers and sex workers may not get treatment.”

NGO workers in West Bengal report that ART is still inaccessible to those in rural areas or those not within the reach of NGO programmes. In the strategic plan of NACP-III, NACO states that it would link targeted intervention programmes with treatment. But what about vulnerable groups who are not part of the targeted intervention programmes? The programme needs to develop systems of recording marginalised groups on treatment to help programme planners assess the reach.

All state reports point out that HIV and AIDS prevention and treatment services are urban centric. Quality as well as quantity of services starts reducing as one moves from the cities to the villages.

Children and ART: The reports point to concerns on the paediatric HIV and AIDS initiative. Counselling children on ART is an issue that begs attention. The training programme for doctors does not include dealing with children and counsellors’ training ignores special skills needed to communicate with children.

Women and ART: Women have less access to healthcare in general and more so with ART. Women fall ill at least as often as men do, but seek healthcare far less often – because they do not have access to women doctors, health services are too far away, or because it just costs too much.³⁴ Though women make up about 40% of the Positive People, they make up less than 33% of the total number of people on treatment.³⁵ As of December 31, 2006, a total of 35,047 men (62%) were on

34 Nandraj S. *et al.* *Health, households and women’s lives: a study of illness and childbearing among women in Nasik district, Maharashtra.* CEHAT, Mumbai, 1999.
Nandraj S. *et al.* *Women and health care in Mumbai – a study of morbidity, utilisation and expenditure on health care in the households of the metropolis.* CEHAT, Mumbai, 1998.

35 Lok Sabha unstarred question No. 3561.

treatment as compared to 17,454 women (31%). It has been argued that women are at an earlier stage in the epidemic, so their CD4 counts are less likely to be low enough to qualify. These numbers need to be tracked closely in future to understand the true picture.

Strengthening prevention: ART roll-out will not be successful without effective prevention services. Despite ramping up voluntary counselling and testing services, marginalized groups still cannot access them. In Varanasi in Uttar Pradesh, the counselling centre is often closed. Patients have to wait for a week for test results, as many counselling centres do not have testing facilities. Awareness programmes still do not reach rural women and marginalised groups. Drugs for opportunistic infections and treatment of sexually transmitted diseases are unavailable in many public hospitals.

All state reports point out that HIV and AIDS prevention and treatment services are urban centric. Quality as well as quantity of services starts reducing as one moves from the cities to the villages.

Beyond ART

Need for nutrition: There is evidence to suggest that micro-nutrient supplements for Positive People can influence clinical outcomes. Several people expressed the need for nutritional support as part of the ART scheme, as well as care in general. Mike Tonsing and Ricky Tombing from Delhi Network of Positive People say, "all the 270 people who have received ART in the two Delhi hospitals till January 2005 are below the poverty line; most are unemployed and a very small section is employed with NGOs. They cannot afford to buy nutritious food." Good nutrition does not mean high-cost nutrition. Nutritional supplements of multi-vitamins and trace elements like zinc, selenium, magnesium, iron, iodine and copper can be obtained through good diets. Some NGOs have developed inexpensive indigenous diets and also organise sponsorship for those in need. "Ordinary foods like *sattu maavu*, (powdered gram flour) bananas and roasted peanuts are rich in zinc and selenium," says Snehalata, a nutritionist from Sahara, a Delhi-based NGO specialising in care, treatment and counselling of HIV and AIDS patients. Nutritional counselling and information on nutrition needs to be an integral part of the campaign. Despite the strong need, there are no plans for overall nutritional support in the government's ART roll-out programme. Recently the government has announced provision of nutritional supplement to take care of 60% of the calorie, protein and micronutrient needs per day of over 3,000 children currently under the ART regime.

Even free treatment has hidden costs: Though ART and CD4 tests are free, patients have to incur travel costs to reach the centres. Some states like Tamil Nadu have waived travel costs in public transport for Positive People. However, various other diagnostic tests are not free till the patient is enrolled for treatment.

Providing social support: There are innumerable stories of positive women being thrown out of their homes, young illiterate widows suddenly forced to think of running their households, positive sex workers being thrown out of the brothels and affected children dropping out of schools. The programme needs to look beyond ART... at ways of improving literacy among women, lowering rural indebtedness, food security, and improving access to quality low cost health care.

Reducing stigma and discrimination: Even after two decades of the epidemic in India, stigma against those living with HIV is rampant. Such stigma consequently leads to discrimination, which inevitably frequently leads to the violation of human rights – particularly those of women and children. Reports of suicides by those living with HIV, mainly because of fears of stigma and discrimination by the society still trickle in. Almost all the state reports point to stigma and discrimination by medical personnel. Communication campaigns and counselling techniques need to tackle stigma and discrimination and help people accept and live with their HIV status.

There are several issues at the root of the problems enumerated by journalists from all over the country.

ART vs. Public health

Numerous reports point to problems with the public health infrastructure in general, leaving aside ART. Public hospitals today are often under-staffed and under-stocked. They are sometimes unable to manage even opportunistic infections, forcing patients to buy basic drugs from private pharmacies. Indeed, the quality of the ART programme in a state seems to depend, at least partly, on the quality of its health care system. In this regard, Tamil Nadu's HIV management is far ahead of most other states in the country, though much remains to be achieved. At the same time, the abysmal public health infrastructure of states like UP raises questions on both surveillance and the system's ability to provide care.

Is it just a problem of an unprepared infrastructure?

"It's a matter of commitment," says Dr. Amit Sengupta, Co-convenor of the Jan Swasthya Abhiyan or the People's Health Movement in India. "You're treating a few thousands when more than half a million need it. That's not even touching the tip of the iceberg. To treat all those who need it, the government will have to invest more in the public health infrastructure."

The Public Health infrastructure must be strengthened not only in public hospitals, but at all levels down to the village community. In order for people to be referred to a hospital for ART, health centres at the primary level must be able to refer people for more advanced treatment. However, this supportive role cannot be played by the existing public health services, as noted by Dr. Alpana Sagar of the Centre for Social Medicine and Community Health at Jawaharlal Nehru University.³⁶

Public Health is a state subject, while national programmes – such as AIDS treatment – are funded by the central government. Researcher Ravi Duggal of the Mumbai-based Centre for Enquiry into Health and Allied Themes notes, "80% of public health financing comes from state government budgets, 12% of funding comes from the national government and 8% from local governments."³⁹

If this suggests that states alone should be held accountable for the quality of health programmes, the picture isn't all that simple.

"All health programmes depend on the infrastructure and administrative machinery in each state," says Dr. Mohan Rao. "When states are starved of funds (by the national government) they have little money to maintain their own public health infrastructure."

Government funding has remained stagnant in the last three decades. Most of it is spent on salaries and other recurring expenditure as opposed to capital investment. "This means that new investment in public health has almost ceased," notes Dr. Duggal. This is one of the reasons for a 30% decline in the use of public health care facilities between 1987 and 1996.⁴⁰

The weakening of public health systems is linked to the increased reliance on market mechanisms to address welfare needs. According to the Central Bureau of Health Intelligence at the Ministry of Health and Family Welfare, government expenditure on health is 17.9 % while private expenditure is 82.1%. This makes India's health sector the most privatised in the world.

36 Dr. Sagar was speaking at a conference on 'Realising the right to health: a Global South dialogue on HIV/AIDS and access to treatment', Mumbai, March 20, 2005.

37 Duggal R., The out-of-pocket burden of healthcare. *Infochange Agenda*, Issue 2, pp. 20-25, April 2005.

38 See footnote 37.

But there are also variations in states' commitment to social expenditure for health, education and welfare. Kerala, where AIDS indebtedness³⁹ was documented, also has a history of state government supported services. It continues to spend more on health compared to other states, despite cut-backs since the 1980s. Kerala announced its own ART scheme, close on the heels of the national announcement. The 'Trissur model' which integrates itself into the health system, provides comprehensive out-patient and in-patient care for about 800 people. Using funds from the state government and the Kerala State AIDS Control Society, it also provides ART for 200 people.

However the question of sustainability is an issue, as the state government is starved of funds.

Do we have the money?

Reports on finances for the ART programme do not give easy answers.

The NACP-III Plan lays down a financial requirement of approximately Rs 134,000 lakhs (\$ 3045 thousand) for ART roll-out over a period of five years. The budget for paediatric ART is Rs 11,100 lakhs (\$252 thousand) and Rs 1560 lakhs (\$35.45 thousand) for setting up paediatric centres of excellence. It is not clear where this money is coming from. Currently, support for the ART programme comes through the WHO (technical assistance and drugs), Clinton Foundation (paediatric ART), UNICEF (Prevention of Parent to Child Transmission Programme), MSF (implementing treatment roll-out in selected states) and Global Fund (training, treatment literacy, counselling). NGOs like AIDS Healthcare Foundation are also supporting the government by taking over the roll-out in some states.

The Clinton Foundation has supported the Government of India with \$35 million of the US\$ 50 million needed for providing ART drugs for life to children under 15 years of age. The rest will come from the Indian government.

Under Phase II of the Global Fund on AIDS, TB and Malaria, NGOs like YRG Care in Chennai, ARCON in Mumbai and Freedom Foundation in Bangalore have been given a grant of \$12 million for 'Upscaling of Antiretroviral Therapy through Public-Private Linkages'. The grant amount will go towards funding to provide ART to Positive People for five years, under several heads of expenditure.⁴⁰

A written response to a question in the Lok Sabha states that India received Global Fund approval for \$ 122.668 million (Rs 564.27 crore) from August 1, 2005 to July 31, 2010, for use in six high-prevalence states.⁴¹

Comprehensive information on the programme's financing and disbursement of finances is not easily accessible. Some guidelines and statements mention provision of treatment for five years. This casts doubts as to whether the programme will ever be comprehensive and sustainable.

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39 Timothy Rakkee K., *The economic impact of HIV/AIDS in Kerala: a household level analysis*. M Phil thesis. Centre for Development Studies, Thiruvananthapuram, 2003.

40 As told by Suniti Solomon, Director, YRG Care

41 Lok Sabha unstarred question No. 454.



ABOVE

ART drugs line a counter. Though India has one of the biggest pharmaceutical companies in the world, the majority of people in India cannot afford ART even at the lowest rates today. The picture is further complicated by the Patent (Amendment Bill), 2005, passed in March 2005.

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Are we making good use of our pharmaceutical industry?

The picture is complicated by a new crisis on the horizon – the Patent (Amendment Bill), 2005, passed on March 23, 2005 which is expected to have serious implications for access to affordable essential drugs.

This amendment to the Patent Act of 1970 was made to fulfil the government's obligations on Trade-Related Aspects of Intellectual Property Rights (TRIPS) as a member of the World Trade Organisation (WTO). India now recognises patents retrospectively from 1995; formulations developed since then may be manufactured only with the consent of the patent holder and on payment of royalty.

Health networks lobbied hard for modifications to the original bill and managed to include clauses enabling the manufacture of essential drugs, including compulsory licensing of essential drugs. Still, it is felt that the Act is more restrictive than required by TRIPS, and the clauses difficult to implement – as they are poorly worded and because the government will not exercise its rights under these clauses.

First-line drugs currently in the ART programme date before 1995 and will not be affected by changes in the Patents' Act, if any, notes Gopa Kumar, researcher at the Centre for Trade and Development in Delhi. Second-line antiretrovirals that are out of patent, such as tenofovir, will not be covered either. Some new applications on tenofovir are pending; if accepted, this would prevent the off-patent production of the drug. Activists have challenged these applications.

But the real issue is with drugs developed after 1995. “The ability of Indian companies to manufacture post-1995 drugs depends on the government issuing compulsory licenses,” says Dr. Sengupta who closely followed negotiations on modifications before the Patent Act amendments were passed. “That is something that we will have to see.”

AIDS activists and patients are also concerned with a challenge by Swiss drug giant Novartis to a local patent law, which could restrict the global supply of cheap anti-AIDS drugs. Novartis is using Section 3(d) of the Patents Act on the premise that it violates India’s WTO obligations. Section 3(d) of the Patents Act, 1970 contains a key public health safeguard, which in simpler words means that patents can be awarded only when there is a substantive improvement of the existing drug formulation, something ‘new’ in the right sense of the word. Changes sought by Novartis to the Patents Act could adversely affect access to essential medicines including ARV not only in India, but also all the developing countries that import Indian generic medicines.

Will Indian companies push for compulsory licensing of second-line antiretroviral drugs?

Indian companies have not used compulsory licensing so far. However, responding to the challenge by Novartis, the Indian health minister has recently said that India may be forced to overrule patents and issue licences for firms to produce vital drugs. Dr. Sengupta feels that large Indian drug companies may not be interested in selling cheap drugs and second-line ART to developing countries. They are now eyeing the generic markets of the US and the European Union. “The US, Japan and the European Union make up 75% of the global pharmaceutical market,” says Dr. Sengupta. These highly regulated markets – especially the US – require higher standards of manufacturing but are lucrative. “More than 50% of Ranbaxy’s and Reddy’s exports have gone to developed markets, where the money is.”

“This will only be through a strong commitment to a public sector programme,” says Dr. Sengupta. Much depends on mobilisation of public opinion. Dr. Sengupta also feels that the argument on drug resistance while introducing second-line ARVs should be made carefully. “This was used to delay the programme. My position is, it’s not an either-or question. The ART scheme must go hand in hand with strengthening the public health infrastructure. We cannot shut our eyes to the fact that HIV has caused a whole continent – Africa – to slide back 20-30 years in development.”

Dr. Sengupta’s comments reflect an interesting change in the public health perspective on AIDS. A decade ago, there was a huge gap between public health activists and organisations working on AIDS. There was a belief that it wasn’t going to be as bad in India as it was elsewhere. Estimates and projections of HIV in India were viewed with scepticism. “This doesn’t mean that you only do HIV and AIDS; I can see the Indian government doing that. You cannot address HIV and AIDS meaningfully without a fundamental strengthening of the infrastructure. We need a health systems approach. It should be able to address any crisis. Today it is HIV and AIDS, tomorrow it could be something else.”

Perhaps this is the take-home message.

The answer is comprehensive health care. We must strengthen our health-care system, so that it can meet the needs of people with HIV and AIDS, just as it must meet the needs of all people needing treatment for any illness.

The ART roll-out must be seen as an opportunity to demand a better and more responsive health-care system for all.

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MAHARASHTRA

Two years down the line...is the system in place?

Drug shortages, weak infrastructure, burnout of counsellors, weak monitoring – are we in a position to look at providing second-line treatment?

SANDHYA SRINIVASAN



■ It's Friday morning at the Sir Jamshed Jejeebhoy Hospital in Byculla in central Mumbai and there's a long line outside Out Patient Department 20, though it starts functioning only at 2 pm. An elderly man who can barely walk is accompanied by his sister. A woman in a burqa sits in a corner without looking up. A young, middle-class couple has travelled from a distant suburb because they heard that the pills they were taking on alternate days to save costs, are now available through the government for free.

■ Four resident doctors crowd around a single table in the 'AIDS OPD' of Sangli's civil hospital. They have been working non-stop for the last six hours but there is no sign of the crowd outside thinning out. So, one resident takes the patient's weight, another scrutinises papers, a third fills in forms, and a fourth gets patients to sign their 'informed consent'. "Eat well, take the medicine every day and come back after a month. Come back immediately, if you experience any side-effect, don't have sex with your wife; but if you do, remember to use a condom," the resident rattles off to the bewildered man, handing over the medicines and turns to the next patient.

■ A man is waiting outside the out-patient department of the Sassoon General Hospital in Pune. This is the third time he has come here, travelling five hours from his village. But he has been told that he must come back later – there are hundreds of people already on the list who have not yet been put on treatment.

The western state of Maharashtra, with a population of 96.7 million¹, is one of the six states where the ART roll-out began in the first phase itself. The first centre at JJ Hospital in Mumbai was already known for its work in treating Positive People.

Nine per cent of the population of Maharashtra contributes more than 20% of the country's industrial output and 13% of India's gross domestic product. Its per capita income of Rs 22,179² in 2001-02 was much higher than the national average. The capital, Mumbai, is seen as the country's commercial and financial capital. Not surprisingly, the rural-urban divide in the state is quite sharp. The per capita income of Mumbai, for instance, has remained consistently about 2.5 times that of rest of Maharashtra. One comes across acute poverty among large sections of the state's rural population. The state's achievement in respect of poverty alleviation is far from flattering, though it is the third richest state in the country. The Maharashtra State Development Report (MSDR) describes the state as having "islands of urban prosperity in a sea of rural poverty".

Health and health care in the state are above the national average. The infant mortality rate in Maharashtra is 32 per 1,000 live births, as compared to the national figure of 57. Around 75.3% of pregnant women received an antenatal

1 Census of India 2001.
www.censusindia.net

2 USD 504
(1 USD=Indian Rs 44)

check-up in the first trimester of their pregnancy, compared to 50.7% nationally. And, 70.7% births were attended by a health personal, compared to 45.3% nationally.³ Over 77% of the state is literate compared to 65% nationally.⁴

But, like a number of other states in India, Maharashtra's public health system is in the midst of a crisis. The state economic survey notes that while the public health infrastructure was expanded in the 1980s, public health investment and expenditure has been reduced since then. This has contributed to the "qualitatively and quantitatively wide gap in health care infrastructure available in the rural and urban areas of the state. Over 80% of the beds in government hospitals are in urban areas where about 40% of the population lives."⁵ Following the introduction of user fees in government hospitals, patients have to pay for case papers and some drugs, tests and procedures. Their frustration is compounded by the attitude of over-burdened staff trying to work with limited resources. It is no wonder that Mumbai newspapers regularly report assaults on doctors by people who feel their relatives have been mistreated.

Interviews were conducted with a range of individuals and organisations concerned with the ART roll-out programme, in the state capital of Mumbai, the satellite city of Pune, and Sangli, a large town in interior Maharashtra. All three are high-prevalence districts. Those interviewed include doctors implementing the programme, NGO representatives, members of support groups for Positive People, activists working with marginalised groups, women in antenatal clinics, counsellors, private practitioners, government officials and the representative of a pharmaceutical company.

Based on these interviews, the following insights emerge:

- Treatment is available to only a fraction of those who need it.
- There is no evidence that it reaches out to marginalised groups who have faced discrimination in the health care system.
- The process is reasonably burdensome, with financial and time costs.
- The scheme requires testing, counselling and regular monitoring, along with proper data maintenance, but NACO provides inadequate support and NGOs' involvement has been erratic.
- The ART roll-out is not integrated within a comprehensive care and support programme. Therefore, it remains an ambitious programme imposed on a resource-starved public health care system.



BELOW

ART clinic in Nair Hospital, Mumbai. Only 12,000 (16 per cent) people receive treatment in Maharashtra, more than two years after the government ART programme started here.

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3 National Family Health Survey (NFHS-III), Government of India, 2005-2006. <http://www.nfhsindia.org/pdf/IN.pdf>.

4 Census of India 2001. www.censusindia.net

5 Government of Maharashtra. Economic Survey of Maharashtra 2002-2003. http://www.maharashtra.gov.in/english/ecoSurvey/esm_e/cha02e.pdf

HIV and AIDS in Maharashtra

Maharashtra is one of six high-prevalence states in the country – more than 1% of the general population is believed to be positive, as are more than 5% of groups at high risk, such as injecting drug users, men who have sex with men (MSM) and sex workers. HIV prevalence in the general population, as extrapolated from antenatal clinic samples, is 1.25%. Though HIV prevalence rates are decreasing among injecting drug users (from 29.20 in 2004 to 12.80 in 2005), in groups like MSM (11.20 in 2004 to 10.40 in 2005) and female sex workers (41.69 in 2004 to 23.62 in 2005) it is still relatively high.

Treatment options in the state

There are between 750,000 and 1 million Positive People in Maharashtra, says Dr. V. L. Kulkarni, who is in charge of the ART programme in the state. Presuming that 10 % of those affected are at a stage where they will benefit from treatment, about 75,000 - 100,000 people need ART. Approximately 12,000 people are accessing treatment through the government programme and other agencies. A large number access private clinics for treatment. It is difficult to estimate the number of people accessing private clinics, as documentation is pathetically inadequate. "Prescription tracking needs to refer to the three-drug regimen as well as the suboptimal estimates," says Dr. Sanjay Pujari, Head of the Department of HIV Medicine at Ruby Hall Clinic, Pune. Dr. Pujari and Dr. Vinay Kulkarni, also in Pune, are among the handful of Indian physicians whose practice focuses exclusively on HIV and AIDS. Between the two of them, they provide treatment to around 10,000 -15,000 people. Some of them are on ART.

Dr. Pujari estimates that 10,000 people are on suboptimal regimens at any given time – with new patients being put on such regimens even as others drop out. "These days I see fewer 'treatment naïve' patients," he says. He and his colleagues did a prescription audit of their patients' previous therapies and found that only a fraction had followed established guidelines, and even fewer had been part of a comprehensive diagnostic and treatment programme. "The number of people who have ever been on suboptimal and quack regimens probably exceeds the number of people on ART," adds Dr. Pujari.

The market cost of these drugs is about Rs 1,500 a month. Some of Dr. Kulkarni's patients pay about Rs 500 a month, in a deal worked out directly with a drug company. But even this is too much for most patients. Other doctors report that their patients on ART pay between Rs 2,000 and Rs 5,000 per month for treatment. Dr. Pujari's inquiries following his prescription audit revealed that people often stopped taking the antiretroviral drugs and bought just the supplementary vitamins and antacids.

For some time now, government employees have been reimbursed for ART expenditure. Before the government programme started, many patients in government out-patient departments (OPDs) were prescribed ART, but it had to be bought from the private sector at market rates. Some government and private doctors negotiated with drug companies and have been providing drugs at reduced rates to selected patients.

A number of other public sector companies and NGOs are also providing ART.

Other Agencies Providing ART in Maharashtra		
Agencies	Total on HIV Care	Total on ART
BEST	200	178
MPT	311	107
Western Railway	533	33
ARCON	6376	191
MSF	365	149
TOTAL	7785	658

The Brihanmumbai Electric Supply and Transport Undertaking (BEST) started prevention, care and treatment programmes after 200 of its staff tested positive. Employees of the Mumbai Port Trust (MPT), the largest cargo-handling port in the country and their dependents receive published material on HIV and AIDS by Maharashtra District AIDS Control Society (MDSAC). At present, 107 people are on ART at the Port Trust hospital.

The government ART programme

The ART programme started on April 1, 2004 at the government JJ Hospital in Mumbai. The government programme is directed at the following groups: children under 15, pregnant women who have been part of the prevention of parent to child transmission (PPTCT) programme, and patients attending government hospitals for AIDS-related care.

The programme was extended to the civil hospital in Sangli on December 1, 2004. Registration for ART in Pune's Sassoon General Hospital started on January 5, 2005 and drug dispensing started shortly thereafter. New centres have come up in Nagpur and in three Mumbai municipal hospitals. All centres are run from the Departments of Medicine. Currently, there are 13 functional ART centres in Maharashtra. There is a proposal for nine more ART centres at district hospitals and Medical College hospitals.

The numbers have been going up ever since the programme started. As on December 31, 2006, 11279 people were on ART in Maharashtra covering 13 ART centres. This includes 5322 people enrolled in Mumbai alone, covering four ART centres.

Government centres providing ART in Maharashtra – 31 December 2006

NAME OF THE CENTRE	NO. OF PATIENTS ON ART			
	Male	Female	Children	Total
JJ Hospital, Mumbai	2359	1154	110	3623
KEM Hospital, Mumbai	611	300	78	989
Nair Hospital, Mumbai	104	55	0	159
Sion Hospital, Mumbai	321	169	61	551
TOTAL CENTRES IN MUMBAI (4)	3395	1678	249	5322
Government Medical College, Sangli	802	591	159	1552
B. J. Medical College, Pune	884	646	166	1696
Government Medical College, Nagpur	797	323	125	1245
NARI, Pune	104	55	0	159
Medical College, Aurangabad	137	54	8	199
Medical College, Dule	156	52	4	212
Medical College, Akola	77	29	10	116
Medical College, Yawatmal	109	35	8	152
Medical College, Ambejogai	409	214	3	626
TOTAL CENTRES IN MAHARASHTRA (13)	6870	3677	732	11279

Paediatric ART in Maharashtra

From December 2006, paediatric formulations are available in all government ART centres. Paediatric cases which require specialized care are referred to Sion Hospital, which is the regional paediatric ART centre.

Inequities in access to treatment

If there are around 12,000 people on ART in Mumbai's programme, at least 10 times as many need it, but don't get it.

Does the programme reach marginalised groups? We do not know. There is no provision of information on marginalised groups availing treatment in the data collection forms.

"This was an opportunity for a very systematic data gathering and monitoring exercise," says Dr. Nagesh Shirgoppikar of the Salvation Army, Mumbai. "Patient intake forms could have been designed, so as to collect various details indicating how people got on to the programme, whether they are linked to an NGO for follow-up, and so on. They could also have looked at treatment adherence, complications and their management, and so on." This would have functioned as a social audit. Today, only common sense tells us that people are falling between the cracks of the system.

In general, government hospitals are used by a fraction of those seeking care. Marginalised groups such as sex workers and transsexuals have faced so much discrimination in health care that they may hesitate to approach the tertiary hospital where drugs are available. People living in rural areas must spend extra resources to reach the city for treatment. Many patients travel more than 300 kilometres to get to the Pune centre. Some patients must travel overnight to reach the Sangli centre in time for the morning OPD.

Dr. A L Kakrani is the head of the ART centre at Sassoon General Hospital. He says the centre was started in January 2005. Since then a total of 7000 patients were screened and around 1800 patients were put on ART. On a daily basis, there is a waiting line of at least 80 patients in the centre; there are 10-15 new enrolments (those whose CD 4 count is less than 200) every day. After enrolment, the patient is taken for screening, X-rays and other blood tests. This takes approximately three weeks, after which the person is put on treatment. Those who are screened and do not qualify for treatment are called for a follow up after six months to check whether they require ART.

Women make up about 40% of those with HIV but fewer women receive treatment. For Mumbai, in December 2006 women made up just above 30% of those on treatment (3395 men, 1678 women, 249 children). One possible reason, according to Dr. Alka Gogate, project director of the Mumbai District AIDS Control Society, is that women are at an earlier stage in the epidemic. Therefore, fewer women than men will approach health care services. And, women on the PPTCT programme are likely to be newly infected and therefore do not meet the medical criterion for ART – a CD4 count of less than 200. Such women should be followed up so that they can be registered when they need treatment. But unless there is systematic follow-up of positive women in the PPTCT programme, they will not get ART when they need it.

“We run a PPTCT programme where our focus is on general prenatal care, and HIV is only one issue – it certainly isn’t the woman’s only concern,” says Sanjeevani of Prayas, Pune. “So, whatever the HIV test result, the woman is supported throughout her pregnancy and delivery. Positive women get access to care and support services when they become necessary.”

Counsellors at ART centres must also ensure that people starting the programme bring their partners for testing and treatment, if found necessary. But, whether this guideline is being followed consistently is anybody’s guess.

Is the system in place?

According to the NACO guidelines for the ART roll-out programme, NACO was to provide each institution: one senior medical officer, one medical officer, one counsellor, one lab technician and one record keeper/ computer operator. It also had to train the entire team in ART, provide equipment for free tests of CD4, ‘contingency funds’ for renovation, and, of course, the drugs themselves.

“As for staff, we have the numbers specified in the NACO guidelines but we need many more people given our patient load,” says Dr. Deshpande in Mumbai. The CD4 machine in Mumbai breaks down frequently. So, technicians do only 10 tests a day so as not to ‘overuse’ the machine. This means a forced wait of a month for people, at times. The alternative is to get it done privately but some doctors distrust these results. This problem persists ... even more than a year after the programme started. “Our machine has not been replaced, but we have made arrangements with two municipal hospitals to get the tests done there,” says Dr. Deshpande.

Dr. A.L. Kakrani, Head of the ART centre at Pune’s Sassoon Hospital says, “ We

The ART roll-out is not integrated within a comprehensive care and support programme. Therefore, it remains an ambitious programme imposed on a resource-starved public health care system.

Monitoring and co-ordination of the different agencies involved in implementing the programme is weak. ART consultant, Dr. Dilip Vaswani says, “One of our biggest challenges is to keep track of the private organisations and force them to report or practice the national guidelines.”

need people to do counselling, paperwork and so on. We involve NGOs in the follow-up.”

In Sangli, there were no test kits in the voluntary and counselling testing centres for more than one and a half months, in late 2006. The government ART Centre does not accept any test result from ‘outside’. According to the guidelines, the centre needs to first conduct an HIV test and then a CD4 count test. Even if a positive person comes with a private lab investigation showing a low CD4 count, the person is sent back because the civil hospital has no kits to test for HIV.

There is also concern about the quality of training in the government programme. “You can’t train doctors for five days and tell them to prescribe ART,” says Dr. Vinay Kulkarni from Pune. Shabana Patel, President, Network in Maharashtra by People Living with HIV and AIDS says, “Training programmes for doctors in paediatric care should not only give technical information, but also help them respond to the special needs of the children.”

“We found that some people on the programme didn’t know that ART must be taken at specific times every day, and that adherence is very, very important,” says Gopa Kumar, NGO representative, Centre for Trade and Development, “Counsellors should be giving this information.”

Monitoring and co-ordination of the different agencies involved in implementing the programme is weak. ART consultant, Dr. Dilip Vaswani says, “One of our biggest challenges is to keep track of the private organisations and force them to report or practice the national guidelines.” Dr. B.B. Rewari, ART Consultant, NACO was concerned that MSF had started implementing the ART programme in the state, without consulting NACO, “Any independent donor agency has to work with NACO and follow NACO guidelines.”

Another issue voiced by Dr. Vaswani is the burnout among the staff in the programme. “The psychological impact of working with chronically sick patients leads to huge turnover of staff. This further means, not just loss of skills, trained manpower, but also re-developing a centre. Constant supervision of such staff to ensure productivity then becomes a necessity.”

Counselling children on ART is also a major concern. Shabana Patel of the Network in Maharashtra by People Living with HIV and AIDS says, “The counsellors at the ART centres are not prepared to provide quality child counselling as well as counselling to parents. There are situations where the children know their HIV status after the counselling, but are unaware about the ART treatment. Also, most children don’t know why they need the medicines and that they need to adhere to treatment. Doctors also are quite unclear about the paediatric ART roll-out.”

The hidden cost of treatment

“They told me, my husband and I should be prepared to spend Rs 3,000 for tests, in order to be considered for the programme,” says a woman at a support group for Positive People. Her husband is a roadside vendor. “We barely earn enough to feed ourselves. Where are we to get that kind of money?” she adds.

Although, the government has waived charges on CD4 tests, those whose CD4 count meets the inclusion criterion for the programme must pay for tests that provide baseline information on liver function, haemoglobin levels and so on, to enable monitoring for drug-induced toxicity. In Mumbai, doctors have asked the hospital to do it free, as ART is a national programme.⁶ People who enter the programme through an NGO such as the Salvation Army might be able to get the tests done at a highly subsidised rate.

⁶ This of course brings up the question of whether it is fair to people needing treatment for other conditions, but for whom tests are not free.

“Ordinary people, the really poor, will not be able to access treatment,” says Meena Seshu, Director of the NGO Sangram in Sangli. “Especially, if they have to pay for tests, when the government’s machines don’t function.”

Spectre of shortages

“The first consignment of drugs arrived at JJ Hospital, after office hours, the day before drug dispensing was to start,” says one of the people in the Mumbai programme. It was sufficient for just 100 patients for a month and doctors were not sure when the second consignment would come in. So, a four-month programme for 25 patients was formulated. The NGO forum in the city was told to refer more patients for treatment as the drug stocks increased.

In Sangli, patients must sign an ‘informed consent’ form agreeing to pay for tests if needed, and to buy drugs from the market, if the supply is stopped suddenly. “We are worried about what will happen if the drug supply is interrupted,” says one doctor. Meena Sheshu says, “Two years down the line, the physical infrastructure in the government ART centre has improved. The centre now has a CD4 count machine and the NACO appointed staff. But the informed consent form still exists.”

Indeed, doctors in Pune and Sangli repeatedly expressed concerns about possible drug shortages. This may be why the programme is given little publicity, as doctors fear a rush of people demanding treatment. The administration also fears pressure from NGOs trying to get treatment for their contacts, which might explain why NGOs are in the dark about the programme.

Dr. Vaswani concedes, “Relocation of drugs to far-off centres is a concern at the moment. To avoid shortages, we need meticulous planning as part of monitoring and evaluation of the programme.”

Criteria for inclusion

In this atmosphere of ‘perceived scarcity’, there is also a feeling that the inclusion criteria is not applied uniformly, and people with ‘connections’ are more likely to get treatment. This would be difficult to ascertain but it is certainly plausible.

In Mumbai, inclusion and exclusion criteria were modified for non-medical reasons. For example, the 200 CD4 count limit (the cut-off point for ‘resource-constrained settings’) was raised, and people already on ART from the private sector were included, as doctors became more confident that the drug stock could meet the demand. The domicile requirement was dropped, as was the requirement that the patient be accompanied by someone else. Patients were not required to sign an informed consent form.

Interestingly, the Mumbai programme announced that ‘earning family members’ would be given first priority. This sent out wrong signals that women’s household work and care-giving were not equally critical for the family’s survival. And, Mumbai NGOs have also agreed that people over the age of 65 would be given low priority for ART.

