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The Mess

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- Despite Rs 1,000 crore spent on AIDS prevention yearly, the virus runs riot.
- Over 4 million Indians are HIV positive, double the figure in 1994.
- It signals a massive failure of government strategy to combat AIDS.
- Poor accountability sees fly-by-night NGOs sprout, siphon off funds.
- Blood banks do not inform donors who test HIV positive, abetting the spread of AIDS.

by Shefalee VASUDEV

HEALTHCARE WORKERS call G.B. Road, Delhi's notorious red-light district, India's AIDS factory. Teeming with commercial sex workers, the area is a giant reservoir for the deadly virus. It feeds the thick arteries that have carried the disease across the country with frightening rapidity in recent years.

Despite the Rs 1,000 crore being pumped every year into AIDS prevention—more than for any other health problem in India—G.B. Road is symbolic of how things have gone terribly wrong with the anti-AIDS campaign. Among the easiest ways to prevent the spread of virus is to have customers use condoms, and part of the government's drive has been to make the contraceptive freely available in the area.



AIDS FACTORY: At G.B. Road, Delhi's red-light district, AIDS NGOs have done precious little

Yet Rashida, a dark, attractive 32-year-old sex worker at G.B. Road, says, "We haven't got free condoms for two years. We buy them at Rs 30 a packet." Parul, 24, adds, "A government official does come to distribute Nirodh Deluxe condoms, but he charges his 'cut' of Rs 10 per packet." This when the premier central agency, National AIDS Control Organisation (NACO), is headquartered only 3 km from the area.

Though nine non-governmental organisations (NGOs) are working to prevent AIDS in the area, they have achieved precious little. Last week, days before the World AIDS Day on December 1, Oscar Fernandes, MP and convener of the Parliamentary Committee on HIV-AIDS, visited the area for the first time after taking charge nearly a year ago. When told that even doctors

specially assigned to the area refuse to treat sex workers, a shocked Fernandes admitted, "A lot needs to be done."

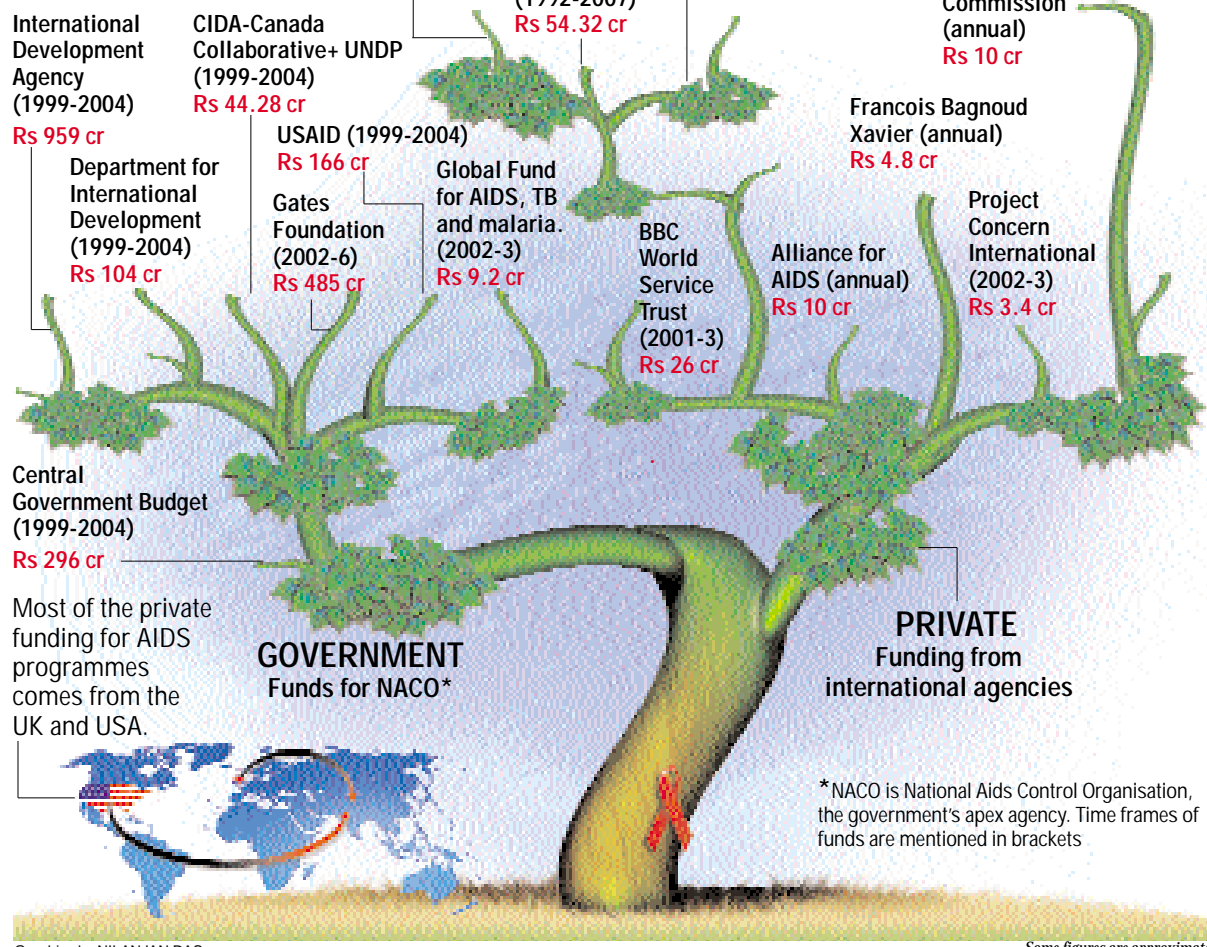
A testimony to Fernandes' statement is three-year-old Babita, born HIV positive and currently housed at the Chelsea Hospital in east Delhi. The disease was passed on to Babita by her mother Bhagwati, 19. A head injury has now left her speech-impaired. The hospital, run by a private charity organisation, could do with more facilities in patient care. "Our testimonies are sold like furniture by AIDS organisations to get funds," says Naveen Kumar, who is HIV positive. President of the Delhi Network of Positive People, a group formed two years ago to fight for the patients' rights, Kumar says, "When it comes to our care and treatment, AIDS workers disappear."

