Recognising and tackling vulnerabilities

Responding to HIV-AIDS in India

The backdrop

Every now and again, human society faces a new disease or condition of such virulence that it disrupts normal life. Of the 39 new pathogens that have been discovered between 1967-2007, by far the best known is HIV (WHO 2007). According to the 2007 Global AIDS report by UNAIDS:

- An estimated 33.2 million people worldwide were living with HIV. Of these, 2.5 million were children under 15 years and 15.4 million were adult women;
- An estimated 2.5 million were newly infected with HIV in 2007; and
- An estimated 2.1 million people had lost their lives to AIDS in the same year.

The report noted a 16% drop over the previous year due mainly to revised estimates in Angola, India, Kenya, Mozambique, Nigeria and Zimbabwe with the biggest revisions in India's estimates. Following these revisions, India has dropped to third place behind South Africa and Nigeria in numbers of people living with HIV in the country.

In 1986, the first infection with HIV was discovered on Indian soil in Chennai among two sex workers, following an intensive screening programme initiated in 1985. Screening during 1986-87 found that as many as 3-4% of sex workers were infected in Vellore and Madurai and that 1% of STD patients in Mumbai was infected with HIV.

HIV AND AIDS ESTIMATES 2007 INDIA

- Number of people living with HIV: 2,400,000 [1,800,000 - 3,200,000]
- Adults aged 15 to 49 prevalence rate: 0.3% [0.3% - 0.5%]
- Adults aged 15 and up living with HIV: 2,300,000 [1,700,000 - 3,100,000]
- Women aged 15 and up living with HIV: 880,000 [670,000 - 1,200,000]

Source: Epidemiological Fact Sheet on HIV and AIDS, UNAIDS 2008

The HIV epidemic in India is now over 20 years old and is counted among the most serious public health problems in the country. The history of the HIV-AIDS programme in India is one of a developing country that has methodically responded to a new pathogen with the potential to ravage its population, taking reference of an emerging evidence base and in collaboration with its partners.

A brief history of the programme

Shortly after reporting the first AIDS cases in 1986, the government set up an AIDS Task Force under the Indian Council of Medical Research and established a National AIDS Committee with membership of several departments of the government. Based on the available information at the time, the focus of the programme was to monitor HIV infection rates among risk populations in select urban areas. By 1987, a National AIDS Control Programme (NACP) was initiated to coordinate the national response to HIV-AIDS. In the first four years, the programme undertook screening of 'sexually promiscuous populations' and blood donors, and commenced awareness programmes regarding modes of transmission of HIV.

Phase I :: 1992-1999 :: establishing the paradigm

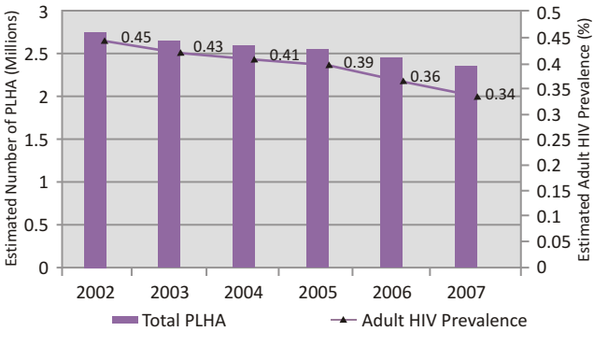
By 1991 several international donors, viz. DFID, USAID, NORAD, the World Bank, UNDP and UNDCP had expressed their willingness to support the NACP. A Strategic Plan for Prevention and Control of AIDS in India for what was the first 'phase' of the NACP. The National AIDS Control Organisation (NACO) was established in 1992 and State AIDS Control Societies constituted in all states to implement activities locally. At the time, not much was known about the dynamics of the epidemic in India. The programme therefore expanded its

scope gradually, establishing strategies and activities based on methodologies tested with support from various partners notably DFID, NORAD and UNDP. The DFID supported Sonagachi Project with female sex workers in Kolkata and its Healthy Highway project served as prototype for the programme elsewhere. As evidence mounted of the especial risk that certain subpopulations faced, a component termed 'targeted interventions' (TI) or interventions targeting at mitigating the risk of these populations was added to the programme.