Some Positive People have also challenged NACO’s guidelines for prescribing ART. According to these guidelines, based on WHO clinical staging, ART must be offered to those with WHO stage IV disease and those with CD4 counts of less than 200. Those with WHO stage III disease and CD4 counts of less than 350 will be monitored and considered for treatment. “If the western standard is 300, why should I wait till my CD4 count goes down from 300 to 200?” asks one activist. Dr. Sanjay Pujari notes that the Association of Physicians of India has recently

developed guidelines for ART in the private sector. The API's CD4 cut-off is 250. "The rationale is that, there will be 30 per cent variability in any given CD4 estimate," says Dr. Pujari. And, when the CD4 count falls below 200, the person is likely to develop an opportunistic infection. The higher cut-off point reduces the risk.

Essentially, the NACO guidelines are meant for decisions at the population level not individualised decisions. However, they also contain an element of rationing. Raising the cut-off point would immediately increase the number of people eligible for treatment – with all the implications for resources. On the other hand, the lower cut-off point accepts that people will be at a higher risk of developing opportunistic infections.

Discrimination and stigma

"Why is it that Positive People are always placed next to the toilet?" asks a member of a positive support group in Pune. "They won't touch us, they serve us food from a distance," says another.

Positive People have faced extensive discrimination from both the private and public health sectors. This is bound to affect their use of the government ART programme.

The ART programme must maintain patient confidentiality. "My patient told me she went to join the programme since it would save her a lot of money. She stood in line only to find that the 'AIDS queue' was very obvious. Her son learned of her status as a result," says Dr. Pujari in Pune.

"Counselling is done in public," says a positive person from one of the care and support programmes in Pune, referring to the regular programme before government ART came along. "The doctors are moralistic, as if AIDS is a punishment for some sin," says another.

A clerk behind a glass-fronted counter at the entrance to the Sassoon virology OPD in Pune wears gloves and a makeshift mask. So does one of the four residents at the Sangli OPD, who justifies this by saying he is protecting himself from open TB cases – even though no one else sees the need to do the same.

RIGHT

People waiting to enrol outside an ART centre. Extensive discrimination of Positive People from both public and private health sectors is bound to affect their use of the ART programme.

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In crowded clinics, patients congregate around doctors' tables, providing no room for any confidentiality. "One of my patients received no adherence counselling, and when she reported toxic reactions, the doctors did not take note and suggest how to manage them," says Dr. Pujari. He, however, concedes that this could happen in the private sector as well.

Members of the positive support group Amich Amche in Sangli with a membership of 325, of whom about 25 are on ART, describe extensive discrimination by doctors. "We used to face a lot of discrimination at the civil hospital," says Shevanti Rano of VAMP (Vaishya Anyaya Mukti Parishad, an organisation of sex workers formed to prevent atrocities against sex workers) in Sangli. "But we fought, and things have changed."

Private fears of drug resistance

Private doctors feel that the roll-out programme has not properly involved those who have been prescribing ART for years – both for their experience and to ensure their co-operation in a national programme. "We need a true public-private partnership, if the ART roll-out is to succeed," says Dr. Sanjay Pujari, Head of the Department of HIV Medicine at Ruby Hall, Pune.

They also feel, the crisis of drug resistance will only be compounded as the public sector goes on with a programme without adequate training and infrastructure, and without looking at a comprehensive programme for care and support, including nutritional support.

Dr. Pujari reports that 83 per cent of his patients on ART have no issues with adherence. But, his is a highly structured programme and he does not believe that this is possible in the public programme today. As Ashok Row Kavi of Humsafar Trust, Mumbai asked at a meeting of NGOs, if compliance for a six-month course of DOTS for TB is so low, how will the government ensure that people will take ART life-long?

People starting ART are not told that irregular treatment will lead to drug resistance and require a shift to second-line drugs. Nor do they know that second-line drugs are not available in the programme and are five times more expensive than first-line drugs.⁷ Worse, no one is told that even with proper compliance, there is a chance of developing drug resistance within a few years.

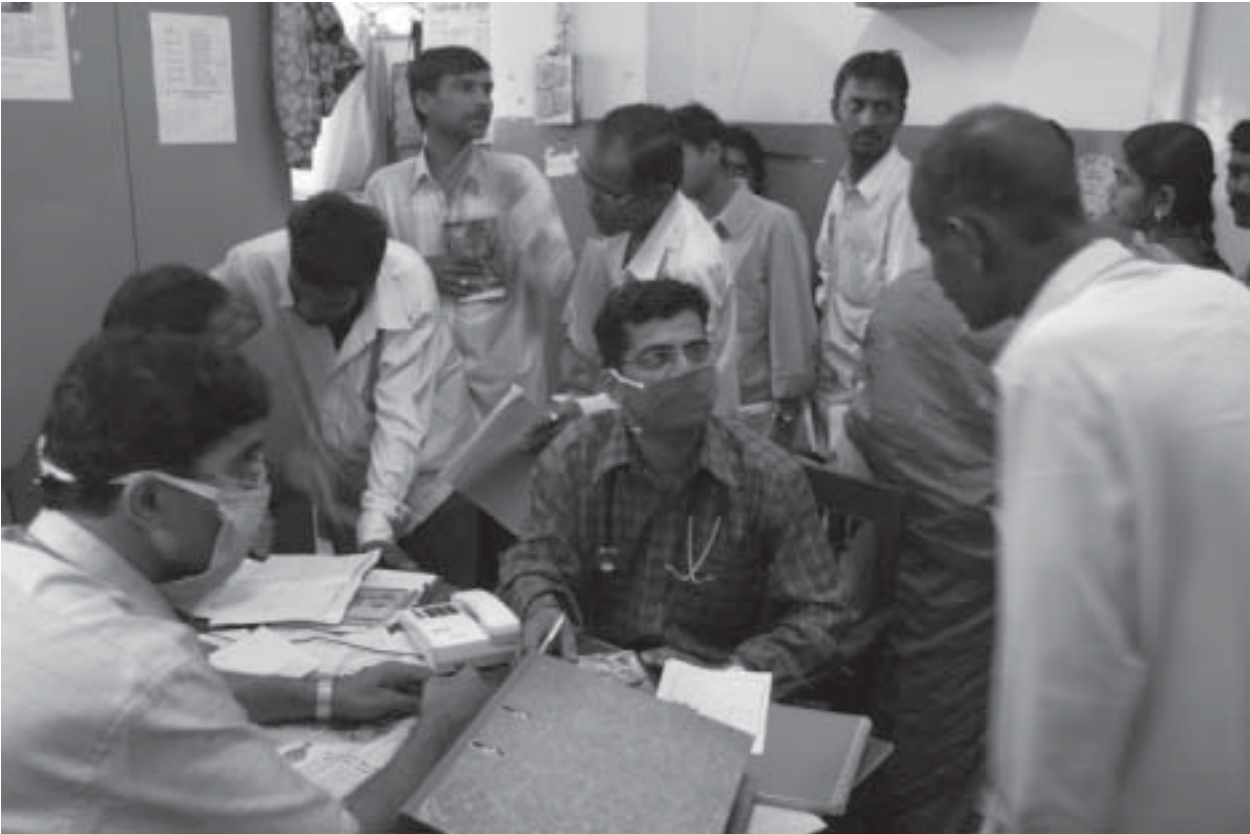
"The roll-out programme is sowing the seeds of anti-retroviral drug resistance in India," says Dr. Shashank Joshi, a private doctor in Mumbai.

Can we think of second-line treatment?

According to Dr. Kakrani, 2-3% of the 1800 patients need to be switched to second-line treatment, "Since we are targeting masses, 2-3% of patients requiring second-line treatment are acceptable (up to 5% patients on second-line treatment are acceptable in any programme)." However, he cautions against initiating second-line treatment, "Though NACO has initiated some discussions on the issue, our country has to go a long way before introducing second-line treatment. Firstly, there is no provision for viral load testing. A CD4 test is a good marker of the body's immune system – but it does not necessarily indicate how heavy the viral load is. Moreover, there is no provision for testing of resistance to drugs in the national ART programme. Lastly, we need a stronger system to monitor drug adherence. The whole success of the ART hinges heavily on adherence to treatment. Sixty tablets a month is the standard treatment. If a patient misses one or two it is ok, but the patient cannot afford to miss more."

People starting ART are not told that irregular treatment will lead to drug resistance and require a shift to second-line drugs. "The roll-out programme is sowing the seeds of anti-retroviral drug resistance in India," says Dr. Shashank Joshi, a private doctor in Mumbai.

⁷ The system will be under further stress as new drugs developed after 1995 come under patent.



TOP

Crowds thronging doctors at an ART centre. Without the support of an NGO, patients may have to spend hours in getting the right direction and documentation.

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Community organisations' involvement

NACO guidelines⁸ emphasise that community organisations, including Positive People's organisations, will educate people on how ART works, build community support for the programme and enable treatment adherence and monitoring for side-effects. NGOs can prepare the community for the programme and ensure the group they are working for, is benefited.

Interviews in Mumbai indicate that some NGOs have been relatively active. Organisations like the Humsafar Trust, Udaan and the Salvation Army station their staff at the JJ ward to ensure that people entering the programme through them are counselled properly, complete all the requirements and get on to the treatment as fast as possible. On the other hand, sex workers at the Asha Project seem to have limited access, going by their unenthusiastic responses.

Clearly, NGOs can be an important link between the health-care institution and those needing care, playing a key role in informing people about the programme, counselling, and promoting adherence. For example, in Sangli, Sangram's visibility and assertiveness have enabled sex workers to get on the programme. In fact, without such support, people are likely to face problems at every stage – from understanding the treatment and meeting various paperwork requirements, to following treatment.

There is a need for genuine consultation between the government and community organisations, which play a critical role in the programme's implementation. The protocol for involving NGOs and community-based organisations is still being developed, according to reports of meetings between programme officials and NGOs.

8 National AIDS Control Organisation (NACO). Programme implementation guidelines for a phased scale up of access to anti-retroviral therapy for people living with HIV and AIDS (draft). http://www.nacoonline.org/guidelines/guideline_1.pdf

According to Gopa Kumar, there is very little Positive People's participation in Maharashtra. Tension also exists between Positive People's organisations and other NGOs. "The interests of Positive People are not always transparent and their contributions to discussions are not well thought-out." Such statements are made not only by government doctors and administrators but also by health professionals running NGOs working with Positive People. This could be a perceived flaw, due to the lack of communication and articulation skills among positive groups. If this be true, then there is an urgent need to help them understand and articulate their thoughts better.

Without the support of a pro-active NGO, patients may have to stand for hours in the wrong queue, come for registration with incomplete documentation and so on. This story was repeated over and over in all the centres visited...Mumbai, Sangli and Pune. It is clear that the programme works best wherever there has been active involvement of NGOs – people are better informed, they have the right documents, if tests are not available at the government centre, they may get tests done at the NGO at subsidised rates, and they get on to the treatment faster.

"How long do I have to take this medicine?" asked a woman outside the Sangli OPD. If she had come to the programme through an NGO, their social worker stationed at the government hospital would have told her that the drugs needed to be taken life long and without break, and at the same time, each day. In Sangli, people who are brought to the programme through active NGOs like Sangram seem to have been well counselled in advance on the benefits and problems of starting ART.

Is ART the priority?

"I'm not so worried about ART right now; I need a job," says a woman at a Positive People's support group run by the Committed Communities Development Trust (CCDT) in Mumbai. CCDT and other NGOs like the Society of Friends of the Sassoon Hospital in Pune provide packets of pulses, grains, cooking oil and other essentials to each person attending the meeting.

Indeed, doctors, NGOs and administrators commented on the need for nutritional support in the ART programme. As a meeting of the NGO Forum in Mumbai pointed out people coming for government ART will definitely not be able to afford the nutritious food that must be taken along with the drugs. However, no nutritional support will be given, only advice. "When the social worker told me to eat fruit and meat, I laughed," said another woman in Sangli. "Where's the money for chapatti and chutney?"

"Positive sex workers are often thrown out by the brothel owner and need a place to stay, to rest, to get off the road," says a peer educator in the Asha Project in Mumbai.

"I stay with my sister and her husband. She pays for my medicine, but her husband doesn't know of my illness," says one woman. "I've spent at least Rs 20,000 so far." There are innumerable such stories of women learning of their HIV status when they go for antenatal care, or long after their husbands fall ill. Once the husband dies, the women are often abandoned by their in-laws. It is clear that the response to HIV and AIDS must also address the socio-economic problems faced by the affected.

ART can only be one part of a comprehensive care and support programme. "The government has no care and support scheme in place," says Dr. Gore. Some NGOs have started such programmes but NGO efforts will always be limited. Indeed, the problem involves strengthening people's access to health care as a whole, as well as allied support such as food security, employment, family support and property rights.

It is clear that the programme works best wherever there has been active involvement of NGOs – people are better informed, they have the right documents, if tests are not available at the government centre, they may get tests done at the NGO at subsidised rates, and they get on to the treatment faster.

ART in a weakened health care system

“Last month I sold my ring to pay for my daughter’s treatment at a government hospital. This month, I sold my earrings for some other care,” says a woman at a support group in CCDT, Mumbai.

Is it possible to provide ART without comprehensive care, support and drug treatment in a comprehensive health care system for all illnesses? Can the ambitious ART programme be provided through a resource-starved and dysfunctional public health care system?

Maharashtra used to once boast of a relatively better public health system in the country. But it has been steadily weakening over the years, in step with the national trend of the government withdrawing from health care, and the growth of private health services. Tertiary care centres such as JJ Hospital in Mumbai and Sassoon Hospital in Pune represent the apex of a pyramid of health care, starting from the auxiliary nurse midwife and moving up to primary health centres and district hospitals. They were once centres of excellence, with the best of medical education and care. Today, dedicated health professionals in government hospitals find themselves struggling to do their jobs. The complaints are the same everywhere: absent staff, broken machines, pharmacies empty of essential drugs, and a price to be paid for everything. Positive People complain that government hospitals are often unable to provide even antibiotics, vitamins and drugs for opportunistic infections.

A surgeon in another state government hospital says, “There’s lots of money for HIV, but we face shortages in all drugs. We would like money to be given for basic medicines, not just for one programme.”

Conclusion

Though Maharashtra has one of the oldest centres for AIDS treatment in the country, barely 12,000 people receive treatment, more than two years after the government ART programme started here. This is just 16 per cent of 75,000 who need it. In this situation, serious doubts exist as to whether the marginalised receive access to care and support. Activists and health professionals identify several limitations in the programme. But, the most significant question remains: Will the public health system be strengthened to take on this new challenge?

ANDHRA PRADESH

“The absolute numbers in AP are very challenging...we can't cope with existing infrastructure”

Strong political involvement, a consultant to increase the involvement of Positive People, 13 ART centres, 3 paediatric ART centres...yet challenges remain.

S. SANKAR with inputs from ANUSHREE MISHRA and SANDHYA SRINIVASAN

The southern state of Andhra Pradesh (AP) has been at the centre of a highly visible and aggressive AIDS prevention programme. The ‘campaign’ was considered an example of successful advocacy with political leaders and had the public support of the then-chief minister, Chandrababu Naidu. Among Naidu’s actions was a government order that all party functionaries speak about the AIDS programme at every public function. The present chief minister, Dr.Y.S. Rajasekhara Reddy, was the first to take the HIV test in the glare of the media. He urged all Members of the Assembly to “get tested” and inspire others. Given this, one would expect the ART programme to have had a smooth induction in the state.

Interviews were conducted in three districts. HIV prevalence is 0.75% in government antenatal clinics in Mehbubnagar in Telangana. It is 1.75% in Anantapur in Rayalaseema and 3.75% in Guntur in south coastal Andhra.

Andhra Pradesh has a population of 75.7 million. The 61% literacy level is lower than the national average of 65%. Life expectancy is 62 years as compared to 61 nationally. The infant mortality rate is 65/1,000 compared to the national figure of 68.¹

The state is spread out over three regions – Telangana, coastal Andhra and Rayalseema. The comparatively lesser developed Telangana region is home to some of the poorest people in the state, who migrate out for several months a year. The capital city of Hyderabad, which lies within Telangana, has a large industrial belt, attracting migrant labour from various parts of the state. Coastal Andhra includes nine districts that have developed faster than other parts of AP. Agriculture is mainly labour-intensive farming of paddy and sugarcane, which is heavily dependent on seasonal migrant labour. Visakhapatnam is a major seaport and has a number of associated small-scale industries. Rayalseema once a prosperous industrial and farming centre, now reels under regular drought. Suicides by farmers and weavers in rural areas, have tragically become commonplace in the state.

It is also emerging that health spending is among the fastest growing components of rural family debt, notes development journalist P. Sainath in a report. Sainath reports that a “common thread running through the farmers’ suicides plaguing the state has been very high medical spending.”² Indeed, this is a national trend as the government slowly but steadily withdraws from health care. People sell their land and steadily fall into a debt trap in order to pay medical bills.

Such cruel realities of privatised medical care are particularly vivid in Andhra Pradesh where corporate hospitals and private clinics have almost totally taken over health care in the state. Health economist Dr. K.V. Narayana of the Centre for



Development journalist P. Sainath reports that a “common thread running through the farmers’ suicides plaguing the state has been very high medical spending.” Indeed, this is a national trend as the government slowly but steadily withdraws from health care.

1 Andhra Pradesh Human Development Factsheet. <http://www.undp.org.in/Programme/Fact%20Sheets.pdf>

2 Sainath P., Anatomy of a health disaste, *The Hindu*, July 1, 2004. <http://www.thehindu.com/2004/07/01/stories/2004070103681200.htm>

Social Studies in Hyderabad estimates that by 1995 -1996, more than 75% of rural health care in the state, and more than 60% of urban care, had moved to the private sector.

In this context, many doubts have been voiced about the state's health sector reforms funded by international loans.

Public health experts argue that while the reforms are meant to identify gaps in existing programmes and improve the public health system, this has not happened. "No efforts were made to assess the gaps in the system and the reasons for their failure," says a consultant working in one of the funding organisations active in the state.

Further, health experts are aghast that these reforms require the government to withdraw even further from health care in favour of a 'public-private partnership'. Dr. K.V. Narayana argues that such 'partnerships' are at the expense of the public sector. For example, the health sector reforms project discourages upgrading primary health centres, if there is a private service in the vicinity. At the same time, public services are deprived of funds. Patients are turned away because of their inability to pay user fees. There has also been an exodus of government staff to corporate hospitals.³ User fee, however, was withdrawn recently.

"The reforms have specific objectives in order to de-emphasise the public sector's role, especially in tertiary health care," notes Dr. Narayana. "They introduced user charges, started private wards in government hospitals at the secondary level and outsourced services like diet, security – even doctors! They would like to make all the hospitals self-financing and autonomous."

The result has been a marginal improvement in public services and a slight increase in usage but the beneficiaries are mostly government officials, says Dr. Narayana. Still, all the public hospitals are over-flowing with patients from the lowest economic strata, of which 99% are daily wage earners.

The HIV and AIDS programme

Once listed as a low prevalence state, the AIDS programme received a shock in 1998 with the results of an upgraded HIV surveillance system. Today, with a state-wide antenatal prevalence of 2%,⁴ AP has the highest recorded general prevalence in the country, the only state with a prevalence of more than 1.5%.⁵ Nineteen of the state's 23 districts have an antenatal prevalence of more than 1%.⁶

As on August 31, 2006, total number of AIDS cases reported to NACO from Andhra Pradesh is 15,099.⁷ Findings from the behaviour sentinel surveillance conducted by the National AIDS Control Organisation in 2004-2005 reveal huge gaps in knowledge and behaviour. For example, though 75% of the migrants were aware of ways to prevent HIV, 33% reported having casual sex in the past 12 months.⁸

Clearly people's behaviour is influenced by factors beyond their control. And it might be more relevant to look at conditions that place people at risk for HIV. Long-standing rural impoverishment creating a large migrant population with an associated sex trade, and a health system that is unable to reach all those in need of care, are but two issues which raise the risk levels.

Perhaps policy-makers believed that the AIDS programme could succeed like the contraceptive programme in the state. After all, the state had managed to bring about a sharp drop in fertility levels without addressing socio-economic development, lowering infant mortality, promoting an increase in women's age at marriage, or increasing women's literacy rates. All these factors have been

3 Srinivasan S. Public health infrastructure: what we need and what we have. *Infochange Agenda*, April 2005. http://www.infochangeindia.org/agenda2_14.jsp

4 *HIV and AIDS Epidemiological Surveillance & Estimation Report for the Year 2005*, National AIDS Control Organisation, Ministry of Health & Family Welfare, Government of India, April 2006.

5 Observed HIV prevalence levels state-wise: 1998 - 2004, National AIDS Control Organisation, Ministry of Health and Family Welfare, Government of India. www.nacoonline.org/facts_statewise.htm

6 http://www.prb.org/pdf06/FactsFiguresResponse_HIVAIDS_AndhraPradesh.pdf

7 http://www.nacoonline.org/facts_reportaug.htm

8 http://www.prb.org/pdf06/FactsFiguresResponse_HIVAIDS_AndhraPradesh.pdf

Comparative yearwise HIV prevalence (per cent positive) among different population groups⁹

Population groups	2003	2004	2005
ANC	1.25	2.25	2.00
STD	21.47	16.40	22.8
FSW	20.00	16.97	12.97
MSM	13.20	16.00	6.45

With a state-wide antenatal prevalence of 2%, AP has the highest recorded general prevalence in the country, the only state with a prevalence of more than 1.5%. Nineteen of the state's 23 districts have an antenatal prevalence of more than 1%.

traditionally linked to a reduction in family size. Instead, the state focused on an aggressive sterilisation programme. Female sterilisation in AP is 62.9%, far above the national average of 32.3%.¹⁰

The response

Public health experts argue that the state government's programme based on targeted interventions is inappropriate for the kind of problem it faces. The state has currently 110 targeted interventions working with seven high-risk groups, covering a population of almost one million people. In addition, awareness programmes on radio and television, directed at the general population, urge people to use condoms, to seek treatment for reproductive tract infections at any of the 85 STD clinics,¹¹ and to get themselves tested at one of the more than 209¹² voluntary counselling and testing centres in the state. Pregnant women are asked to visit any of the 98 government antenatal care centres for HIV testing to be followed, if necessary, by drugs to prevent vertical transmission.¹³ The state has various educational programmes for school children and youth. A network of 162 licensed blood banks has been established to ensure safe blood.¹⁴

"In 1998, AP realised the extent of the HIV epidemic. But, as late as 2000, the state programme was still concentrating on targeted interventions," says a health researcher, who does not wish to be named. "The first care and support centre was set up only in 2000. Positive People were dependent on the neighbouring state of Tamil Nadu for services."

"Three years ago, we could not think about ART," says Dr. Troy Cunningham who runs the Freedom Foundation's care and support home near Hyderabad. "Today, things have changed dramatically. Many people can afford it through the private sector or through NGO subsidies. And there's also the government programme."

9 *HIV and AIDS Epidemiological Surveillance & Estimation Report for the Year 2005*, National AIDS Control Organisation, Ministry of Health & Family Welfare, Government of India, April 2006.

10 *National Family Health Survey (NFHS-3), 2005 - 2006*, Government of India. <http://www.nfhsindia.org/pdf/IN.pdf>

11 <http://health.groups.yahoo.com/group/AIDS-INDIA/message/4723>

12 http://www.prb.org/pdf06/FactsFiguresResponse_HIVAIDS_AndraPradesh.pdf

13 A total of 549 women received nevirapine in 2004.

14 Presentation by J. Subamma, LEPRASociety, at Novib HIV and AIDS Mainstreaming Workshop, Bikaner, September 12-14, 2005.

Positive People on ART in Andhra Pradesh – 31 December 2006

NAME OF THE CENTRE	NO. OF PATIENTS ON ART			Total
	Male	Female	Children	
NACO SUPPORTED ART CENTRES				
Osmania Medical College, Hyderabad	1582	699	84	2365
Government Medical College, Guntur	672	457	106	1235
Government Medical College, Vizag	735	323	16	1074
SVRR GGH, Tirupati	53	16	3	72
GGH, Anantapur	117	66	0	183
GGH, Vijayawada	245	133	3	381
RIMS, Kadapa	44	14	4	62
Govt. Dist. Hospital, Prakasam	296	175	3	474
GGH, Kakinada	192	95	0	287
Gandhi Medical College, Secunderabad	98	34	5	137
Medical College, Warangal	100	55	4	159
Medical College, Karimnagar	28	11	0	39
Govt. General & Chest Hospital, Hyderabad	130	70	0	200
TOTAL ART CENTRES IN AP (13)	4292	2148	228	6668
ART IN GFATM ROUND II CENTRE				
Freedom Foundation	80	36	10	126

The ART roll-out

The programme started in April 2004 at the Osmania Medical College Hospital, Hyderabad. On 30 December 2004, a second centre began functioning at the Government Medical College in Guntur and the third centre was opened at the Andhra Medical College in Vizakhapatnam on 1 January 2005. As on 31st December 2006, a total of 6668 people including men, women and children have been put on the government-supported ART programme under NACO.

“There has been a heavy rush at the hospital ever since we began treatment,” says Dr. Immanuel, senior medical officer of the ART programme at the Osmania Hospital in Hyderabad. “Some 20-25 people come daily for registration. Most of them are very poor.” Initially people with TB/HIV co-infection were put on DOTS or

on TB treatment that did not include rifampicin, a drug which precludes the use of the nevirapine-based regimen. More recently, an efavirenz-based regimen has been made available, permitting ART with DOTS.

"There were some initial difficulties with the government programme," notes Dr. Cunningham of the Freedom Foundation. "They just could not cope with the sheer numbers. And there were so many formalities, that at the end of it, the patient would be frustrated. But they have changed their protocol and there's a shorter period between registering for the programme and receiving the drugs." Dr. Cunningham believes the government has begun slowly but cautiously. "They didn't want to face a sudden drug shortage. We are working with the roll-out sites. We have been satisfied with the linkage with the government."

"Initially the government was not organised and did not have enough test kits to meet the demand," says P.V. Ramesh from Vijayawada who is the convenor of the Telugu Network of Positive People (TNP+) and secretary of the Indian Network of Positive People (INP). "And, at one point they were just overwhelmed by the crowds coming for treatment." There was no support, no information about the programme, and no advertisements in the papers. "The government's fear was that if they give an ad, everyone would come down, and they wouldn't be able to cater to all the people," says Ramesh.

"Some people were afraid of breach of confidentiality and gave false addresses," says Dr. Somasekhar Reddy of APSACS. "Some of them would default and when we sent outreach workers to trace them, we would learn that they had given false addresses."

The state programme has overcome several of its teething troubles and provides better services than elsewhere, says Dr. Reddy. "Initially some states charged Rs 500¹⁵ for CD4 testing. But NACO recently issued an order to provide CD4 tests free of cost. However, AP has never charged for CD4 tests. We presume that when someone comes to the ART centre, they would have, by then, exhausted all their finances, so all the investigations are done free of cost."

Dr. Reddy accepts that they did have difficulties with staff at first. "Though NACO supplied equipment, the tests had to be run by the regular laboratory staff, who felt the pressure of extra work. We also had problems with recruiting suitable doctors. But now, things have been sorted out and we have two medical officers, a counsellor, a lab technician and several outreach workers. We also do family counselling and repeat the CD4 test after four months."

"Still, the numbers going to the government hospital are just a fraction of the total number of people on ART," says Mekhala, Consultant, Greater Involvement of People Living with HIV and AIDS (GIPA) who is helping set up support groups of Positive People in the state. "People know about the treatment; APSACS advertised it in major newspapers. But registering for ART involves making your identity known to the health-care staff and giving proof of residence. Though there has been no breach of confidentiality, patients are scared of their names being leaked out and the stigma that follows. We believe that therefore many people prefer private clinics. Even their wives or husbands do not know they are on ART."

A number of Positive People have complained about the medical exclusion criteria which is based on the WHO's guidelines for ART in 'resource-constrained settings'. "The government gives ART only to those whose CD4 count is below 200," says Priya, the organiser of a Network of Positive People (NPP+) based in Secunderabad, supported by the Lepa Society. Priya suggests that treatment, especially for widows, should start when the CD4 count is around 300-350, "so that they can look after their fatherless children".

Health economist K.V. Narayana of the Centre for Social Studies in Hyderabad estimates that by 1995 - 1996, more than 75% of rural health care in the state, and more than 60% of urban care, had moved to the private sector. Most people are taking ART from the private sector. They take the medicines for six months and drop out when they can no longer afford the monthly payments of Rs 1,500 - Rs 2,000 per person.

15 USD 11.36
(1 USD= Indian Rupees 44)

Dr.Reddy acknowledges the implications of the guidelines, but believes this is a limitation in poor countries. Medically, it would be appropriate to put people on treatment with CD4 counts of 350 and lower, he says. "But in poor settings, you just can't provide treatment to all considering the magnitude of the problem, with more than 50,000 people needing treatment..." Dr. Reddy has also seen cases of couples sharing the monthly drug quota because only one partner qualified for government ART. The other's CD4 counts were low enough to justify ART – but not low enough to qualify for government treatment. "But we counselled them and this problem has come been brought under control," he adds.

"The doctor doesn't even do a CD4 test unless the person looks very sick," says Ramesh. "Such people will be sent back without even medicine for opportunistic infections, without prophylactic drugs or even vitamins."

Though the programme is supposed to be available to everyone who needs it, doctors apparently ask the better-off to buy the drugs from private pharmacies. "It is impossible to dispense the drugs free to all patients in AP. At times we have to tell the rich who are prepared to buy the drugs to procure them from outside," says a doctor.

Private doctors, NGOs – and quacks

Private practitioners are a serious threat, according to both government and NGO personnel. "There is no counselling before commencing of ART to prepare them for the consequences, life-long, adherence, side-effects, etc. They must be clearly told that it is not a cure," says Dr. Reddy.

Members of the TNP+ and associated organisations also express their concerns over quacks swindling people of huge sums of money by promising a cure for AIDS. At least 30 people have approached the network so far, complaining that their condition actually worsened after following the prescriptions of a self-professed doctor. The quack got away even after complaints were lodged with the police," says J. Siva Krishna, secretary of the Network.¹⁶

"Drug adherence is a serious problem," says Priya. Most people are taking ART from the private sector. They take the medicines for six months and drop out when they can no longer afford the monthly payments of Rs 1,500 - Rs 2,000 per person.

Counselling and confidentiality

"Things have improved in the last few years," says Suresh, another member of the NPP+. "Today, the government has set up counselling and testing centres at the district level. But quality of counselling at many government centres is still a cause for concern. On the other hand, private testing centres either have no counselling facilities or regularly breach confidentiality."

Indeed, confidentiality breaches are very common, says Hema Bedi of STREE, an NGO working in Kadiri in Anantapur district. G. Rashmi of Vasavi Mahila Mandali in Guntur agrees. "Many people don't even know that they have the right to confidentiality of information about themselves." An associated issue is the quality of counselling. "Recently, a woman showed me her test report and asked me what 'positive' meant, since the doctor had just handed her the report without explaining it," says Hema.

Staff at the PPTCT centres need to be sensitised as well. "When I first attended the centre, they made me feel ashamed for wanting to have a child," says Latha. "I was accused of being inconsiderate and selfish. I wanted to die after hearing the doctor's words."

16 Staff Reporter, Quacks under fire for 'fleecing' HIV-affected, *The Hindu*, October 18, 2005. <http://www.thehindu.com/2005/10/18/stories/2005101816050400.htm>



LEFT

A pharmacist explains the dosages to a woman. Around 65 per cent of people on ART are men. Very few women are coming forward for treatment because of the low levels of information on ART and how to access it.

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Women and ART

In Andhra Pradesh, the HIV prevalence rates among wives of truck drivers and agricultural workers is very high.¹⁷ Yet, very few women seem to have come forward for ART.

According to Dr. Somashekhar Reddy, about 65% of people on ART are men. One possible reason for this is that few women know of their HIV status. And even when they do know, most positive women are faced with more pressing problems. Women have been thrown out of their homes and are worried about who will look after their children when they fall ill. They must fulfil the dual responsibilities of earning as well as looking after the household. "For these women we stress the importance of good nutrition and yoga," says Mekhala. Further, HIV infection is more likely to be found among women who are less educated in the state.¹⁸ So, many of the women in need of ART may not even know about it and how to access it.

Children and ART

There are no reliable statistics available for the number of children affected by HIV and AIDS. Wilson, state co-ordinator of TNP+ based in Vijaywada says that there are around 2000 children in their network. Approximately 50% of them are on ART. The government has started three paediatric centres in December 2006 at Guntur, Hyderabad and Vishakapatnam. Though a welcome move, Wilson feels that providing ART alone for children will not be enough. He says, "Many children are orphans with no homes or semi-orphans in the care of relatives. Drug adherence is a major problem in children who are on the streets or in the care of relatives who are indifferent. Since there are only three centres for children, people from far-flung villages have difficulty in bringing children as it involves additional costs for travel and stay." TNP+ has therefore sent in proposals to NACO and APSACS to set up orphanages for children living with or affected by HIV and AIDS to provide them quality care and treatment.

Shiksha, State Advocacy Officer, TNP+ feels that paediatric ART centres need specialised counsellors. "Currently, the counsellors in the ART clinic are trained but they have undergone a general training. One needs to be more sensitive in dealing with children," she says.

17 http://www.prb.org/pdf06/FactsFiguresResponse_HIVAIDS_AndraPradesh.pdf

18 see footnote 17

Rashmi, a counsellor working in Guntur agrees, "Services to offer psycho-social support to children hardly exist. No one comes forward to adopt positive children. They remain in the care of the NGOs. When affected children are HIV negative, relatives and community members might help with food, shelter and clothing, and often some form of education or skills' training. But rarely do they provide the emotional counselling that affected children need most." Wilson says, "When children living with AIDS start showing symptoms of opportunistic infections, they are discriminated against by their relatives who fear that the children may transmit AIDS. The symptoms of the infection and the reactions of the caregivers confuse a child. But there is no support." Ratnam, co-ordinator of NGO HELP, which works with children living with HIV in Chilakaluripeta, says it is extremely difficult to motivate children living with HIV and AIDS to study. "So all we do is provide them with food and facilitate antiretroviral therapy in advanced cases."