The key to combating AIDS lies in evolving an effective preventive strategy while simultaneously providing treatment and setting up rehabilitation centres. With big money pouring in—Microsoft's Bill Gates added \$100 million (Rs 480 crore) last month to the burgeoning AIDS care kitty—focused and closely monitored programmes should not be a problem. Unfortunately, however, India's nascent AIDS strategy seems to be coming apart.

The disease that afflicts an estimated four million people in the country has already spawned an industry of profiteers. Despite the enormous public and private funds (see box) flowing into the AIDS work—NACO spent Rs 228 crore or 20 per cent of the Union Health Ministry's annual budget in 2001-2—the benefits are marginal. A large com-

THE AIDS MONEY PLANT

AVERAGE FUNDS ANNUALLY
Rs 1,000 crore



Graphics by NILANJAN DAS

Some figures are approximate

*NACO is National Aids Control Organisation, the government's apex agency. Time frames of funds are mentioned in brackets

Rs 5,000 crore has been spent on AIDS control since 1992, more than on any other disease in the country.



AWARENESS

NARENDRA BISHT

PREVENTIVE SPREAD: High-risk groups being educated on condom use in Delhi

ponent of the health budget goes to the State AIDS Control Societies for speedy implementation of the programme. But according to an evaluation by international experts, only one-third of India's states are successfully enforcing the programmes. Another third fall into the marginally acceptable category while in the remaining states the project is in a shambles.

BESIDES a horde of questionable NGOs gobbling up unaccounted sums of money, preventive strategies like creating awareness about the disease are executed lackadaisically. Worse, treatment facilities are almost non-existent. Nowhere is this more evident than in Manipur, India's AIDS capital and locus of Myanmar's heroin trafficking. The Manipur AIDS Control Society has been repeatedly hauled up by the state auditors for diverting vital AIDS funds to other health programmes. "There is much talk about money for fighting AIDS. But where's the money?"

asks Mary Joy of the Society for HIV-AIDS Lifeline Operation (SHALOM) in Manipur. With drug addiction a major problem, the transmission of the virus is largely through infected needles and patients are often treated inhumanly (see box). The state Government is not the only one to blame. There are about 100-odd AIDS NGOs in the state. "Everybody from ministers and bureaucrats to small-time drug peddlers have set up NGOs," says Yambem Laba, member of the Manipur Human Rights Commission. But little genuine work is done.

