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Kieth

Todd A. Summers
10/27/98 08:19:33 AM

Next Wednesday 9:00
No session
Call Ted –

Record Type: Record

To: Sandra Thurman/OPD/EOP

cc:
Subject: [1437] The Hidden Costs of AIDS Obsession

---------- Forwarded by Todd A. Summers/OPD/EOP on 10/27/98 08:21 AM ----------

Sea-aids <sea-aids @ lists.inet.co.th>
10/27/98 04:51:06 AM

Record Type: Record

To: sea-aids @ lists.inet.co.th

cc:
Subject: [1437] The Hidden Costs of AIDS Obsession

Dear SEA-AIDS subscribers,

One of the leading Indian journalist RUPA CHINAI is questioning the idea of the government of India plunging into the second phase of the AIDS prevention and control programmes without evaluating the result of the first phase of the programme. [the Hidden Costs of AIDS Obsession., The Times of India, wednesday 2 September 1998]. Will the World Bank authorities care to develop evaluation parameters to measure the efficacy of their AIDS related funding in India?.

As Ms. Chinnai is asking certain crucial questions on the policy directions of AIDS prevention in India the following article may be of interest to the SEA-AIDS members.

(forwarded by Joe Thomas for reference. joethomas@hivnet.ch)

The Hidden Costs of AIDS Obsession
By RUPA CHINAI

WITHOUT any evaluation of how its AIDS control and prevention programme has worked in the past decade, India is plunging into the second phase of the programme bent upon repeating the same mistakes. With many questions still remaining unanswered about HIV/AIDS, the disease is being given top ranking status, eclipsing all other killer diseases, and skewing India's health policy.

AIDS is a unique disease because it is linked to a range of opportunistic infections that arise with its

onset. It provides a window to look at what is going wrong within the health system, in our patterns of social and economic development. It provides impetus for change.

Three Questions

By pouring money into a narrowly conceived AIDS policy, India is yet again missing the bus. The past decade's experience reveals that an AIDS programme cannot stand in isolation, while general primary health care remains in a state of shambles.

In the first phase of the programme (1992-1999) the AIDS programme received Rs 320 crores; the second phase will see an unprecedented Rs 800 crores assured through World Bank loans. Over the past decade, three questions have consistently been raised by public health experts in India. While donor agencies and the Indian government have spoken of `projections' and `estimates' about the AIDS epidemic sweeping India, where is the epidemiological data supporting those claims?

Secondly, AIDS is connected with a range of diseases like TB, diarrhoea, malnutrition or malaria (the presence of these factors depress the immune system leading to the faster onset of AIDS). Why then are we seeing the eclipse of all other disease programmes, and a major portion of the `AIDS funds' poured into a `targeted' intervention programme, gearedat condom promotion and sex education?

Thirdly, the hysteria and scare tactics being used to create awareness about AIDS is wreaking social havoc. In the past months, reports have poured in from across the country about incidents of lynching and ostracism by entire communities against AIDS patients.

To date, the National AIDS Control Organisation records 5,204 AIDS cases in India, primarily reported from four states. Meanwhile, those testing HIV positive number 75,000. Until 1997, these samples were drawn from 55 `sentinel surveillance sites' -- blood banks, sexually transmitted disease clinics and ante-natal clinics -- that are not uniformly spread across the country. Bihar, for instance, has none, and its one testing centre in Patna reports 29 HIV cases and 3 of AIDS. Meanwhile, Maharashtra reports 46,000 testing HIV positive and 2,518 AIDS cases. Such uneven trends, drawn from selectively chosen groups in a few urban areas, are being extrapolated to the general population across the country.

Despite the absence of epidemiological data, India unquestioningly follows the diktat of donor agencies in pursuit of a vertical AIDS programme. Countries like Thailand have integrated AIDS into a strong primary health system. They are now seeing results in AIDS prevention, and simultaneously in malaria control. India's primary health services remain in shambles. A vertical AIDS programme cannot work when there is no primary health base it can stand upon. Indian health experience offers one key insight: When the community receives a comprehensive package of curative services it needs, only then does it becomes receptive to the prevention message.

Comprehensive Care

Meanwhile, a fundamental debate rages internationally on whether HIV is the sole cause of AIDS. Is AIDS related to abuse of lifestyle rather than a virus? Do factors such as antibiotic and recreational drug abuse, anal sex, nutrition and stress disorders play any role in immune system suppression? Does AIDS research need to look at drugs that modulate or boost the immune system response? When so many questions remain unanswered about HIV/AIDS, shouldn't our interventions be as broad-based as possible?

There are also questions about whether public policy should encourage HIV testing when there are doubts about the accuracy of the kit and whether the virus itself has been isolated. If HIV exists, but is ``constantly mutating'', can the HIV test show a false negative result? When the HIV test is conducted on persons suffering from malaria, TB, malnutrition and other common infections, can there be a cross-reaction, leading to false positive results?

After a decade of living with AIDS, maybe this disease seeks to teach us that there is more to it than condoms and sex education. AIDS is about creative responses to social and economic needs, comprehensive health care and education.

Moderator's note: Just a quick note re. the paragrap on whether HIV causes AIDS. On the Healthdev discussion forums we assume that HIV is the cause of AIDS. If you would like to join a debate on whether this assumption is correct or valid write to: Rethinking AIDS - ben@aidsinfobbs.org

HIV/AIDS IN INDIA

A STATUS REPORT

National AIDS Control Organisation
Ministry of Health and Family Welfare

Government of India

HIV/AIDS IN INDIA
A STATUS REPORT

Prepared for the session on

AIDS in India:

The Problem and Programmes to Address it

India Development Forum

JUNE 23-25, 1997

PARIS

Table of Contents

List of Abbreviations

HIV	Human Immuno-deficiency Virus
AIDS	Acquired Immuno Deficiency Syndrome
NACO	National AIDS Control Organisation
WHO	World Health Organisation
PLWAs	People Living With AIDS
SAARC	South Asian Association for Regional Cooperation
ODA	Overseas Development Cooperation
DFID	Department for International Development
USAID	United States Agency for International Development
IEC	Information, Education and Communication
NGO	Nongovernmental Organisation
STD	Sexually Transmitted Diseases
TNSACS	Tamilnadu State AIDS Control Society
APAC	AIDS Prevention and Control
ARCON	AIDS Research and Control Centre
AUSAID	Australian Agency for International Development

Executive Summary

India is in the eleventh year of the epidemic. The available data clearly indicate rapid increase in HIV prevalence and AIDS cases. As of May 1997, 56,409 of the 3.033 million screened were found to be positive. At the same time a cumulative total of 3551 AIDS cases have been reported. The most rapid spread of HIV is being documented in Maharashtra and Tamilnadu, and among injecting drug-users in the North Eastern States. The predominant mode of transmission is through heterosexual intercourse followed by injecting drug use and infected blood.