Involving Positive People in the programme

"Three years after AP was classified as a high prevalence state, there was still no support group for Positive People here," says Priya. In 2002, INP+ helped set up a state-level network and four district-level networks. Today, says Mekhala, there is one state level network and 23 district level networks out of which five are networks of women, affiliated to APSACS.

In April 2004, APSACS appointed Mekhala as a consultant to increase the involvement of Positive People in the programme. She is actively engaged in setting up support groups of Positive People at the district level. Emphasis is laid on forming networks of women. "A number of women accompany their husbands to the community care and support centres and just hang around. They are often depressed after hearing of their husbands' health condition. We encourage them to

BELOW

Women waiting outside a centre. Though APSACS is setting up support groups of positive women, more policies and programmes are needed to reduce the impact on young women and children

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form support groups. The majority are illiterate, they are not aware of their rights - they cannot even think of voicing them. We therefore concentrate on getting them to stand on their feet," adds Mekhala. Other programmes encourage members of the district networks to speak on HIV and AIDS at the village level, to train outreach workers to motivate pregnant women to visit PPTCT centres, and so on.

Thus, today there are a number of efforts in which positive organisations are working with the government to ensure that the programme benefits those who need it the most. Ramesh is exhilarated by a recently-launched initiative to reach information to districts, jointly run by INP+, Freedom Foundation and three other NGOs. "We started in April this year. The idea is to tell people about treatment issues - the benefits and the cautions, including the need for rational treatment and adherence. The project will be in six high prevalence states. In AP, we will do it in all the 23 districts." Currently, these treatment counselling centres, as they are called, are functional in five ART centres in Guntur, Krishna, Warangal, Vishakapatnam and Prakasam. Positive People are also involved in referrals, follow-up and providing treatment literacy.

However, some Positive People feel their voices are not being adequately heard. "Our involvement is mere tokenism. We are called for events organised by APSACS, but are never involved in any planning. They do not listen or respond to our needs. Even articulate people who are aware of their rights are not speaking up about their concerns at these meetings," says Priya from NPP. For example, she says, "When ART treatment was initiated in the state all the networks were simply informed about it in a meeting. No one was involved in the planning."

"Positive People's involvement in AP is certainly lower than it is in Tamil Nadu," says D. Dhanickachalam, Advocacy officer at Futures International, a marketing and planning organisation that runs an AIDS advocacy programme in the high-prevalence states and Delhi. "But, one must remember that the response in Tamil Nadu started in the 1990s. In AP, the emphasis on involvement of Positive People began only in 2004."

Beyond ART

"We welcome the state's programme to provide free ART but how will the government ensure a steady supply when even drugs for opportunistic infections are not available in hospitals?" asks Shiva, a member of NPP+.

"But most importantly, what is the point of giving ART when people do not even have enough to eat?" he adds. Indeed, Positive People repeatedly asserted, that ART without a complementary comprehensive care and support programme would be ineffective. This includes not only medical care but also child care, economic aid, employment opportunities, psychological support and information on legal rights. Wilson from TNP+ lists two major concerns, "Many people on ART are unable to take nutritious food. ART has to be combined with nutritional support. The state government should also waive fees on travelling to the centres."

"Many people who are affected by this illness are poor," says Santoshamma, a 26-year-old woman widowed by AIDS in Guntur. "Even if the medicines are available free we cannot afford to spend Rs 500 to travel to Hyderabad and back, plus food, plus money for the various tests they ask for. We can only get money if we work. But if we are sick, how can we work? And we must look after our children also," she adds.

There have been many drop-outs, according to Ramesh. "People have also died - they don't have food to eat and they can't live just on ART."

Positive People feel their voices are not being adequately heard. "Our involvement is mere tokenism. We are called for events organised by APSACS, but are never involved in any planning. They do not listen or respond to our needs. Even articulate people who are aware of their rights are not speaking up about their concerns at these meetings."

– PRIYA from NPP+

Issues of the affected

The epidemic's impact on women and children is clearly visible. Young women who have never stepped out of their homes alone suddenly find themselves having to worry about their children's health and education – and their own survival. Can they look up to the government for help?

NGOs such as the Social Economical and Educational Development Society (SEEDS) in Guntur are trying to meet the needs of the infected and affected children. The NGO has initiated a community-based programme to reduce the impact of AIDS on families. This includes providing home-based care for children, livelihood skills training for parents and caregivers of orphans and vulnerable children, and vocational training for child-headed households. The project has networked with government schemes, but will need many more such linkages in order to have an impact.

"We provide soft loans and vocational training to widows and pay school fees of affected children," says Priya from NPP+. "But this is just a drop in the ocean. The government must collaborate with other departments and implement comprehensive schemes for affected children and families."

Wrinkles in the programme and questions for the future

More than two years down the line since the first ART centre came into existence, most people seem to agree that the programme is running smoothly in some centres. Some, however, believe that the government should have ensured adequate preparations before rolling out the ART programme. The initial fears of drug shortages seem to have been overcome. At one stage, says Dr. Reddy, APSACS got around a delay by procuring the drugs directly, using NACO tenders. "Today, there are no limits set on the number of people who will be given treatment," says P.V. Ramesh of TNP+. Patients are normally referred to the ART centres by the district and state level networks.

Still, representatives of networks of Positive People and NGOs have serious concerns.

There are a number of reports indicating the need for more staff and better training. "The doctors who have been trained in ART administration are never there; the people handing out medicines are junior doctors and they don't have sufficient knowledge of side-effects," says Ramesh, pointing to the need for better counsellors as well. "Every person will come for follow-up, but there are not enough trained staff to clarify their doubts. They are not providing any information on things like resistance." Mekhala feels that monitoring needs to be strengthened. "The outreach workers in the districts are asked to keep records, but we have not been very systematic with monitoring treatment adherence."

"There are huge queues for enrolment at well-established and functional ART centres – sometimes there are 50 new patients in a day," says Priya. "The pre-treatment tests take time. Very few people can afford to stay away from work and in the city for so long." People come from all corners of the state, notes Ramesh. "They travel long distances, and there is not even a shelter at the ART centre. And, the first time they come, they must stay for three days for tests before they can be considered for ART."

"The absolute numbers in AP are very challenging," notes Dr. Cunningham. "It can't cope with the existing infrastructure and facilities." The only option seems to be to expand the programme to provide it at all district hospitals as well as through a

core group of well-trained NGOs and private practitioners. The government will also have to involve the private sector. “We’re seeing many examples of irrational ART prescription, in semi-urban and rural areas.”

Dr. Cunningham voices another apprehension. “Even without irrational prescriptions that are widespread, we can expect that a certain number of people on ART will stop responding to the current drugs and will need the second-line drugs. But, this is not part of any programme.” This issue must be discussed urgently. “Availability and cost have to be looked at right now,” says Dr. Cunningham. “You can’t tell people later on, that we can’t give you anything else. We will have to plan ahead for this requirement and factor it in, in terms of finances, skills.”

However, the government does not seem keen on making any such plans. “Second-line drugs are very costly,” says Dr. Reddy. “We are already working in resource-constrained settings, we are not in a position to provide drugs to all who need them.”

“I don’t think they will be able to handle such an intensive programme,” says Dr. Narayana of the Centre for Social Studies in Hyderabad. “They are overburdened with routine problems.”

Conclusion

The appointment of a consultant to encourage the formation of support groups throughout the state seems to be showing results. In little more than a year, there is a more human face to the epidemic and more voices of Positive People are being heard than were heard in the last seven years. Yet, the numbers of those who require treatment are staggering and systems for treatment adherence and monitoring are still not in place. The problem is compounded by an unregulated private sector, where a vast majority go for treatment. With HIV prevalence rates rising among young married women and children, there is also the need to look beyond targeted interventions among “high risk groups” to focus on the special needs of young married women and children.

Lastly, the programme needs to look beyond HIV and AIDS, to make its prevention efforts more successful as well as to reduce the impact on the affected. This may include improving literacy among women, controlling rural indebtedness, food security, mitigation of the drought crisis and improving access to low-cost, quality health care. Till this happens, even commitments from the top political leadership may not yield desired results.

KARNATAKA

“Even the middle income groups seem unaware of the ART programme”

Level of information and involvement of marginalised groups outside the cities remains low.

MARIETTE CORREA



The southern state of Karnataka (population 52.7 million)¹ was one of the states selected for the first phase of the ART roll-out. Along with Andhra Pradesh and Maharashtra, it is one of the worst affected states in India, with an estimated 500,000 Positive People. Though the HIV prevalence among female sex workers is on a decline (21.60% in 2004 to 18.39% in 2005), it is rising among men who have sex with men (10.00% in 2004 to 11.61%) and STD clinic attendees (12.00% in 2004 to 13.60% in 2005). The HIV prevalence among antenatal clinic attendees has remained steady at 1.25%.² Eighteen out of the state's 23 districts have a generalised epidemic.³ The poor are particularly affected by the HIV epidemic. Illiteracy is considered a risk factor for HIV.⁴

The state HIV and AIDS control programme used to be managed by the Karnataka State AIDS Control Society (KSACS) and the India-Canada Collaborative HIV/AIDS Project (ICHAP). Currently, the programme is run by KSACS and the Karnataka Health Promotion Trust (KHPT). These organisations function independently to support NGOs in their respective areas. KSACS works in nine districts and KHPT in 18 districts. KHPT works in high-prevalence areas, KSACS works in low-prevalence areas and ICHAP focuses mainly on developing demonstration models.

Interviews for this article were conducted in the capital Bangalore (formerly Bangalore), Mysore, Belgaum and Hubli districts.

The ART roll-out: a cautious beginning

NACO's ART roll-out programme in Karnataka began on April 1, 2004, in Bowring Hospital and Lady Curzon Hospital in Bangalore. On August 15, 2004, the programme was launched in KR Hospital in Mysore and Karnataka Institute of Medical Sciences in Hubli.

Selection for ART is done according to NACO guidelines, which include a CD4 count of less than 200. The CD4 and other tests are done free at the government hospital. The state government provides infrastructural and manpower support. Drugs for a first-line regimen – nevirapine, stavudine and lamivudine – are procured by NACO and sent to the state. NACO also pays for salaries and equipment in this programme. Patients come once a month for a check-up and are provided a month's supply of medicine; they are advised to come more frequently if they experience side-effects or other problems.

NGOs have been actively involved and provide counselling and follow-up services in all the ART centres. The Karnataka Network of Positive Persons (KNP+) provides peer counsellors from its own budget at each of the centres.

1 Census of India 2001.
www.censusindia.net

2 *HIV/AIDS Epidemiological Surveillance Estimation Report for the year 2005*, National AIDS Control Organisation, Ministry of Health and Family Welfare, Government of India, April, 2006

3 Generalised epidemic is defined as an HIV prevalence of more than 1% among antenatal clinic attendees

4 *Report on HIV Sentinel Surveillance Karnataka 2004*, KSACS and ICHAP, Karnataka, 2004.

BANGALooru (formerly Bangalore)

At Bowring Hospital in Bangalore, as of 31st December 2006, 1495 patients were on ART. This included 969 men, 453 women and 73 children. Former Head of Medicine and in charge of the ART programme, Dr. Chandrasekhara said that people on treatment were mostly between 20 to 35 years of age. They came from different parts of the state.

The adherence to the regimen has not been causing problems; at least, not yet. Dr. Chandrasekhara attributes this very low drop-out rate to systematic counselling (there are four counsellors – one from KSACS, one from KNP+ and two from Samraksha, one of the first NGOs in the state working on HIV and AIDS prevention and care). Once people come in for ART (almost all are referred by doctors in the government hospitals and from Bangalore-based NGOs), their HIV test results are first confirmed. Those whose results are not from a recognised government facility are sent to the voluntary counselling and testing centre (VCTC) for pre-test counselling, testing and post-test counselling. These are usually located near the ART centre. Then, after registration at the centre, they are sent for the first ART-related counselling session. Here, the counsellor also gauges people's financial capacity to adhere to the treatment – whether they can make regular visits to the centre, whether they can afford adequate nutrition and so on. A doctor then examines them and prescribes the necessary tests, including a CD4 count. Once these results are received, people eligible for ART must undergo one or two more counselling sessions on treatment adherence. There is also one session with a peer counsellor from a positive network or from an NGO. These tests and counselling sessions take place over a number of visits. Once ART starts, the person must visit the centre once a month for follow-up and medication. Initially, the ART centre could manage with the staff prescribed in the NACO guidelines as the patient load was manageable. However, doctors at the ART centre now feel that the patient load is steadily increasing, while the infrastructure and the health care providers remain the same. Therefore, there is a need to review existing guidelines, keeping in mind the demands on the system. In November 2006, even the existing guidelines were not followed, as the position of a senior medical officer was and had been vacant for a long time. So, the resident medical officer had to treat nearly 150 new or old patients every day, single-handedly.

MYSORE

The ART centre at the KR Hospital in Mysore is run in tandem with the Swami Vivekananda Youth Movement (SVYM), an NGO, which runs various health and education programmes in the state. Most of the staff at the ART centre at this hospital is employed by the NGO SVYM, which is supported by the AIDS Healthcare Foundation and Global Immunity, Amsterdam, to provide free ART to 100 patients per year. These include one physician, one male and one female counsellor, one laboratory technician and one data interpreter. The hospital provides one physician and one counsellor. As of December 31, 2006, there were 653 people registered for ART.

HUBLI

The number of people on ART in the Karnataka Institute of Medical Sciences (KIMS) were 1205, as on 31st December 2006 – 441 women, 678 men and 86 children. About 35% were from Hubli, with the rest from neighbouring districts from different parts of North Karnataka. Doctors estimate that over 90% adhere to the prescribed treatment.

A 40-bed hospital attached to KIMS functions exclusively for HIV and AIDS-related treatment; the charges are a nominal Rs 10 per day. This fulfils a major need, according to Dr. Dattatreya Bant of KIMS who is currently the technical officer with ICHAP. "In fact, it was the success of our HIV and AIDS work at KIMS that prompted NACO to start a roll-out centre here." People from rural areas have facilities to stay at the centre during their initial counselling and investigations.

A robust communication campaign informing people about the ART centres in the state and encouraging them to go for treatment is missing. Ashok Rau, Managing Trustee of the Freedom Foundation, Bangalore, estimates that 90% of Positive People are not aware of the roll-out, because of the low publicity.

Positive People on ART in NACO centres in Karnataka – 31 December 2006

NAME OF THE CENTRE	NO. OF PATIENTS ON ART			
	Male	Female	Children	Total
Lady Curzon Hospital, Bangalooru	969	453	73	1495
K R Hospital, Mysore	416	231	6	653
VIMS, Bellary	180	92	21	293
KIMS, Hubli	678	441	86	1205
District Hospital, Raichur	38	12	0	50
District Hospital, Davengere	167	125	18	310
Wenlock District Hospital, Mangalore	153	74	36	263
District Hospital, Bijapur	114	53	0	167
District Hospital, Gulbarga	79	41	4	124
District Hospital, Belgaum	135	90	22	247
District Hospital, Kolar	49	21	2	72
District Hospital, Bagalkot	57	47	0	104
TOTAL ART CENTRES (12)	3035	1680	268	4983

In addition to the government, organisations like AHF (see box), NGOs and the corporate sector are providing ART. ACC Ltd, India's foremost cement manufacturer has set up a state-of-the-art ART centre in Wadi.

Major concerns

However, several major concerns are being aired about the programme. Perhaps, most important of these is that roll-out centres have not been guided by a need-analysis. Out of the 18 districts with a high prevalence of HIV, ART centres function only in 12 districts. This means that people from other districts have to travel long distances, at their own cost to get to the nearest centre. This will naturally limit access for those who cannot afford to spend at least a day travelling and waiting for treatment, besides the cost of travel and the loss in wages.

Dr. S. M. Jangay is the ART Consultant under KSACS. Dr. Jangay says, one reason the programme covers so few people is because it is not backed by a strong communication campaign. Initially, the authorities feared a rush of applicants and did not advertise widely. Even today, a robust communication campaign informing people about the ART centres in the state and encouraging them to go for treatment is missing. Indeed, the only publicity consists of informing doctors of training programmes, holding meetings between KSACS, NGOs and health providers and newspaper advertisements on the list of ART centres in the state.

There are no vehicles to reach information to the illiterate, especially in the rural

areas. Ashok Rau, Managing Trustee of the Freedom Foundation, Bangalore, estimates that 90 per cent of Positive People are not aware of the roll-out, because of the low publicity.

Dr. Jangay anticipates adherence problems in future, as people are forced to travel long distances at some cost to obtain treatment. "Do you think people like me will be able to get them easily?" asks Monisha, who lives in a Bangalore slum. "Who will earn, when I have to go to the hospital and wait in queues to meet the doctor?"

"One of the biggest concerns of the ART roll-out is that it does not address issues of treatment adherence – the fall-out is mind-boggling. It will ultimately create strains of the virus that are resistant to any drug," says Ashok Rau.

Dr. P. Sivarama runs a private AIDS counselling and treatment centre in Belgaum. He feels that there are several problems with the way the programme is conceptualised. "The government wants to give free ART, only when the CD4 count is below 200. But, there are many indications that by this point, the immune system is so badly damaged that ART will not help much or for long. It is better to start early, when the CD4 count is higher," he says.

Dr. Sivarama also feels that the government AIDS control programme has sidelined traditional systems of medicine. "There may be herbal remedies to manage the disease, but the authorities are simply not interested in studying them. Nor do they ban medicines that they believe do not work and take action against those with false claims. At the same time, the current attitude results in the impression that anybody working on alternative therapies is, by definition, a quack."

Public – Private Partnership

Under its "Cutting Edge Medicine and Advocacy Regardless of Ability to Pay (CARES)" programme, AIDS Healthcare Foundation (AHF) India is providing ART services in Koppal and Mysore districts.

The Mysore Medical College ART Centre is a collaborative effort between AHF, Karnataka State AIDS Control Society, Swami Vivekananda Youth Movement (SVYM) and Mysore Medical College. The centre offers outpatient services, acute care inpatient services, HIV pre and post test counselling, nutritional counselling, adherence counselling and couple and family counselling services. Since its inception, more than 2,640 patients have been registered for care at the centre. Among them, 627 people are on ART and treatment support. More than 50-60 patients attend the ART Clinic services every day.

The Kushtagi site, located in the Koppal district, is a unique partnership between SVYM, Samraksha and AHF-India CARES. It is one of the first rural-based service delivery models for ART management and treatment of opportunistic infections in Karnataka. Currently, 50 Positive People from low-income families of rural areas are receiving ART services, free of cost.

AHF-India CARES follows the World Health Organisation criteria to initiate ART. Currently, all regimens are according to NACO guidelines. The patient is followed up in each of the first three months on treatment, and once every three months subsequently. However, patients can drop in at the centre anytime, if they are ill. Adherence counselling is done before initiation of ART and at every visit. Family members are also counselled.

“Private doctors are prescribing ART without the necessary training,” says Dr. Bant of ICHAP. “Pharmaceutical companies are only interested in selling their drugs, and pharmacies are selling them to all and sundry. Indirectly patients are being murdered, as they are being given strong drugs, which are often too expensive. There should be a law to prevent prescription of drugs by doctors who are not trained.” People are sometimes prescribed single-drug and short-term regimens, though the correct treatment is a three-drug regimen and is to be taken for life. “Even in the government centres the doctors are at sea, as they have been rushed through a short training programme,” says Ashok Rau.

This problem is inherent in the design of the programme itself. The duration of training depends on the qualification and ranges from 5 (paramedical staff) to 12 days (senior postgraduate medical specialists). Many of the staff have been employed on a contract basis and have received very little training.

Ashok Rau, who is also on various HIV and AIDS programme advisory bodies, says, “The ART roll-out is a major step forward, but it is currently a mess. Even basic issues like drug supplies can be a problem.” As he says, “For three weeks, treatment centres did not receive drug supplies. How is adherence possible in such circumstances?” Drug supplies continue to be a cause of concern, according to Dr. V. Ravi, Head of the Neurovirology department of the National Institute of Mental Health and Neuro Sciences (NIMHANS) and an advisory member of NACO. “For example, stocks from NACO were low in June-July 2006, so we were cautious about starting new people on ART.”

“But the biggest cause for concern is that though women and children were supposed to be the highest priority beneficiaries, most of those accessing ART are men,” says Rau. Less than a third of those accessing ART through the government centres are women. “And, till as late as December 2006, children had not been covered, on the grounds that no paediatric formulation was available!” From December 2006, the Bangalore and Hubli ART centres have been providing free paediatric drugs. Dr. Jangnay says, “It will take some time to get the paediatric drugs in place in rest of the ART centres.”

There are administrative wrangles as well, as other doctors protest the fact that ART centres are housed in prominent government medical colleges and hospitals. There is still high stigma and discrimination associated with HIV and AIDS.

At the same time, Positive People find themselves further stigmatised by the location of these centres. Those visiting the ART centre or the VCTC are identified as positive and are stigmatised as a result. Breach of confidentiality and stigma and discrimination seem to be big problems at all the centres. There are no mechanisms in place, yet, to prevent this.

Listening to the voices of the marginalised

In the waiting area outside the ART Centre in Bangalore, an informal discussion with Positive People and their relatives revealed that most of them had no idea about positive networks or state NGOs working on issues related to HIV and AIDS. All of them were from poor families and were referred to the centre by government doctors or hospitals in the city.

Still, the involvement of Positive People in decision-making and planning seems relatively better than in many other states. Representatives of KNP+ are present on all bodies at various levels, and their voices do get heard. R. Elango, former President of KNP+, says, “We are called for all the relevant meetings. We provide adherence counselling at the centres and have been able to ensure 98 per cent compliance.”

But, not all vulnerable sections are represented. Devanand of Gelaya, a Mysore-based network of men who have sex with men (MSM), says, KNP+ (as well as its parent body, the Indian Network of Positive People or INP+) has consistently refused to focus on the problems of MSM, so much so that most MSM have left these networks. Ashok Rau agrees that the networks do not adequately represent the interests of all Positive People. Dr. S.N. Mothi, chairperson of Asha Kirana, a centre for AIDS care and research in Mysore, feels that “though INP+ and KNP+ are involved in various bodies, Positive People do not really have much say in agenda setting.”

“It is nice to belong to the group, but I am not aware of what takes place within the organisation,” said a young member of INP+. “I had no idea that we were on any government body. We have not been told about all that.”

Says Dr. V. Ravi of NIMHANS, “The attitude is: ‘we are including KNP+ in different activities and that’s good enough.’ Unless specific groups like sex workers, truckers, MSM, injecting drug users and positive networks are represented, these sections will get marginalised.”

Basavaraj of Karnataka Integrated Development Society in Hubli, an NGO working with street-based sex workers, feels that it is difficult to involve sex workers in planning, because “most of them are not open about their trade.” While this is true of street-based sex workers in some areas of the state, the fact remains that sex workers’ forums and networks have not been adequately represented in agenda setting.

“Decisions are taken by government officers and doctors who haven’t treated anybody in years, without listening to doctors who are actually treating people living with the virus,” says Dr. Sivaram. “Even among NGOs, only Bangalore-based NGOs are involved.” Vulnerable groups and Positive People are even less involved in the remoter districts where NGOs are less active. Positive networks have become active only recently and it will take some time before their voices are heard at different levels of the programme.

A strong NGO presence but...

“At this stage the involvement of NGOs in the ART programme is adequate,” says Dr. Jangay. “But, a lot of effort will have to be taken to identify good NGOs as the programme spreads out to the district level.”

Indeed, the recent, but fast-evolving active NGO involvement at all stages is one of the heartening features about the ART programme in Karnataka. As mentioned earlier, the centre at KR Hospital in Mysore is run in collaboration with the Swami Vivekananda Youth Movement. Samraksha is actively involved in the Bangalore centre. Many NGOs are the major source of referrals to the government ART centres. Most of the follow-up with people who come to the VCTCs is done by NGOs, according to the counsellors at NIMHANS, Bangalore. Most cases to the ICHAP VCTC in Hubli are referred by NGOs, says Vinayak Chavan, a counsellor.

The Freedom Foundation in Bangalore has been at the forefront of NGO activism in the ART roll-out. They have been negotiating with manufacturers and pharmacies to reduce the prices of drugs. It provides ART to 400 people, at present. Based on the person’s financial capacity, some are provided ART free, while others get it at a discount. Priority is given to widows and destitute women. Freedom Foundation’s Ashok Rau is categorical in his assertion that ART should be provided free to all children.

Samraksha and KNP+ have also been pioneers in care and support work in Karnataka. The Seva Clinic has provided a range of support services, in addition to

The involvement of Positive People in decision-making and planning seems relatively better than in many other states. R. Elango, former President of KNP+, says, “We are called for all the relevant meetings. We provide adherence counselling at the centres and have been able to ensure 98 per cent compliance.”

The fast-evolving active NGO involvement at all stages is one of the heartening features about the ART programme in Karnataka. But there seems to be a considerable drop in the NGOs' skills and knowledge the further one moves away from the state capital. NGOs in Bangalore and Mysore are knowledgeable and articulate, but staff in Dharwar and Belgaum districts have little information about the costs involved in ART, and do not even understand the need for adherence

ART to needy patients at subsidised rates. Several other organisations work on activities from prevention to care to advocacy. Some were providing ART even before the government programme roll-out.

Milana is a HIV-positive women's support group supported by Action Aid. Some positive women in Milana were on ART before the roll-out took place, spending around Rs 1,500 per month for this. Today, all women from Milana on ART are getting it from the government centre at Bowring Hospital.

Asha Kirana Charitable Trust Hospital in Mysore is probably the only place which has had a regular programme since 2003, providing ART for children. Currently, they have 152 children registered under HIV and AIDS care, of which 52 children are on free ART. Adult patients have to buy their own drugs; Asha Kirana gives them referral letters so that they can get the drugs at about Rs 1,000⁵ per month, as against the cost price of Rs 1,300 from local pharmacies. Of the 3065 Positive People who have visited since they opened in 1997, 1000 are on ART. Some started and then dropped out due to lack of funds.

Dr. Swamy, medical officer in Asha Kirana says, that they will continue to provide HIV and AIDS services to men, women and children who come to their hospital and continue to keep the linkages with KR hospital in Mysore for better co-ordination, as they have been doing in the past. Opening of the ART centre in KR Hospital in Mysore will mutually strengthen public-private partnership in addressing the needs of the infected and affected communities better.

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Anil Naik of Society for People's Action for Development in Hubli says that they received training from ICHAP on a number of issues related to HIV and AIDS, but ART had been discussed only in passing. The Belgaum Integrated Rural Development Scheme, the main NGO identified in this city for conducting HIV and AIDS interventions, works in several districts in Karnataka, playing a major role in the VCTC programme. Some of the staff have no knowledge of ART. In such a situation, upgrading of skills becomes not only essential, but also urgent and imperative.

Another concern is that NGOs often treat HIV and AIDS as a separate category, without linking it to other issues like women and development. For example, the Rural Welfare Trust in Belgaum runs a targeted intervention on HIV and AIDS. A counsellor in the Raji Family Counselling Centre, another of the trust's projects, was not even aware of the existence of the VCTC, located just a few kilometres away in the government hospital, and had never heard of ART.

Media and Misinformation

Most interventions on HIV and AIDS are related to prevention, focussing on the sexual route. Messages on care and support are increasing in recent years but there is nothing on improving quality of life through ARTs or on the ART centres. "The media has been supportive to women in prostitution and has effectively highlighted their problems, but they have done very little on the links between prostitution and HIV and AIDS," says Stanley of Odandi Trust, an organisation working on rescue and rehabilitation of sex workers in Mysore.

Perhaps, more worrisome, is the role the media has played in spreading false information.

5 USD 22.7 (1 USD= Indian Rs 44)

“On ETV Kannada, the programme ‘Crime Diary’ ran a feature in which a positive woman said she was feeling better after herbal treatment,” says Chaitra Naik, a counsellor. “This was little more than a plug for the woman giving the treatment.” Dr. V.H. Swamy of Asha Kirana cites the example of the paper Vijaya Karnataka which published an article stating that HIV and AIDS is hereditary. Then, there is the coverage given to the ‘AIDS amma’ temple, dedicated to a goddess who supposedly has the power to cure AIDS.

“The government’s education campaigns only promote fear,” says Dr. Sivarama from Belgaum. And, the media goes along with this approach, he adds. “The media should tell people how to live a productive life,” says Dr. Sivarama. Documentaries shown before feature films, or programmes on TV could reach even those without formal education.

Not surprisingly, a decade after HIV was recognised as a serious problem in Karnataka, the general population knows relatively less about it. This is especially true in the more remote parts of the state. But, even many in the middle classes in Bangalore seem unaware of the ART programme – or even that there are drugs to prolong the lives of Positive People.

Cart before the horse: the role of donors

As a high prevalence state, Karnataka has been the focus of international agencies which either fund local NGOs or run their own programmes related to HIV and AIDS. Some questions are being asked: How is accountability maintained? What if the funds dry up all of a sudden? What is the role of the state and how much does the state commit to health needs of the people from their coffers? Is too much emphasis being given to HIV and AIDS at the cost of other social and health problems?

BELOW

Posters about how HIV spreads and does not spread at an ART centre. Though Karnataka has a generalised epidemic, most communication material still focuses on prevention. Messages on care and support are increasing in recent years but very little is available on improving the quality of life through ARTs or on the availability of ART

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The state government's tie-up with international agencies such as ICHAP and KHPT has also created some confusion. People question the logic of having three state-level organisations managing the programme, dividing districts among themselves. This is seen as an example of donor-driven logic. Independent structures are necessary as KSACS, ICHAP and KHPT get their funds directly from different organisations. Co-ordination seems to be adequate at present but the structure is fertile ground for future chaos.

While NGOs' involvement is welcome, patients may get mixed messages from different NGOs. For example, at KR Hospital in Mysore, the Swami Vivekananda Youth Movement caters to people from below the poverty line. The government ART programme in the same centre imposes no socio-economic criteria. It is not clear how the two organisations function in tandem under the same roof. An applicant could fail the NGO's criteria even while meeting the government's criteria.

Dr. Mothi of Asha Kirana Charitable Trust Hospital questions the NGO strategy of restricting ART to those below the poverty line. "Many poor patients do not have the wherewithal to travel to collect the drugs. ART needs to be given to people with better socio-economic status as well, who will be able to adhere to the regimen."

Access to services: A bridge too far

Stigma and discrimination continues to be a major problem. Since the ART centres are located within larger medical facilities, it becomes extremely difficult to ensure confidentiality. On the other hand, Positive People at the centre in Bowring Hospital reported that there was considerable anonymity in this larger facility, and hence less fear of confidentiality being breached. Still, this is an active concern in Hubli and Mysore.

Elango, former president of Karnataka Network of Positive People and president, Indian Network of Positive People says, "ART centres are located in a corner in the hospitals. There is a need to sensitise ward boys and paramedical staff in the hospitals who guide patients to the centre."

Some groups suffer more stigma and discrimination. Devanand of Gelaya says, MSM experience it within the government sector, where he feels there is a clear attempt to marginalise them. He recounts the struggle they faced with KSACS. The

RIGHT

A bold sign informs people about the ART centre. Signs like these outside centres in larger medical facilities often lead to stigma and discrimination against Positive People.

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group did a need analysis and proved the need for an intervention. The Society however said, Gelaya did not meet the criteria for implementing such an intervention – but did not state what these criteria were.

Likewise, Stanley of Odanadi Trust says, “Counselling methods at the VCTCs must change if commercial sex workers are to feel more comfortable. Things have improved – 13 years ago when we started work, sex workers would not go near a government hospital. But, while stigma and discrimination against them may have reduced, the required concern for their problems is still not there.”

Nutrition is a big problem for poor patients. Just the cost of travelling to the ART centre can be a major burden.

“ART should be provided free to all who need it,” says Dr. Ravi of NIMHANS. “This is the only way we can tackle the first issue, that of access. Issues like adherence can be looked into later. He suggests that the DOTS system be applied to ART as well. “Only through this kind of doorstep monitoring can issues of access and adherence be tackled.”

Side-effects of ART do not appear to be much of a problem at this stage. “We have not had any problems of resistance, so far with the first-line regimen,” says Dr. Jayashree Naik, head of the department of skin and STD at the Belgaum Civil Hospital. However, according to Shankar Hoskeri, counsellor at the VCTC at the Hubli ART centre, about 10 patients taking ART have experienced side-effects, which are being dealt with by the doctors.

One of the weaknesses of the government programme, according to activists, is that it is restricted to first-line regimens. The extent of drug resistance to first-line treatments is not well documented. But it is reported that NACO has agreed to provide second-line drugs to some people through INP+. It will be important to know how these people will be selected.

KNP+ has devised an innovative response to the problem of accessibility outside the main centres. The organisation buys drugs at a low cost just before the expiry date and supplies them to districts, where the ART roll-out has not yet taken place. “We have 10 networks all over the state and are thus able to provide the drugs at a cost of just Rs 15-25 per day,” says Elango. The treatment is monitored by doctors.

But there are also problems of gaining access to many other HIV and AIDS services. For example, an insignificant proportion of positive women have access to the prevention of transmission from parent to child (PPTCT) programme. Elango, says, “The whole focus of the PPTCT programme is the child and not the mother. Efforts are not made to link the mother with ART services. Three of our members have died after delivery.”

Padmini Rao and Hanumantha Rayappa are counsellors at the VCTC and PPTCT centre at Bowring Hospital in Bangalore. They see people from all over the state. “Private doctors in the districts are often not aware of the district VCTC, so they send their patients to us. Of course, people also worry that staff at the local VCTC will breach confidentiality.”