The story is much the same in the rest of the country. While there are about 1,800 NGOs claiming to work for AIDS prevention, nearly 80 per cent are suspect; many are bogus and others are run by an individual or a family. The NGO culture spawned by HIV-AIDS has brought in its wake other social wars. "There are more people living off HIV than dying from it," says Pune-based Dhiren Rawat, president of Act Up India, a group of people living with AIDS. Adds Eddie Mall, executive director of

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- Though 60 per cent of the AIDS funds are allocated for prevention programmes it has made no dent.
- A NACO survey revealed that rural, high-risk women had the lowest levels of awareness.
- Educated and affluent classes believe it is still a "poor man's" disease and will not affect them.

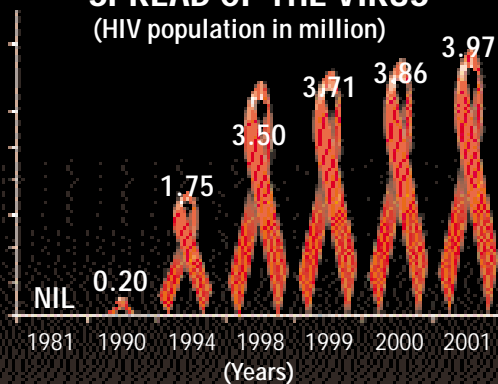
Delhi-based CANA, a group representing 500 NGOs countrywide: "Without an accountable mechanism to assess sustainability, genuine work and ownership, how can funds be allocated?"

The Union Government, which funds many such NGOs and is expected to monitor their progress, is quick to defend itself. "While there are excellent NGOs in the field, others need hand-holding. We must put in place mechanisms through these public-private partnerships," says Meenakshi Datta-Ghosh, additional secretary and project director, NACO. The fear is that by the

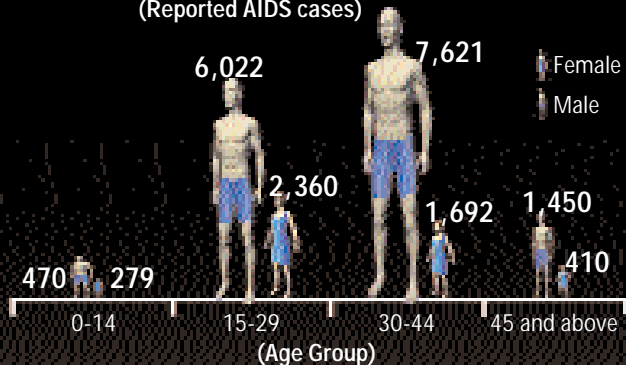
35 % of AIDS cases in India occur among youth in the 15-24 age group, but only a few projects educate them about the risks.

HIV/AIDS IN INDIA

SPREAD OF THE VIRUS (HIV population in million)



AGE/SEX DISTRIBUTION (Reported AIDS cases)



AIDS: A PRIMER

HIV: Human Immunodeficiency Virus is transmitted into the bloodstream through unsafe sex, blood transfusion or from pregnant mother to the unborn child.

INFECTION: Within three weeks to six months, the infected blood becomes sero positive. The virus can stay in the body from three to 10 years without any symptoms.

AIDS: The disease triggers a collapse in the immune system causing cancers, TB, chronic diarrhoea and high fever leading to death.

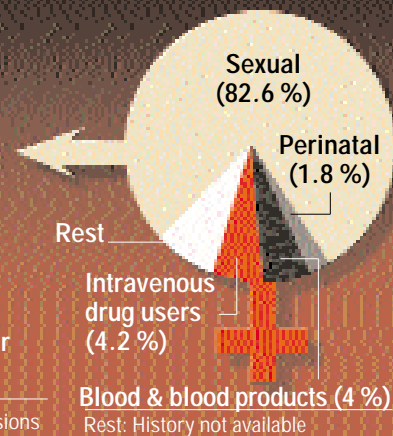
TREATMENT: No known vaccine. Drug cocktails check progress and can prolong life.

HOT ZONES



Maharashtra, Tamil Nadu, Andhra Pradesh and Manipur are the most affected states

SOURCES (1986-2001)



■ Below 5% high risk groups ■ Above 5% high risk groups ■ 1% ante-natal transmissions

Source: NACO

time NACO puts its mechanisms in place, it will be too late to undo the damage.