India initiated the National AIDS Control Programme in 1987, a year after the first case of AIDS was reported in 1986. In 1992, the National AIDS Control Organisation was established and a Five Year Strategic Plan was implemented with a US $84 million loan from the World Bank. A range of bilateral and multilateral agencies and NGOs contribute to this national effort. WHO provided the initial policy guidelines, technical assistance and support.

This Strategic Plan, which is national in scope, has as its main focus key metropolitan areas and epicentres of HIV infection. A comprehensive structure has been established for effective programming at the central level and the State AIDS Cells in each of the states are responsible for prevention and care efforts including the management of grants to NGOs at the state level.

During the last five years, the programme was successful in raising public awareness of HIV/AIDS through mass media campaigns, community mobilisation and HIV/AIDS education in schools. Comprehensive interventions comprising of HIV/AIDS information and education, condom promotion and treatment of STDs targeted at populations practising risk behaviours have been implemented especially in the major metropolitan areas. Some of these, such as the commercial sex worker project in Sonagachi, Calcutta have succeeded in increasing condom use and reducing the STDs levels.

Progress has also been made in STD treatment through training in syndromic management of STDs. Likewise, efforts have been made to promote the use of condoms. To address the need for epidemiological data, 62 sérosurveillance centres and 55 sentinel sites have been established. A major achievement has been in ensuring blood safety with the Supreme Court Directive of 1996 which instituted mandatory HIV testing in all blood banks. Projects in Care and Support have been initiated in collaboration with NGOs.

However, available HIV/AIDS data and epidemiological observations indicate that HIV prevalence continues to increase and spread from the urban to the rural areas, and from individuals practising risk behaviours to the general population. Studies indicate that more and more women attending antenatal clinics are HIV positive increasing the risk of perinatal transmission. This rapid spread of the infection and the changing trends could be attributed to factors such as labour migration and mobility, low literacy levels, gender disparity and high levels of STDs and RTIs which make the population susceptible to HIV infection.

Increasing rates in HIV infection and death through AIDS will have an impact not only on individuals, households and communities, but also on some of the benchmarks of human development: life expectancy, per capita income, school enrollments and health. The most dramatic immediate impact will be on individuals and families affected, as indicated by results of studies in India. This might undermine any gains made in poverty eradication. The impact on the health

sector will also be felt in the coming years. Because HIV infection will increase the onset of opportunistic infections such as TB, the health system which is already overburdened will be strained even further.

To respond effectively to these infection trends and to reduce the impact of AIDS, the national response, initiated by the government in 1992, needs to be accelerated, intensified and expanded by adopting a multisectoral approach.

However, for the implementation of an expanded response, constraints which slowed the implementation of a number of programme components and limited the effectiveness of others during the last five years will have to be overcome. These are lack of commitment at state level and poor management, cultural inhibitions about dealing with matters related to sex, unavailability and inaccessibility of condoms in some pockets of the country, insufficent number of skilled personnel in all aspects of programming and the dearth of epidemiological data.

Therefore immediate action in: advocacy and sensitisation, strengthening of surveillance data collection, analysis and dissemination, decentralisation and promotion of ownership at state level, and strengthening of capacity and human resource development are prerequisites to laying the framework for the development and implementation of a strategy for an expanded response.

Within this expanded response, **HIV/AIDS prevention** efforts will continue to be the main priority, with a focus on promotion of safe behaviour and practices through strengthening of community mobilisation, interpersonal communication and counselling. Efforts will be made to ensure that youth have access to preventive information and support services. There will be a wider implementation and strengthening of comprehensive targeted interventions for commercial sex workers, truckers, injecting drug users and street children to meet the needs of vulnerable populations nationally.

A second area of priority is **Treatment, Care and Support** for people living with AIDS and impact reduction. With the epidemic into its second decade, people infected with HIV are now falling ill and progressing to AIDS. A Continuum of Care comprising of clinical management, nursing care, counselling and social support will be implemented. Emphasis will be on community-based initiatives such as home-based care through community mobilisation and participation of people living with AIDS.

Pilot studies will be conducted on the use of anti-retrovirals to test its effectiveness in India. The short and long term impacts of the epidemic on individuals and households will be assessed so that policies and interventions to reduce the impact of the epidemic can be implemented.

Based on experience from other countries, it is becoming extremely clear that the future strategy will have to address not only the prevention of HIV/AIDS but at the also same time the key issues affecting susceptibility to infection. This calls for a collective response through empowerment of communities, widening the response to include other sectors and through mobilisation of the private sector.

The national HIV/AIDS prevention programme is at a critical juncture. The Government of India is fully committed to preventing a catastrophic epidemic. Therefore a concerted effort will be made to accelerate, intensify and expand the national programme that has been implemented. At the same time, immediate action will be taken to confront the key issues that increase susceptibility to the HIV/AIDS epidemic.

HIV/AIDS in India

1. INTRODUCTION

The HIV/AIDS epidemic continues its expansion across the globe with approximately 8500 new infections a day. As of July 1996, WHO estimates that 27.9 million adults and children have been infected with HIV since the start of the epidemic.*

This global epidemic has been fueled by a number of explosive epidemics especially in Asia. The region, which accounts for 18 percent of the world's total HIV infections, has already overtaken Africa in recording the fastest-growing rates of new HIV infections in the world. This is of critical concern, given that it is home to 60 percent of the world's total population. What happens in Asia will have a major impact on the global pandemic.

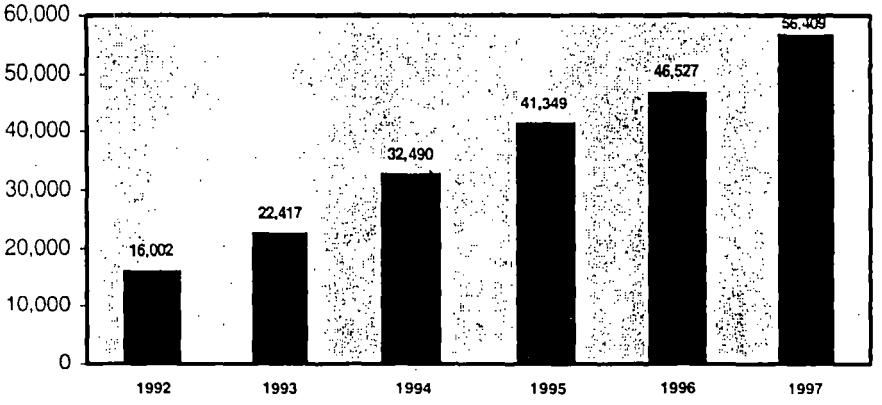
The epidemic in Asia has predominantly been spread through heterosexual contact, and is strongly influenced by gender inequality and the frequent practice of men visiting commercial sex workers.

Governments in Thailand, Singapore, Malaysia and India have committed extensive resources to responding to the HIV/AIDS epidemic. However, most governments continue in a state of denial and are reluctant to release surveillance and behavioural information.