The ART programme can give people an incentive to be tested and use health care services, if necessary. Accessibility is particularly important; those using the state services are mostly from marginalised sections and lower socio-economic groups. People who approach these services with considerable trepidation are likely to get put off by the lengthy forms devised for pre-test counselling. “They take at least 15-20 minutes to fill up. With our patient load, we spend more time filling forms than counselling,” says a VCTC counsellor. Some prefer to fill it after the session, as it disturbs the counselling and can be uncomfortable for the person.

“ART centres are located in a corner in the hospitals. There is a need to sensitise ward boys and paramedical staff in the hospitals who guide patients to the centre.”

— R. Elango, former president of Karnataka Network of Positive People and president, Indian Network of Positive People

Involving the private sector

At least 60 per cent of those on ART were prescribed by private doctors, according to Rukmini C, a counsellor at the VCTC in NIMHANS, Bangalooru. Many people prefer private doctors even where the government programme has started, for the personal attention they offer and assurance of confidentiality.

“The number of private doctors prescribing ART is increasing and we must ensure that they are properly trained,” says Dr. Bant. The private sector will continue to play a major role in ART, and proper attention needs to be paid to this aspect.

Chandragupt V. Jain, a pharmacist from Mysore, has been stocking and selling anti-retroviral drugs for the last six years. He reports that pharmaceutical companies do not replace expired drugs. As this burden must then be borne by the pharmacist, smaller pharmacies will not stock these drugs. Jain supplies ART to over 35 patients. Most are from rural areas and from the lower income group. This means that some drop out, even though he advises them not to. Interestingly, Jain was not aware of the ART roll-out at KR Hospital in his city. “We are in contact with the people in need. If I had known about the programme, I could have sent poor people to the government centre. Most people drop out because they cannot afford to continue.” If this is the case with someone like him, one can understand why around 90 per cent of Positive People are unaware that such a programme has started.

Several pharmacies in Belgaum and Hubli were unaware of ART, and do not stock the drugs. As with other services, the situation is better in Bangalooru and the neighbouring districts. Dr. B. Satish in Bangalooru is among the private practitioners closely linked with NGOs. He says, he has about 50 well-off patients in his private practice, taking ART combinations (first-line and second-line) costing between Rs 6,000 and Rs 18,000 monthly. Dr. Satish also works along with Samraksha, and here, he puts poorer patients on a basic combination which costs about Rs 1,200.

However, many Positive People report that private practitioners refuse to treat them. “I was refused by four doctors,” says Shivappa. “Of course, they don’t say directly that it is because of my positive status. They give some excuse or the other. And this is when I am ready to pay. I wonder what happens to those who cannot afford to pay. Finally, an NGO referred me to the doctor who is currently treating me.”

The voices of affected and infected communities are also raising serious concerns about the reported deaths of Positive People due to irrational prescriptions of ART medications by private practitioners. While the government ART centres go through stringent quality control measures before providing the drugs at their outlets, private hospitals do not.

Still, the situation is not all bleak. In areas where there has been no roll-out as yet, some private practitioners as well as government doctors are taking extra efforts to reach out to Positive People. Before the ART roll-out in Belgaum, Dr. Jayashree Naik at the Civil Hospital in Belgaum was helping 25 patients to take ART. She had worked out an arrangement whereby patients could access the drugs directly from the wholesalers, enabling them to avail of lower prices. She has also referred clients to KIMS in Hubli. One of her concerns is women in prostitution. “Right now, women in prostitution have no access to ART.”

Conclusion

“It is great that the ART roll-out has finally happened,” says Ashok Rau. “But many issues need to be tackled, if the programme is to be a success. It must not flounder because of bureaucratic ineptitude. Nor should it fail to be responsive to those in need. It is imperative that we get it right.”

MANIPUR AND NAGALAND

Special concerns of drug users cry for attention...

High prevalence among injecting drug users, continuing conflict and a difficult geographical terrain make a relook at the standardised, top-down national HIV and AIDS strategies imperative

CHITRA AHANTHEM

"Despite having vast potential resources, the north-east region remains much below the national average in terms of developmental indices...Fifty years of planning in the country has made very little change, if any, in the socio-economic life of the region. All these have led to a widespread feeling of neglect."¹

The seven north-eastern states have, without doubt, been neglected in development; and it is not without reason that the people here feel isolated from the rest of the country. These states also have special problems linked to continuing conflict in the region, in some cases right since India became independent in 1947.

Injecting drug use drives the HIV epidemic in the Northeast. Manipur and Nagaland border Myanmar and lie along a major route for the illegal drug trade. Sentinel seroprevalence surveys starting from 1998 have reported high HIV prevalence among injecting drug users. The prevalence has dropped since, reportedly due to the introduction of harm-reduction practices such as needle-exchange programmes. However, both continue to be high-prevalence states, with over one per cent of samples from antenatal clinics testing positive in the 2005² surveillance round. HIV interventions have been further complicated by the local conflicts between militant groups, the government, armed forces and society. Militant groups have opposed harm reduction programmes and assaulted drug users, dissuading them from visiting drop-in centres and collecting information and clean needles.

MANIPUR

Manipur's population of 2.38 million is spread over 22,000 sq km. The state shares an international border with Myanmar and is located along a major transit route for drug smuggling. The state is witness to tensions between its diverse ethnic populations, various militant groups and the armed forces. Some groups have been known to extort from NGOs and government departments. The Manipur State AIDS Control Society (MACS) had to stop functioning in certain areas after it came under attack from militant groups. Senior MACS officials have often been abducted. Reports of corruption plague both government departments and some NGOs.

As a result of the tensions of insurgency, the state shuts down by 5 pm. Youth routinely face army harassment as suspected insurgents. Underdevelopment, insurgency and army harassment converge to deprive most youth of meaningful opportunities. Injecting drug use is widespread.

The conflict situation increases the vulnerability of people already at risk of HIV, especially women. Insurgent groups regularly conduct campaigns to punish sex



Injecting drug use drives the HIV epidemic in the Northeast. Both Manipur and Nagaland continue to be high-prevalence states, with over one per cent of samples from antenatal clinics testing positive in the 2005 surveillance round.

1 From a report by the North-East Network, a regional non-governmental organisation. Quoted by Rahul Goswami in: *Healthcare in the north-east: Education and sanitation is the key*, *Infochange News and Features*, April 2005. <http://www.infochangeindia.org/features228.jsp>

2 *HIV and AIDS Epidemiological Surveillance & Estimation Report for the Year 2005*, National AIDS Control Organisation, Ministry of Health & Family Welfare, Government of India, April 2006.

workers and drug users. The limited health facilities come to a standstill in areas ravaged by conflict.

In this situation, media coverage of drug use and HIV and AIDS is mostly statistics, with little in-depth writing and few interviews with those affected. Journalists say that HIV interests them but conflict reporting is more newsworthy.

In the course of most interviews it was repeatedly asserted that planners and funding agencies do not consult local voluntary organisation workers before designing programmes. They do not look at the special concerns of drug users, especially women drug users and women affected by drug use.

HIV and AIDS in Manipur

HIV in Manipur was first reported in a 1989-90 Indian Council of Medical Research study of blood samples of injecting drug users (IDUs). HIV prevalence among IDUs shot up from 2-3% in 1989 to over 50% in 1991.³

NACO estimates that by 2005, IDU prevalence had come down to 24.1% and the HIV prevalence among women visiting antenatal clinics to 1.3%.⁴

State response

Manipur was the first state where politicians put AIDS on their party manifestos. It was the first state in India to have a state AIDS policy in 1996, long before even NACO came up with one. The policy supported harm reduction practices such as needle exchange schemes to reduce HIV transmission among injecting drug users, who are the most affected group in the state. Harm reduction is supported by public health experts but has often been opposed by the community. Other programmes supported by MACS include targeted interventions with truck drivers, drug users and sex workers, based on the guidelines provided by NACO.

Community response

As the epidemic progressed, the community turned its ire on drug users for crimes committed to sustain their drug habits. The physical nature of addiction was ignored and drug use was seen purely as immoral behaviour. Users were verbally and physically assaulted and sent to jail but treatment was rarely thought about. In some cases, users were arrested at the insistence of their families.

It has been documented in studies that police and insurgent groups are known to harass drug users, effectively cutting off their access to harm reduction services.⁵ For example, student groups, women's groups and various banned underground outfits have regularly indulged in public thrashing of drug users, shaved their heads and paraded them in public to humiliate them. Some groups have even shot drug users in their ankles as 'deterrents'. However, members of support groups of Positive People report that currently insurgent groups are more supportive of Positive People. A member of the Manipur Network of Positive People (MNP+) says, "They (the insurgent groups) don't interfere in the work of the Positive People's network, and don't collect money from us, as they do from other NGOs."

The development of peer-based initiatives in the late 1980s heralded a new stage. Today, most effective programmes in drugs and HIV and AIDS are run by former users who provide services ranging from counselling and detoxification to rehabilitation, condom promotion, needle exchange and health care, including

3 Godbole S, Mehendale S., HIV/AIDS epidemic in India: risk factors, risk behaviour and strategies for prevention and control, *Indian Journal of Medical Research*, April 2005, pp 356-368.

4 *HIV/AIDS Epidemiological Surveillance Estimation Report for the year 2005*, National AIDS Control Organisation, Ministry of Health and Family Welfare, Government of India, April, 2006.

5 Singh D.H., Sharma M., *Rapid Situation Assessment of Drug Use in Imphal: 1999-2000*, Sharan, New Delhi, The Kripa Society, Imphal, 2001.

home-based care. Self-help groups have been formed by reformed users, their widows, Positive People and so on. The NGOs and community-based organisations play an important role in fighting stigma and discrimination and mobilising community participation in the response to HIV and AIDS.

Still, harm reduction programmes continue to be a low priority. Treatment centres are still overwhelmingly focused on abstinence. Various studies point to the non-availability of clean injecting equipment: Up to 90% of injecting drug users share syringes and needles; 62% of them do not clean their equipment and even those who do, rarely use bleach. The main reason as to why IDUs share equipment is for fear of being caught by the police with paraphernalia.⁶ The problem is exacerbated by delays in the disbursement of funds from MSACS to NGOs implementing targeted interventions.

The gender equation

Haibi comes to the ART centre every month from Imphal East in Manipur for her quota of medicines. "I was advised rest after surgery but they will dispense ART only when you are present personally. If I become confined to bed, I will have to stop my medications."

A major limitation of the AIDS programme in Manipur is the emphasis on targeted interventions among drug users. The programme needs to look beyond the focused interventions on intravenous drug users to other vulnerable groups such as partners of drug users. Addressing the spread of the infection through the sexual route and reducing the impact on women becomes important in the light of the fact that more and more sex partners of IDUs are now being infected. It has been reported that more than 80 per cent of women acquired HIV infections from their husbands out of the total HIV positive women in Manipur.⁷

There are a few programmes for women and children: Social Awareness Service Organisation (SASO) received support for one year from the Elton John AIDS International Foundation for nutritional and medicine support for women and children. The Salesian Sisters run a 15-bedded drug rehabilitation centre for female drug users. But many women may not know about ART, and even if they did, many may not have the negotiating power to get access to them. Nutrition for infected and affected women and their children, reduction in stigma and discrimination as spouses or widows of IDUs, property rights – such issues remain totally unaddressed.

Free ART

The state government announced free ART roll-out on the eve of World AIDS Day 2003. For the next three months, nothing was done to consult different stakeholders: health care professionals in the field, NGOs providing HIV and AIDS-related services and Positive People. Dr. Ibohalbi Singh, Deputy Director in charge of the ART programme at MACS, justifies, "Till March 31, 2004 – five days before the programme started – we received no communication from NACO about the programme, so we could not make plans to involve various groups."

Free ART started – with little publicity in the media – at the Regional Institute of Medical Sciences (RIMS) in Imphal on April 5, 2004. Initial plans were to provide treatment to 300 people. A second centre was started on December 1, 2005 at

6 Andersson-Singh Å., An outreach intervention among injecting drug users and their sexual partners in Manipur, India, The International Bank for Reconstruction and Development, 2004. <http://www.worldbank.org/wbi/reducingpoverty/docs/FullCases/India%20PDF/India%20HIV-AIDS%20SIDA.pdf>

7 www.manipuronline.com/Features/July2002/hivandsocioeconomy

Positive People on ART in NACO centres in Manipur – 31 December 2006

NAME OF THE CENTRE	NO. OF PATIENTS ON ART			
	Male	Female	Children	Total
RIMS, Imphal	634	275	32	941
Jawaharlal Nehru Hospital, Imphal	702	446	123	1271
Ukhrul	63	59	10	132
Churachandpur	77	48	4	129
TOTAL ART CENTRES (4)	1476	828	169	2473

Jawaharlal Nehru Hospital, with initial plans to treat 200 people. Subsequently, two other ART centres were started in 2006 in Churachandpur District Hospital and Ukhrul District Hospital.

A regional paediatric centre started functioning from November 14, 2006 at Jawaharlal Nehru Hospital, Imphal.

The ART centre at the Regional Institute of Medical Sciences (RIMS), Imphal, is open from 10:00 am to 2:00 pm. The programme at RIMS is run by six doctors. People enrolling in the programme must submit ELISA test results for HIV, after which their names are registered. They then undergo tests for CD4 count, hepatitis B and C, liver function and complete blood count and a chest X-ray. The results are assessed by the doctor on duty, who then counsels the patient about ART. At present, ART drugs are procured by Manipur State AIDS Control Society (MACS) from NACO.

ART in the private sector

The number of people on ART through private practitioners is not well-documented. It is estimated that the numbers stand between 500 and 1,000. Many Positive People have to buy medicines on their own, as they had started on the first-line regimen earlier itself and have now become resistant to the drugs available under the free roll-out. Their expenses depend on the regimen they are on, and the additional costs of consultation and diagnostic tests. NGOs do not provide ART free, though a few manage to obtain ART at wholesale rates and pass on the discount to their clients. For example, Social Awareness Service Organisation (SASO) provides ART at subsidised rates to 25 Positive People, while the Care Foundation provides ART to 35 positive people. The NGOs also provide free health check-ups, nutritional support and other medicines, depending on their sources of funding.

Medecins Sans Frontieres, Holland (in India), is providing ART for 200 patients in district Churachandpur. MSF follows the guidelines set by NACO and reports regularly to NACO. Though MSF has helped expand access to ART, Positive People's networks are concerned about the sustainability of the programme by an NGO.

Areas of concern

According to Dr. Apabih, ART Consultant, MACS, the government ART roll-out programme is functioning well. However, a key area for concern for him is, "ART centres in all the hospitals have very limited space. Each day, we have 30-40 people on an average, which cramps the place. We need to sort this out with the hospital administration."

Specialised treatment for IDUs with AIDS: The nature of the epidemic in Manipur is quite different from other parts of the country. Treatment for IDUs with AIDS includes more than the standard first-line regimen under the government ART roll-out. In addition to HIV, IDUs also have a wide range of co-infections, such as infections with blood borne viruses (hepatitis B and C) and bacterial infections such as tuberculosis.⁸ For instance, there is 98% and 92% prevalence of hepatitis C co-infection with HIV in districts Churachandpur and Imphal respectively.⁹ People with co-infection of hepatitis C and HIV cannot use certain ART combinations on the government programme as they may produce liver problems. Though lamivudine-containing regimens may control hepatitis B infection, Interferon, a drug needed for those co-infected with hepatitis C is not available through the government centres. Patients co-infected with hepatitis-C virus therefore need to spend a significant amount of their own money on Interferon injections.¹⁰ A six-month course of Interferon to treat hepatitis C costs nearly Rs 300,000¹¹ – in a state where the per capita income was Rs 12,825 in 2000-2001.

MNP+ continues to advocate treatment for hepatitis C as part of NACP III. NACO is non-committal on this issue, as the drug to treat hepatitis C is patented. Therefore, MNP+ is in the process of applying for 'Post-Grant Patent Opposition'¹² Prior to this, INP+ and MNP+ had filed a pre-grant opposition¹³ against the drug combination zidovudine and lamivudine owned by Glaxo Group Limited. A final decision is awaited.

Children with HIV

Nine-year-old Thobi is on the current free ART roll-out in Manipur. She does not know that she is HIV positive. However, she does know that her mother died after repeated illnesses. She also knows that her mother contracted her illness from her father who was a drug user and fell ill and died. Her 11-year-old brother is also HIV positive, but is healthier and is not on ART. Thobi says that she is tired of having to take her medicines every day. She is cared for by her grandmother, who is a heart patient.

There is no estimate of the number of children living with HIV or affected by AIDS. Parents and elders have been protective of a child's positive status because of stigma and discrimination. It is usually the child's parents or guardians who are counselled. Guardians or parents report that administering ART to children is difficult. Tablets for adults are broken in half and administered to children regardless of their age.

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8 http://www.euro.who.int/document/SHA/WHO_Chapter_5_web.pdf

9 Devi K. S. *et al.*, Seroprevalence of hepatitis B virus and hepatitis C virus among hepatic disorders and injecting drug users in Manipur: a preliminary report. *Indian Journal of Medical Microbiology*, 2004, pp 136-137.

10 <http://fxb.org/www2/Dec05/Missing%20the%20Target:%20India-%20report.pdf>

11 USD 6818.18 (1 USD=Indian Rs.44)

12 Under the Indian Patent Amendment Bill, 2005 any interested person can file opposition to the patent after a patent has been granted, within 12 months from the date of publication of the grant of patent in the Patent Office Journal at the appropriate office.

13 The Indian Patent Amendment Bill, 2005 also allows for opposing a patent before a patent has been granted, where an application for a patent has been published but a patent has not been granted.

Drug shortages are a major issue: TB is one of the most common opportunistic infections with HIV. Persons who are co-infected with TB and HIV, and have CD4 counts of less than 200 must start ART. Efavirenz an antiretroviral drug that can be used concurrently with TB drugs. But it was not available initially. Even after it became available through the programme, there have been complaints of repeated shortages. The ART centre at JN Hospital started giving out efavirenz from January 5, 2005, but faced intermittent shortages: since the drug was introduced, stocks ran out for at least a week at a time in February, March and April. Efavirenz became available again after a highly publicised campaign using e-groups, letters to NACO and a public interest litigation.

Improving counselling facilities: Members of MNP+ also expressed the need for improving the counselling facilities at the ART centres. The counselling centres have two counsellors and are open for six hours (10.00 am– 2.00 pm). During this time, approximately 30-40 patients come to collect drugs. The centre has only two counsellors to cater to the requirements of the patients. With this limited time and manpower, effective counselling cannot be ensured, which in turn, affects patient adherence. In an effort to improve counselling and provide treatment literacy services, Treatment Counselling Centres (TCCs) have been set up next to ART centres under the Access to Treatment (ACT) project supported by the Global Fund. But N.G. Ratan Singh, State Co-ordinator, MNP+ feels that in the absence of information material on different aspects of treatment in local languages, counselling is not very effective. He says that NACO should provide information material on ART in both English and the local languages, so that it can be handed over to the patients. Material in local languages will serve as a reiterating message for patients and their families. Patient compliance will also be enhanced if they understand the information on treatment.

Testing facilities: There is also a need to expand testing facilities to the district level. There are two government testing facilities in Manipur – RIMS and JN Hospital – and two private testing centres. The district hospitals have no facilities for confirmatory tests, only a few basic drugs for opportunistic infections.

Drug adherence: ART consultant, Dr. Apabhi, voices the need for a strong monitoring system and operational research on resistance to drugs. Drug adherence is a major problem. According to a report made available by MACS, 176 people (7 per cent) of the total patients who began ART, either stopped taking treatment or could not be followed up or never returned to the ART centre.¹⁴ These patients are more likely to develop resistance than those who are currently enrolled in the ART roll-out programme.

Whose voice matters?

In 2004, just after the ART roll-out, an alliance of four drug user organisations, two networks and 40 self-help groups was formed. The main task of the alliance was to formulate demands regarding access to care and treatment and respond to government decisions. The alliance held consultations and state workshops with government representatives, health-care professionals and its own constituents. The first state-level consultation saw the participation of MACS officials and health professionals. The meetings discussed specifics of drug regimens, inclusion criteria, issues to be dealt with during monitoring and evaluation of therapy, and drug distribution. NGO activists believe that the recommendations, if implemented by NACO, would have enabled a roll-out programme more in tune with people's needs.

Among the alliance's suggestions were:

- setting up a state technical committee involving positive organisations and NGOs;
- a centralised drug depot at MACS;
- provision of ART at all district hospitals and competent NGO set-ups, improved diagnostic facilities, and recognising the importance of counselling (including support mechanisms such as telephone counselling and follow-up and monitoring) for treatment preparedness and adherence.

¹⁴ *Monthly HIV Care/ Antiretroviral Treatment (ART) Centre Report*, Manipur AIDS Control Society, September, 2006.

- strict implementation of WHO inclusion and exclusion criteria, with priority given to children and people who could not otherwise afford ART.
- more drop-in and day care centres, and a health forum of health-care workers and positive people.

However, these suggestions were evidently not received or ignored by NACO as even after two years many of the issues remain unresolved.

The voices of peer-based initiatives are rarely heard in decision-making bodies. Much has been written on Manipur's harm reduction strategy, but the average Manipuri is unaware that a state AIDS policy exists, let alone what it means. According to L. Birendrajit, former General Secretary of SASO, "The state's programmes are based on the national programme, which focuses on creating awareness and providing condoms. Needle exchange is provided without support services like abscess management, short-term detoxification and drug substitution."

According to Rev. V. L. Muana, Project Director of the Society for HIV/AIDS and Lifeline Operation in Manipur, NGOs were not involved in the run-up to the much-touted state AIDS policy, endorsing harm reduction. The policy was apparently put together by external health experts without consulting NGOs who had already been implementing the strategy, and learning from their experiences. Even the deputy director of MACS, who initially claimed that NGOs were consulted, later conceded otherwise.

L. Deepak Singh, President of the Manipur Network of Positive People (MNP+), describes even the inclusion of Positive People in the MACS executive committee as "mere tokenism" which does not translate into any decision-making power.

As a result, the Rapid Intervention and Care Programme, a targeted intervention for IDUs involving needle exchange and condom promotion, was drawn up by MACS without anticipating opposition from police, insurgent groups and other members of society.

The consequences

L. Birendrajit Singh of SASO says, "Some pressure groups ban the entry of drug users in a particular area. Users then become afraid to turn up at the drop-in centres and end up sharing needles and syringes, increasing their risk for HIV transmission."¹⁵ Drug users have often been shot in their legs. One group recently warned that anyone found using or selling drugs would be shot without any prior warning. Birendrajit Singh added that it is difficult to convince the various groups of the value of harm reduction; they see these initiatives as 'encouragement to drug users'. "Even if we convince one group, there are others. We need to look at how we can handle such situations. We cannot talk with these groups directly. We are NGOs taking funds from other agencies and we do not want to be caught in between."

There is also a widespread belief that organisations working in drug use and HIV are bloating drug use estimates, in order to get more funds for their personal use. Affected groups want funding agencies (including MACS) to make public how much money they are giving for various programmes and the components in the programme. They argue that such financial transparency would enable grass-roots organisations to better understand and participate in the process.

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¹⁵ These statements were made three months before L. Birendrajit passed away

NAGALAND

Over 82 per cent of the 1.98 million population¹⁶ of Nagaland, lives in villages bordered by Assam and shares an international border with Myanmar. Agriculture is difficult in the hilly terrain. Like Manipur, Nagaland is in the grip of conflict. Here, the conflict is between “mainland Indian interests” and “indigenous people” and between militant groups fighting for a sovereign Naga nation and the Indian Army.

Corruption is a concern in government programmes, including the AIDS programme. The AIDS programme was one of seven departments censured by the state public accounts committee for misusing funds. Rs 1.78 million meant for the state AIDS control programme was diverted towards the unauthorised purchase of five vehicles.¹⁷

HIV and AIDS in Nagaland

Nagaland is among the six high HIV prevalence states in India. The HIV prevalence among antenatal clinic attendees was 1.63%. Initially, HIV prevalence was high among the IDUs, but it is now declining. The steady increase in HIV prevalence among female sex workers is however a cause for grave concern (10.80%). AIDS awareness is ironically low in Nagaland, despite the state’s relatively high

Comparative yearwise HIV prevalence (per cent positive) among different population groups¹⁸

Population groups	2003	2004	2005
ANC (8)	1.13	1.43	1.63
STD (1)	0.98	1.72	3.50
FSW	4.40	4.44	10.80
IDU	8.43	3.22	4.51

16 Census of India 2001. www.censusindia.net

17 Goswami R., Healthcare in the north-east: Education and sanitation is the key, *Infochange News and Features*, April 2005. <http://www.infochangeindia.org/features228.jsp>

18 *HIV/AIDS Epidemiological Surveillance Estimation Report for the Year 2005*, National AIDS Control Organisation, Ministry of Health and Family Welfare, Government of India, April, 2006.

19 *Profile of substance abusers: Meghalaya, Assam, Nagaland, Manipur and Mizoram*, North East India, HIV/AIDS Network, Swedish International Development Co-operation Agency, New Delhi, 2003.

literacy rates. A 2003 study by five NGOs in the north-east states¹⁹ found that, while 191 respondents were aware of the risk of HIV transmission through unprotected sex, only 22 knew that it could spread through blood transfusions and 178 said that it could be spread by sharing utensils.

Response towards HIV and AIDS and drug use in Nagaland

The Church is a powerful force in the state and has often opposed harm reduction initiatives for needle syringe exchange or condom promotion. Drug users, unfortunate enough to be caught, have often been punished by being locked up in wooden cages for days. This practice is recommended by church leaders and often has the support of the drug users’ families.

Armed groups in the state also take up populist measures like punishing corrupt officials by parading them in public, or publishing their photographs in the newspapers. Also targeted for punishment are alcoholics, sex workers and drug users – all vulnerable to HIV. Such actions can even fuel the epidemic, as they prevent people from seeking help or receiving harm reduction services.

According to Abu K Mere, Project co-ordinator of the Kripa Foundation, which runs a rehabilitation centre, “Long-term abstinence-based treatment is the only solution but harm reduction measures are necessary for those who are unable to avail of treatment services, or who are not ready for abstinence. This is needed to minimise HIV transmission and to improve the health of IDUs.”

Though the risk of HIV through injecting drug use was a concern in the late 1980s, the focus at that point of time had been on rehabilitation centres promoting abstinence, which had a high relapse rate. In the mid-1990s, Nagaland started harm reduction programmes, which have the approval of the political leadership. But, it was only in 2001-2002 that the Nagaland State AIDS Control Society set up its first targeted intervention for IDUs, consisting of needle exchange, condom promotion and counselling. Today, the state has a mix of abstinence and harm reduction programmes.

Beginning 2003, the Nagaland Legislative Forum on HIV/AIDS, consisting of the state’s Members of the Legislative Assembly (MLA), promised that each MLA would set aside Rs 100,000 for HIV and AIDS awareness in his or her respective constituency. NGO activists say, the problem is that there has been hardly any monitoring of how AIDS awareness and programme implementation is carried out.

The gender equation

With few employment opportunities, poverty-driven sex work is a major concern in Nagaland. Media reports indicate that sex workers are looked down upon by the community and harassed and physically abused by the police and pimps alike. This situation makes them more vulnerable to HIV.

Some sex workers also peddle drugs and many of them start injecting drugs. There are no specific interventions for women IDUs. Those who can afford treatment are referred to Sneha Bhavan, a rehabilitation centre for women users of drugs and alcohol in Imphal, and the Kripa Foundation, Mumbai. Most women IDUs have no option other than the drop-in centres. There is little visibility of partners of IDUs in current programmes, since most available services are targeted at male IDUs.

Though the risk of HIV through injecting drug use was a concern in the late 1980s, the focus had been on rehabilitation centres promoting abstinence. It was only in 2001-2002 that the Nagaland State AIDS Control Society set up its first targeted intervention for IDUs, consisting of needle exchange, condom promotion and counselling. Today, the state has a mix of abstinence and harm reduction programmes.



LEFT
IDUs sharing needles. IDUs feel that for intervention and treatment programmes to be effective, the states should not follow national guidelines. Needle exchange programmes should include support services like abcess management, short-term detoxification and drug substitution.

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ART roll-out

ART roll-out started in April 2004 in Kohima. At present, there are three ART centres located in Districts Kohima, Dimapur and Tuensang.

Positive People on ART in NACO centres in Nagaland – 31 December 2006

NAME OF THE CENTRE	NO. OF PATIENTS ON ART			
	Male	Female	Children	Total
Naga District Hospital, Kohima	119	68	10	197
Dimapur	50	28	4	82
Tuensang Civil Hospital	23	20	1	44
TOTAL ART CENTRES (3)	192	116	15	323

Issues of concern in the ART programme

For most Positive People from interior Nagaland, visiting the ART centre at Kohima is a two-day affair. They travel for hours over hilly terrain, spend the afternoon at the centre, find a place to spend the night in the city and travel home the next day.

The ART centre at Naga Civil Hospital is on a small hillock secluded from the rest of the hospital structure. People worry that segregating the ART centre makes Positive People more identifiable. They desperately want more convenient ART dispensing, through public, private and NGO centres.

The media has an important role to play in the ART roll-out by highlighting the programme and focusing on positive issues instead of indulging in sensationalism. Some people feel the media needs training to ensure accurate reporting.

There needs to be more research on the prevalence of hepatitis C in Nagaland. Service providers say that they come across such cases but they do not have a clear picture of the problem. Other concerns raised are: the limited ART regimen, the lack of other support like counselling services; questions of effective monitoring and follow-up of clients and drug resistance. Finally, SACS officials are unclear about the time frame for NACO's commitment to the programme.

Whose voices are being heard?

There seems to be a major communication gap between the Nagaland State AIDS Control Society (NSACS) and NGOs, including those funded by the Society. NGO providers say that they have little idea of the decisions being taken at the state capital, Kohima, or how they are being implemented in the field.

This view is reiterated by W. C. Humtsoe, Executive Director of the Bethesda Youth Welfare Centre, Dimapur, which runs a drug rehabilitation centre and a targeted intervention for IDUs. "There must be criteria for ART access but we don't know what these are," he says. Humtsoe feels that the government does not trust NGOs and Positive People. "But NGOs need to re-evaluate their commitment also." Ricardo of the Nagaland Network of Positive People (NNP+) says, "We have a representative in the executive body of NSACS but he is in the Information,

Education and Communication wing and not in any major policy-making or programme implementing body. Even in the IEC wing, his opinions are not really taken into consideration." Ricardo reports that NNP+ was not consulted before the programme started though it was invited to the launch. Similar sentiments are aired by Humtsoe who also chairs the Network of Nagaland Drugs and AIDS-related Organisations, a platform of NGOs in the state. Adds Lalu, a positive person, "The government keeps saying that they will involve us but this has not happened." Officials in the Nagaland State AIDS Control Society say they are just implementing NACO decisions.

Ricardo of NNP+ adds, "IDUs are not involved in the programme. They are denied treatment by doctors. The hospice referral centre for Positive People, run by the Naga Mothers' Association, admits only 'sober' people – current IDUs or alcoholics are not accepted. They have refused to admit those of our members who are current IDUs."

Dr. K. Chetry, the SACS Nodal Officer for ART, admits that the ART roll-out had been "hurriedly conceived, hurriedly planned and hurriedly executed without involving grass roots organisations." As a result, 311 patients are enrolled in ART from all the three centres out of the total 500 patients registered till the end of September 2006. Many people prefer to buy the drugs on their own, despite the high expenses because of fears of stigma and breach of confidentiality at the government centres.

Conclusion: The way forward for ART in the Northeast

- There is desperate need for more information on ART management in IDUs: an accurate estimate of HIV burden as well as of the number of drug users in the state, trends in drug usage and prevalence of hepatitis C among IDUs; drug reactions if any among IDUs with a liver disease (hepatitis B and hepatitis C). The health system must institute monitoring for drug resistance.
- The ART roll-out programme should develop a mechanism to incorporate feedback from the users
- Doctors in the Northeast have provided care to Positive People long before they received structured training. The medical community must be involved in the programme. There is a need to scale up the training programmes on ART. More doctors and other paramedical staff must be trained.
- NGOs and positive organisations must be involved properly in the ART roll-out programme, to bring clients in, counsel and monitor treatment. Communication between SACS and NGOs needs to be more regular and open.
- Prevention needs to work along with treatment. Sensitisation programmes need to be taken up for different stakeholders – from the media and community leaders to church groups and students – on harm reduction, Positive People's right to treatment, treatment preparedness and so on.
- There is a need to improve the management and treatment of opportunistic infections by ensuring the availability of diagnostic and treatment facilities at different levels.
- Financial transactions in the AIDS programme, whether by the state society or by NGOs, must be made public.

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UTTAR PRADESH

“UP is a sleeping giant”

Can treatment succeed without effective prevention services and a supportive health system?

SUTAPA MUKERJEE with inputs from NASEERUDDIN HAIDER KHAN



It is said that every sixth Indian lives in the country's northern state of Uttar Pradesh (UP). This means, the state in its 70 districts holds 170 million people, making it the country's second largest state. But a scan of its health, education and development conditions – the overall quality of life indicators are shocking – to say the least.