Take Sudhir Nautiyal, 23. Last year, the unsuspecting youth responded to a newspaper advertisement by a Delhi-based NGO, inviting fresh graduates to become "training officers for HIV-AIDS". In exchange for original degree certificates, the candidates were given appointment letters and identity cards to find donors for an upcoming AIDS

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- The situation is abysmal with most of the government hospitals yet to open separate AIDS clinics.
- The drug treatment that arrests the disease costs Rs 8,500 per patient every month which few can afford.
- Though many patients suffer from depression and suicidal tendencies, there are few counselling centres.



DIGNITY IN DEATH: Hospices do what hospitals can't

NARENDRA BISHT

hospital. "We were warned that unless we got five members each donating Rs 250-Rs 1000, we wouldn't get our salaries," says Nautiyal, who quit when he couldn't raise the money. However, the real danger from such deceptions is the spread of half-baked knowledge about HIV-AIDS. Nautiyal thinks sharing a comb can transmit HIV, a presumption he advocated as a field executive.

ACCORDING to NACO, 700 targeted intervention projects are being implemented in states, but on a site map, Delhi, Bihar and Uttar Pradesh show no projects having been initiated till the end of 2000. This despite all demographic studies showing Bihar and Uttar Pradesh with the maximum number of migrant labourers, considered a high-risk population for AIDS. While the biggest share of AIDS money is channelised into advocacy, it doesn't seem to have made a dent. Compared to men, women are at a greater risk of contracting HIV, but NACO's survey reveals that rural women have the lowest levels of awareness; even the risk of mother-to-child transmission is not recognised.

The epidemic is also gaining ground because the risk to educated classes and youth is still not accepted. Meet Bhupen Yadav, 27, an MBA. Head hung low, he talks about his heady encounters with a high-society call girl five years ago. After frequent bouts of undiagnosed fever two years ago, he tested HIV positive. "I never thought an educated guy like me could be infected. I thought it was a poor man's disease," he says.

Much like Yadav, a large section of the Indian society takes refuge in denial. "When I go to conduct HIV awareness workshops in corporate houses, managers indicate that such awareness is necessary only for the labour class, not their cadre," says Sandhya Bhalla, project director for CII's HIV business trust.

Worse, the resistance to introduction of sex education in schools is telling. Almost 35 per cent of all reported cases in India are in the 15-24 age group. Young men are at high risk because many have their first sexual experience with sex workers. Says Dr Everold Hosen, who's global communication adviser: "India's challenge is to engage people in talking about sex beyond disease and death. Especially youth, because sex is on their minds most of the time and there are no comfort zones to discuss these issues."

A rare effort in this direction is, how-

UNAIDED VICTIMS

VANKUDOT SUKUNA, Andhra Pradesh

When Vankudot Sukuna injured her wrist and developed gangrene, her furious father chopped off her hand, and to stop the bleeding, dipped it in boiling oil. Numb

with pain and shock, Sukuna, an HIV suspect, went to Osmania General Hospital, where she was turned away by doctors. Back home near Hyderabad, her family and neighbours too threw her out. It was a local AIDS activist who brought her to the notice of the state Government. Minister of State for Home Vidyasagar Rao, who brought Sukuna into media glare, hugged her in front of the cameras to drive home the point that the virus doesn't spread by casual contact. Rao has donated Rs 50,000 to enable Sukuna to buy a small shop. She will get a house under the Indira Awas Yojana and a state-funded artificial palm. But will her faith in humanity be restored?



B.K.RAMESH

—Amarnath K. Menon

RATTAN, Manipur

Chained to a post, Rattan's ruptured ankles bleed profusely. He is among the 124 HIV positive men and women tied by Dousel Zenkhoman, 62, and her husband, both

former government servants working at the Gamnuam Christian Home in Churachandpur district of Manipur. As they take Rattan away from prying eyes, Zenkhoman says, "They taste spiritual rejuvenation here." The girls have it worse in this "alternative universe". They are shackled to their cots or confined in cage-like spaces and not allowed to mix with the boys. A few yards



SAIBAL DAS

away is Happiness Home, a veritable prison for HIV positive drug users. Moia, a 26-year-old inmate, says that they are denied medicines and if they protest, are starved from a day to a week. A neighbour, working in the state Education Department, insists the confinement is to get church funding. Anyone listening?

—Suman K. Chakrabarti

4,000 beds have been set aside for treating AIDS patients in the country. This is way short of the required 4,00,000.