2. HIV/AIDS IN INDIA

The first case of AIDS in India was registered in 1986. Since then, HIV prevalence has been reported in all states and union territories except Arunachal Pradesh. By May 31, 1997, of a total of 3.033 million individuals practising risk behaviours and suspected AIDS cases who were screened for HIV infection, 56,409 were found to be seropositive, indicating a seropositivity rate of 18.6 per thousand. At the same time, a cumulative total of 3,551 cases of AIDS have been reported. Available data from the start of sentinel surveillance to the present clearly indicate rapid increases in HIV seropositivity. *(Figures 1 and 2).*

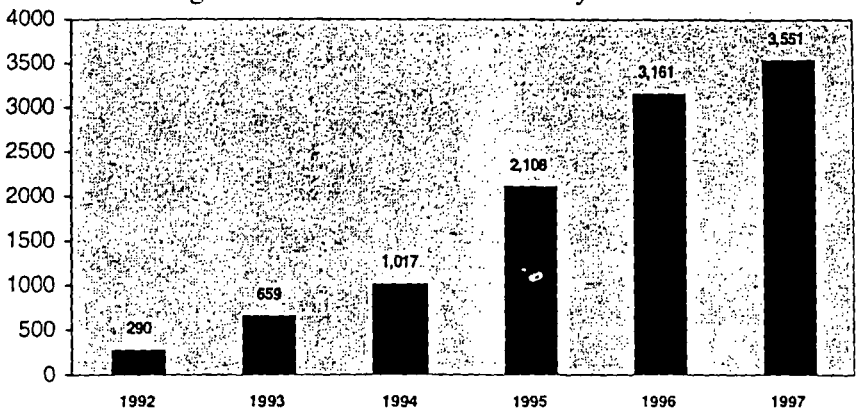
Figure 1: Increase in HIV Prevalence



Source: NACO 1997

* *All global figures are from WHO and national figures are from the National AIDS Control Organisation unless otherwise indicated.*

Figure 2: Increase in Number of AIDS Cases

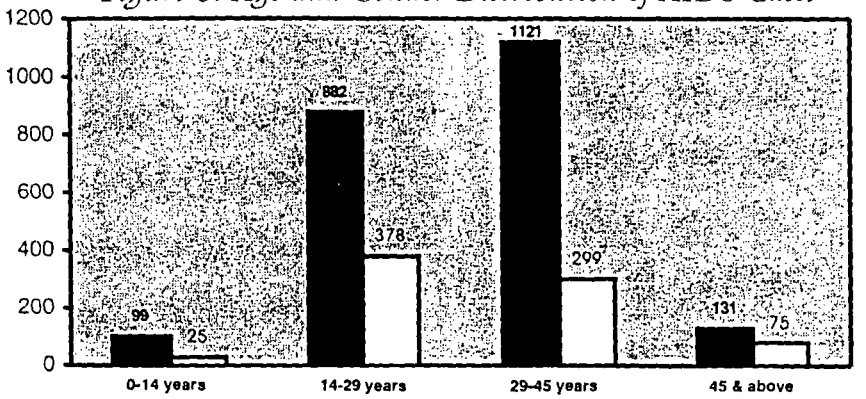


Source: NACO 1997

Analysis of epidemiological data and survey reports in India indicate that:

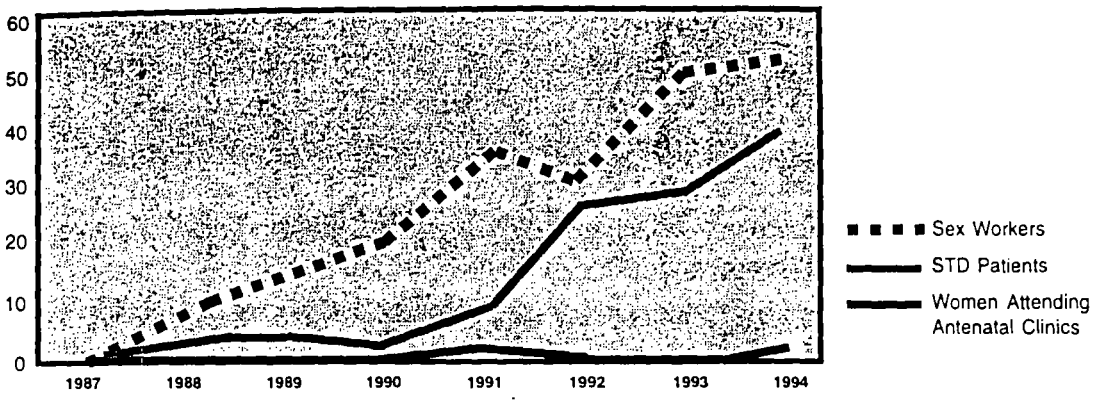
- The highest number of HIV infections have been reported in Maharashtra and Tamilnadu and among Injecting Drug Users (IDUs) in the North-Eastern states such as Manipur.
- 89 percent of the total reported AIDS cases occur in the sexually active and economically productive 15-44 age group *(Figure 3: Age and Gender Distribution of AIDS Cases)*
- Of the total reported AIDS cases, 76.7 percent are men, and 22.3 percent are women.
- The predominant mode of HIV transmission is through heterosexual contact (76.8 percent), followed by intravenous drug use (9 percent), blood transfusion and blood product infusion (7.4 percent) and unspecified others (8.6 percent).
- Trends indicate that HIV infection is spreading in two ways: from urban areas to rural areas, and from individuals practising risk behaviours to the general population. Data from antenatal clinics indicate rising HIV prevalence among women, which in turn contributes to increasing HIV infection among children *(Figure 4: HIV Prevalence in Different Population Groups)*.

Figure 3: Age and Gender Distribution of AIDS Cases



Source: NACO 1997

Figure 4: HIV Prevalence in Different Population Groups in Mumbai



3. WHY AIDS IS DIFFERENT FROM OTHER DISEASES

- HIV/AIDS presents an unusual challenge. Unlike other diseases, it selectively and disproportionately targets two groups -- young adults who are in their prime reproductive and economically productive years, and very poor, economically marginalised populations.
- Large mobile populations, rapid urbanisations, illiteracy and the presence of STDs influence the spread of the disease
- HIV infection occurs not randomly but through specific risk behaviours -- the most common mode of HIV transmission is unprotected sex -- that are mostly within the realm of private life.
- Unlike other diseases, AIDS retains a long period of "invisibility," with opportunistic infections appearing years later. In the absence of a cure -- treatment options are only in the initial trial stages and are prohibitively expensive -- HIV/AIDS is essentially an incurable and fatal disease.
- There is a strong likelihood of multiple cases of AIDS within a household. Studies indicate that increasingly the disease is being transmitted from husband to wife, and from mother to child.
- The personal and social repercussions of the disease include severe discrimination and stigmatisation of people living with AIDS (PLWAs). This has a bearing on the implications of the disease and how the people affected cope with them.