The infant mortality rate in the state is 73 per 1000 births (national average is 57 per 1000 births), only 29.2% births are assisted by a health care personal (compared to a national average of 48.3%) and child immunisation in 12-23 months is 22.9% (the national average is 43.5%).¹

According to the UP government's website, its per capita income is among the lowest in the country.² Its per capita net state domestic product is Rs 6,117³ compared to the national average of Rs 9,647. Thirty-one per cent of the state's population lives below the poverty line, as compared to 21% at the national level. More than 80% of the population lives in rural areas. The literacy rate of 57% compares poorly with the national literacy rate of 65%. Only 43% of women in UP are considered literate compared to 54% nationwide. The child sex ratio is 916 – that is, there are only 916 girls for every 1,000 boys in the age of 1 to 5 compared to 927 nationwide.⁴

Conditions at government health centres and hospitals

As in other states in the country, government health services in rural areas are provided through a tiered system of primary health centres, sub-centres, community health centres and district hospitals, with outreach services through auxiliary nurse midwives and multi-purpose health workers. Urban health services are provided through health posts, municipal maternity homes, peripheral hospitals and teaching hospitals.

A survey of government health-care facilities in UP in 2000, found that only 10 of the 486 primary health centres (PHCs) surveyed had a working telephone; 418 did not have a working vehicle; 107 primary health centres did not have medical officers. Moreover, 442 PHCs did not have all the stipulated number of female staff; 403 did not have the stipulated male staff and 342 PHCs did not have labour room equipment. While 418 had no basic delivery kits, 467 did not have emergency delivery kits or drugs. Of 34 first referral units (community health centres and district hospitals where surgical facilities including those for caesarean sections should be available) surveyed, 16 did not have a working vehicle and 24 did not have a telephone. Eighteen had an obstetrician posted, but only two had anaesthetists. Sixteen had anaesthesia equipment but only six had emergency labour drugs. And, only 19 had oxygen cylinders.⁵

1 <http://www.nfhsindia.org/pdf/UP.pdf>

2 Uttar Pradesh: economy in fifty years. http://www.upgov.nic.in/upinfo/up_eco.html

3 USD 139.0 (1USD=Indian Rs 44)

4 Uttar Pradesh Human Development Fact Sheet. <http://www.undp.org.in/Programme/undpini/factsheet/up.pdf>

5 Referred to by Abhijit Das in: NHRM: new hope for the poor. *Infochange Agenda*, April 2005. [http://www.infochangeindia.org/agenda2_09.jsp\[0\]](http://www.infochangeindia.org/agenda2_09.jsp[0])

HIV and AIDS situation

Uttar Pradesh is classified as a low prevalence but highly vulnerable state. The HIV prevalence among antenatal clinic attendees is officially 0%, due to lack of available information, while the HIV prevalence among STD clinic attendees is 0.40% and among female sex workers is 3.50%.⁶

Uttar Pradesh is considered a highly vulnerable state for HIV for several reasons. Almost 48% of the population is aged between 15 and 49 years and are sexually active or potentially sexually active; the state shares borders with a moderate prevalence state, Gujarat. A large migrant population lives part of the year in conditions that put them at risk, resulting in many returning to the state with HIV. Further, given the abysmal state of government health care facilities, people with sexually transmitted diseases may not seek treatment and care.

Dr. Abhijit Das is a public health worker and activist based in Uttar Pradesh. He argues that as more than 60% of births take place outside institutions, the sentinel surveillance system cannot provide representative information on the prevalence of HIV in antenatal women. Dr. Das says that he is acutely aware of the state's vulnerability to HIV – a consequence of extreme rural poverty and forced migration to cities in search of work. As he notes in an article for the website India Together: "... the disease has quietly started making its presence felt in the rural settlements of Eastern Uttar Pradesh, one of the poorest regions in the country."⁷

Das is aware of the problem from his own work in the state. He found that in a particular village "one person from every second household has left the village in search of livelihood elsewhere." They have travelled all over the country; about one fourth of all inter-state migrants in the country are from Uttar Pradesh. Some of them come back ill, with the *Bambaiwallah bimari* (the Bombay disease, as HIV and AIDS is referred to in these parts).

These numbers will not figure in the official surveillance, which is restricted to samples from the government's voluntary counselling and testing centres.

Das points out: "The reality in Uttar Pradesh is that the poor living away from their homes are getting infected every day. Many are coming back home and are staying home, without any specialised care. Women are getting infected as well."⁸

Sudhir Mishra, a Lucknow based journalist working on an AIDS project for the Bill and Melinda Gates Foundation agrees. "The numbers game can continue, irrespective of the truth. But what needs to be realised and is worrisome is that the disease exists and is predicted to swarm the state if stringent, appropriate and timely measures are not taken immediately. The health system is extremely shaky, as of now. Even if HIV prevalence is lower, the state's system is woefully unprepared for any onslaught in future. And neither does it seem concerned."

The government's response

S.P. Goel, Project Director of UP State AIDS Control Society (UPSACS), admits the vulnerability of the state to HIV and AIDS. He reassures, "I agree the threat is large and UP is a carrier state and we are trying to contain the problem. I think there is a need to talk more about myths and misconceptions about HIV and AIDS." The Uttar Pradesh State AIDS Control Society (UPSACS) has focused its efforts on condom promotion to prevent sexual transmission among high risk groups, including sex workers and truckers along the national highways and the floating populations in industrial townships and pilgrimage centres. UPSACS works in partnership with non-governmental organisations, providing technical assistance and funding. Efforts are

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6 HIV and AIDS Epidemiological Surveillance & Estimation Report for the Year 2005, National AIDS Control Organisation, Ministry of Health & Family Welfare, Government of India, April 2006.

7 Das A., Wake-up call for HIV and AIDS in UP, *India Together*. <http://www.indiatogether.org/2005/aug/hlt-uphiv aids.htm>

8 See footnote 7

made to involve all sections of society in the programme. For this, networks have been formed with Panchayati Raj institutions, National Cadet Corps, Mahila Mandals and religious leaders. However, NGO participation is abysmally low in Uttar Pradesh and the government is apparently unable to reach vulnerable populations.

This is clearly reflected in the statistics. For example, the awareness levels on HIV and AIDS among women in UP is 40% compared to the national average of 57%.⁹ Researcher Murali Dhar Vemuri visited rural central UP and interviewed people who tested positive, as well as their relatives. He notes that government data show that only 11.3% of rural women in the state had heard of HIV or AIDS. And those who knew about it held many misconceptions about how HIV was transmitted – some believed that it could be transmitted only through sex with a female sex worker. Vemuri's interviews indicate that AIDS is a growing but unrecognized problem in the state. Migrant workers return to their villages, too ill to work, to be cared for by their families. They die, leaving behind widows who must care for their children while managing their own illnesses. Interviews with government health staff strongly indicate that there is an increase in the number of people falling ill with HIV and AIDS in the state, writes Vemuri. "Unless immediate action is taken, UP will be pushed into a health situation, that will be difficult to handle."¹⁰

Goel of UPSACS points out that strengthening the NGO response in the state is key to increasing the outreach. Unlike in other states, the performance and co-operation of the non-governmental sector here has been disappointing.

Till recently, the care, support and treatment component consisted of providing voluntary counselling and testing through 70 centres, free treatment for opportunistic infections and prevention of parent to child transmission (PPTCT) programme, run through eight medical colleges in the state. According to the NACO website, health-care staff exposed to the virus can be given post-exposure prophylaxis. Free distribution of ART is a very recent development.

9 <http://www.nfhsindia.org/pdf/UP.pdf>

10 Vemuri Dhar M., Bombay Bimari in UP, *Economic and Political Weekly*, October 30, 2004. <http://www.epw.org.in/showArticles.php?root=2004&leaf=10&filename=7856&filetype=html>

ART Roll-out

In December 2005, the state's first ART Centre was inaugurated at King George Medical College (KGMC), Lucknow. The second free ART centre became functional in early 2006 in the Institute of Medical Sciences, Benaras Hindu University (BHU), Varanasi, followed by a third one in LLRM Medical College, Meerut. Till 31 December 2006, around 2038 patients were on treatment at the three centres.

Positive People on ART in NACO centres in Uttar Pradesh – 31 December 2006

NAME OF THE CENTRE	NO. OF PATIENTS ON ART			
	Male	Female	Children	Total
BHU, Varanasi	848	353	41	1242
KGMC, Lucknow	478	183	27	688
LLRM Medical College, Meerut	76	28	4	108
TOTAL ART CENTRE (3)	1402	564	72	2038

For one of the biggest states in the country with an area of 2,94,000 sq km,¹¹ three ART centres are grossly inadequate, assert activists. And rightly so. In a state where 80% of the population lives in rural areas,¹² people have to travel long distances to avail ART. Further, a programme manager with CARE, an NGO working with vulnerable groups in the state says, “we refer and motivate many sex workers to access the centres. But they drop out as drugs are not available. The publicity about the whole process is equally poor. The general population is completely unaware about the provision of ART. This being the situation in cities like Kanpur and Varanasi, one can imagine the awareness levels in rural areas and the situation at the primary health care (PHC) level.”

The first-line drugs under ART are also available in some private pharmacies but are priced at a whopping Rs. 1,600 and Rs.3,000 per month per prescription for an affected individual. This is definitely beyond the reach of the poor. At the same time NGOs say that many Positive People are selling their lands and assets to avail treatment at private clinics in the hope of receiving quality care.

Non-availability or shortages of drugs and the hope for better quality services drive many people to neighbouring Delhi for ART. They register by claiming that they work in Delhi. However, counsellors at the Delhi ART centres say they are forced to refer such cases to the nearest ART centre of the patient’s domicile state, due to overcrowding at the Delhi ART centres.

Situation at the ground level

Accessing care and support services is also difficult for vulnerable groups. Goel of UPSACS says that the massive awareness drive has created a demand for testing. “Many sex workers realise they are vulnerable to HIV and want to know their HIV status,” he adds.

Durga is one such sex worker from Lucknow. She tested negative but was found to have other sexually transmitted diseases. However, the 20-year-old admits that it requires great effort to get the medicines. Sometimes, she does not go because of the travel costs and time spent in long queues. “I need to travel eight kms to the government hospital to get the medicines; there are huge queues and a whole day goes just for some medicines. Many a time, the medicines are not available.” she adds.

“All VCTCs are housed in government hospitals and people need to commute long distances and later wait for days to get the report. Further, the VCTCs face a staff crunch. There is no provision for counselling in the districts either,” laments Shyam Shukla, an outreach worker with an NGO in Varanasi. For example in Varanasi, which has a population of 2.8 million, the two government-run VCTCs here are almost non-functional reportedly because of frequent staff transfers. “The VCTCs are functioning only on paper,” says another member of a local NGO. “Neither of them provides any counselling. They only work as testing centres and people are made to wait for a fortnight and sometimes even a month for the test results.” In one VCTC, the counsellor stopped counselling due to non-availability of testing kits for almost six months, says Pavan Sharma, Secretary, Etah Positive People Welfare Society.

Instances of stigma and discrimination by the medical fraternity are also common. Positive People allege that doctors at KGMC, Lucknow, refuse to operate upon positive persons saying that they don’t have proper protection. If this is the situation in one of the reputed institutions, one can imagine the situation in the district hospitals. “Given the stigma, people tend to stay away from medical care even if they know they are HIV positive,” says a private medical practitioner in Lucknow. “But in many cases, most people have no idea if they are at risk and so they do not get tested,” he adds.

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11 http://iic.nic.in/iic2_bup.htm

12 <http://openmed.nic.in/352/01/TLANCH03.PDF>

Involvement of Positive People

NGOs and Positive People's organisations have several concerns. "There has been no involvement of Positive People or even people working with AIDS in policy planning," says a member of a support group of Positive People in Lucknow. A classic case of non-involvement was an information and awareness campaign in the state in 2005, which was developed without the participation of Positive People. Messages in the campaign perpetuated stigma and discrimination against Positive People as they were depicted as failures. Some of the hoardings in the campaign were withdrawn after protests from NGOs and positive groups.

Mangal Ram Pandey, an AIDS activist from Meerut was resentful of the lack of involvement of Positive People in the government programme, "It is easy for NACO and UPSACS to take the problem of drug shortages lightly. The perspectives of Positive People do not find a place in the programme. NACO and UPSACS have yet to recruit an employee living with HIV. Greater involvement of People Living with HIV and AIDS (GIPA) is just a juicy slogan for NACO, even after 14 years of existence."

To increase the acceptance and involvement of Positive People in UP, the Uttar Pradesh Network of People living with HIV and AIDS (UPNP+) organised a silent march on 27th January 2007. UPNP+ was formed on 7th March 2005 at Allahabad and currently has presence in 11 districts of Uttar Pradesh. At present, UPNP+ has a membership of 1000 Positive People across the state.

However, according to Arif who runs an intervention programme with MSM in the state, many Positive People are still not coming out as there are no services for them. He says, "People are not ready to go public with their status, as the government does not provide services to mitigate their suffering, possible humiliation or ostracism." Anil from Kushinagar, who has formed a Positive Forum for Care and Support, adds that it is even more difficult for positive women to come out. There are no services to mitigate the impact on women. He says, "Women are the most neglected. In most cases, they have lost their husbands to AIDS and are looking for treatment and education for their children. But, the government is not providing anything. Care and support services for women and children are non-existent."

Conclusion

"Uttar Pradesh is a sleeping giant," emphasises P. Sinha, regional manager of CARE. "We will be face - to - face with a serious epidemic if we don't act soon."

How will UP tackle an epidemic of HIV? In 2003, Abhijit Das commented on the weak state response to the regular outbreaks of diseases like dengue and Japanese encephalitis. The state government undertook health-care systems reforms with a US\$110 million loan from the World Bank to implement the Uttar Pradesh Health Systems' Development Project. In 2005, towards the end of the health-care systems' reforms project, the annual outbreak of Japanese encephalitis killed more people than ever before.

Referring to the resurgence of dengue in the state, Das writes: "It is especially galling to note that this inefficiency is despite the fact that the state has taken a huge loan to improve the health system...Responding to the dengue epidemic, it required co-ordination between the curative and preventive systems, between the private and the public health care systems, and last but not the least, between the primary, secondary and tertiary care systems. The experiences in Lucknow prove that none of these linkages are working."

Clearly then, the state has a long way to go if it must tackle the slower, silent epidemic of HIV. Mere scaling up of ART services will not be enough if basic infrastructure is not strengthened. Further, for treatment to be effective, prevention services need to be strengthened. Awareness programmes should reach the vulnerable groups. Medicines for opportunistic infections need to be available in the public health care systems. Counselling and testing centres as well as treatment centres for STDs should be accessible, and should have staff and basic supplies in place.

GOA

“People are unwilling to go to Government Medical College for testing and treatment fearing breach of confidentiality and the stigma that follows.”

Can an excellent public health infrastructure guarantee access to all?

MARIETTE CORREA

The coastal state of Goa has a population of just 1.4 million, which is less than one-tenth of the population of Mumbai city. Though one of the smallest states in India, it has some of the best development indicators in the country. For instance, the infant mortality rate is 15% per 1,000 live births; compared to the national average of 57/1,000. Ninety five percent mothers had at least 3 antenatal care visits for their last delivery as compared to the national average of 50.7%.¹

The maternal mortality ratio is 39.6 for every 100,000 live births compared to the national average of 407. Life expectancy at birth is 68 years for females and 72 years for males, in comparison with the national figures of 59 and 59.7.²

The public health infrastructure system in the state is also relatively well-developed. Each hospital serves an area of 23.9 sq km compared to the national average of one per 292.1 sq km. Each hospital serves 9,054 people, compared to the all-India figure of 61,810 people. Each doctor serves just 636 people compared to 2,148 nationally.³ The general hospitals and primary health centres function relatively well as compared to other states. Doctors are usually available at primary health centres in the morning. And general hospitals here are better staffed and stocked than they are in neighbouring states. There is, of course, scope for improvement.

Situation and response to HIV and AIDS

Goa is classified as a moderate prevalence state (concentrated epidemic with more than 5% HIV prevalence in some groups). The state's high level of literacy (82%) is believed to be responsible for people's high awareness of HIV and AIDS. At least 83% of women and 92% of men are aware of how HIV is transmitted and how it can be prevented, as against the national average of 80% and 57%.⁴

HIV prevalence is declining among women attending antenatal clinics (from 1.1% in 2004 to 0.0% in 2005) and sex workers (15.7% in 2004 to 14.01% in 2005), but rising among men who have sex with men (1.7% in 2004 to 4.9% in 2005).⁵

Work on HIV and AIDS has however, focused essentially on prevention. There are awareness-building programmes among the general population and targeted interventions among sex workers, migrant populations, truck drivers, MSM and hotel staff along the tourist belt. In line with the national policy, some work has been done in care and support for Positive People. Two community care centres were opened in 2003. The centres provide palliative care. Those in need of shelter can stay at these centres for up to 15 days.



1 National Family Health Survey (NFHS-3), 2005 - 2006, Government of India. (<http://www.nfhsindia.org/pdf/GO.pdf>)

2 *Health Profile Goa - 2004*, Health Intelligence Bureau, Directorate of Health Services, Panaji, Goa, 2004

3 *Health Profile Goa - 2004*, Health Intelligence Bureau, Directorate of Health Services, Panaji, Goa, 2004

4 National Family Health Survey (NFHS-3), 2005-2006, Government of India. (<http://www.nfhsindia.org/pdf/GO.pdf>)

5 *HIV and AIDS Epidemiological Surveillance & Estimation Report for the Year 2005*, National AIDS Control Organisation, Ministry of Health & Family Welfare, Government of India, April 2006.

“Few doctors have been trained to prescribe ART, though many are prescribing it anyway. Poorly informed doctors will not take steps to ensure compliance. They will not know the effective combinations. They will not emphasise the importance of a healthy lifestyle, the side effects...They are, therefore, unable to provide appropriate counselling.”

**– DR. SAVIO RODRIGUES,
Head of the Department of
Microbiology at Goa Medical
College**

Most of the targeted interventions, the community care centres and the tertiary and district hospitals are in the four talukas of Marmagoa, Salcete, Tiswadi (location of Panjim, the capital) and Bardez.⁶ Situated along the coastal belt, these talukas house the main towns, the construction industry and the tourist belt and are believed to account for 70 % of HIV and AIDS cases. For this article, interviews and discussions were held with individuals and with representatives of organisations and institutions in all four talukas.

Government work on HIV and AIDS is led by the Goa State AIDS Control Society (GSACS), a decentralised unit of the National AIDS Control Organisation (NACO). There are a number of NGOs, a few working exclusively on HIV and AIDS and several others doing HIV and AIDS-related work. Most NGOs receive some support from GSACS. A few like Population Services International and FXB (India) get support from other sources as well.

One such intervention was in the red-light district of Baina, Marmagoa taluka where government and NGOs collaborated in a system allowing commercial sex workers easy access to regular check-ups and medical assistance. Education and awareness-building programmes were also well-established. With the support of NGOs and the government, condoms were easily available and sex workers were able to negotiate safe sex. Presumably, as a result, HIV prevalence among sex workers at Baina dropped from 51% in 2000 and 53% in 2001 to 24% during 2002 and 2003.⁷

However, in June 2004, the government ignored the warnings of NGOs and AIDS experts and demolished the Baina red-light area, raising concerns about the impact on HIV prevention programmes there.

The demolition of the red-light area, without the rehabilitation of sex workers has only resulted in the dispersal of sex workers all over the state. No surveillance of sex workers could be carried out in 2004 as their houses had been demolished. Scattered and disorganised, the sex workers are unable to negotiate safe sex. They will, without doubt become more vulnerable to the virus. Without medical support or assistance, their health status will also be in question.

The Goa ART programme: A late start for the roll-out

Goa would seem to be an ideal location to begin ART. “It is a small state, it has a good health care system, and there is easy accessibility,” notes Dr. Savio Rodrigues, Head of the Department of Microbiology at Goa Medical College. Given that it is considered important to locate ART within a comprehensive response and in the primary health care context, the existing health infrastructure in Goa and the high levels of awareness of HIV should make it an ideal place to build a model for other states to emulate. But as a ‘medium-prevalence’ state, Goa was not included in the first stage of NACO’s ART roll-out plan.

The state’s programme started on April 1, 2005, at the Department of Medicine at the Goa Medical College. Before the programme was started, eight government doctors from different departments were trained at JJ Hospital in Mumbai. One of them is the Head of the Department of Medicine, who now supervises the ART programme. He has trained the two doctors who are running the programme; one is a paediatrician and the other holds a diploma in Skin and STDs. There is also a counsellor and a staff member for documentation. The medical college employs these four staff on contract basis with financial support from GSACS.

⁶ Goa has two districts, North Goa and South Goa, with 11 talukas.

⁷ Sentinel surveillance reports of GSACS

Positive People on ART in NACO centres in Goa – 31 December 2006

NAME OF THE CENTRE	NO. OF PATIENTS ON ART			Total
	Male	Female	Children	
Goa Medical College	214	114	20	348

As on 31 December 2006, there were 348 persons on ART. These cases had been referred by the government hospitals, NGOs and private practitioners.

All tests are done free of cost at the hospital. This includes confirmatory tests for those whose reports are not considered satisfactory – such as single rapid tests at private laboratories. It also includes free CD4 tests and routine blood tests. There is just one CD4 count facility in the state at the Government Medical College. “Liver function tests may be done if the person is an alcoholic,” says Dr. Rodrigues who is also in charge of the CD4 counts. “Moreover, the patient might be started on ART, even if the CD4 count is higher than the prescribed 200 cut-off, if there are clear clinical signs and symptoms.⁸ This is decided in consultation with the Head of the Department of Medicine and other treating doctors.”

Muddling through the implementation

“The ART roll-out needs considerable preparation,” says Dr. Rodrigues. “Few doctors have been trained to prescribe ART, though many are prescribing it anyway. Poorly informed doctors will not take steps to ensure compliance. They will not know the effective combinations. They will not emphasise the importance of a healthy lifestyle, the need for compliance with the drug regimen, the side effects... and even the fact that ART once started, must be continued for the rest of the person’s lifetime. They are, therefore, unable to provide appropriate counselling.”

Even doctors at GMC who prescribe ART do not counsel the patients properly. “Sometimes, the doctors themselves may not know that the drugs have to be taken life long,” says a counsellor at the Voluntary Counselling and Testing Centre (VCTC) at GMC.

The programme needs sufficient people trained in counselling related to ART, particularly on issues of side-effects and treatment adherence. But the counsellors must be sent to neighbouring states for training, as there is no institute in the state for this purpose and the few existing counsellors cannot be spared for days at a stretch.

During the initial period after the ART roll-out programme was launched, NGOs felt that they had not been adequately involved. For example, NGOs supported by GSACS were informed of Goa’s ART programme during one of their monthly meetings. They were asked for their suggestions; but this was within an already prescribed framework. Some NGOs feel that this was mere tokenism.

⁸ The 200 cut-off point and the clinical signs are standard criteria used by NACO based on WHO staging for ART in poor countries. However, medical professionals agree that ART is best started before CD4 counts fall to 200.

Breaches of confidentiality, stigma and discrimination

The ART programme also has to contend with wide-spread discrimination within the public health system. Though NGOs, who have referred migrant workers and sex workers to the ART centre report of the groups being treated as any “other” patient, fears of breach of confidentiality keep Positive People, especially those from the most marginalized sections, away from government hospitals. “Confidentiality and stigma/discrimination are probably the biggest problems faced by positive persons. People are even unwilling to go to GMC for testing and treatment for fear of their confidentiality being breached,” says Meera who works with the Goa based NGO Positive People. Discrimination is more if one belongs to a lower socio- economic class or a marginalized group. “If you’re from Baina, you will be treated badly at GMC and the Chicalim cottage hospital,” says Juliana Lohar of Arz, an NGO working on combating trafficking in the red-light area. “It doesn’t matter whether you’re HIV positive or negative.”

“The VCTCs have all the right personnel and facilities, but people don’t want to go there, because they fear that their confidentiality will be breached. This fear is heightened for those from marginalised groups like MSM.”

– ARUN TOMAR of Zindagi Plus, a network of Positive Persons.

“Doctors bring their students to see us,” says Sunita*, a positive person. “The students won’t touch the patient, but the patient’s HIV status becomes public.”

“The nurses shouted my husband’s status across the ward,” says Rekha* of Baina. “They were not even willing to come near him. The medical staff treated me also badly, even though I was not positive.”

“The VCTCs have all the right personnel and facilities, but people don’t want to go there, because they fear that their confidentiality will be breached,” says Arun Tomar⁹ of Zindagi Plus, a network of Positive Persons. “This fear is heightened for those from marginalised groups like MSM.” People are willing to pay much more and go to private practitioners.

“Confidentiality is difficult to maintain within the government system,” admits Dr. Rodrigues.

RIGHT

R and A are two gay men who work in a drop-in centre for MSM. Though HIV prevalence in MSM in Goa has risen from 1.7% in 2004 to 4.9% in 2005, their access to prevention and treatment services is limited because of high levels of stigma and discrimination.

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⁹ These comments were made some weeks before Tomar died in a drowning accident.

* Names have been changed to protect identities

Positive perspectives: a chequered history

The involvement of Positive People in planning and implementation of HIV and AIDS prevention programmes, prior to the roll-out, has been limited. Positive People admit that this could be because of their limited skills in planning and decision-making. "Positive People who are open about their status don't necessarily have the knowledge and capability to campaign properly," says Meera, a positive person. And, the government apparently distances itself from them. "The rich and the educated are usually not open about their status and are unwilling to get involved. Maybe, this is also because they already have access to whatever they need," she adds.

"The environment for Positive People's greater participation is not there," agrees Karl de Souza, of the Freedom Foundation's project in Goa. "It is partly due to the bureaucratic approach used by NACO and WHO. For example, people who are not supported by the GSACS are not invited for the meetings. And they are not listened to, when they are called. Discrimination is so strong, that many Positive People just don't come forward. They're also usually marginalised and are too busy trying to eke out a living."

Positive People, a support group of people living with HIV and AIDS, is currently involved in referrals and follow-up of patients in the government ART centre. Positive People also organised a state level ARV consultation on access to treatment with government doctors administering ART, representatives from the GSACS, NGOs and the civil society in October 2006 in Goa. Some of the recommendations that emerged from the consultation to strengthen the ART roll-out programme in the state are:

- setting up more ART centres in the districts/talukas;
- setting up more CD4 count facilities;
- recruiting two counsellors (one male and one female) for each ART centre;
- providing regular training to health care providers on ART and ethical issues around HIV and AIDS
- providing outreach workers at ART centres for follow-up/ home visits along with peer counselling.

The consultation also stressed on a state level awareness campaign on ART through media and provision for first and second line drugs to be made available at all ART centres.

However, while there is a strong demand for free ART, not many feel the government should provide it free of cost to all in need. They feel the drugs should be subsidised based on socio-economic criteria, to help the government sustain the roll-out. The selection process should be objective and transparent. Subsidies should be progressively higher for the poorer classes. Currently, the programme has no socio-economic inclusion or exclusion criteria. Patients' eligibility for ART depends on their medical condition alone.

Others believe that priority should be given to treatment of opportunistic infections. "Many Positive People cannot even afford antibiotics for prophylaxis against pneumocystis carinii," says Maya Chodankar of the support group Positive People. "And this is becoming increasingly common in Goa, though it gets diagnosed by doctors in Bangalore. "People can't afford TB medicines like rifampicin and they are often not provided by the public health services," says Meera. "Even paracetamol is often unavailable at government clinics." Further, she says that new opportunistic infections are emerging. Cryptococcal meningitis is becoming increasingly common among Positive People in Goa, and it is not even diagnosed by the doctors here – the patients have to go to Bangalore.

Knowledge of ART

Interestingly, till recently, there was very low awareness about ART, even among NGOs working with vulnerable populations. “Many people came to us asking about ART, but at that time the government showed no signs of starting the programme,” says Chodankar of the support group Positive People. She said there was no point in giving people false hopes, at that point of time.

“Are there drugs available that can prolong our lives? How come none of the NGOs here have told us about it?” asks Shanta*, a positive sex worker from Baina. As an afterthought, she adds, “Maybe, we were not told because we cannot afford the drugs. We cannot even be sure of getting our meals regularly; what is the point of talking about medicines? If we have to die, we will. Of what use are our lives anyway?”

Even after the roll-out began in Goa, people in vulnerable pockets with low literacy levels knew almost nothing about the existence of ART. Supriya Arolkar, a counsellor at the VCTC at the GMC says, “Almost none of those who come to the VCTC know about ART. This ignorance is rampant. We have to deconstruct the messages, which have been deeply rooted in the minds of the people and make them understand that there is life after HIV infection.

“The government has done nothing to reach out to vulnerable communities, most in need of free ART,” says Arunendra Pandey, director of Arz. “Apart from the press releases after the programme was launched, the state has not taken any initiative to reach communities who do not have access to newspapers.”

Role of the media

Some responsibility for this state of affairs lies with the media. The local print media (the local TV news channels are relatively new) has played only a peripheral role in the matter. In the early days of the epidemic, the entire focus was on sensationalism, which often only reinforced the stigma attached to being positive. The Baina red-light area was portrayed as the ‘source’ of AIDS. Journalists also generally play along with politicians in labelling ‘outsiders’ (both tourists and migrants) as the cause of HIV and AIDS. Arun Tomar of Zindagi Plus regretted that politicians never give out any positive messages.

A few balanced stories have appeared in recent years but these also tended to portray Positive People as victims, rather than individuals who can lead normal lives and deserve the same consideration and treatment as others. In a random scan of newspaper reports on HIV and AIDS in the last two years, one could only find two stories on ART and general care and support of Positive People. One report highlighted the plight of the marginalised in accessing drugs.

“The media could be involved in informal monitoring and critiquing the programme’s implementation,” says Shakeel Sheikh, Programme co-ordinator of FXB India. However, most media people do not find HIV reporting – whether to increase awareness or fight stigma and discrimination – a priority.

NGOs and donors: trepidation and scepticism

No NGO currently provides ART. One reason is that donors are not willing to fund it, especially since it involves long-term commitment. UNAIDS has agreed to provide ART to two men from Zindagi Plus. This will be done through Nipasha, a national body of organisations and networks of positive MSM.¹⁰ This was decided in July 2004, but it is not clear when it will begin or for how long it will be given.

¹⁰ Nipasha was established in 2002 and has representatives in 14 states. UNAIDS plans to provide ART directly to two persons from each of the states in which Nipasha has representatives.

NGO appeals to pharmaceutical companies for free drugs have gone unanswered. Cipla has a plant in Goa (along with other pharmaceutical companies), but it has refused to subsidise ART to NGOs, let alone provide it free.

Even NGOs with more resources are unable to consider providing ART. “Our services stop at prevention,” says a senior member of Population Services International, which runs HIV and AIDS prevention programmes in port areas all over India. “There is no scope for us to give ART under this USAID-supported programme.”

“NGOs may not be around tomorrow,” says Arunendra Pandey. He feels that only the government can implement ART; NGOs can be facilitators and help identify beneficiaries and monitor adherence. Most NGOs share this view. They, however, would like to be involved as partners in the project, with some responsibility for implementation.

But even NGOs have failed to come up with relevant programmes. Supplementary nutrition, medication and home-based care are not often a part of NGO programmes – either because the focus is on prevention or because they don’t raise the money for such services.

Treatment problems

“Only 50% of people eligible for ART opt for it after counselling,” says Dr. Rajesh Naik, one of the few private medical practitioners who have undergone intensive training in the field. And, despite trained counselling, 20% drop out after six to eight months. “After a few months of taking the drugs, they start feeling better. But, then they also feel the financial pressure. ART is quite expensive.” If Dr. Naik’s patients drop out after intensive counselling, one can only imagine what happens to patients treated by doctors who have not been trained properly in ART prescription and counselling.

Even NGOs with more resources are unable to consider providing ART. “Our services stop at prevention,” says a senior member of Population Services International, which runs HIV and AIDS prevention programmes in port areas all over India. “NGOs may not be around tomorrow,” says Arunendra Pandey. He feels that only the government can implement ART.

BELOW

NGO outreach workers implementing a prevention programme. Care and support activities are often not part of NGO programmes in Goa.

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Many Positive People complain that that drugs often run out of stock in the pharmacies. "Only a few pharmacies in Goa keep ART, as distributors do not give refunds when the drugs expire," says Raj Vaidya, chief pharmacist at Hindu Pharmacy. "We get 90% and even 100% refund for other drugs, but not for ART drugs, and this is a major inhibitor."

Erratic drug availability in the state's pharmacies and at the ART centres forces some patients to go to private practitioners or to neighbouring states, particularly Karnataka where the drugs are cheaper and more easily available. In such cases, patients also have the confidentiality which comes with distance.

From private to public: a rough ride

Before the government programme started, about 100 persons in Goa were on ART at private facilities. Currently, three-four private practitioners prescribe the drugs on a regular basis, and others do so off and on. One of the major barriers to ART is its high cost; treatment expenses come to around Rs 3,000 - 4,000¹¹ per month all inclusive; the medications alone cost Rs 1,500 - 2,000. Despite the high costs, those who can afford it still prefer to go to private practitioners. One is for reasons of anonymity. Goa is a small place and people can be easily identified at the government centre. Further, those who were taking drugs from private practitioners before the ART roll-out in the state continue to do so.

Monthly expenses for ART and related treatment

The lowest drug combination is Diovir which costs Rs 1,864 a month. People with CD4 counts below 200, who also have TB, may be prescribed Efavir which costs 3,500 per month or Diovir plus another Rs 250 for TB drugs. Vitamins and iron tablets cost about Rs 100 a month and a month's dose of antibiotics (Sulfamethoxazole-trimethoprim) to prevent pneumocystis carinii costs Rs 36.



In addition, people on ART will have to take half yearly tests of their CD4 counts. Although it can be done free of cost at the government hospital, most people prefer to spend Rs 1,500 in private hospitals where confidentiality is seemingly better maintained. Liver function tests, costing about Rs 200 must be taken every two months. All this must be supported with good nutrition and medication for side effects.