1,800 is the number of NGOs involved in AIDS care. Experts say that the performance of a large majority is questionable.

ever, being initiated by Andhra Pradesh in December this year, when an education programme aimed at creating awareness about the threat posed by AIDS-HIV will be launched in all the 11,464 government and private high schools in the state.

International experts also believe that India grossly underestimates its HIV positive figures, saying it is five times the official four million. One reason for the ambiguity is NACO's method for estimating infection rates. It has surveillance centres which cover only 384 sites nationwide to concentrate on certain groups. These include high-risk groups (truck-drivers, sex workers, migrant labourers), sexually transmitted disease clinics, ante-natal clinics in rural areas, MSM (men having sex with men) groups and intravenous drug users' clinics. Dr David Miller, country programme adviser at UNAIDS, a UN agency that monitors the disease across the globe, questions the accuracy and quality of the tests conducted at these sites. Besides, these exclude figures from private testing labs which re-

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- With no accountability, a host of dubious NGOs have mushroomed to cash in on the flush of funds.
- Former Union minister Arun Jaitley says there are more AIDS activists than patients now.
- NACO guidelines are openly flouted by the NGOs.



BANDEEP SINGH

port a worrying rise in numbers.

While WHO and the UN have been pressing the Indian government for mortality figures, NACO lists only 2,524 AIDS deaths between 1986 and 2001. "The official figures should be multiplied by 10 for a correct estimate," says Dr V.L. Muana, director, SHALOM, Manipur. His hospital has recorded 166 AIDS deaths in the past four years. Another way to crosscheck the figures is the blood banks where an HIV test is mandatory for all donors. While NACO is only now taking cognisance of these figures, the banks shockingly do not inform the donors who test positive. Now, Datta-Ghosh promises NACO will commission a study to analyse the burden of HIV-AIDS and its socio-economic implications. "This will give us updated

DUBIOUS SYMBOLS: Inmates of an AIDS care centre making AIDS ribbons

data to resolve the dialogue," she says.

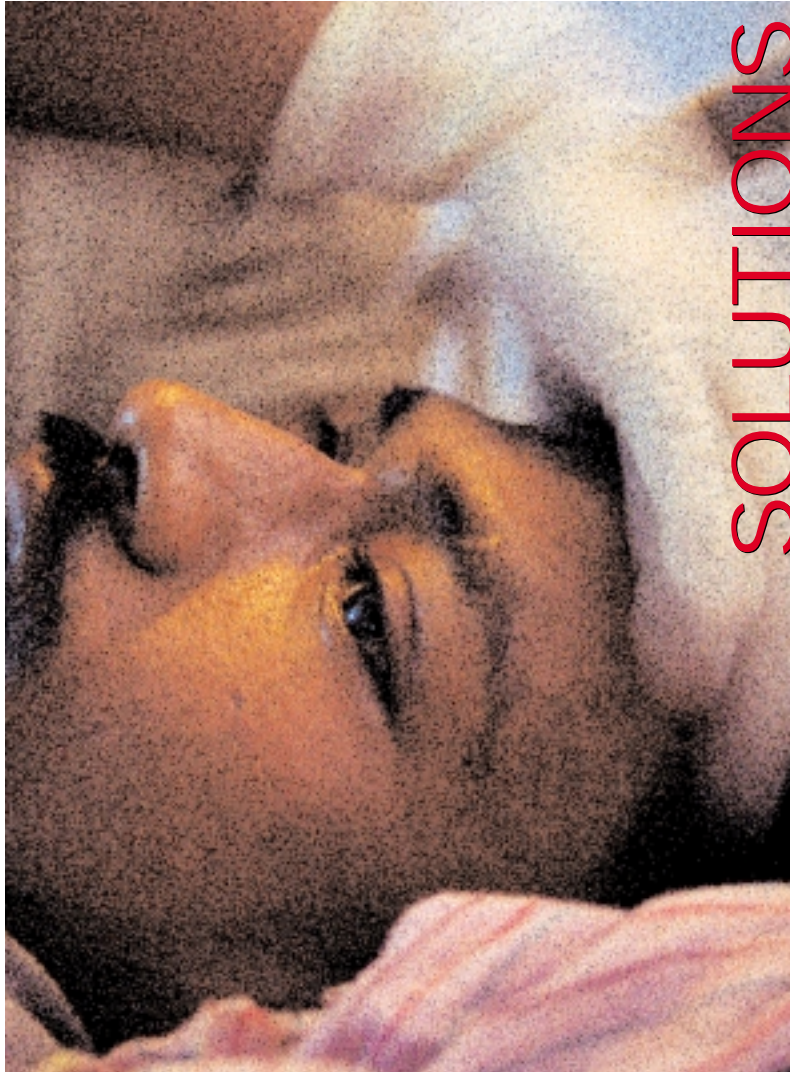
For the burgeoning HIV-AIDS population, discrimination and stigmatisation are other problem areas. A study by the HIV-AIDS unit of Lawyer's Collective, a Mumbai-based legal firm, on the nationwide litigations by HIV positive people reveals they are at the receiving end of multiple problems—psychological, medical, infrastructural. "There is no sustained counselling programme," says Kumar, admitting that like many affected he often feels suicidal.