4. LONG-TERM IMPLICATIONS OF HIV/AIDS

Because HIV/AIDS is a fairly recent disease, its long-term implications are only just being recognised. What is clear, however, is that it will have a multiplier effect that will impact not only individuals, households and communities, but also some of the benchmarks of human development: life expectancy, per capita income, school enrollments and health. HIV/AIDS therefore will have a long-term and profound impact, unless effective steps are taken to check the spread through advocacy, safe blood products, safe sex practices and control of STDs.

Impact on the Economy and Society

The first generation of economic research on AIDS considered the impact of the disease on macroeconomic indicators such as national economic growth to be significant. However, more recent studies based on assumption-free frameworks indicate that HIV/AIDS is unlikely to have a statistically significant impact on macro economy -- *in the initial years.*[1] This is because its occurrence is concentrated mostly on economically marginalised groups whose participation in the economy is limited. However, for that very reason, its impact on households that are already disadvantaged and least able to cope will be especially severe. Therefore, economic research on AIDS is now beginning to focus on the impact of the disease at a microeconomic level, on individuals and households.

In India, four key studies have contributed to highlighting the microeconomic impacts of the disease. A study conducted in New Delhi, using major illness and death as a proxy for AIDS-related morbidity and mortality, reveals that the household expenditure on health care in India is four to five times the level of state expenditure on health care.[2] Discrimination in treatment expenses and ostracisation of individuals and families affected by the disease further exacerbate their economic hardships, leading to their increasing pauperisation.[3] This will undermine (any) gains made in poverty eradication, a primary goal to which India has made renewed commitment both in the Ninth Five Year Plan as well as at the recent Ninth SAARC Summit.[4]

Women, the prime caregivers in a family, are likely to be the worst affected. A Mumbai-based study of the household and community responses to AIDS reveals that the household responses were more supportive and positive in the case of HIV-positive males than females.[5] Because the wife of an HIV-infected man is also likely to be infected herself, her physical capacities will also diminish.

Impact on the Health Sector

HIV infection will increase the onset of opportunistic infections such as tuberculosis, one of the leading causes of adult death in the region. Between 30 and 50 percent of people in developing countries have dormant TB which will become active once HIV weakens the immune response. In fact, studies indicate that 60 percent of AIDS cases in the country manifest themselves as TB cases. The increased levels of TB, even among those who are not HIV-infected, increases sharply the medical expenditures of the individuals and families affected, and further strains a fragile and overburdened health system.

Despite the increasing prevalence of HIV infection, India is still in the early stages of the epidemic's progression. Because prevention and control efforts were initiated right from the beginning, there are still opportunities to mitigate the tragic consequences of a large-scale epidemic. This calls for an intensification, expansion and diversification of efforts that are already in place.

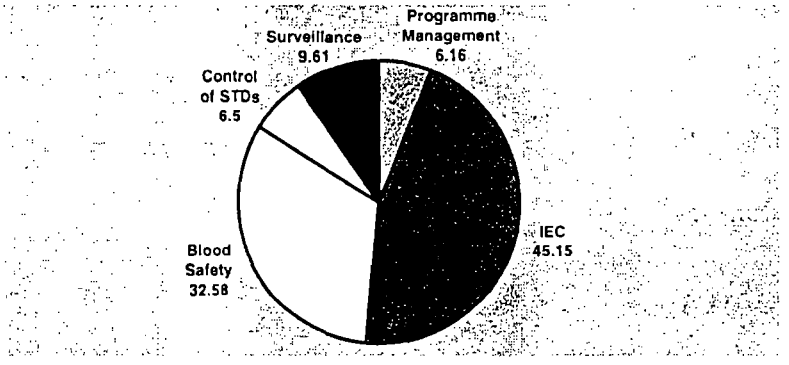
1. INTRODUCTION

Soon after the first case of AIDS was registered in the country in 1986, a National AIDS Committee was constituted. The following year, the government launched the National AIDS Control Programme which focussed on increasing awareness of HIV/AIDS, screening of blood for HIV, and testing of individuals practising risk behaviours.

In 1992 the National AIDS Control Organisation was established by the Ministry of Health and Family Welfare to manage the programme of activities. NACO is supported by a multisectoral committee and a National AIDS Control Board as well as various specialist advisory committees. NACO collaborates with a range of bilaterals, multilaterals and UN agencies, with WHO, DFID and USAID providing financial and technical support in state-level design, implementation and monitoring of the programme.

The same year, a Five-Year Strategic Plan for HIV/AIDS prevention and control was implemented on an allocation of US $15 million from the Government of India and a US $84 million loan from the World Bank. The plan which is national in scope has as its main focus metropolitan areas and epicentres of HIV infection. The programme components of the plan are: programme management, IEC and social mobilisation, surveillance, increasing blood safety, clinical management, condom promotion, and treatment, care and support. Resources are allocated according to the prioritisation of programme areas *(Figure 5: Allocation of Resources for Programme Components)*.

Figure 5: Allocation of Resources for Programme Components from 1992 to 1997



Source: NACO 1997

2. OVERVIEW OF PROGRAMME

Programme Management

- Establishment of a National AIDS Committee and AIDS Control Board at the centre;
- Decentralisation and the setting up of State AIDS Cells in 25 states and 7 Union Territories to manage state efforts for HIV prevention and care, including the management of NGO grants;
- Strong support from the State Directorate of Health especially for State AIDS Cells in Maharashtra and Tamilnadu;
- Conversion of SAC in Tamilnadu to a Society.

IEC and Social Mobilisation

- Six-strategy programme including intersectoral collaboration with the Ministry for Information and Broadcasting, mass media, advocacy, NGO involvement, training and research;
- Intensive campaign using range of media launched by advertising agency;
- Implementation of school education programmes in 15 states; development of curriculum and training packages;
- Development of IEC packages for all groups practising risk behaviours;
- Prevention Indicator surveys conducted in 1996 in four states on knowledge about practices for HIV/AIDS prevention, STD incidence, condom availability and accessibility. Data indicate that knowledge of at least two HIV/AIDS prevention methods was between 54.4 percent and 77.9 percent in the targeted metro areas, and between 13.4 percent and 63.8 percent in the rural areas;
- One of the findings of the 65-City High Risk Behaviour study, initiated and implemented by NACO, is that contrary to popular belief, multiple partners is very common both in rural and urban areas. Such studies provide data imperative to strategic planning;
- Implementation of cross border intervention projects;
- Counselling.

Condom Promotion

- Promulgation and enforcement of policies for upgrading condom quality to international standards;
- Implementation of social marketing to increase the use of affordable quality condoms;
- Condom use during most recent intercourse with non-regular partner varies from 19.4 percent to 77.8 percent and 8.6 percent to 25 percent in rural areas. Condom use with regular partner continues to be limited.