(Source: discussions with positive groups and Hindu Pharmacy)

11 USD 68.18-USD 90.9
(1 USD= Indian Rs 44)

Roadmap for the successful implementation of the ART roll-out in Goa

One of the concerns expressed by government officials, doctors, NGOs and positive persons alike was the danger of introducing ART without long-term commitment. Systems must also be in place to ensure easy accessibility, affordability, confidentiality and an end to stigma and discrimination. The success of the ART roll-out in Goa will depend on how well its public health infrastructure, including manpower resources, is used. It is also dependent on intensive training of doctors and counsellors to monitor treatment adherence and compliance. ART must be part of a multi-pronged strategy in which care and support are integrated with prevention programmes.

One major issue concerns the mechanism through which ART is now being administered. Most Positive People distrust the government system. In general, vulnerable populations like sex workers, MSM and migrant labourers also face stigma and discrimination within the government health system. It must be available at the two district hospitals. ART would then be available to people from far-flung areas. The drugs must be distributed in a way that maintains confidentiality. People on ART must be monitored regularly.

Positive People from all vulnerable groups – women, MSM, migrant labourers, sex workers – must be brought into the programme, notes Albertina Almeida of Bailancho Saad, a women's collective. Else there is a danger that only the concerns of the most vocal sections will be addressed.

ART Consultant, Dr. Dilip Vasanmal Vaswani, suggests some ways for smooth implementation and sustainability of the ART roll-out programme. Primary among them is developing strong monitoring systems to ensure regular supply of stocks of HIV testing kits, CD4 testing kits and ARV drugs. Follow-up of training and monitoring patients on ART need to be strengthened. IEC material for adults and children on treatment must also be developed. ART centres at the state level need to be more involved in planning the programme. Currently, the states only follow guidelines set by NACO. ART centres need to be linked to community care centres. At the same time, guidelines need to be developed for patient referrals to tertiary care centres. Lastly, the public sector needs to network with private agencies that offer both first and second line treatment. Operational research should be carried out in clinical- drug resistance, patient load and staff commitment.

Conclusion

The state has still not been able to utilise its working public health infrastructure to implement the ART roll-out largely because of a top down programme which ignores topical realities. Further, stigma and discrimination by medical practitioners against Positive People and those vulnerable to HIV and AIDS make it difficult to ensure access to treatment for all, particularly the most marginalised.

GUJARAT

“There are no queues, we get nutrition and quality care”

The corporate sector steps in to fill the gap

DARSHAN DESAI



The state of Gujarat (population 50.596 million) is an intriguing study in contrasts. The per capita income of the state in 2005 - 06 was Rs. 26,979 compared to the national average of Rs.25,825.¹ It holds 25% of national investment in the stock market and is second only to Maharashtra in industrial investment. While acknowledging these strengths, the state's Gender Equity Policy, framed in 2003 notes: “Performance on social indicators, however, has been slower than that on economic indicators, revealing a wide gap between the status of women and men. The female literacy rate in the state is 58.6%, while the same for males is 80.5%. The male-female sex ratio in Gujarat has declined from 934 in 1991 to 921 (878 in the 0-6 years age group) in 2001. Another area of concern is gender-based violence at home and at the workplace. Most of these cases are not reported due to the attached social stigma and a patriarchal mindset.”

Gujarat may appear to have a good health infrastructure. With as many as 984 primary health centres (PHCs) in 2000, each PHC served 19 villages compared to the national average of one PHC for every 27 villages. However, the state human development report notes the “low utilisation of existing health facilities because of the staff not staying at the facility.” The situation is even worse at the next level of care, with each of the 224 referral community health centres (CHCs) centres serving a rural population of 1,21,000 against the prescribed ratio of one for every 1,00,000. Further, there is only one specialist per CHC, as against the prescribed four per CHC, as doctors are unwilling to work in rural areas. As the state's human development report notes, “At least 71.3 % of the doctors in Gujarat reside in urban areas, while nearly 65 % people live in rural areas.”

Not that the urban health care infrastructure is much better. When the rural poor migrate to Gujarat's cities, they stay in slums or poor localities, which are as deprived of health services as poor areas in other parts of the country. The rich and the middle class have access to modern medical facilities. But, government hospitals and dispensaries are overflowing with poor patients, who cannot afford private treatment.

Factors which increase vulnerability to HIV

Gujarat is a ‘moderate prevalence’ state i.e, where the HIV prevalence among certain groups is 5% or more and the HIV prevalence in the general population is less than 1%. While the HIV prevalence among STD clinic attendees and sex workers has been declining (3.60 in 2004 to 2.00 and 9.20 in 2004 to 8.13 in 2005 respectively) the HIV prevalence in men that have sex with men (MSM) is rising (from 6.80 in 2003 to 10.67 in 2005).

The state is vulnerable to HIV and AIDS due to many factors such as a large population of internal migrants, driven by massive industrialisation and also by stagnating agricultural growth. The M.S. Swaminathan Research Foundation has

1 http://www.maharashtra.gov.in/english/ecoSurvey/ecoSurvey2005-06/eng/cha_5e.pdf, http://mospi.nic.in/nad_press_note_31may06.htm

listed Gujarat among the six “severely food insecure” states in India. The Planning Commission has ranked the tribal-dominated Dahod and Panchmahal districts in Central Gujarat and Dangs district in South Gujarat among the 100 poorest districts in India. Severe deprivation in the tribal areas sends 60 -70% of the population to cities in the state and outside, to work for the better part of the year. For instance, around 300,000 to 400,000 people from nearby rural areas go to Surat daily in search of work, says Prof. Ghanshyam Shah, former director of the Surat-based Centre for Social Studies.

Surat, one of the most affluent cities in the state with a large population of diamond merchants, has a flourishing sex industry. Till four years ago, Surat was the only city in the state which had a red-light district, but sex work is now dispersed through the city after the authorities ‘cleared out’ the red-light area. Today, at least 300,000 of these sex workers form a floating population. They come in on the morning trains and buses and leave by night. This makes it difficult to implement intervention programmes effectively.

At the same time, consumerism, media and the communication revolution in the urban areas have spawned a culture that makes youth more vulnerable to HIV without necessarily educating them on how to protect themselves.

Still, the state does little more than implement the national programme. There is no independent policy based on the state’s special needs. For example, there is no vehicle to reach information to the large tribal population. Nor is there anything to address the problems of a population like diamond merchants with huge disposable incomes but low levels of awareness. “Though prevention efforts show signs of working, we have not focused on the factors that make people vulnerable,” says Vibha Marfatia of Sahas, an NGO working with migrant diamond unit workers.

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Provision of ART

Initially, the government machinery in Gujarat had not taken any responsibility to provide ART either free or at subsidised rates, arguing that HIV prevalence in Gujarat is low. There was also a feeling that provision of ART would be a drain on the government’s resources. However, as NACO announced plans to scale up ART, active lobbying by the Gujarat State Network for Positive People (GSNP+) saw roll-out at the ART centre in Ahmedabad in the central region in early 2005. More recently, a second centre began functioning at Surat in the southern region in September 2006. Thirteen hundred and fifty two people, including men, women and children were accessing treatment at these centres as on 31 December, 2006.

Positive People on ART in NACO centres in Gujarat – 31 December 2006

NAME OF THE CENTRE	NO. OF PATIENTS ON ART			
	Male	Female	Children	Total
Civil Hospital, Ahmedabad	766	332	59	1157
B.J. Medical College, Surat	149	46	0	195
TOTAL CENTRES IN GUJARAT (2)	915	378	59	1352

The Reliance Industries, as the first case of corporate help, offers fifty percent subsidy on medical costs. Another encouraging development in Surat is the formation of Aarambh, a consortium of seven medical specialists. The organisation runs free out-patient services from the premises of a charitable trust. Its specialists conduct home visits for poor patients when necessary. GSNP+ has also used innovative approaches in getting the affluent class of diamond merchants in the state to pay for the ART of those who cannot afford it.

A common complaint of members of GSNP+ is that the two centres are not enough. People in rural areas have to spend money on transport and stay, or be forced to use these drugs without monitoring. GSNP+ is currently lobbying for a third centre in Rajkot in the western region so that ART centres are spread evenly and travel costs of Positive People are reduced.

Antiretroviral drugs are also available at private pharmacies. They cost between Rs 1,500² and Rs 4,000 for a month's supply, depending on the type of treatment prescribed. These are not the only costs. Private laboratories charge between Rs 1,400 and Rs 5,000 for CD4 and other diagnostic tests.

The Reliance Industries, as the first case of corporate help, offers fifty percent subsidy on medical costs.

Another encouraging development in Surat is the formation of Aarambh ('beginning'), a consortium of seven medical specialists. "We decided to work with Positive People when we saw the general apathy of the medical fraternity and realised that NGOs focus only on awareness activities," says Dr. Pradeep Pethe, who works with Aarambh. The organisation runs free out-patient services from the premises of a charitable trust. Its specialists conduct home visits for poor patients when necessary. It has recently started providing free monthly rations of grain worth Rs 500 each to 14 families. "Sixty per cent of one person's calorific needs are met with this packet," says Dr. Pethe. Aarambh also provides medicines for opportunistic infections, free of cost.

GSNP+ has also used innovative approaches in getting the affluent class of diamond merchants in the state to pay for the ART of those who cannot afford it. After an open space cultural programme in Surat, diamond merchants were requested to "adopt" a patient annually for ART at Rs. 10,000 each. The diamond merchants support ART through an NGO, the AIDS Care Trust, and provide support for first line treatment. Second-line treatment is subsidised by paying 25-50% of the costs, depending on the economic status of the patient.

GSNP+ supports the ART programme by providing treatment literacy to the patients. Says Rani Parekh of GSNP+, "We have been making people aware that ART should not be started till the CD4 count goes below 200. We take other precautions to avoid opportunistic infections – we drink only boiled water and include fresh lemon juice and amla (Indian gooseberry or *Emblica Officinalis*) in our diet."

GSNP+ members are happy with the Government's efforts to involve them, even though they are not seated in the front rows. Their demands include availability of drugs for ART as well as for opportunistic infections; nutrition for the poor; employment opportunities for those who lose their jobs when employers discover their HIV status and regular payment of widow pension (as given by the Gujarat government). The network is doing what NGOs apparently cannot do. "We have no complaints about the NGOs but they cannot help us tackle various social pressures and the medical profession's apathy. Despite the huge stigma and discrimination prevalent in the state, more and more Positive People are coming forward to disclose their status in GSNP+ meetings," says Rani. "This is where we step in... for we have all faced such things."

One of the biggest problems faced by positive groups is getting the medical fraternity to change its apathetic, sometimes even hostile, attitude.

² USD 34
(1 USD=Indian Rs.44)

Filling the gap: A case of corporate - NGO partnership

In Hazira in Surat, a small clinic run by the Reliance Industries dispenses ART everyday from 9.00 AM to 5.00 PM. Hazira has a large migrant workforce employed in several local industries. The clinic has a staff of eight (two administrators, one laboratory technician, two counsellors, a doctor and a chief medical officer). A yoga teacher and a nutritionist visit the clinic every 15 days. Unlike the government ART clinic in Ahmedabad, this clinic has no queues, especially if one enters after 2.00 PM. All patients to the clinic are referred by GSNP+. Enrolled patients have to buy drugs for 15 days from outside. The cost amounts to Rs 400 - Rs 450. Currently, there are approximately 500 patients enrolled at the clinic. This includes 20 "adopted" children whom the clinic provides medicines and also nutritional support, free of cost.

The Reliance management plays a key leadership role in shaping the program and extending its outreach beyond company employees to the neighboring community. But partners such as Lok Samarpan and GSNP+ have also been very active in implementing the programme. Lok Samarpan, a local blood bank, conducts CD4 tests at a subsidised rate of Rs 650 per test. Further subsidy by Reliance reduces the cost to Rs 300 per test. Tests are free for widows and orphans.

Despite the additional cost of drugs, though subsidised, patients from across the state, especially southern Gujarat prefer to access drugs from Reliance for several reasons. The obvious reason is very short or negligible queues. Says Umesh Patel, a member of GSNP+, "In the government hospital, there are huge queues and we need to spend almost 4 to 5 hours to get the medicines. People from upper middle class and high income groups do not want to jostle with the huge crowds in the public hospitals and people from low income groups lose their day's earnings. So, they come to Reliance where they can get drugs in an hour or even lesser time, if they reach after 2.00 pm." Moreover, Reliance arranges to get X Rays, free of cost, from laboratories in Mumbai. In the government hospitals, patients have to pay for the X-Rays and have to brave long queues for that as well.

The quality of care at the Reliance centre is better and extends beyond dispensing drugs. The services offered at the centre are counselling, yoga training, pranayama coaching (breathing exercises to boost physical and mental spirits), and nutritional support. Malnourished patients, weighing less than 40 kilograms, are given food and nutrition supplements. The government hospital only provides Vitamin A tablets, which are sometimes out of stock. A GSNP+ member says, "The government hospitals change the drug company frequently. Many Positive People fear that this may lead to resistance. In the Reliance clinic, only drugs from Cipla are provided."

GSNP+ members also feel that monitoring and follow-up are better in the Reliance clinic, as all referrals are made through the GSNP+ network. District level networks of GSNP+ follow all patients regularly and counsel them on the importance of treatment adherence. In the government ART clinics, sometimes, several patients enrol on their own without coming through a network. Follow-up of these patients is a very difficult task.

The medical fraternity

The medical profession in Gujarat is also influenced by the mercantile ethos in the state. There have been several reports of doctors behaving unethically towards Positive People.

Senior medical professionals involved with the state programme say that many doctors, mainly in the private but sometimes also in the public sector, do not know how and when to administer ART. Some just prescribe ART to every positive person, irrespective of their symptoms and CD4 counts.

Such indiscriminate prescription and erratic use of ART without adequate knowledge will lead to a disaster. It will only hasten the process of drug resistant strains of the virus and even hasten death. Dr. Pethe says, "Once ART administration starts, it cannot be stopped for life. Or the virus hits back with a vengeance. It is vital to know when and how to start the drugs." So intense training for doctors on ART is an absolute necessity and should be extended to all government hospitals. Private practitioners also need to be trained. As Dr. Yogesh Marfatia from Vadodara says, "We need interested as well as trained doctors; both are necessary in equal measure."

A review of case records at a Vadodara hospital in January 2005 found that 16 of 42 people on ART developed adverse drug reactions. "In most of these cases, we had to temporarily substitute the drugs," says Dr. Marfatia. "In three cases, the reactions were life-threatening and we had to change drugs permanently – immediately raising the monthly expenses from Rs 1,200 to Rs 3,000. Remember, patients in government hospitals are poor and affordability of this treatment is a major issue for them." Treatment needs to be monitored properly, notes Dr. Marfatia. "There is a need for constant training as well as motivating the medical fraternity. These patients came to us and we took proper care for we know the subject. This, often, is not the case with private practitioners."

Medical professionals argue that they are kept out of policy discussions and even training programmes. Currently, ART training is only provided to selected staff of the government hospital where ART services are implemented. Dr. Saxena of GSACS denies this accusation. "The Indian Medical Association is always involved in national policy framing. At the state level, we have regularly organised training

RIGHT

Doctors talk to a migrant worker in a hospital. There have been several reports of doctors behaving unethically and abusing human rights of Positive People in Gujarat.

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sessions for medical professionals, covering all aspects of prevention and cure.”

Interviews in Vadodara and Ahmedabad suggest that such training is not always enough. While Positive People find doctors in Surat supportive, in Vadodara they complain of a powerful, but cold and apathetic medical fraternity.

“Not so long ago, when a Positive Person was admitted to the government hospital, the staff put up a board next to the bed reading: ‘This is an HIV patient’,” says Atul Ravrani who heads the Positive People network in Vadodara. “In another case, a Positive Person was made to sleep outside in the lobby. The approach has changed a bit since then, because I got local journalists to report such cases.”

If getting Positive People admitted to public, charitable and private hospitals has been a struggle, the case with the private sector is worse. Some private practitioners don’t even allow Positive People to touch their desks. Many refuse to treat them even for small ailments like coughs and fevers. There are reports of doctors with post-graduate degrees in Medicine taking pride in not accepting HIV patients and discouraging families from performing the last rites of loved ones who died of AIDS. There are also reports of private doctors who charge exorbitant sums to treat Positive People.

NGOs have been an important pressure group influencing health professionals and hospitals reluctant to admit and treat Positive People. They have been a bridge between patients and the medical fraternity. A campaign is needed to bridge the divide between the medical fraternity, positive patients and groups with high-risk behaviour. This can happen only if Positive People, peer educators of high-risk groups and the medical fraternity are actively involved in policy framing. “The effort has to be holistic and not just NGO-centric or government official-centric,” a senior medical professional points out.

Unfortunately, this is not what happens. “When people fall ill, they visit the doctor. If they are treated badly at the entry point because they are HIV positive, their morale breaks down,” notes Dr. Pethe. “The problem of HIV and AIDS must be seen beyond statistics.”

However, the scene is not totally bleak. There are the stories of a handful of concerned medical practitioners. Dr. Pethe in Surat and Dr. Mafartia in Vadodara have been bringing the medical fraternity together to help Positive People. But, the question remains as to how long a group of individuals can sustain this help, given the fact that ART is a lifetime regimen for those affected.

Conclusion

The government claims that its focused campaign on awareness and targeted interventions has resulted in controlling the rise of HIV infections in the state. Yet, vulnerable groups and Positive People are not happy with the government’s overdrive on awareness and prevention efforts. They feel the government should be doing more on care and support, such as access to ART and other medicines for opportunistic infections at subsidized cost, timely medical treatment “just like any other people”, counselling and testing facilities (including CD4), employment opportunities for Positive People and job security to those already working. The private sector, the affluent class in the state and NGOs are trying to bridge the gap by not only providing services on care and support but also providing opportunities for Positive People and vulnerable groups to implement and manage programmes. But there is a great risk of this development becoming counter-productive, if the medical fraternity continues to practice stigma and discrimination towards Positive People. Moreover, while a weak public health system does not hinder the services of the private sector, it does not provide support either, thus making extension of these services to a wider population extremely difficult.

One of the biggest problems faced by positive groups is getting the medical fraternity to change its apathetic, sometimes even hostile, attitude. Some private practitioners don’t even allow Positive People to touch their desks.

WEST BENGAL

“Until March 2005, the only source of antiretroviral drugs for the poor was through some NGOs.”

The state provides key insights to improve the involvement of NGOs in the roll-out programme

SWATI BHATTACHARJEE



■ For over a year, 52-year-old Sanatan Sarkar* received antiretroviral therapy free of cost from a charitable organisation in Kolkata. Then, in November 2004, the organisation informed him that it had decided to stop dispensing allopathic drugs. He could either take the Ayurvedic drugs they were dispensing or stop all treatment. Sarkar saw no choice but to accept the Ayurvedic medicines.

■ Ganesh Das*, who received ART from the same charitable organisation for over three years, refused to switch. “My doctor said, once you start ART, you have to stay on it for life.” Dr. S. K. Guha, Das’ doctor, supports him saying, “There are only two reasons to stop ART– if there are excessive side effects or if the medicines are not working. We do not know of any Ayurvedic medicine which can take the place of ART. Stopping ART for AIDS patients who are responding well is, in my view, unethical.” When Das refused the Ayurvedic medicine, the charitable organisation refused to give him any other kind of care and support.

For Das and Sarkar, the government ART roll-out programme brought happy news. Prior to the government roll-out, many were victims of irrational and arbitrary ART in West Bengal. With the introduction of the free government ART roll-out in March 2005, the situation has improved remarkably. A large number of HIV positive patients, who were initially with private practitioners or NGOs, have now shifted to government ART centres.

The state of West Bengal in eastern India stretches 600 km from the Bay of Bengal to the Himalayas. Strategically positioned with three international borders with Bangladesh, Nepal and Bhutan, it also borders the states of Assam, Bihar, Orissa and Sikkim. It has a population of 80 million. The life expectancy at birth is 62 years compared to 61 nationally.¹

Health infrastructure

Seventy-six per cent of health institutions in the state are run by the government, compared to the national average of 40 per cent. The West Bengal Human Development Report 2004 notes that government hospitals have four times as many beds (57,022) as do private institutions (13,592). There is one hospital bed for every 1,136 people. The doctor to population ratio is 1: 830 in urban areas, and 1: 4,727 in the rural areas.² The state has a total of nine government medical colleges and 17 district hospitals.

However, our report notes that the picture is changing. Public health systems have been badly hit by a massive shortage of funds for current expenditure – medicines,

1 West Bengal Human Development Factsheet. <http://www.undp.org.in/Programme/undpini/factsheet/westbengal.pdf>.

2 *West Bengal Human Development Report*, Development and Planning Department, Government of West Bengal, May 2004.

materials, staff salaries and money to maintain and expand existing infrastructure. The poor must increasingly rely on private health care, and are also increasingly denied health care because of their inability to pay.

Nobel Laureate and social scientist Amartya Sen³ points to a survey in West Bengal, which found that primary health centres were understaffed, forcing patients to go to private doctors. The economic costs can be ruinous. There are four times as many non-allopathic doctors (40,415) as allopathic doctors (12,213) in the state. A significant proportion of private health care in the villages comes from unregistered practitioners or 'quacks'.

HIV and AIDS in West Bengal

West Bengal is categorised as a "low prevalence, highly vulnerable state". According to the National AIDS Control Organisation's surveillance in 2005, HIV prevalence is 0.84 per cent in nine antenatal centres representing the general population, and 2.16 per cent in twelve STD sites. It is evident from the table that HIV prevalence among drug users and female sex workers is increasing.

Comparative yearwise HIV prevalence (per cent positive) among different population groups ⁴			
Population groups	2003	2004	2005
ANC (9)	0.50	0.50	0.84
STD (12)	1.61	0.88	2.16
FSW	6.47	4.11	6.80
IDU	2.61	3.83	7.41
MSM		1.33	0.54

Interviews were conducted in the state capital of Kolkata, Domjur block of Howrah district close to Kolkata, and Jalpaiguri block of Siliguri district.

Drugs for AIDS

The ART roll-out was introduced in West Bengal in March 2005, almost a year after it first began in the high-prevalence states. By 31st December 2006, about 1258 people were on ART at the School of Tropical Medicine (STM) in Kolkata, which has run an out-patient department for HIV for some years and sees at least 500 Positive People on any given month. In December 2006, the government started a paediatric ART centre at the APEX Medical College, Kolkata. Dr. Goswami, Programme Officer (ART), WBSACS, is hopeful that two new ART centres at Midnapore Medical College and Burdwan Medical College MC will start functioning from April 2007 under the umbrella of The School of Tropical Medicine, Kolkata.

In his opinion, 3A's: 'Accessibility', 'Adherence' and 'Awareness' are key in scaling up of ART services to the affected and infected communities. In order to qualify for ART, Positive People must have a CD4 count of less than 200 and demonstrate that they will adhere to the treatment. A supporting family member should ensure

3 Varadarajan S., India's poor need a radical package: Amartya Sen, *The Hindu* January 9, 2005. <http://www.hindu.com/2005/01/09/stories/2005010900161400.htm>

4 *HIV and AIDS Epidemiological Surveillance & Estimation Report for the Year 2005*, National AIDS Control Organisation, Ministry of Health & Family Welfare, Government of India, April 2006.

Positive People on ART in NACO centres in West Bengal – 31 December 2006

NAME OF THE CENTRE	NO. OF PATIENTS ON ART			
	Male	Female	Children	Total
School of Tropical Medicine, Kolkata	943	278	37	1258
North Bengal Medical College, Siliguri	71	24	3	98
TOTAL ART CENTRES IN WB (2)	1014	302	40	1356

that the patient will attend the clinic regularly and both patient and relative are counselled together. Medicines are provided for 30 days at a time.

It is difficult to arrive at an estimate of the total number of patients under ART, inclusive of both the public and private sectors. Some buy the medicine from the market, but many obtain ART through non-governmental organisations (NGOs) at a discount or, in a few cases, free of charge. Paediatric ART is only provided by the government hospital.

With the start of the government programme, several people taking ART through NGOs have now switched to the government scheme. A number of patients, who were taking ART from Boruka Bhalobasa, a care and support programme, now go to the government ART clinic.

But NGOs must continue to offer subsidised treatment, says Palash Ghosh, project co-ordinator of Boruka Bhalobasa. For one, only the poorest of the poor, who just could not afford subsidised ART, switched.

The CD4 test is a problem with the Kolkata Network of Positive People (KNP) as well. Sudeshna Banerjee, a counsellor and the co-ordinator of KNP, says that while they are happy with the free ART programme and the recent waiving of charges on CD4 tests, members still have to incur travel costs to avail of these facilities.

The gender issue in ART

There are also fewer women than men in the government ART programme. But Dr. S.K. Guha at the STM says, "The clinic now encourages every male patient to bring his wife for HIV testing before he is put on free ART." Dr. Guha adds that he is in touch with NGOs and exchanges patient lists regularly to see that no patient is accessing medicine from more than one source.

Niran Sharma, President of Sanghabaddha, a Positive People's network based in Siliguri says, "We have an equal number of men and women in Sanghabaddha."

But, in general, men are more likely to get on ART than women are. "I know of a woman whose CD4 count is less than her husband's, but only the husband gets treatment," says Sunil, a member of KNP working in Domjur. Seventy-five per cent of people on ART at Sparsha, a Kolkata based NGO, are men. "They were infected first, so they have become symptomatic earlier," says an activist. "But of the 30 members needing treatment who can't afford it, most are women, widows abandoned by their families."

Pushpa* comes to an NGO in Kolkata every week to collect medicine for her husband. She knows that she is HIV positive. "I have lost weight, and I am always tired," she says. But she refuses to get a CD4 count done. "What is the use? Even if I am positive, I can't afford the medicines. Shall I stop feeding my sons to buy my medicine?" Pushpa has even stopped going to the hospital for her treatment, because doctors keep asking her to get the CD4 test done. She was not aware of the free ART roll-out programme initially and did not get any kind of support from her family.

"A family's savings are exhausted in the early part of the man's sickness," says Dr. Subir Dey at Medical College in Kolkata. "During the final crisis, jewellery is sold. By the time the man dies, there are no resources left for treatment or even the woman's basic needs. She is left to die." Women patients might take treatment for some time but eventually, quietly disappear to the village to die unnoticed.

Thirty-year-old Navin Jha* from Samastipur, Bihar, works as a night guard in a corporate office in Kolkata. When admitted to Medical College for complications of AIDS, he mentioned that his wife was pregnant with their second child. However, he is unwilling to bring his wife to Kolkata for testing and, if necessary, a dose of nevirapine to reduce the chances of the virus being transmitted to the baby.

To help increase the access of women to the ART centre, the Bengal Network of Positive People (BNP+) has constituted a state level monitoring group, which will interact with vulnerable groups as well as the programme manager in charge of ART in WBSACS.

Another reason may be that women are not a "target group" in the NACO guidelines on targeted interventions and therefore do not come in regular contact with NGOs. "We focus only on truckers, migrant labourers and sex workers," says Mahadeb Saha in Domjur, when asked whether any special initiatives have been taken by panchayats for the wives of migrant labourers. Nothing is done, for example, to sensitise women members of the panchayat to protect positive women from social stigma.

"In general, men are more likely to get on ART than women are. I know of a woman whose CD4 count is less than her husband's, but only the husband gets treatment."

– SUNIL, member of KNP working in Domjur.

BELOW

Migrant workers at a health clinic in West Bengal. Women have less access to prevention and treatment services. One reason may be because women are not a "target group" in the NACO guidelines on targeted interventions.

© NILAYAN DUTTA/DRIK, Panos-STOP TB Fellow, 2005.



Adherence to ART

Doctors in government institutes are concerned about patients' adherence to ART. They suggest that ART should be closely supervised, like directly observed treatment strategy (DOTS) for tuberculosis patients.

Dr. Subir Dey followed 50 patients for five years. He found that nearly 70% dropped out within a year of starting treatment, 20% took treatment intermittently and only 10% took treatment regularly.

Dr. S.K. Guha at STM followed 300 patients for five years and found that barely 15% took treatment meticulously. Such practices encourage the development of resistant HIV strains, which are then treatable only with second-line drugs. Second-line drugs are virtually unaffordable, as of today.

Some people drop out as soon as they feel better. Sometimes, positive couples split the month's medicines, with each person receiving an inadequate dose. Often people are not clearly informed about treatment. "The doctor writes '15 days' on the prescription, intending that the patient should return after 15 days. The patient takes this to mean that the medicine should be taken for only 15 days," says Palash Ghosh. "Only about 20% of AIDS patients who come here with a prescription of ART are aware that the treatment is life-long." This clearly throws light on the lack of counselling before putting people on ART.

But, the main reason people drop out is the lack of money.

Thirty-two-year-old Swapan* worked as a tailor in Mumbai before he fell ill and returned home to Domjur block in Howrah district. He came to Kolkata looking for treatment. An NGO gave him treatment at a subsidised rate, but he had to drop out when he could not pay Rs 600⁵ a month to the NGO. He owes the NGO nearly Rs 1,000.

Who gives ART?

Until March 2005, the only source of antiretroviral drugs for the poor were some NGOs and community-based organisations who bought the medicines from pharmaceutical companies at a discount of 10-15%. NGOs and individual philanthropists still play a role in providing a small number of people with second-line drugs in the absence of these drugs in the government programme. Some NGOs give further subsidies to the patients, the amount varying from organisation to organisation and from patient to patient. NGOs' subsidies range from 33-75% of the cost. NGOs say that they offer subsidised ART to people who have a doctor's prescription after counselling them on the need for continuous adherence for life. They also ascertain whether the person will be able to continue to pay the subsidised costs of ART and meet other expenses such as the periodic CD4 count tests. In a few cases, people have received free ART, but this has sometimes been withdrawn abruptly, severely affecting adherence.

How long will these NGOs be able to sustain supplies is the big question. In the absence of sustained donor support, there is danger of more cases like Das and Sarkar. Treatment would become unmanageable and costs will escalate.

Currently, majority of the NGOs also act as facilitators between the government and the patients on ART. All the targeted interventions for drug users, MSM and sex workers supported by the West Bengal State AIDS Control Society (WBSACS) are either linked to the NGO or to an organization of Positive People.

The main role of NGOs is in following up with vulnerable groups on regular CD4 tests and to monitor individual adherence to drug regimes. However, even NGOs

⁵ USD 13.6
(1 USD= Indian Rs 44)

find it difficult to follow up with vulnerable groups outside their territories in difficult to access rural areas. NGOs like Child in Need Institute (CINI) admit that the most marginalised in far-flung areas either do not access treatment or drop out more frequently.

CINI has a close tie up with the WBSACS and is involved in referrals and follow up of patients. A strong need identified by CINI is to strengthen counselling services in the ART programme to help people understand the importance of treatment adherence and right nutrition. CINI is also involved along with a group of NGOs and the government in providing counselling to those on paediatric ART.

According to the NGOs, the key issue around the ART programme in West Bengal is introducing second-line drugs within the state for children and adults.

The politics of treatment

When Basanta* fell ill, he returned home to Kakdwip from Mumbai, where he worked as a cook in a Mumbai hotel. In order to get access to ART, he became a member of a local NGO, selling condoms. But this job did not strengthen his case. "If the doctor wrote a prescription for one month's medicine, they would buy me only 15 days' worth. For two months I would visit the office of an organisation, which promised a free CD4 count, but I got nothing. Wherever I go, they say I must pay between Rs 300-500. Since I cannot pay, I am refused."

Positive networks have many misgivings about NGOs. Says Tarit Chakravarty, President of the BNP+: "NGOs get more funds if they have a large number of Positive People on their registers. So they use ART as bait to register positive patients. We are displayed like animals in a zoo in front of government officers and international donors. But the money does not reach us."

Kishore Kumar Shaw, Secretary of KNP, received ART from an NGO, free of cost, for six years. One day, he was told he would not be given free treatment. He was given no reason for the abrupt decision. "I have not had ART since that day, I cannot afford it. It is by the grace of God that I am still feeling fine."

Positive organisations believe NGOs are inducing Positive People to join their rolls in order to attract funding. NGOs however claim they are only responding to a humanitarian crisis. But, they are doing this without any guidelines on who should be given the treatment and how. "There is no policy on ART treatment by NGOs," says one NGO worker. "If we don't evolve a policy, we will soon face a crisis."

Bhoruka Bhalobasha says it uses organisational funds for ART and the NGO Disha raises money from members' subscriptions, local donors, and an annual lottery. Treatment for members of the Durbar Mahila Samannay Samiti, which runs a sex workers' collective in Sonagachi, comes from the Rs 25 annual fee paid by its 65,000 members. Sparsha, a Kolkata-based organisation, raises money through cultural programmes, members' contributions and individual donations, and uses physicians' samples for treatment of opportunistic infections. CINI Bandhan raises money through individual donations. World Vision India says it uses organisational funds.

However, BNP+ members allege that many NGOs are not transparent about the way they raise funds or spend them. The West Bengal State AIDS Prevention and Control Society does not intervene. Former Project Director of WBSACS, Suresh Kumar, says, "I advise the NGOs not to start treatment unless they are sure it can be sustained. But they do not listen to us." Pallab Bhattacharya, Evaluating and Monitoring Officer of WBSACS, says the government could not demand accountability from NGOs till now, as ART was not supported by the government programme.

"NGOs get more funds if they have a large number of Positive People on their registers. So they use ART as bait to register positive patients. We are displayed like animals in a zoo in front of government officers and international donors. But the money does not reach us."

**– TARIT CHAKRAVARTY,
President of BNP+**

Wrong prescriptions

Irrational prescriptions are a great concern. "When our members try to talk to doctors on treatment issues, they refuse to talk. 'Are you doctors?' they ask," says Tarit of BNP+.