Phase II :: 1999 - 2007 :: stemming the epidemic

NACP phase II was launched in November 1999. The focus of the programme now moved from the general goal of generating awareness to prevention among whom the epidemic was located. Based on growing evidence that the epidemic was concentrated among certain sub-populations, NACP-II set up more than 1,000 TI for female sex workers, men who have sex with men, injecting drug users, truck drivers and migrant labourers. It also addressed the general community through mass education campaigns and sex education programmes for the youth. Other important achievements were establishing Voluntary Counselling and Testing Centres, Prevention of Parent to Child Transmission Centres, truckers programme, licensing of Blood Banks, programme for opportunistic infections, antiretroviral treatment programme, and the establishment of community care centres for terminally ill AIDS patients. Many of these efforts were supported by the World Bank, USAID and DFID through state based support to the Government of India. Work also continued with NGO and CBO partners, and the establishment of advocacy networks supported by the UN and other partners marked the 'coming of age' of several affected communities.

Trend of adult HIV Prevalence and PLHA number, India



Phase III::2007-2012::ensuring comprehensive coverage

The goal of phase III of NACP is to halt and reverse the epidemic in India over a period of 5 years. The focus is to move from a project to a programme mode; strengthen the district and sub-district level response; and integrate prevention, treatment and care and support programmes with the general health services of the country. Important evidence from surveillance and behaviour surveys which indicated a rising awareness of HIV-AIDS among the population and the increasing spread into the general population determined the reformatting of the NACP design. The programme recognizes and responds to the epidemic at three levels of priority: the first with the highest risk of exposure to HIV are the 'core transmitter' groups - sex workers, men who have sex with men and transgenders, and injecting drug users; the second the 'bridge populations' - that bridge the core group and the general population; and the third being those in the general population who are vulnerable such as women (who bear 30% of the burden of infection) and youth among whom 50% of new infection takes place.

Evidence for planning

An important feature of the NACP has been the incremental establishment of ever more sophisticated and extensive data collection for monitoring and evaluating the programme. India's HIV data gathering systems owe much of their present configuration to lessons learnt from partners' support to state and national programmes since 1995.

HIV Sentinel Surveillance: Surveillance is used to estimate the prevalence of HIV infection in the community using 'sentinel' groups among whom infection rates are tested. HIV surveillance in India was initiated in 1985 under the aegis of Indian Council for Medical Research and was limited to blood donors and STD patients. Sentinel surveillance has been instituted annually in clinics for various population groups from 1998 and is carried out in 1122 sites since 2006. New patients attending the clinic sites are tested for HIV in an unlinked, anonymous manner.

Behavioural Surveillance Survey: These surveys of various subgroups which may be difficult to reach through traditional household surveys, and provide an understanding of knowledge, awareness and behaviours that make them vulnerable to HIV infection. The first national Behavioural Surveillance Survey was conducted in the year 2001 and the second wave in 2006 among the general population, high risk groups, clients of female sex workers and intravenous drug users.

Integrated Behavioural and Biological Assessment: These surveys supported by the Bill and Melinda Gates

Foundation in India capture an array of data elements socio-demographic, HIV risk behaviour including condom use and prevalence of HIV and several sexually transmitted infections.

National Family Health Survey: The National Family Health Survey, a large-scale, multi-round survey conducted in a representative sample of households throughout India, added a module on HIV in Round 2 and HIV testing in Round 3. The focus is to assess the level of knowledge on HIV, sexual behaviour, issues related to stigmatization and HIV prevalence.

Strategic Information Management: The programme has also established a detailed computerized information system which goes beyond Monitoring & Evaluation. The system includes a basic monitoring at implementation units level such as TI/STI clinics/Blood Banks; computerized national level information sourcing and analysis software; district level vulnerability assessment and other research studies required during programme implementation; and a computerized Project Financial Management System. Apart from these, other studies and surveys conducted by the programme such as AIDS case surveillance (estimates of the number of people living with AIDS and the number of people who have died from AIDS) and STD surveillance has also helped in tracking the epidemic and provides the direction to the programme.

DFID and other partners have helped to build a strong response by helping the centre and the states generate data for decision making. During its initial phase, DFID undertook the exercise of mapping of high risk groups in 5 states. These provided evidence of the size and location of high risk groups, patterns of transmission and the importance of underlying factors such as mobility which varies from state to state. These have since been replicated in all states of the country.

Responding to vulnerability

What determines the spread of the virus? What makes people vulnerable to it? Who does it infect? What are the effects of the disease on the human condition? These questions are central to formulating a response to the epidemic.