Blood Safety

- The Supreme Court Directive of 1996 making HIV screening mandatory at all blood banks; envisages complete elimination of all professional blood donations by end 1997;
- Framing and dissemination of a national HIV testing policy addressing key issues such as HIV testing procedures, mandatory screening and confidentiality;
- National and State Blood Transfusion Councils set up as registered societies to oversee all aspects of the blood safety programme;
- Strengthening of 815 public sector and voluntary blood banks have been strengthened;
- Comprehensive programme to modernise blood banks that makes licensing contingent on banks meeting minimum requirements;
- Mandatory testing for HIV, Hepatitis B, malaria and syphilis of all blood units collected for transfusion;
- Dissemination of rapid test kits for HIV testing at all district level blood banks;
- Increasing voluntary blood donations and reducing professional blood donations;
- Establishment of 154 zonal testing centres to give backup facilities for blood banks.

Surveillance

- Establishment of 62 serosurveillance centres and 55 sentinel sites all over the country; The surveillance centres monitor the geographical spread of HIV and the sources of infection among individuals practising risk behaviours, and the sentinel sites monitor HIV trends over time in certain sections of the general population such as women attending antenatal clinics and the groups at risk such as injecting drug users and persons with sexually transmitted diseases;
- Implementation of reporting mechanisms for monitoring HIV/AIDS progression and programme implementation;
- Training programme for surveillance staff;
- Regional workshops to review surveillance activities.

Control of Sexually Transmitted Diseases

- Strengthening of 504 existing public STD clinics through training in diagnosis and management, training in syndromic management of STDs;
- Promotion of quality condoms for STD prevention and provision of drugs at STD clinics;
- Provision of training at primary health care centres for better diagnosis and management, and reduction of discrimination and stigmatisation of PLWAs;
- Production of training guidelines.

Clinical Management

- Provision of training to the "Physicians Responsible for AIDS Management" (PRAM), a network of professionals;
- Provision of training to 7,500 private doctors and 44,817 public doctors at general hospitals and primary health care centres in AIDS diagnosis and case management. This was done in collaboration with the Christian Medical Association, the Indian Medical Association and State AIDs Cells;
- Training programme for nurses is underway.

Care and Support

- Judgement by the Bombay High Court ordering financial compensation by a company to an employee who was fired upon being diagnosed HIV-positive;
- Implementation of pilot Continuum of Care programme in Manipur;
- Development of a training module and a guide on home care for PLWAs;
- Implementation and development of a national training programme for counselling, identification of apex institution and five regional counselling centres; development of training modules including one for grassroot level counselling in western region.

3. OTHER PROGRAMME ACHIEVEMENTS

Targeted intervention projects, the active involvement of NGOs, and collaborations with the public and private sectors have contributed in large measure to the achievements of the programme.

Targeted Interventions

Several very effective targeted intervention projects have been implemented for groups practicing risk behaviours. These interventions include outreach activities, IEC and interpersonal communication, condom promotion, and general health and STD service provision. Targeted intervention projects such as that for commercial sex workers in Calcutta's Sonagachi area, the Men who have Sex with Men project in Madras, truck drivers in Rajasthan and Injecting Drug Users in Assam, Manipur and Nagaland have increased condom use and reduced STDs, yielding lessons in best practice *(Box 2 Examples of Best Practice)*

Role of Non-Governmental Organisations

NGOs have played a major role in initiating and ensuring effective interventions, defending the human rights of people living with HIV/AIDS and in providing care and support to PLWAs *(Box 3: Care and Support Initiatives)*

The Government of India has also made active efforts to involve NGO participation. The USAID supported AIDS Prevention and Control project in Tamilnadu is being implemented by an NGO, showing the confidence invested in them by the government. Some State AIDS Cells have been particularly effective in mobilising community

BOX 2 Examples of Best Practice

■ The targeted intervention project for commercial sex workers in Calcutta's red light district, Sonagachi, is DFID-supported and part of the broader West Bengal Sexual Health Project. Project evaluation conducted in 1994 indicates that regular condom use has increased from 1.1 percent to 47 percent, and percentage of people reporting that they often or regularly use condoms increased from 3 percent to 68 percent. The total number of reported STD cases dropped from 80.6 percent to 59.3 percent, while HIV prevalence remained at virtually the same level. The project highlights the effectiveness of approaches such as peer education, condom promotion and needs-based provision of health care such as STD clinics.

■ Men who have sex with men (MSM) are the focus of targeted interventions implemented by the Community Action Network (CAN) in Chennai. The WHO/GPA supported project, the first of its kind in India, has as key objectives addressing STD/HIV prevention in the context of general health, providing income-generation and reducing the consequences of marginalisation. The use of peer education and the implementation of needs-based projects such as general health, income generation, savings, education and housing to gain the support of the community was integral to the success of the project. Evaluation studies indicate an increase in condom use from under 10 percent in 1994 to 50-55 percent at the end of 1995, and STD referrals increased from 40 percent to 72 percent.

■ Injecting Drug Users are the focus of the AUSAID-supported SHALOM project in Churachandpur. The project, which lays emphasis on participation, has as its key feature a cafeteria approach that includes a range of choices ranging from detoxification through confidential HIV counselling and testing, community education and rehabilitation. Some of the factors that assisted in harm reduction were learning from existing models and groups in the region, using community and government leaders as educators and lobbyists among their own peers, introducing harm reduction in the context of the other concerns of the community and documenting all agreements with government and enforcement agencies.

■ Street children and youth are the focus of a project implemented by the Naz Foundation (New Delhi) in collaboration with Salaam Balak Trust and the Delhi Brotherhood Society. The project provides sexuality and sexual health awareness and counselling, in the context of the other needs of the children: night shelter, drop-in centres, non-formal education, food and medical treatment. Efforts especially focus on older boys who are the decision-makers in most sexual encounters, and condom use has increased among street boys who visit commercial sex workers.

Source: Review of Best Practice in Interventions for Sexual Health, DFID, 1997.

involvement. The Maharashtra State AIDS Cell, for example, works through a nodal NGO to coordinate the work of all other NGOs in the state, while the TNSACS has a nodal NGO officer on its staff. An NGO AIDS cell has been established at the All India Institute for Medical Sciences to encourage networking among NGOs. State AIDS Cells have been authorised to make grants of upto Rs. 500,000 to NGOs.