Medical professionals also share Tarit's concern. "Doctors are pushing drugs in an ad hoc manner without assessing the person's ability to sustain treatment. The only training they get on ART is as part of two- or three-day 'continuing medical education' programmes organised by bodies like the Indian Medical Association. How much can they pick up from these meetings?" says Dr. Subir Dey.

"We see prescriptions with wrong combinations and incorrect dosages," says Dr. Guha at the STM, who sees patients from as far away as Jharkhand, Bihar and rural West Bengal in his clinic. "Also, doctors lacking adequate training tend to prescribe ART as soon as AIDS is diagnosed, without probing whether the complaint, such as fever, can be treated conventionally."

Suresh Kumar admits that these problems persist. "Some doctors give single drugs, some give two-drug regimens," S. S. Hossain, representative of a drug company, says. "In the districts of Bengal, doctors prescribe just two drugs, because it is cheaper for patients."

Care and support

"Not everyone can adhere to the strict ART regimen life long," says Tarit Chakravarty of BNP+. "People must know that good food, adequate rest and precaution against infections can keep people well for a long time."

"The focus should be on care and support, rather than treatment, says Pawan Dhal of Solidarity and Action Against The HIV Infection in India (SAATHII), an NGO promoting multi-sectoral dialogue among Positive People, care providers and policy makers. "The government has declared it wants to give treatment to 100,000 AIDS patients, but which 100,000? And for how long? We need alternate, more sustainable ways of treatment." Dhal suggests that NGOs in West Bengal should provide home-based care as they do in Tamil Nadu and Manipur.

RIGHT

A patient getting tested for TB at a mobile clinic on a boat in a remote area in the Sunderbans, West Bengal. NGOs agree that the most marginalised in far-flung areas cannot get treatment and drop out more frequently as NGOs find it difficult to access these areas.

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Access to treatment: Kolkata and the districts

According to the NACO programme, medicines for opportunistic infections should be available at all hospitals. "TB treatment is available freely, but medicines for fungal diseases like oral candidiasis or streptococcal meningitis are not easily available," says Dr. Dey. "Around 25 per cent of my patients are suffering from inadequate treatment."

Drugs are even scarcer as one moves out of the state capital. "We don't have anti-fungal drugs," says Bidyut Bikash Gharami, Block Medical Officer, Domjur. People who might be HIV positive are referred to the School of Tropical Medicine in Kolkata, a practice that seems to be followed by other rural hospitals as well. The Block Task Force on health is considering opening a separate out-patient department for HIV.

Sunil of KNP in Domjur says, "We told staff at the district hospital at Bongaon to treat people for ordinary problems instead of referring them, but hospital authorities keep saying they have no infrastructure. They won't even start an out-patient department for HIV." Sunil believes that many more people would volunteer for testing if rural hospitals offered testing and treatment.

Dr. Rudranath Bhattacharya of the North Bengal Medical College admits that anti-fungal drugs are not available there. WBSACS recently promised that the microbiology department would get a CD4 machine. Right now, many patients go to Kolkata just for their CD4 count, spending Rs 3,000 for travel for the patient and a companion.

As part of the run-up to the treatment programme, 23 voluntary counselling and testing centres have been set up all over the state (17 in the districts) with another seven planned in the near future. While people in districts have greater access to testing today, there have been complaints that the centres are crowded and understaffed.

Discrimination in health services

Private hospitals test patients for HIV before a surgery, without counselling them or obtaining their consent. People found positive are informed of their status without prior counselling and summarily asked to leave. "I have received patients, even emergency patients, who have been refused by practically every private hospital in the city," says Dr. Guha at STM. Palash Ghosh of Bhoruka Bhalobasa says that private hospitals often send emergency positive patients to STM, though the hospital does not have emergency services.

When Kishore Kumar Shaw's wife was admitted for a medical termination of pregnancy at the Medical College three years earlier, the doctor treated her well but the nurse and group D staff put her in a trolley outside the room and refused to come near her. "It is not enough to train doctors in the districts," says Dr. Guha. Entire teams of health-care workers in hospitals, from nurses to sweepers, have to be trained."

"The man at the STM ticket counter asked me, 'Why have you brought this nasty disease from Nepal?'" says Niran Sharma of Sanghabadha. Such comments discourage people from approaching hospitals. "The person handing over the report asked me, 'Why you do these dirty things?'" says Pawan Dhal of SAATHII.

According to the NACO programme, medicines for opportunistic infections should be available at all hospitals. "TB treatment is available freely, but medicines for fungal diseases like oral candidiasis or streptococcal meningitis are not easily available," says Dr. Dey. "Around 25 per cent of my patients are suffering from inadequate treatment."

Access to Nevirapine

The only intervention targeting housewives is the Prevention of Parent to Child Transmission (PPTCT) programme. This is meant to reduce vertical transmission of HIV to the child, by giving a dose of the drug nevirapine to the mother during delivery and to the child after its birth. It was started in West Bengal on January 1, 2004. It is being done in six centres in Kolkata and four in the districts.

Dr. Debashis Banerjee is the Head of the Department of Obstetrics and Gynaecology at the Nilratan Sarkar Medical College in Kolkata. He says that all pregnant women visiting the gynaecology outpatient clinic are counselled in groups and persuaded to take the test. According to the counsellors, most of the women have heard about HIV and AIDS, but know nothing of how HIV is transmitted. Most agree to getting tested. Those found positive are counselled individually and given the choice of carrying the pregnancy to term or undergoing a medical termination of pregnancy. If they choose the former, they are offered nevirapine.

Mothers are advised to keep in touch with the department after the delivery, presumably to follow up on their health, but two of the four women administered the drug so far have disappeared. Very few husbands accompany their wives to the hospital, and fewer still consent to get themselves tested.

Dr. Rudranath Bhattacharya, Head of the Department of Community Medicine at the North Bengal Medical College and HIV intervention co-ordinator for North Bengal, says the year-round data collected in the PPTCT programme suggests a higher rate of infection than was previously found from the two-month sentinel surveys. These findings might be worth pursuing in more detail.

Positive People in policy making

Tarit Chakrabarty of BNP+ says Positive People are much more involved in planning and implementation than they were earlier. "We have been able to make an impact. We arranged for HIV out-patient departments in three hospitals in North 24 Paraganas. We are also involved in selecting patients for free ART from government hospitals."

However, positive organisations often find themselves isolated from WBSACS as well as donor organisations. "Donor organisations do not always understand our concerns," says Chakrabarty.

According to Chakrabarty, the biggest challenge in the present context is the non-availability of treatment literacy on ART. The programme is intended to cover more Positive People who are eligible to be enrolled on ART. However, the programme falls short in its coverage due to various reasons, one being lack of information among people on availability of free ART at government hospitals. The 'Bula Di' campaign, centred on the friendly figure of authority – Bula *di* (elder sister in Bengali), is an initiative in this direction to spread awareness through print, electronic and mass media. There are still other systemic problems, which need to be addressed, such as hospitals often facing shortage in supply of essential medicines and O.I. medicines. Long waiting lists for CD4 count testing at ART centres could also make the process of access to treatment difficult for positive persons.

"We try to involve Positive People in all programmes and activities," says Pallab Bhattacharya of WBSACS. However, he acknowledges that positive voices from all levels are not being heard. "We are trying to strengthen positive networks. Positive organisations should have a say on selection of patients for ART."

Rajshree Chakrabarty, Secretary of Manas Bangla, an organisation of men who have sex with men, points out that MSM are particularly marginalised. "NACO policies are framed

with female sex workers in mind. The sex trade among MSM is a moving trade, often using suburban trains. But funds are sanctioned according to the brothel-based sex worker model. Even the questionnaire for the sentinel survey had to be redesigned for MSM.”

Soumitra Poddar, counsellor at Sparsha, says that most Positive People, if asked, would demand free first-line and second-line ART. But this is also because most of them have very little understanding of policy issues. “We at Sparsha look at the issue in a much wider socio-economic context. The duty of the state is to ensure the productive life of Positive People to create self-employment opportunities so that they can use their skills to earn and fund their own treatment. Today, we have a large population of migrant workers returning home after testing positive. They need economic rehabilitation. This involves the health department, the State AIDS Control Society, and other ministries as well. But people in the finance or labour ministry are not ready to listen to Positive People.”

Dr. Samiran Panda, Director of Sparsha says, “Positive People are still not being adequately heard in agenda setting and programme implementation. One reason is that only the poorest feel the need to come forward and declare their positive status. The better-off prefer to keep out of the limelight.”

Conclusion

As West Bengal rolls out ART, the complexities of the HIV and AIDS epidemic, so long characterised as low prevalence here, are coming to the forefront. Positive People in the state admit that treatment cannot be considered without focus on prevention issues. They feel both must be tackled side by side and that they must have a say in implementing both. NGOs, Positive People and vulnerable groups need to build stronger partnerships to increase the efficacy of the programme. Past examples of NGOs providing ART provide key lessons to programme planners in NACO and SACS as they invite tenders from NGOs for ART roll-out. Key among them are the need for guidelines for implementation, strong monitoring and evaluation systems and follow-up of patients enrolled with the NGOs, in case funding comes to an abrupt halt.

* All names have been changed to protect identities



LEFT

'Buladi', a cheery, stuffed doll, who is the mascot of WBSACS' HIV and AIDS awareness campaign rules the billboards in Kolkata. However, the mass awareness campaign will not be effective until a number of systemic problems, like shortage of supply of medicines for opportunistic infections are addressed.

© DEVALINA MOOKERJEE

Kishore Kumar Shaw, Secretary of KNP, received ART from an NGO, free of cost, for six years. One day, he was told he would not be given free treatment. He was given no reason for the abrupt decision. "I have not had ART since that day, I cannot afford it. It is by the grace of God that I am still feeling fine."

PUNJAB, HARYANA, HIMACHAL PRADESH AND CHANDIGARH

“Truck drivers are using condoms more often than before.... but their level of concern for their partners has not improved.”

High levels of stigma and discrimination prevent many Positive People from disclosing their status even to their partners, thereby increasing the impact on women and children

SHAYDA BANO



There are a number of characteristics linking the northern states of Punjab, Haryana, Himachal Pradesh and the union territory of Chandigarh. Though they are also low prevalence states like Uttar Pradesh and Bihar, this group of four is much more prosperous. They also have better developed health care services, though largely in the private sector. According to the 2001 census, Punjab, Haryana, Himachal Pradesh and the Union Territory of Chandigarh are also among the states which have the sharpest decline in child (0-6 yr) sex ratio. Some of the important reasons for the skewed sex ratio were: the neglect of the girl child, sex-selective female abortions and female infanticide. The Post-Graduate Institute of Medical Education and Research (PGIMER) in Chandigarh serves patients from the entire region as it is the main regional referral hospital.

PUNJAB

This northern state with a population of 24.3 million in 2001 is one of the most prosperous in India. Almost 70 per cent of adults are literate. The bulk of the population is engaged in agriculture. The state has the highest per capita milk and egg production in the country. Punjab also has a high incidence of sex selective abortions, reflected in an under-six sex ratio of just 793 girls for every 1,000 boys.¹

There are 2,775 medical institutions in the state, including medical colleges, district hospitals and primary health centres. With 25,192 hospital beds in the state, there is approximately one bed for every 1,000 people.² According to the Punjab State AIDS Control Society (PSACS), voluntary counselling and testing centres are functional in all the district hospitals and four medical colleges.

Interviews were conducted with at least 50 Positive People in hospitals, through NGOs, truckers' unions and private doctors, and at roadside dhabas. Ten of them were on ART.

1 Census of India 2001. www.censusindia.net

2 Statistical abstract of Punjab, 2004. <http://www.punjab.gov.in/General/Abstract/default.asp>

Situation of HIV and AIDS

Punjab is a low-prevalence state, according to sentinel surveillance figures. However, because of the presence of a huge migrant population, the state has now been termed a highly vulnerable, low prevalence state.³

The Punjab State AIDS Control Society has been ineffective, probably because of frequent staff transfers. Many people are unaware of the existence of an AIDS society. "I have not heard of the State AIDS Control Society," says Gurmukh Singh, *Sarpanch* of village Manuke in Ludhiana district and winner of the Godfrey Philips Red and White Bravery Award for his fight against stigma and discrimination against Positive People. Singh holds regular awareness camps with the moral (but not financial) support of the local health departments. "I don't know what the society does. Twelve people have died in my village from AIDS but we have seen neither SACS officials nor NGOs here."

ART in Punjab

Currently, there are two ART centres in Punjab, one in Amritsar and one in Jalandhar. CD4 tests are available only in the Government Medical College, Amritsar. "Few of the 100 Positive People I treat are on ART," says a doctor from the Amritsar Medical College. "Generally patients don't know about it. We talk to them about the drugs and suggest treatment when their CD4 count reaches 200."

Positive People on ART in NACO centres in Punjab – 31 December 2006

NAME OF THE CENTRE	NO. OF PATIENTS ON ART			Total
	Male	Female	Children	
Government Medical College, Amritsar	129	54	12	195
Civil Hospital Jalandhar	65	53	5	123
TOTAL ART CENTRES (2)	194	107	17	318

Private doctors in Amritsar, Jalandhar and Ludhiana see the maximum patients with HIV, several more than those in Patiala and other cities in Punjab, according to Vinod Goel, representative of the pharmaceutical company, Cipla. Goel supplies ARV drugs in Punjab and Chandigarh. He estimates that each doctor has an average of three patients. "There are many patients in Bathinda, Faridkot and Ferozpur, but because of stigma and discrimination, they prefer going far from their homes to buy the drugs."

In the absence of any regulatory mechanisms for private practitioners, unscrupulous practices abound. Absence of treatment literacy material makes it easier for private practitioners to exploit ignorant patients. A large number of patients are being treated by quacks and registered medical practitioners who have no training in HIV and AIDS treatment. Ironically, some of the people on treatment are not even positive.

3 *Strategy and Implementation Plan, National AIDS Control Programme: Phase III (2006-2011)*, National AIDS Control Organisation, Ministry of Health and Family Welfare, Government of India, November 30, 2006.

“I agree that people like me need to come together to raise our voices. But to form a group I will have to give up earning a livelihood and face the world. What will society say? What will my own family say? I’m dying anyway; I don’t want to bring shame to my family.”

– RAM SINGH*, a truck driver from Moga district, Punjab

“About 50% of the 500 plus people on my records are on ART. Out of these, 500 plus patients registered over the last five years, at least 10% are unaware from where they got the virus,” says Dr. Rakesh Bharti, a retired deputy medical commissioner from the Punjab Health department, now a private practitioner. He agrees that many patients in the state are being administered ART without confirming their HIV status. Those who belong to the vulnerable groups are the ones who get exploited.

If a person from a vulnerable group has any symptoms vaguely resembling those in opportunistic infections which are related to AIDS, they are put on ART. Prolonged and unwarranted drug use puts their health at risk. These irrational practices extend even to qualified medical practitioners with postgraduate degrees. Dr. Bharti says, “I have seen even postgraduate doctors prescribing ARV drugs in tapering dosages (like steroids) without bothering about the long term effects in terms of affordability and thus continuity of ART.”

Follow up and monitoring to ensure treatment adherence is also difficult in the private sector. “Patients come from all classes – from the corporate sector, from rural areas, from business houses and from slums. More than 50 per cent stop treatment eventually. Sometimes, they start with the cheapest combination that costs nearly Rs 1,100⁴ per month, but stop treatment when they need costlier combinations. For people with TB co-infection, I prescribe a drug combination costing Rs 2,400 monthly. Very few can afford the best combination which costs about Rs 6,000 monthly,” says Dr. Bharti.

People from rural Punjab – where the majority of Positive People live – have to come to the city for drugs and treatment. The drugs alone cost some Rs 2,000 per month. Travel and boarding costs are beyond the means of most people.

Positive voices are silent

The groups of Positive People in the state should highlight a number of these issues. But, unlike other states, Punjab does not have a strong NGO presence. Stigma and discrimination are widespread. All this hinders the formation of support groups. This, in turn, limits the involvement of Positive People in not only planning and decision making, but also referrals and follow-up of patients.

Positive People’s groups are being formed, but it is a very recent development. The name of one positive person does appear in the governing body of the Punjab State AIDS Control Society, but there is no meaningful involvement of Positive People in decision-making.

“We need more committed people at the planning and policy level,” says a doctor from the Government Medical College, Amritsar. “Positive People will not come forward fearing the stigma. And, people at the planning and policy level are not taking steps to involve them.”

“Truck drivers live away from their homes for long durations,” says G.D. Arora who implements a targeted intervention project with truck drivers. “When they are not travelling, they spend time waiting for their turn in truck unions. It is not possible for them to be in touch with organisations.”

“I agree that people like me need to come together to raise our voices,” says Ram Singh*, a truck driver from Moga district. “But to form a group I will have to give up earning a livelihood and face the world. What will society say? What will my own family say? I’m dying anyway; I don’t want to bring shame to my family.”

Many like Ram Singh are afraid of disclosing their status, not only to the wider community but also to their wives and immediate family. For example, 32-year-old

⁴ USD 25
(1 USD= Indian Rs 44)

Maninder Singh* is a resident of Garh Shankar *tehsil* in Hoshiarpur district. Maninder discovered that he is positive a year ago. He says his wife is not infected as he takes precautions. But, despite the doctor's advice, he refuses to inform his wife and take her for an HIV test. He hasn't told anyone else about his status either.

"Truck drivers are using condoms more often than before," says Ramnik Sharma who runs an intervention programme with truck drivers in Rajpura *tehsil* of Patiala district. "But their level of concern for their partner has not improved." Mr. Sharma wonders whether people change their behaviour after knowing of their vulnerability to HIV.

Increasing impact on women and children

Perhaps a more visible problem is the increasing number of positive women and children. Stigma and discrimination against women is more. At the same time, awareness of HIV among women is very low. The prevention from parent to child transmission programme is currently being implemented at all medical colleges and district hospitals in the state. Yet, interviews with some of the beneficiaries of the programme reveal that they do not know what the programme is about. For example 25-year-old Ranjana* from Navan Shaher district discovered her positive status when she went to the hospital for tests during her pregnancy. She and her child have received doses of nevirapine but she does not know whether the child has been protected as a result. "I only know that a medicine was given to me to try and prevent the disease from passing on to the child," she says. "I am not sure whether it will happen or not. I don't know what ART is. I am fine now. I am following the doctor's instructions not to breast-feed the child."

Till a person is put on ART, a positive person has to pay Rs 250 each time he undergoes a test. Once on ART, tests and treatment become free. Majority of the women affected by and living with AIDS are struggling to make ends meet. In this scenario, it becomes difficult for them to pay for the tests. "An NGO helped me to get a free HIV test. But, to get further tests done, I will have to pay for the travel. I also have to deposit Rs 250 each for me and my two children to get registered for treatment. For me, the choice is between feeding my children for a month or two or getting the tests done. With no source of income, I give the tests a go-by", says Sukhwider*.⁵



LEFT
Building for life. An HIV and AIDS awareness workshop with young school-going girls. It will be difficult to reduce the impact on women, unless the position of girls in the northern states is improved, and young girls and women have a greater influence over the messages and programmes that are designed to protect them.

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THE TRIBUNE

5 Garewal N., AIDS and Punjab - III, Tribune News Service, November 22, 2006

HARYANA

Haryana has a population of 21.08 million.⁶ Many people migrate to work in industries near Delhi or to join the transport business in neighbouring states. The state has the highest per capita income in the country. The literacy rate is 67.59%.⁷ There are a total of 3,079 hospitals, dispensaries and health centres in the state. With a total of 11,082 hospital beds, the bed to population ratio is 52 beds for every 10,000 people.⁸

The state is classified as a low prevalence, vulnerable state. Antenatal prevalence has stayed below 0.5% since 1998; prevalence in STD clinics was 5.30% in 1999 but has remained below 1.2% since 2001.⁹

ART roll-out

The government ART programme began functioning from the Post Graduate Institute of Medical Sciences (PGIMS), Rohtak since July 2006. As on December 31, 2006, 178 HIV positive persons were enrolled with the government ART roll-out programme comprising of 117 men, 58 women and 3 children. Dr. Umesh Lamba, Additional Director, Haryana State AIDS Control Society says, "A team of ten doctors has been trained from JJ Hospital, Mumbai. NACO is providing drugs for 400 people to start up operations and has assured us that if the enrolment in this centre crosses 1000, we will have another ART centre. PGIMS has a CD4 count machine also. Currently we have a community care centre in Yamuna Nagar, run by the state branch of the Red Cross Society. But soon, we will have another community care centre for those terminally ill with AIDS and are planning for two drop-in centres also."

Currently, at least 100 people are on ART in the state from their own resources. Medicines for opportunistic infections are available in all district hospitals and at the post-graduate institute, Rohtak. HIV testing and voluntary counselling facilities are available in all district hospitals.

Positive voices

However, the needs of Positive People go beyond free ART. "Just initiating ART treatment is not enough," says Lakshman Singh, President of the Network of HIV Positive People (Haryana). Drugs must be available – that's the most important thing. And, after that, people who lack economic and social support should be provided for. A programme should be developed for affected children and other family members."

Indeed, Lakshman Singh is despondent after starting the network. "Hundreds of thousands of rupees are spent on seminars and workshops in the name of welfare of Positive People. It will be better if this money is actually used for people's welfare. I started the network to make our issues heard; Positive People like me should have our own platform."

Impact on women and children

Like neighbouring Punjab, stigma and discrimination is high, especially against women. According to Dr. S.B. Siwach, Head of the Department of Medicine and nodal officer for ART, most women at the treatment centre come after their husbands have died and they suspect that their symptoms are similar to those experienced by their husbands.

6 Census of India, 2001.
www.censusindia.net

7 Census of India, 2001.
www.censusindia.net

8 *Statistical Abstract*,
Economic & Statistical
Organisation, Planning
Department, Government of
Haryana, 2003-2004.

9 *HIV and AIDS
Epidemiological
Surveillance & Estimation
Report for the Year 2005*,
National AIDS Control
Organisation, Ministry of
Health & Family Welfare,
Government of India, April
2006.

Rani* is a patient at the Civil Hospital, Panchkula. Her husband was being treated for TB when he was tested for HIV. After he came to know the results “he went out and never come back.” Now, Rani is positive. “I went to the doctor complaining of a skin rash. I got tested and have been told I am HIV positive.” She lives with her two-year-old daughter and her elderly father-in-law. “The villagers may not know about my positive status... but since they learnt that my husband had AIDS, they started avoiding us. These days, we are not invited to social functions in the village. I know the virus cannot spread by touching or by sharing toilets, but the villagers don’t understand.” No NGO has ever visited Rani’s village.

“I came to know I am positive, two years ago,” says Vishakha, a sex worker from Ambala. “Since then, whenever I am excessively sick, I discontinue my work. Otherwise, I carry on. I live with my mother in a one-room tenement. The household runs on my earnings. I can’t even think about participating in policy or planning. On the one hand, we fear the police and on the other, this disease. It’s trouble either way. The government has never done anything in the past for people like us, what will it do now? We are considered the source of all disease. But I contracted this disease from a man, didn’t I?”

CHANDIGARH

This union territory is also the capital of both Haryana and Punjab. The population of 900,000 includes a large number of migrant workers, truck drivers and sex workers. Its relatively high literacy rate (82%) is countered by its sex ratio of 845 women for every 1,000 men.¹⁰ The Post Graduate Institute of Medical Education and Research (PGIMER) located here is the treatment referral centre for Punjab, Haryana, Himachal Pradesh and Jammu and Kashmir. Patients from all over north-west India visit this specialised hospital.

Chandigarh has been classified as a low prevalence, vulnerable state. HIV prevalence in antenatal sites in the state has remained below 1%. Prevalence in STD clinics has fluctuated between 0.8% and 3.78%.¹¹

The government ART programme

Free ART roll-out was started on January 14, 2005. As on December 31, 2006, a total of 961 patients were enrolled with the government ART roll-out programme comprising of 539 men, 318 women and 104 children. “The maximum number is from Punjab, some are from Haryana and Himachal Pradesh, very few are from Chandigarh” says Dr. Ajay Wanchu, Associate Professor, Department of Internal Medicine, PGIEMR, Chandigarh.

Even after three centres have been added – two in Punjab (Jalandhar and Amritsar) and one in Haryana (Rohtak, PGI) – PGIMER’s load continues to mount for obvious reasons. It has better trained staff to handle and administer ART and it inspires faith among adults as well as children on treatment. Considering PGI’s treatment load, it is no surprise that doctors have been calling for more and more effective ART centres.

Positive People join the ART programme at the PGIMER’s ‘immunodeficiency clinic’. To register, they must give a photograph of themselves, their complete address and contact number, if any. They are then given a registration card which should be brought along when they come for medicines. “There are no economic inclusion or exclusion criteria,” says Dr. Wanchu. “But, if we find somebody can get reimbursed from their workplace we ask them to buy the drugs from the market.” Quality of counselling seems to be high; people have clear information about ART and how their lives can be improved. They are also referred to other clinics for specific

Quality of counselling at PGIMER seems to be high: people have clear information about ART and how their lives can be improved. When both husband and wife are being treated, they are called on the same day for follow-up or monitoring. Such small gestures raise patients’ confidence levels and also help better management.

10 Census of India, 2001. www.censusindia.net

11 *HIV and AIDS Epidemiological Surveillance & Estimation Report for the Year 2005*, National AIDS Control Organisation, Ministry of Health & Family Welfare, Government of India, April 2006.

Positive People on ART in NACO centres in Chandigarh – 31 December 2006

NAME OF CENTRE	NO. OF PATIENTS ON ART			
	Male	Female	Children	Total
Post-Graduate Institute of Medical Education and Research (PGIMER)	539	318	104	961

problems; people with alcohol or drug problems are directed to the nearest de-addiction centre. All tests are done on the same floor. When both husband and wife are being treated, they are called on the same day for follow-up or monitoring. Such small gestures raise patients' confidence levels and also help better management.

Dr. N.K. Kulshreshta, Head of the ART centre at PGIMER says that there is a 95 per cent adherence rate among the people who are receiving ART from PGIMER.

Interestingly, it is believed that people preferred government hospitals even before free ART became available here. "Only those in a position to spend money and wanting to conceal their identity would go to private clinics," says Dr. Neeraj Nagpal, a private practitioner. Dr. Nagpal believes that Positive People are best monitored in PGIMER. Many patients come with multiple problems and private clinics do not have the necessary infrastructure to provide appropriate care.

"Providing free ART will definitely lead to lower morbidity and longer lives for Positive People," says Dr. Wanchu. But, there are concerns. "The treatment roll-out must ensure uninterrupted medicine supply." At present, there are no complaints of shortages. "Secondly, one must consider how far the patient must travel to collect the medicines. Some people travel 250 kilometres to reach the hospital." There is also no mechanism to deal with patients' day-to-day problems.

Second-line treatment is another concern. "When we start ART, some patients will develop resistance and their only option is to start second-line treatment. But, we don't have anything planned for this category of people," says Dr. Wanchu. "I don't know what will happen then." Second-line treatment costs at least Rs 6,000 per month and is currently not available in the government programme.

Positive networks

Not only is the impact of AIDS more on women, but it is also more difficult for women to voice their concerns. Positive People say that when the Chandigarh Network of Positive People (CNP+) was formed, no one was ready to disclose their status to become the president of the group. When a woman, Meena, agreed to be the president, her son and mother-in-law threatened that they would disown her if she joined the network.

Increasing number of children on treatment

A noticeable trend is the increased registration of positive children. The PGIMER and the Red Cross community care centres are seeing an increasing number of women and children with HIV. Krishna has come to the Red Cross Centre with one of her sons who is on ART from PGIMER. She believed her husband when he told her he only had TB and found out the truth only after he died. Today, she lives with her brother and is finding it difficult to look after herself and her two children.

"We see a new positive child every second week," says Dr. Surjit Singh of the Department of Paediatrics. "We have 105 children on ART. Till now we are giving them half the adult formulation, though they need the paediatric formulation. Some will lose their parents to AIDS but the social structure here is so strong that they will be looked after by the extended family. I came across two children who are being looked after by their father's friend."

Interactions with people standing in the queue reveal that they have come from far-flung areas like Karnal, Gurgaon, Fatehabad, Hamirpur and Sangrur (towns in neighbouring Himachal Pradesh, Haryana and Punjab), not for their treatment, but for the treatment of their children. Some of these children have been on treatment at the PGI for as many as seven years and are in good health.

The first HIV positive child in the region was detected at the PGIMER in 1991. At present there are at least 250 registered children, some positive themselves and others who have positive parents.

The Prevention from Parent to Child Transmission (PPTCT) programme is implemented at PGIMER as well as the other two main hospitals in Chandigarh. From its inception in 2004, till March 2006, a total of 395 pregnant women were registered, 187 were counselled and tested for HIV, 63 were found positive and 34 women received nevirapine at the time of delivery. The remaining 36 did not come back for delivery. All three hospitals provide voluntary counselling and testing services.

The first HIV positive child in the region was detected at the PGIMER in 1991. At present there are at least 250 registered children, some positive themselves and others who have positive parents.



LEFT

Young AIDS orphans in Chandigarh cut a birthday cake. The impact of HIV and AIDS on children is visible in the northern states.

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THE TRIBUNE

HIMACHAL PRADESH

This hilly state in north-west India has a population of a little over six million with a literacy rate of 76% and an under-six sex ratio of 897 girls for every 1,000 boys.¹² Renowned for its fruit production, the state sees a heavy influx of seasonal migrant labour. The state's per capita income is Rs 22,576. A total of 10,811 hospital beds are available for the population.

Himachal Pradesh is categorised as a low prevalence, yet vulnerable state. HIV prevalence among STD clinic attendees has stayed below two per cent; it was 0.4% in 2005. Prevalence among antenatal clinic attendees has remained at below 1%; it was 0.13% in 2005.¹³

As the state has a low prevalence of HIV, free provision of ART started only in February 2006 at the Indira Gandhi Medical College, Shimla. Dr. Sulaxna, Project Director of the Himachal Pradesh State AIDS Control Society (HPSACS) says, "As on December 31, 2006, we have a total of 101 people on ART." Dr. Vijay Sharma, Head of the ART clinic, provides a further breakdown, "We have registered 50 males, 43 females and 8 children for ART. Usually we give medicines for a month. As of now, all the patients are regular with the medicines. Adherence will be a problem in December and January as some of the people have to come from the upper hills and it is not easy for them to come and collect medicines every month during winter. The distance is not the only problem, the landslides and extreme weather conditions are bound to affect adherence." Indeed, planners must take the state's geographical peculiarities into account when preparing the programme. Four out of the total 12 districts, Lahoul-Spiti, Kinnaur, Pangi and Dhauladhar are covered with snow from October till April. The area is officially closed for all from October 15 till May 15 every year. This presents a problem in accessing services.

A community care centre is run by an NGO, Harigiri Ashram, with the help of the Himachal Pradesh State AIDS Control Society and NACO. It provides palliative care. It has also taken responsibility for providing care to Positive People. As of June 2006, 70 patients have been discharged from the hospital. There is also a positive network in the state, formed as a result of efforts by M.D. Sharma who runs an NGO in Paonta Sahib. Currently, the network has 19 members.

Since Himachal Pradesh is a low prevalence state, the programme's emphasis is on generating awareness. But despite high levels of awareness, various factors prevent people from changing their behaviour. For example, a number of truck drivers who have tested positive, have not changed their practices accordingly.

"Gender stereotypes and extreme poverty are the two main barriers to behaviour change," says J. S. Tomar, who runs an intervention programme on the highway. "The situation with sex workers who live along the national highway is worse. Women living close to the barracks of truck unions are in a miserable condition."

Parwanoo is the first industrial town in Himachal Pradesh as one enters the state from Haryana. Sushma, a sex worker, lives here. She is HIV positive. "I know what can happen. I always keep a condom handy and advise others to do the same. Now, who listens to me is anybody's guess."

12 Census of India, 2001.
www.censusindia.net

13 *HIV and AIDS Epidemiological Surveillance & Estimation Report for the Year 2005*, National AIDS Control Organisation, Ministry of Health & Family Welfare, Government of India, April 2006.

Regional round-up

Stigma and discrimination are still very high in these northern states, especially for women. In a strong patriarchal society with low respect for the girl child, more effort is needed to bring about an enabling environment to help Positive People, especially women, to come together and raise their issues. At the government level, efforts should be made to meet some of the needs voiced by Positive People. Only then will prevention, care and treatment programmes be successful.

A two-day State consultation on ARV Treatment Access, organised by the Indian Network of Positive People and the Chandigarh Network of Positive People in October, 2006 in Chandigarh recognized the growing impact of HIV and AIDS on the women and children in the northern states. At least 30 Positive People and their family members participated in the consultation from Punjab, Haryana and Chandigarh. Officers of the Border Security Forces also took part in the consultation.

The key recommendations of the consultation include:

- practical suggestions like providing adequate facilities such as drinking water, proper seating arrangements, sanitary facilities and shelters/waiting rooms at the ART centres
- formation of support groups for women living with HIV and AIDS;
- ensuring access to accurate information on treatment, care and support to various groups (family members, care providers and communities);
- reducing the impact on women by ensuring access of women living with and affected by AIDS to the existing government schemes and programmes for women (Rural Employment Guarantee Scheme, widow pension, schemes for homeless women, economic empowerment for SC/ST through the girl child marriage scheme, vocational training for girl children and various other support schemes).

The consultation also called for greater involvement of children living with HIV AND AIDS (GICA) and support for children affected by HIV and AIDS (CAHA) by:

- revising the existing guidelines for counselling to address needs of positive children;
- prioritising reduction of stigma and discrimination of affected children through the school AIDS education programme and adolescence education programme;
- including measurement of stigma and discrimination among school children and young people in the national behaviour sentinel surveillance conducted periodically by NACO.