Even in treatment, where tangible work can be measured, efforts are abysmal (see box). In government hospitals, HIV patients are sent to skin and venereal diseases wards, which lack an

empathetic environment crucial for imparting dignity in death. Private hospices (holistic care centres) like Sahara, Michael's Care Home and Naz Foundation in Delhi offer hope, but beds are limited. Many patients with full-blown AIDS are easily besieged by opportunistic infections like chronic diarrhoea and fever, tuberculosis, pneumonia and jaundice. Death often precedes the bed's availability.

It is not just lack of empathy. Though pharmaceutical companies like CIPLA have hammered down the cost of anti-retrovirals (ARVs) which check the progress of AIDS, they continue to be expensive—Rs 1,200 a month per prescription for each

25 million is the number of people who will be HIV positive by 2010 making India the AIDS capital of Asia.



BANDEEP SINGH

FACE OF AIDS: Terminally ill patients need specialised and empathetic care

patient. There is also the need for constant tests to ascertain the progress of treatment. "There is a dearth of diagnostic facilities that cost Rs 4,000 per patient and tests need to be conducted every three months," says Dr Chinkholal Thangsing, director of Delhi-based NGO Action India's AIDS project. With nutritional supplements each patient would need to spend Rs 8,500 a month.

India requires at least \$500 million (Rs 2,400 crore) every year just to provide ARV treatment. But with NACO not offering monetary support, most patients languish. The AIDS vaccine may still be a decade away, if at all. After an agreement between the Indian Council for Medical Research and the International AIDS Vaccine Initiative to develop an India-specific vaccine for the C-sub-

strain of HIV at the National AIDS Research Institute, Pune, clinical trials on humans are yet to begin.

Such silver linings provide scant hope in a bleak scenario. There are, of course, spiritual missions like the Ramakrishna Trust and the Aga Khan Mission that have done good work, while industrial groups and other government departments are also getting into the act. But what is essentially required is a joining of hands. Since the epidemic in India is still in its infancy, it's the right time to initiate more structured plans, say experts. "We need a comprehensive approach involving the health sector, voluntary sector, education system, labour organisations, the government and other stakeholders," says Miller. Otherwise, the eco-

SOLUTIONS

THE WAY OUT

- The Union and state governments should form a clear and comprehensive strategy to combat AIDS.
- There must be strict control of NGOs with regular monitoring of fund distribution and utilisation.
- Bogus NGOs must be weeded out swiftly and penal action taken against those who commit fraud.
- Sex education must be urgently introduced in schools and colleges to educate youth about the risks.
- Treatment centres must be set up urgently to cope with the demand.

nomic and social burden created by AIDS will seriously affect the GDP levels and increase the national debt.

Bobby John, director, Massive Effort Campaign, Pune, says, "We need to be effective stewards of available resources or there will be a dual tragedy—rampant HIV and a growing national debt." For this, says Anand Grover, director, AIDS unit of Lawyer's Collective: "Both donor agencies and NGOs need strict monitoring in accounting, payment and spending."

ACCORDING to NACO's written agenda, NGOs should be credible, have a minimum three-year experience in community work, financial transparency and an understanding of HIV-AIDS issues. Says Datta-Ghosh: "This is an opportunity for us to instal a series of paradigm shifts on diverse fronts. The national AIDS control programme will then be more vibrant, responsive and closer to ground reality."

Union Minister for Health Shatrughan Sinha recently roared, "We have the will, we want the money." He got it wrong. India has the money, but the enormity of AIDS needs efforts bigger than the clout and manipulations of business. Otherwise, many more like Babita will be born, awaiting slow, painful deaths.

—with Suman K. Chakrabarti, Nidhi Taparia Rathi and Amarnath K. Menon

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