Intersectoral Collaboration

NACO has promoted intersectoral collaboration with other ministries such as Human Resource Development, Information and Broadcasting and the Railways. NACO

BOX 3

Care and Support Initiatives

- The Continuum of Care project in Manipur has been particularly effective in providing care and support to IDUs. The pilot care and support programme was started by NACO in collaboration with OXFAM and WHO, the government of Manipur and local NGOs. Training modules have been developed for health workers and community workers, and a protocol is being developed for use in all states for implementing community-based care programmes. A handbook on home care for PLWAs has also been developed[6].
- The AUSAID-supported project by the YR Gaitonde Centre for AIDS Research and Education in Chennai uses an integrated care model providing home-based and residential care and psychosocial support to PLWAs, training for medical staff, volunteers and community workers. It links home and hospital care and has a walk-in voluntary testing centre.[7]
- The AIDS Research and Control Centre (ARCON) project in Mumbai, a collaboration between the Maharashtra government and the University of Texas, are promoting clinical ward rounds that demonstrate not only signs and symptoms to medical teams but also helps them change their attitudes and overcome fears of caring for patients. Currently two hospitals in Mumbai are participating in this initiatives.[6]

has successfully collaborated with the Steel Authority of India and the Indian Oil Corporation in HIV/AIDS prevention efforts.

Private Sector Collaborations

Effective collaborations have also been built with the private sector through the Confederation of Indian Industries and the Bengal Chamber of Commerce. The Tata Iron and Steel Company, for example, has incorporated HIV/AIDS prevention into their ongoing family welfare programmes.

4. CONSTRAINTS AND LIMITATIONS

- The states are already overburdened with the immediate morbidity and mortality of other health problems such as malaria.
- The slow utilisation of funds by the some states, delays in the release of funds from the state finance department to the programme have slowed the pace of the programme considerably. The performance and utilisation of funds across states varies from very high to very low.
- Despite the increase in general awareness of HIV/AIDS, misconceptions and risky behaviours persist. IEC capacity of most states is uneven.
- In general, little is known about the factors influencing health-seeking behaviour. Because sex and sex-related infections are especially clouded in ignorance and secrecy, there is a reluctance to seek treatment for STDs. Inadequate infrastructure results in the underutilisation of many government clinics. Many individuals prefer private practitioners or alternative health care providers.

- The unavailability and inaccessibility of condoms in some parts of the country have made increasing condom use especially challenging. Culture is another important constraining factor, given male reluctance to use condoms, female inability to negotiate it, and powerful imperatives to have children. Further, despite efforts to promote condoms for the dual purpose of family planning and protection from STD/HIV infection, they continue to be negatively perceived and associated solely with family planning.
- Widespread societal refusal to acknowledge or address sex and sex-related problems further exacerbates the problem.

Despite the progress made, there are certain constraints to HIV/AIDS prevention and control efforts in the country which have forced us to assess longstanding issues and inadequacies inherent in our country. These include the fragile health infrastructure, the dearth of credible surveillance data and the lack of skilled human resources in the field of public health which make strategic planning for AIDS prevention and control especially difficult, and socio-cultural factors and the high levels of ignorance combined with a reluctance to address issues related to sex. The AIDS epidemic has brought to the forefront many of these constraints, providing a window of opportunity for addressing them.

Future Strategy

KEY ISSUES AND PRIORITY AREAS FOR ACTION

1. INTRODUCTION

India is in the eleventh year of the epidemic. Available HIV/AIDS data and epidemiological observations indicate that HIV incidence is increasing and affecting populations previously untouched. Therefore the national response initiated by the government in 1992 and implemented in collaboration with other sectors and the Non Government Organisations, supported by bilateral donors and the UN agencies, needs to be intensified and expanded by adopting a multisectoral approach. Changes and developments have taken place during the last five years that have created a more conducive environment for this expanded response:

- Media campaigns have increased HIV/AIDS awareness and highlighted the underlying socio-cultural factors which increase susceptibility to HIV infection;
- Improvements in safe blood provision, hospital infection control and STD treatment have been initiated;
- The experience, knowledge, tools and strategies required to prevent HIV infections are now available in the country;
- India's commitment to the Programme of Action of 1994 Cairo International Conference on Population and Development set in motion changes in approach to reproductive health including STD/HIV prevention;
- The 73rd and 74th Constitutional Amendments have paved the way for decentralisation to states, districts and right down to the Panchayat level;
- India's renewed commitment to the eradication of poverty as outlined in the Ninth Five Year Plan and the recent SAARC Summit;

2. Framework for an Expanded, Multisectoral Strategy

For the implementation of this expanded response, the constraints that slowed the implementation of a number of programme components and limited the effectiveness of others during the last five years will have to be overcome. In this connection, immediate action in the following areas is seen as a prerequisite to lay the framework for the development and implementation of a strategy for an expanded response.

2.1 Advocacy and sensitisation

As in many other countries, there is still continuing denial of the epidemic at various levels in the society. Advocacy efforts in countries like Thailand and Uganda have had an important impact on public perceptions of the epidemic and were instrumental in setting policies that were conducive to the adoption of safe behaviour and practices.

The advocacy programme that was initiated in 1996 will be continued and sustained not only at the highest levels with politicians, policy makers and leaders in society but at all levels and fora. The objectives of this nationwide programme will be to:

- sensitise policy makers and implementers to all the issues related to HIV/AIDS;
- generate political commitment to prevention and care at both central and state levels; and
- advocate for legislation and policies that will enable people to adopt safe behaviour, protect the rights of people living with the virus as well as prevent discrimination and exploitation, and social policies that will reduce the impact of the epidemic.

A collaborating institution will, within the next six months, develop a plan of action for the further development and implementation of the programme. At the same time, the programme will be implemented in Kerala, Gujarat and Uttar Pradesh.

2.2 HIV/AIDS/STD surveillance data collection and dissemination

There is an immediate need for a concerted effort to study the reach and penetration of HIV infection by using the existing surveillance system and the available epidemiological tools. This surveillance data is necessary to assess the current status of the epidemic, select population groups for targeted interventions, perform trend analysis and to measure the potential impact of the interventions.

For an effective strategy to be developed and implemented, a fully functional surveillance system must be in place to enable a systematic collection of current HIV prevalence data which can be analysed and used as a basis for planning programme interventions, for making projections and to determine the possible impact and burden of the epidemic.

A plan of action for the next five years will be developed by an expert committee to fully functionalise the 62 surveillance centres and the 55 sentinel sites which have been established all over the country. The priority will be to improve progressively the quality and effectiveness of the existing centres by localising technical assistance at the state level. There are also plans to increase the number of sites to cover the rural areas.

2.3 Decentralisation and promotion of ownership at state level

It is recognised that prevention of a major AIDS pandemic in India requires commitment and action not only at the central level but also at the state level, down to the Panchayats.

Each state is responsible for preparing their plan of action. However, the level of implementation differs depending on various factors.

Prior to the implementation of the next strategic plan:

- the advocacy programme will be implemented in all states to sensitise the policy makers and to increase their level of support;

- policy dialogue will take place between especially low-response states and NACO to define roles and for effective transfer of responsibility to promote ownership;
- advocacy efforts in the form of study tours to states with high-response and efficient management structure will be organised;
- technical assistance will be given for the establishment of a management structure, which will expedite decision-making in the flow of funds, implementation of the programme and its monitoring and evaluation.

Once an effective management structure has been established at the state level, the states will be encouraged to decentralise further to involve the districts and sub-districts down to the Panchayat levels in all stages of planning, implementation and monitoring.