* All names have been changed to protect identities

TAMIL NADU

“Tamil Nadu has aggressively promoted community participation”

First off the mark ... and chugging along, a strong state response and greater involvement of affected communities help in improving access and quality of treatment.

LAKSHMI NAIR



■ *“Every day we start 2-3 patients on ART. Screening takes a week. Patients get admitted for 16 days, during which time initial complications can be picked up and addressed. Patients have to travel long distances, but we have tried to work around the system by giving them railway concessions provided for TB patients. We are addressing this issue on a war footing. We counsel couples and monitor to see if the untreated partner’s CD4 count is falling.”*

– Dr. Rajasekharan, Superintendent, Government Hospital of Thoracic medicine, Tambaram, Chennai.

■ *“We have been involved a great deal in counselling. We tell people that ART takes a lot of commitment. We tell them what will happen if the drugs are not complemented with proper nutrition and hygiene is not observed. We hold monthly support group meetings for people on ART. Counsellors and health-care workers conduct regular house visits to ensure adherence. You will find agricultural workers carrying boiled water to the fields. This is a great achievement in raising awareness levels in this small village.”*

– Seetha, peer educator and member of a Positive support group

■ *“Studies show that nearly 3,000 children in Tamil Nadu are eligible for ART. We started providing ART to children before the government programme; as on April 15 2007, 1,124 children are on ART in the state. However, adherence counselling for children will be a major challenge, even as we scale up further...”*

– Dr. P. Manorama, Community Health Education Society

These examples illustrate the situation of ART in Tamil Nadu.

Tamil Nadu is the southern-most state in India. It has a population of 62 million. In a study of the four South Indian states (Kerala, Karnataka, Andhra Pradesh and Tamil Nadu) between 1990 and 2001, Tamil Nadu is second in literacy (73.5%), infant mortality rate (49 per 1,000) and life expectancy (men 65.2 years and women 67.6). With a human development index of 0.531, the state ranks second in the south and third in India. However, it also has the largest percentage of population below the poverty line – more than Karnataka, Andhra Pradesh and Kerala.¹

Interviews were conducted in three districts in Tamil Nadu – Chennai, Madurai and Namakkal. Chennai (population 4.34 million; 73% literacy) is the state capital which forms the fulcrum of HIV and AIDS management for the state and has had an ART programme since April 2004 at the Government Hospital of Thoracic Medicine in Tambaram. Madurai (population 2.57 million; 70% literacy) has become the nodal point for southern Tamil Nadu districts. The ART programme for the southern districts of Tamil Nadu was flagged off at the Rajaji Medical College hospital in Madurai, on December 1, 2004. Namakkal (population 1.49 million, 67.6% per cent

1 Report of a study by the Centre for Policy Alternatives summarised in: TN ahead of southern states in development. *New Indian Express*, November 11, 2004. <http://www.tn.gov.in/pressclippings/newindpress/newindpress12112004.htm>

literacy) is believed to have an extraordinarily high HIV prevalence, with an unofficial estimate (by government officials) of nearly 33% among adults. The ART programme however, was started in Namakkal only in June 2005.

HIV and AIDS in Tamil Nadu

The first AIDS case in India was reported in Tamil Nadu in 1986. The state is one of the six high prevalence states in the country. In 2000, the government announced that the epidemic in the state had started slowing down.

HIV prevalence continues to decline among the general population (1.13% in 2001 to 0.5% in 2005), STD clinic attendees (12.6% in 2001 to 9.2% in 2005), injecting drug users (24.56% in 2001 to 18.0% in 2005) and men who have sex with men (2.40% in 2001 to 2% in 2005). Prevalence among female commercial sex workers, included for the first time in the survey in 2003, stood at 5.49% in 2005 as against 8.80% in 2003.²

Response to HIV and AIDS in Tamil Nadu

Tamil Nadu's success is attributed to the autonomous society model, to the appointment of a special advisor to increase NGO involvement and to the participation of affected groups in policy making. The State AIDS Cell was set up in 1993 under the Department of Health with funding from the World Bank and NACO. This was the first state government nodal agency on HIV and AIDS. In 1994, the state AIDS cell became the Tamil Nadu State AIDS Control Society (TNSACS). TNSACS is an autonomous society based on the model successfully used by the national blindness control programme. It is run by a career civil service officer rather than a medical professional. Its financial decisions are independent of the state's health department. It also has three representatives from NGOs.

The society model and the appointment of an NGO advisor proved so successful that NACO made these preconditions mandatory for states to receive funding under the second phase of the National AIDS Control Programme. TNSACS intensified efforts in 1996 with the introduction of care and support projects alongside its existing prevention programmes. It also developed partnerships with agencies like USAID through the AIDS Prevention and Control Project and the Bill and Melinda Gates Foundation through the Tamil Nadu AIDS Initiative (TAI) project.

From 1997, one seat on the TNSACS board was reserved for a representative from a Positive People's organisation. Currently, the positive member on the board is Ms. Koushalya of the Positive Women's Group.

The government ART scenario

ART roll-out started in Tamil Nadu at the Tambaram hospital in Chennai on 1 April, 2004 and the Madurai Rajaji Medical College from December 2004. The programme at Namakkal began in June 2005. Though this is one of the highest prevalence districts in the country, the ART programme was started here only after months of protests and advocacy by the groups of Positive People. The government started the ART programme in Namakkal District Headquarter Hospital in June 2005. This is the first district hospital in the country to provide ART.

Why did this high-prevalence district have to wait so long? Positive People and health workers believe that the delay was because no one wanted to acknowledge the gravity of the problem in the district.

Tamil Nadu's success is attributed to the autonomous society model, to the appointment of a special advisor to increase NGO involvement and to the participation of affected groups in policy making.

² HIV and AIDS Epidemiological Surveillance & Estimation Report for the Year 2005, National AIDS Control Organisation, Ministry of Health & Family Welfare, Government of India, April 2006.

Positive Patients on ART in NACO centres in Tamil Nadu – 31 December 2006

NAME OF THE CENTRE	NO. OF PATIENTS ON ART			
	Male	Female	Children	Total
GHTM, Tambaram, Chennai	2108	1506	280	3894
Madras Medical College, Chennai	500	251	4	755
Government Medical College, Madurai	1099	543	92	1734
Government Hospital, Namakkal	847	669	98	1614
Kilpauk Medical College, Chennai	114	94	66	274
Medical College, Salem	418	341	37	796
Medical College, Tirunelveli	181	92	17	290
Medical College, Coimbatore	215	147	21	383
Medical College, Theni	258	194	55	507
Medical College, Thanjavur	193	116	24	333
Medical College, Vellore	281	166	52	499
Medical College, Kanyakumari	102	53	17	172
Medical College, Trichy	331	222	5	558
TOTAL ART CENTRES IN TN (13)	6647	4394	768	11,809

Today, there are 13 government-run ART centres in Tamil Nadu. A total of 11,809 patients are on treatment in these centres as of December 31, 2006. People eligible for ART are identified and referred to the centres by members of positive networks. They are evaluated for their eligibility to be enrolled on the programme based on NACO guidelines, which include a maximum CD4 count. Those who qualify undergo other tests including a complete blood count and renal function test. Those registered for ART are given one month's supply of drugs at a time.

ART in the private sector: Models of subsidised treatment

A large section of the population, specifically the upper middle classes, continue to buy drugs from the private sector. "Many people are buying drugs from the open market where the prices are coming down as the market expands," says Dr. C. N. Deivanayagam, former Superintendent, Tambaram. "Most patients can now get two drugs for Rs 500³, three drugs for Rs 1,000 and good quality drugs for Rs 1,500 a month."

"The worst hit is the middle class," says Dr. P. Manorama, Community Health Education Services (CHES), Chennai. "The rich can buy their own drugs. The poor will gravitate towards government hospitals. But the middle class is still hesitating. They are not comfortable with their status being revealed. They are not happy accessing government hospitals. They are not happy with someone questioning

³ USD 11.36
(1 USD= Indian Rs 44)

The case of Namakkal – a disaster that has already happened?

There is national concern that government estimates of HIV may be misleading; in the case of Namakkal it makes a substantial difference. The situation here is grave, according to everyone except the administration. According to official surveillance data, approximately five per cent of the general population (as measured in antenatal clinic samples) is positive. One unofficial estimate put the HIV prevalence at 33 per cent of the adult population. If this is true, Namakkal is a disaster which has already happened. There is no second generation in many households. One comes across a large number of households where orphaned children are being looked after by their aged grandparents.

A lot of money is being doled out by private and public agencies in Namakkal, which reportedly has about 40 NGOs. About a quarter of these are engaged in on-going work as against one-off projects. Some are funded by NACO; others have private donors. It is not clear what this money is spent on as the ground reality has changed little in the past several years. Clearly there is a need for closer monitoring of funds.

In Namakkal, the practice of multiple partners within the same household is very common within a particular community. Most people interviewed strongly felt that this practice should be addressed. But these issues are not addressed in training programmes, advocacy drives or data-collection exercises. Most intervention programmes continue to target truck drivers.

The apathy and ignorance of the district administration is disturbing. Three NGO representatives reported that even a former District Collector (in charge of the governance of the district) had initially mistaken HIV for Hepatitis B. If this is the case, how can one expect a strong response?

Even after the introduction of free ART at the district hospital, Namakkal's woes continue. The CD4 count machine did not work for two months in October and November 2006, seriously affecting the ART programme.

their behaviour."

Many more patients are on ART at private facilities. YRG Care, a tertiary HIV referral centre in Chennai has been pioneering research and education on the issue. As of October 2006, they had 3,900 people on ART. YRG follows a graduated cost recovery pattern. People pay between 50% and 100% of the treatment costs depending on their income. Treatment is provided free to those below the poverty line.

Drugs are also available at 40-50% discounts at the TNSACS pharmacy. "We waive sales tax, so drugs worth Rs 1,200 are given for around Rs 650," says Dr. M. Senthamizhan, Joint Director of TNSACS.

Taal, a "one stop pharmacy" has been functioning in Namakkal since mid-2006. Taal is a concept of Emcure Pharmaceuticals Limited, who supply a range of drugs (ART and opportunistic infections) to the pharmacy at subsidised rates. The pharmacy is run by Positive People. The pharmacy also has counselling services and provides access to medical advice regarding treatment. This is a strategy to bring together patients seeking treatment in private institutions and networks of Positive People to ensure drug adherence. At least 150 people have made use of Taal to date.

Synergies between care, support and treatment

The ART centres are supported by 275 integrated treatment and counselling centres (ICTCs). The ICTC is the key entry point of interventions like prevention of Parent-to-Child-Transmission (PPTCT), antiretroviral therapy (ART), tuberculosis (TB) treatment and condom promotion. The centres also give medicines for management of STIs and opportunistic infections (OIs).

According to Dr. S. Dhanapaul, Head of the Department of Microbiology and Medical Officer In charge of VCTC, K.A.P.V. Government Medical College, Tiruchirapalli, in addition to ART, the drugs for opportunistic infection (OIs) are given to patients through the general pharmacy where economic status is the criterion for issuing the drugs. An order has been issued to all government hospitals to dispense all OI drugs on a monthly basis to Positive People. As the Tamil Nadu government has an effective drug delivery system under the broad framework of the Tamil Nadu Medical Services Corporation (TNMSC) all government hospitals, including primary health centres (PHCs), are able to treat opportunistic infections with an uninterrupted supply of drugs.

Besides, the well-structured Revised National Tuberculosis Control Programme (RNTCP) is taking care of treatment of TB through the District TB centres and all microscopy centres in the PHCs (see box).

TNSACS has also appointed STD counsellors in STD clinics through the South India AIDS Action Programme (SIAAP), an NGO based in Chennai.

Government hospitals such as the Government Hospital for Thoracic Medicine, Tambaram have special care wards for HIV and AIDS patients. At any given time, the

BELOW

Diagnostic tests underway at the Tambaram ART centre. Positive People, including those from the marginalised sections like MSM, undergoing treatment seem happy with the treatment at the centre, as it is very friendly to them.

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Status of HIV-TB co-ordination in Tamil Nadu

The objectives of the HIV-TB co-ordination programme are to control HIV and TB. It is, therefore, essential to ensure early diagnosis. The overall goal is the reduction of TB related morbidity in Positive People, while preventing further spread of HIV and TB in the population.

The programme is co-ordinated by a state co-ordination committee which is chaired by the Health Secretary and involves NGOs, Positive People and other public sector representatives. District Co-ordination Committees (DCC) have been formed at each district to review district level HIV-TB co-ordination. The monthly review meeting of DCCs is attended by counsellors and laboratory technicians of Integrated Care and Treatment Centres (ICTCs) to ensure the quality of referrals of HIV and TB patients from ICTC to the microscopy centres of the Revised National Tuberculosis Programme (RNTCP) and vice versa.

All TB sanatoria in Tamil Nadu are being converted to community care centres for Positive People. These TB sanatoria are being developed to serve as ART treatment and distribution centres. ICTCs have also been set up in all the TB sanatoria and TB hospitals, drugs for sexually transmitted infections (STIs) and common opportunistic infections (OIs) are being disbursed. Home-based care for HIV and TB patients is being designed through outreach workers.

Research projects have been initiated in collaboration with the Tuberculosis Research Centre, Chennai, to assess the study outcomes among the rural as well as urban population availing the service at the tertiary health facilities and specialised centres as well as under the general health settings.

Source: TNSACS 2006. *HIV and TB - Double Trouble*

hospital has 250 in-patients. Counselling is an important part of the programme in Tambaram. New patients are hospitalised for 16 days to be monitored for complications. Once discharged, they are entrusted to a guardian, usually from their family or a positive network in the vicinity. This is partly to ensure adherence. NGOs and positive networks are involved in counselling people before they are started on ART and during treatment. Patients are also given good food including two eggs per day and ragi⁴ (millet or *Eleusine coracana*) gruel, free of charge.

TNSACS gets NGOs to depute counsellors and social workers to villages to provide counselling with regard to adherence and nutrition. Patients undergoing treatment at Tambaram seem satisfied with the treatment. "Health concerns of MSM are handled with sensitivity here," says Rex from the Social Welfare Association of Men. "The Tambaram set-up is very friendly to Positive People," says Selvi, a former commercial sex worker. "We need more such centres."

TNSACS has also supported other initiatives to link treatment with support. In collaboration with Madras Christian Council of Social Service (Chennai) and Community Health Education Society (CHES) Chennai, TNSACS has initiated a pilot project for the continuum of care for HIV and AIDS patients. The project aims at improving the quality of care for these persons.

The Community Health Education Society (CHES), funded by TNSACS, started the Hope Club in Chennai to provide moral and emotional support for HIV and AIDS patients. The club meets on the last Sunday of every month. It holds talks and short film screenings on topics such as routine medical care, nutritional advice and yoga therapy. CHES is also exploring 'home care' options for Positive People. It has found that family counselling helps Positive People to live at home, with the support of their families.

⁴ *Ragi* or poor man's millet is a coarse grain, which is superior to rice or wheat in nutritional terms. It is rich in proteins, minerals such as calcium and has high levels of fibre.

Another comprehensive programme is being implemented through the Government Kilpauk Medical College Hospital in Chennai, Government Mohan Kumaramangalam Medical College Hospital in Salem, and Government Medical College Hospital in Tirunelveli. Each hospital caters to eligible families originating from surrounding districts within two hours of travel. As per this plan, Kilpauk hospital in Chennai serves families from Chennai, Thiruvallur, Kanchipuram, Tiruvannamalai and Viluppuram districts; Salem Medical College Hospital serves families from Salem, Erode, Dharmapuri, Perambalur, and Tiruchirapalli districts; and Tirunelveli hospital serves families from Tirunelveli, Tuticorin and Kanyakumari. In addition to routine medical and HIV-related care provided at the hospitals, the patients are served by a network of 16 NGOs who deliver comprehensive care and support services that includes voluntary testing and counselling, adherence counselling, psycho-social services, nutrition services, home-based care, linkages to income generating activities, legal services and housing.

Even before the central government announced paediatric ART in 2006, TNSACS was providing ART to 1000 parents/family members of infected and affected children and care and support, including nutritional support, to 4,000 parents / family members of infected and affected children with support from the Children's Investment Fund Foundation.

Concerns in the ART programme

Cost and access: According to Dr. S. Dhanapaul, "ART is still a costly affair for many at present. The waiting lists to enrol in the programme are huge. Accessibility to ART has to be improved by starting ART in at least all district hospitals." Swami, a staff member of Indian Network of Positive People (INP+) based at Namakkal says, "While ART has been expanded to 13 hospitals, other facilities have not. In some centres like Madurai, one CD4 count machine has to take care of a load of three or four districts. The manpower available at the centre is unable to take care of the load. Reagents run out and centres stop accepting blood samples. Ultimately we miss out people who might require ART. Should NACO scale-up the number of ART centres or should they first plug the gaps related to human-resources, infrastructure, diagnostic facilities and inventory in the existing ART roll-out? This remains the crucial question."

Swami elaborates on some ways of increasing access. "There should be a clear priority to implement ART simultaneously in all the high endemic regions in the state by following WHO guidelines for resource limited settings without the need for CD4 counts. If the ART implementation is delayed at the district level and primary health care level, 30-40% of the population with AIDS may not live long, which is not justified on ethical grounds. As many doctors and paramedical personnel have already been sensitised about HIV and AIDS, ART implementation will require minimal training and logistics. Besides, we have the strong involvement of NGOs and positive groups who can provide care and support services. NGOs can also develop a good referral system of utilising the nearest HIV and AIDS centre for ART registration and creating a drug delivery point at their centre as the number of patients increase." However, Swami feels that successful implementation at the district level will only be effective if there is uninterrupted drug delivery, treatment of drug reactions and there are mechanisms for supervised therapy.

Training of doctors: TNSACS has trained a number of Physicians Responsible for AIDS Management (PRAMS). These physicians are based in Medical Colleges and District Hospitals across the state and are trained in the management of AIDS patients. The Government Hospital of Thoracic Medicine in Tambaram trains PRAMS for various other government hospitals in the state.

However, there is an urgent need to bring more doctors into the training programmes. Many doctors are unaware of the side-effects of ART, while others have known of them for years. Positive networks agree that stigma and discrimination by medical personnel has reduced. But they still feel the need for training doctors on AIDS case-management. “Doctors changed my drug regimens because the drugs weren’t available and this has affected my health,” says Kousalya, President, Positive Women’s Network (PWN), who has been on ART for the last four years. “This may later lead to drug resistance. Doctors rarely enlighten us about drug reactions or interaction with certain foods.”

“There is an urgent need to train doctors from rural areas,” says Dr. Suniti Solomon of YRG Care. “We have come across doctors who prescribe ART for 21 days with one tablet thrice a day. On-site training is very important, especially for clinicians from the districts. It must be intense – two weeks – so that trainees get to see nearly all the opportunistic infections by then.”

“The private sector is worse than the government sector; it is totally disorganised,” says Dr. Deivanayagam who earlier headed the Tambaram hospital. “They do not have an overall view of the disease, as they only see the rich and well-connected. They have seen cases abroad and try to translate that into our milieu. This will never work given the complications in our patients. The West is not aware of things like tuberculosis patterns, candida worm infestations, skin related diseases, scabies, fungal infections and so on.”

There also seems to be a communication gap among doctors and between doctors and other stakeholders. Doctors who use Siddha medicines are convinced of their efficacy, while others have doubts about local formulations. Similarly, many government doctors feel counselling is the job of social workers while social workers point out that counselling is an integral part of treatment. There is, however, light at the end of the tunnel. The AIDS Prevention and Control Project (APAC) supported by USAID is set to launch a virtual learning and training centre for doctors on HIV and AIDS related illnesses. APAC Director Dr. P. Krishnamurthy says that e-learning will supplement classroom-based training on HIV and AIDS management and will also minimise costs and reach out to a wider base of doctors and other health care providers. The key focus would be on rural medical practitioners and nurses, he adds.

Information and awareness on ART: Information dissemination on ART seems haphazard. Majority of the Positive People ‘hear’ of ART from NGOs and pass the word on. Several doctors administering the drugs are unclear about dosages and side-effects. Though the state has one of the best information, education and communication campaigns on HIV and AIDS, many feel the need for material emphasising that treatment must be taken lifelong, that ART is not a cure and nutrition too is of prime importance. Members of support groups of Positive People however seem better informed. “We are trying to disseminate information on ART as widely as possible,” says Daniel Vinod of INP+. “But there is still not much information in rural areas.” Dr. Parthasarthy of the Madurai ART programme agrees. “There is an urgent need to educate the district networks on eligibility criteria. Several people refer others in the network with opportunistic infections to the ART unit. They get referred back to the medicine OPD.” The intricacies of medical treatment are still not well known, points out B. Jayashree, Communication Officer of the Tamil Nadu AIDS Initiative.⁵

There are limitations even in the mass media coverage, says David Daisy, President of Network for Chennai Positive People (NCP+). Given the extensive coverage of farmer suicides, the press is strangely unconcerned about suicides in districts with a high prevalence of HIV and AIDS. Namakkal loses people – sometimes entire families – at regular intervals without creating a ripple. Media coverage reflects its own uninformed phobia about the disease. Press coverage consists primarily of

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⁵ Tamil Nadu AIDS Initiative (TAI) is supported by the Bill and Melinda Gates Foundation.

reports of in-laws evicting women whose status is revealed, sporadic stories of persecution or occasional capsules highlighting how the issue has been mishandled. No one conveys the nuanced messages which should be going out regularly: 'There *is* life after AIDS', 'It's *larger* than we think', 'Act now or panic later', 'It's not a *truckers* virus', 'Those who live with HIV are *not* guilty' 'You can't *hide* from it forever'. Media organisations run by marketing departments suppress anything which brings an uncomfortable social disease too close to middle-class drawing rooms. An advocacy programme arranged by a respected daily in Chennai was reportedly cancelled at the last minute after the organisers discovered that the resource person, who belonged to an MSM group, planned to talk about alternative sexualities.

BELOW

A family counselling session underway at the Tambaram hospital, Chennai. Introduction of paediatric drugs and syrups have made HIV management in children easier. However, persuading children and their caregivers to maintain drug adherence is a problem, mainly because of the number of drugs and vitamins the child has to take.

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Children and ART: Paediatric formulations have been introduced only in November 2006 in Tamil Nadu. Clinicians across the state are deeply concerned that the earlier lack of availability of paediatric formulations may have led to incorrect dosage. "We administered tablets broken into pieces, and it is possible that the dosage may have been inaccurate." says Dr. Parthasarthy.

Even before the government roll-out of ART for children, a lot of research and work has been done in this field in the state, says Dr. P. Manorama of Community Health and Education Society, Chennai. But she agrees that after November 2006, the scene has certainly become more child-friendly. With paediatric syrups and tablets, HIV management in children has become easier.

However, persuading children and their caregivers to maintain drug adherence is a problem. Caregivers require great skill. "Fifteen per cent of children develop opportunistic infections like TB, oral thrush and recurrent respiratory infections," says Dr. Manorama. "To battle this, they are given Septran, Flucanazole and anti-TB drugs along with ART. Imagine a child of three, weighing 10 kg, having to swallow all



these tablets.” “We have 12 children on ART,” says S. Swaminathan from Namakkal. “For this we first instilled the importance of drugs and adherence in the caregivers – the grandparents.” Dr. S. Vijayakumar, former Project Director, TNSACS, agrees that the problem must be addressed more vigorously and they are looking at ways to address the issue.

CHES is in the process of completing a research study to track adherence in about 70 children. Dr. Manorama feels that children in shelters have better adherence than those at home. When feedback questions were made more focussed, it threw up interesting findings. Caregivers still need to fully grasp the importance of giving the medicines at the same time, every day. There were also huge gaps when it came to re-administering the dose, in case the child vomited.

Clinicians are of the opinion that just months into the programme, adherence hovers around 90-95%. But, this is likely to fall as time elapses, if more stringent monitoring is not adopted, says Dr. Manorama.

It also goes without saying that if adherence becomes an issue, drug resistance will follow, close on its heels. As of now, there is only one project under the Tamil Nadu Family Care programme which gives second-line drugs for children. On the positive side, there is brainstorming at the policy level on introducing second-line drugs on a larger scale, as the state was one of the first off the mark in the ART race, making resistance a palpable issue.

Meeting other needs: The programme has, by and large, ignored the need for patients to continue to earn a living. People are debilitated after treatment and physically incapable of arduous work such as truck driving and agricultural labour. Those who manage to hide their status and continue working are often laid off later for shirking.

Another problem is that of the AIDS widow who is forced to return to her parents' home – usually with her children – after her husband's death. Parents are often indigent and incapable of feeding extra mouths. Sadly, only widows aged 40 and above can avail of the State Government's Widows Pension Scheme. Ironically, most AIDS widows are younger than 30 and may not live long enough to claim a pension.

Children living with HIV and AIDS and those whose lives have been affected by the disease too have special problems, which the programme ignores. Whilst an effective programme for the prevention of parent to child transmission is reducing the number of positive children being born, there are a large number of orphans needing care and support. There are hardly any care homes for them. They mostly live with grandparents who find it near impossible to feed them. For many, schooling remains a distant dream.

This may perhaps be because funding agencies are not interested in long-term commitment. NGOs and private donors are driven by immediate results. The state and central governments will have to plan for sustainability, which means raising funding for long-term treatment programmes, care homes, clinics and seed capital for self-employment schemes, apart from prevention and advocacy programmes.

Listening to the voices of the Transgenders: Transgenders with HIV are struggling to be heard. The People's Union of Civil Liberties has documented the atrocities perpetrated on HIV-negative transgenders. The fate of positive transgenders defies imagination. They are treated as medical oddities when they visit hospitals for treatment. They are loathed by everyone they meet. This problem will not disappear if we ignore it and wish it away. Unless such discrimination and ill-treatment is prevented, this group will have restricted access to treatment, care and support. They will also experience alienation disorders of the most serious kind.

Children living with HIV and AIDS have special problems, which the programme ignores. Whilst an effective programme for the prevention of parent to child transmission is reducing the number of positive children being born, there are a large number of orphans needing care and support. There are hardly any care homes for them. They mostly live with grandparents who find it near impossible to feed them. For many, schooling remains a distant dream.

Community participation – achievements and challenges

If the report so far highlights some of the limitations of the ART programme in Tamil Nadu, its strength, without doubt, is the high level of community participation and involvement at all levels.

“TNSACS has aggressively promoted the participation of all those affected,” says S. Vijayakumar, former Project Director, TNSACS. NGO representatives agree. “There is tremendous participation in treatment, care and support in Tamil Nadu,” says Dr. Subhasree Raghavan, founder of the network SAATHI (Solidarity and Action against the HIV Infection in India). “There are several examples: the presence of the Indian Network of Positive People and the Positive Women’s Network in policy making bodies, the family counselling centre in Tambaram with active community participation, the community care centre in Namakkal, the drop-in centres in most places for counselling...”

“Tamil Nadu is one state where there is good involvement of Positive People in policy making,” says Dr. Suniti Solomon, director of YRG Care, Chennai, a pioneer in HIV and AIDS care and support. “The administration involves Positive People in the technical advisory meetings and the joint appraisal committees which go through all project proposals submitted for state support and funding.” K.K. Abraham, General Secretary of the Indian Network of Positive People (INP+), concurs: “Compared to Positive People’s participation in other states, Tamil Nadu is definitely better.”

The state was the first to have a network of Positive People as well as a network of positive women. The Indian Network of Positive People (INP+) and the Positive Women’s Network (PWN) are both based in Chennai. The state network, the Tamil Nadu Network of Positive People (TNP+), was the first state unit of INP+. INP+ is the vice chair of the Country Co-ordinating Network for the Global Fund application. The presidents of both INP+ and PWN+ attend many policy and planning meetings.

Community participation in the programme is high in the metros and districts. It increases the programme’s credibility and heightens the impact of outreach programmes. Most people getting treatment in Tambaram are part of the networks. The networks hold regular support group meetings, inform people about ART, give information about food and

RIGHT

Outside an ART centre in Tamil Nadu. Excellent community participation of groups of Positive People in advocacy, awareness and monitoring adherence is contributing to the success of the ART programme in the state.

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lifestyle, refer those eligible for treatment to the ART centre, counsel those who are on ART or want to be on it, and monitor drug adherence. They also intercede on behalf of patients denied treatment in government hospitals. Excellent community participation is contributing to the success of most programmes in advocacy, awareness and monitoring adherence. Daniel Vinod, a member of INP+, says, "The network's district president must ensure that people on ART adhere to the regimen. They report an adherence of 95-98 per cent."

In Namakkal, it is active community participation that is ensuring the success of programmes. Members of positive networks report interacting with donor communities in planning, programme management and execution. "I am invited to NACO meetings," says Kousalya of PWN+, "some of my ideas are accepted. But the ratio is not at all fair. Mostly, it is just me as a representative of all Positive People." A member from INP+ adds, "Donors are unable to address our priorities. At times, they say there is not enough fund management capacity and English communication skills in our networks. We have the technical know-how and we know our needs better than anyone else. We are also forced to fight the NGOs domination. NGOs tell donors that we do not have the capacity and that they will implement programmes for us."

Community participation is much higher in Chennai than in other districts. People in Chennai get more opportunities to interact with donors, but it is not clear if they speak for all communities. "We have never met any donor or anyone who gives out money," says Selvi, a sex worker from Madurai who feels that funding agencies are creating a 'creamy layer' within the community. "Funding agencies should conduct field studies in the villages – not in Chennai and such urban areas alone. There is no point in asking five top people of large NGOs and networks for their opinions and then going away." Several articulate groups in Namakkal have been speaking out, but it has not had much impact on the situation. "The allocation of funds and the selection of NGOs is ad-hoc," says David Daisy, a positive person. "The most deserving groups never find favour." Regardless, they all agree that organisations will need to become more professional to be heard. More people need to be trained to raise their voices.

Conclusion

Three issues distinguish the ART programme in Tamil Nadu from other states:

- there are attempts in the state to look beyond drugs. The state provides railway concessions to those travelling for ART. In Tambaram, separate quarters have been constructed to accommodate family members caring for their kin.
- the state has adopted innovative methods to meet the growing demand of ART – like opening a TNSACS pharmacy where drugs are available at discounted prices or a virtual training centre for doctors.
- the networks and organisations of Positive People have been actively involved right from providing inputs in policy planning to better management and adherence to ART.

There are shortcomings as well:

- the voices of the marginalised such as the transgenders, MSMs and those from the districts need to be heard.
- HIV management seems to be Chennai-centric which is of growing concern as most Positive People are below the poverty line and the vast majority are in rural areas.

"Tamil Nadu is one state where there is good involvement of Positive People in policy making," says Dr. Suniti Solomon, director of YRG Care, Chennai, a pioneer in HIV and AIDS care and support. Members of positive networks report interacting with donor communities in planning, programme management and execution.

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Further Resources

Comprehensive overviews of HIV and AIDS Global HIV and AIDS links

www.thebody.com
[Médecins Sans Frontières\(www.msf.org\)](http://www.msf.org)
[UNAIDS\(www.unaids.org\)](http://www.unaids.org)
[WHO \(www.who.int/hiv/en\)](http://www.who.int/hiv/en)
[William J.Clinton Foundation \(www.clintonfoundation.org\)](http://www.clintonfoundation.org)
[World Bank AIDS Programme \(www.worldbank.org/aids\)](http://www.worldbank.org/aids)

India HIV and AIDS links for statistics and information

[AIDS Portal \(www.aidsportal.org\)](http://www.aidsportal.org)
[AVERT \(www.avert.org/aidsindia.htm\)](http://www.avert.org/aidsindia.htm)
[Infochange India news and features development news
\(www.infochangeindia.org\)](http://www.infochangeindia.org)
[National AIDS Control Organsiation \(www.nacoonline.org\)](http://www.nacoonline.org)
[Solidarity and Action against the HIV Infection in India - SAATHI
\(www.saathi.org/hiv_services\)](http://www.saathi.org/hiv_services)
[UNAIDS \(www.unaids.org.in\)](http://www.unaids.org.in)
[UNDP\(www.undp.org.in\)](http://www.undp.org.in)
[UNICEF \(www.unicef.org/india\)](http://www.unicef.org/india)
www.youandaids.org

India HIV and AIDS links for perspectives of civil society

[ActionAid India \(www.actionaidindia.org\)](http://www.actionaidindia.org)
[AIDS India e forum \(http://health.groups.yahoo.com/
group/AIDS-INDIA/\)](http://health.groups.yahoo.com/group/AIDS-INDIA/)
[Lawyers Collective \(www.lawyerscollective.org\)](http://www.lawyerscollective.org)

India HIV and AIDS links for perspectives of Positive People

National

[Indian Network for People Living with HIV/AIDS, Chennai
\(www.inplusplus.net/\)](http://www.inplusplus.net/)
[Positive Women Network, Chennai \(www.pwnplusplus.org/\)](http://www.pwnplusplus.org/)

Andhra Pradesh

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Access to Antiretrovirals (ARVs)

has become the subject of a major debate in India. As a result of campaigns by civil society activists and groups of Positive People, as well as commitments at national and international levels, today more people in India have access to ARVs than two years ago. Yet, a greater majority, particularly the most marginalised, have no access still.

This report, part of a global study conducted by the Panos Global

AIDS Programme, contains a collection of articles from 14 states and union territories in India. These articles are a mix of insiders' views and journalistic insights. They look at what it means to get ART from the government programme and outside the government's schemes. They identify the obstacles that need to be overcome to ensure universal access. They contain the voices of Positive People, vulnerable groups, health professionals, public health experts, government officials, industry representatives and others involved with the programme.

Each of the challenges cited in the report can only be overcome with strong leadership from the government, firm commitments from every institution providing ART, active participation by the media and engagement with vulnerable groups including Positive People at all levels of the response to the epidemic.



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