Surprisingly, HIV is rather fragile as viruses go, dying rapidly when removed from the homeostatic environment of the human body. Infectivity varies in different phases of the natural history of the disease but in all events, is quite low. Accordingly, the virus is transmitted best when transferred directly between one person and the next such as in injecting drug use; and when there are numerous chances to do so, as in high volume sex work. The transmission mode of the HIV virus thus leads to clustering of the epidemic in certain population groups characterized by i) their sexual behaviours, such as commercial sex workers - both male and female, their clients, and men who have sex with men; ii) exposure to unsafe blood such as among injecting drug users; and iii) other predicting lifestyle characteristics such as vocation, as among truckers and migrants, and geographical locations with high prevalence. Although much of India has a low rate of infection, the epidemic is more severe in the southern half of the country and the far north-east, with the highest rates to be found in Andhra Pradesh, Karnataka, Maharashtra, Manipur, Nagaland and Tamil Nadu. Because the Indian subcontinent is so large and varied, the levels of health literacy so widely divergent, and the concentration of migrant populations and 'servicing' populations so determined by local economic characteristics, the distribution of high risk behaviour varies quite significantly between different regions.

> Through Avahan, we have learned how important it is to get local communities involved in delivering effective public health interventions at a large scale. The next challenge will be passing on all that we've learned and transitioning Avahan to the government and other partners. We look forward to continuing that collaboration.
>
> *Bill Gates*
> *upon accepting the Indira Gandhi Peace prize 2009*

The communities among whom the epidemic is currently raging are not only among the most marginalized, but also 'criminalized' due to several activities that are in contravention of Indian law. For example, legal provisions drive sex work underground, leading to difficulties in reaching and hence limiting the spread of the virus. Therefore public health systems are unlikely to be accessed by these groups which lie beyond the social pale, and will not be the most efficient way of reaching these groups. India has so far approached these marginalized groups through NGO and peer-based CBO. Where the interventions are well managed, outcomes have been good e.g. Tamil Nadu, Gujarat. The percentage of sex workers who are HIV infected is showing decreasing trend with prevalence declining from 10.3% in 2003 to 4.9% in 2006. However, the prevalence rate among the injecting drug users is on the increase in many states and newer

regions are being detected. Among men who have sex with men, positivity was 6.4% in 2006 (UNGASS report 2008) and has not shown significant decline. Coverage of these two groups continues to be of greatest concern.

This does not argue for complacency. As the epidemic has evolved, rates among some high risk groups have approached 60%. Sexual networks of these groups are known to be wide and inter-digitated, with the potential to spread HIV among the wider community. The increasing numbers of districts in which the rates among the general adult population is over 1%, the rural proportion in some states and the increasing feminization of AIDS cases, describe the potential of the epidemic to spread through the wider community. Summary prevalence figures also mask the infection among spouses of the 'bridges' between the smouldering epidemic and the wider community. Further, it is unclear what affect the changing economic structures and accompanying demographic shifts will have on sexual behaviours in society at large and hence on the potential of HIV to spread more widely.

The larger picture of AIDS in the country often obscures the manner in which the HIV epidemic is a rapidly mounting disaster for children. Children affected by HIV and AIDS are those children whose human rights are threatened as a result of their link to HIV and AIDS. They can be delineated into three categories:

- Children who are HIV-positive themselves
- Children who have a parent (or two) who have died from AIDS related diseases
- Children who have a parent (or two) who are HIV-positive

While there are no reliable estimates of 'affected' children in the country, a recent UNICEF report summarises that India possibly has 150,000 vertically infected children; 1,500,000 children orphaned by AIDS; and 7,000,000 children with HIV-positive parents. NACO estimates that 57,000 children are infected at birth in India each year, but do not estimate how many are living with the virus. HIV affected children face vulnerabilities long before they are orphaned.

Children of sick parents have to drop out of school and assume parental roles becoming de-facto orphans, although not orphaned. A recent UNICEF study documented that affected children are teased, shunned, shouted at or ignored in their homes and neighbourhoods.

Stigma and discrimination continue to be practised against those who carry the virus and their families. HIV infection often becomes a defining characteristic in the lives of those affected, determining their access to services, livelihood options, medical attention, and simple social exchanges. Unless immediate steps are taken to address these issues, HIV and AIDS will remain a clear and present danger to the fabric of Indian society.

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This background was also used by Amaltas to develop several reports including the 'HIV Epidemic in Madhya Pradesh' for UNAIDS, 'Evaluation of DFID's support to India's response to the HIV and AIDS epidemic over the past decade' for DFID, India's submission to GFATM on the Round 2 Continuation Channel for UNICEF, and work being carried out for TCI Foundation on review of the Kavach project.