2.4 Capacity building and development of a human resource base

Acceleration of efforts, decentralisation, effective programme management, strategic planning and a multisectoral programme approach require not only strengthening of existing capacity but also a broader human resource base at both central and state levels. Currently, there is a shortage of skilled staff in all aspects of programming, particularly in management.

A short-term solution to solve the acute shortage in management skills would be to tap these skills from the private sector as is being done in Kerala and Gujarat. However, if responsibility for planning, design, implementation, monitoring and evaluation is to be transferred to the states, then each state will need, as a priority, a strong technical support unit which will provide the immediate technical support. In addition, this unit will together with the state technical advisory committees, develop a human resource development strategy which will be based on:

- the identification of skills required for all programming components
- the identification of appropriate training facilities and materials within the country, in the region and elsewhere.

Partnerships and collaborations in human resource development will be built among institutions, NGOs and the State AIDS Cells. The technical resource base can benefit from the development of information-exchange networks to provide for sharing of experience and knowledge within the country and in the region.

2.5 HIV/AIDS Documentation and Information Exchange

Substantial technical expertise, programming know-how and support material have been accumulated in the country. Behavioural studies are underway which will result in more tools and guidelines. Several efforts were undertaken to document either the experience or the materials, and more initiatives are underway. In order to reinforce these efforts a National information gathering and exchange mechanism will be established to:

- serve as a reference centre and a clearing house for information materials appropriate for local use;

- establish a data base on human and institutional resources available in the country on HIV/AIDS prevention and care;
- provide documentation on projects and studies that could be used as a basis for the design of interventions;
- exchange information on existing partnerships, donor and co-sponsor programmes as well as information networks.

The first phase of the establishment of this information exchange mechanism consisting of a feasibility study and a pilot project will be set up before the end of 1997.

3. Programme Priorities for an Expanded, Multisectoral Response

Within this expanded response, **Prevention of HIV Transmission** will continue to remain a priority. A second area of emphasis will be **Treatment, Care and Support** and impact reduction.

3.1 Prevention of HIV Transmission

- Prevention efforts have been shown to work. There is strong evidence from that firm political commitment, community empowerment and a multisectoral approach to address socio-economic factors has led to reduction in HIV transmission;
- Studies show that it is more cost-effective to prevent HIV infection than to cope with the consequences of a massive epidemic;
- The prohibitive costs of the new protease inhibitor treatment makes it inaccessible to the majority of people vulnerable to HIV infection or already suffering from its consequences in India.

3.1.1 Promotion of safe behaviour and practices

The prevention of HIV transmission through the promotion of safe behaviour and practices will remain the first priority in the national response to the epidemic.

Experiences gained and lessons learnt during the last five years show that implementing education and communication on safe behaviour, condom promotion, and STD prevention and treatment simultaneously through community mobilisation and participation is the most effective way to promote the adoption of safe behaviours. Such interventions have succeeded in increasing condom use and decreasing STD and HIV prevalence.

The implementation of these comprehensive interventions, during the last five years, has been limited to well-defined groups such as sex workers in the major cities. Consequently, the impact of these successful projects have so far been felt only among a small number of targeted groups and their partners. The strategy, therefore will be:

- A wider implementation and expansion of these pilot projects in all sectors to meet the needs of vulnerable groups nationally. This is necessary since infection rates are increasing and affecting populations in urban as well as rural areas;

- to address, at the same time, the key socio-economic issues affecting vulnerability to infection through multisectoral collaboration and mobilisation of the private sector.

For a wider, simultaneous implementation of these successful interventions, the following areas will need strengthening and expansion:

Education, communication and community mobilisation

- Efforts will be taken to make mass media campaigns more effective through designing messages based on results of behavioural studies, by conducting impact evaluation of interventions, and assessing access to media. A recent shift from using only government media channels to exploiting private television and radio channels as well as entertainment media will continue. At the same time, efforts will be made to expand the reach of these programmes to the rural areas;
- These mass media campaigns will be supplemented by **interpersonal communication** offering a range of options for behaviour change through dialogue, peer education and skills training. Studies point to the potential effectiveness of group discussions, especially for women, and of dialogue between men and women;
- Training in **counselling** will continue since there is still a need for counsellors to do preventive counselling and follow-up in STD clinics, in testing centres, and in health care facilities as well as to give psychosocial support to PLWAs and their families. A model HIV Counselling Centre has started functioning in Safdarjung Hospital in New Delhi. An evaluation of this pilot project and others already implemented should be used for the development of a counselling strategy for capacity building as well as for the establishment of accessible counselling centres.

Promotion of safe behaviour for youth

Since one fourth of India's population is made up of young people, the priority is to ensure that all of them have access to information and education, and will be given the skills to respond to social pressure and make the right choices:

- Advocacy efforts will be intensified to introduce family life education including sexuality in all schools. The main focus in school education will be to integrate HIV/AIDS into the teacher training and school curriculum.
- A wider implementation of education on sex and sexuality will be undertaken in schools based on the lessons learned during the last five years. Planning for implementation at state level will be done through regional seminars which will be initiated in 1997. This will be done in collaboration with the Ministry of Human Resource Development and the UN agencies.
- Education on sex and sexuality and accessibility to sexual health clinical services will be part of projects aimed at children and youth outside the school system. An agenda for action will be developed in collaboration with community-based NGOs, UN agencies, the Ministry of Human Resource Development and the Ministry of Welfare to reach street children and other groups of young people who do not attend school.

STD prevention and treatment

- Training will continue on syndromic treatment for government clinic staff and will be extended to alternative service providers.
- The provision of condoms, counselling and follow-up services and the integration of these to the Ministry of Family Welfare Reproductive and Child Health Programme and in primary health care services will receive special attention in the coming years. Special efforts will also be made to make these services accessible and culturally appropriate to women as well as to other vulnerable groups such as street children and intravenous drug users. Results from studies on healthcare-seeking behaviour will contribute to making the facilities more accessible and acceptable.

Condom promotion

- Advocacy for policies to support accessibility and availability to quality condoms should be the first step of the action agenda;
- Promotion of condom use through social marketing and community-based distribution with emphasis on the dual purpose of the condom;
- The Tamilnadu State AIDS Control Society in collaboration with an NGO is planning to conduct a pilot study to test the acceptability and accessibility of female condoms. More such pilot studies should be implemented among different population groups.

3.1.2 Blood safety programme

Steps have been taken to establish HIV testing facilities, modernise blood banks and create a legal framework. National and State Blood Transfusion Councils have been set up to oversee all aspects of the blood safety programme. Efforts will continue to:

- strengthen the training programme for staff in blood banks and in hospitals on the rational use of blood and on proper blood transfusion protocols;
- strengthen the management capacity at the blood banks to ensure the implementation of national guidelines;
- promote voluntary blood donations through communication and education programmes which will be widely disseminated and through the involvement of private practitioners and NGOs.

3.1.3 Prevention of perinatal transmission

Mother-to-child transmission of HIV is currently estimated to account for more than 90 percent of all infections in infants and children. There is a 30 percent risk of HIV transmission from an infected mother to the baby. Research studies demonstrate that the risk is considerably reduced through administration of AZT. A pilot project will be implemented to test the feasibility and effectiveness of such interventions in the reduction of perinatal transmission.

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3.2 Treat e t, C re and Support to PLWAs

A second area of priority is Treatment, Care and Support for PLWAs and impact reduction. With the epidemic into its second decade, HIV-infected people are now falling ill and progressing to AIDS. Experience from other countries and the available knowledge from within the country indicate that the responses called for by infected and affected people, as well as care providers go beyond clinical care. What they require are:

- access to health care and empathy from health staff;
- financial assistance for daily needs to make up for the loss of income;
- material assistance to meet basic needs -- food, clothing, housing, essential medicine;
- some security for survivors.

To effectively respond to these needs, the challenge for the coming years is to build up a continuum of comprehensive care which should comprise of clinical management, nursing care, counselling and socio-economic support. This challenge can only be met by inputs from the health sector as well as from all the other sectors. An agenda to further develop, strengthen and scale up effective approaches will include:

Intensive advocacy and sensitisation to:

- promote positive attitudes among health care workers. There are still reports of patients known to be HIV-infected being rejected by some medical institutions and private practitioners;
- develop empathy within the community for PLWAs and those affected; and
- set policies that will create an enabling environment by dealing with issues related to loss of employment of those infected and ill, health costs, educational and other social support for orphans and other family members.

Continued strengthening of health care provision through:

- assuring provision of essential drugs and supplies for the treatment of opportunistic infections;
- hospital infection control by strictly observing guidelines already in existence,
- setting up of counselling services to give psychosocial support for PLWAs and those affected;
- training of staff in early diagnosis, rational treatment and planning for follow-up of HIV-related illnesses by core-interdisciplinary team of trainers;
- establishment of an efficient referral system to and from testing and counselling sites, hospital or clinics, community-based services and home-based care.

Replication of successful initiatives

The projects such as the Manipur Continuum of care and other NGO community based initiatives in care and support *(Box 3: Care and Support Initiatives)* should be

replicated in other seriously affected states taking into account specific needs. AIDS Homecare Handbook and guidelines have already been developed for the design and implementation of similar projects. A national workshop is planned for the end of 1997 to exchange government and NGO experiences in the field of care in India and in other countries, to share best practices and to explore possibilities of further collaboration between NGOs, governments, bilaterals and the communities for an expanded implementation of care and support.

Community mobilisation and involvement of PLWAs

Experience in other countries have shown that the needs of PLWAs are only partially being met by the formal health and social services. Communities in many African countries and in Thailand have generated innovative responses to provide appropriate care and counselling away from an overburdened hospital system. The way forward is clearly to use this potential for community-based public health initiatives to link up prevention and care. Closely linked to community care is home care, which includes teaching family members to become care providers and the provision of drugs, counselling and hospital-based support through NGOs

Community-based services may also include day care centres, PLWA support groups, with linkages to welfare organisations, income-generating activities and various other services provided by NGOs and voluntary groups.

Mobilising PLWAs as agents of change and as peer educators can contribute effectively to prevention and care efforts in their communities. They should also be actively involved in the development of policies to protect the rights of PLWAs and in strategic planning for prevention and care.

Pilot studies on anti-retrovirals

Combination therapy using anti-retroviral drugs is in use in many parts of the world. The long-term outlook of these therapies is still somewhat uncertain but the results are encouraging in the improvement of the quality of life of PLWAs. A pilot project on the use of antiretroviral drugs is being planned to test their effectiveness in India.

Studies related to impact reduction

Individuals and families need assistance in the years between infection and during the time of illness. The immediate need is to implement social policies to provide this assistance and to reduce the impact of HIV/AIDS on the individual and the household. To do this, studies are needed:

- To ascertain the coping mechanisms that exist within families. This will be necessary to determine the impact of HIV/AIDS on households and on individuals
- Since the health insurance system in India is almost non-existent, the country will have to find resources financial and non-financial to cope with the mounting health costs. Studies are necessary to determine: accessibility to care, which services are feasible in

alternative models of care, their costs and who will bear the costs; it will be important to know the treatment costs in relation to income and the cost effectiveness and sustainability of community-based care and support.

- It will be important to assess the number of children that might be affected and how their needs can be met; the impact of AIDS on school attendance and the resultant increase in child labour.
- Equally important will be studies to assess the impact of the epidemic on the size and quality of the labour force as well on the public and private sectors.

All this information and knowledge is necessary to plan a humane support network for those living with the virus and their families.

4. PROMOTING A COLLECTIVE RESPONSE

It is becoming increasingly evident from experience in other countries that effective AIDS prevention and care are those that have broadened their focus beyond the health sector to create a supportive environment to enable people to adopt safe behaviour and practices.

The link between poverty and susceptibility to infection has been established. Likewise the inability of marginalised and poor populations to protect themselves has also become evident. Poor and marginalised populations are unlikely to participate in strategies promoting safe behaviour if other concerns such as economic survival, children's education are seen as higher priorities. A study among street children in five major cities in India revealed that street children's priority needs are health care, shelter and food. Results of a pilot study in Calcutta showed that the main concern of sex workers was provision of schooling and child care facilities for their children.

Therefore programmes will have to address not only the prevention of HIV/AIDS transmission but at the same time address the key issues affecting vulnerability such as poverty, urbanisation, migration as well as cross-border factors and most important gender disparity. Programmes that lead to improvements in the status of women open up the possibility of improvements in all dimensions of their lives including protecting themselves and their children from infection. All this calls for a collective response through:

- **Empowerment of communities** by actively involving communities, NGOs and women's groups from both health and non-health sectors in policy development as well as in strategy design, implementation and monitoring. This calls for improved mechanisms to advocate and support community-based responses which would ensure participation and strengthen the sense of community ownership.
- **Widening the response to include other sectors:** An agenda for action should be developed that will, for example, integrate HIV/AIDS prevention and care with rural development efforts, with income generating projects that are either already in place or will be established such as credit programmes, agricultural extension services for farmers, women's cooperatives or savings schemes. Widening the response in this way requires coordinated action to form viable public coalitions and partnerships between the National

AIDS Control Programme and the different agencies and ministries in areas like education, rural development, family welfare, water and sanitation in order to strengthen their links with each other as well as with the communities they address.

- **Mobilisation of the private sector:** HIV/AIDS is as much a public sector problem problem as it is a private sector concern. Efforts are being initiated to advocate the formation of partnerships between NGOs and the private sector and to promote good practice in partnerships. However the key to future action lies in the private sector going out into the communities in which they are placed. In times of declining financial support, linkages with the private sector can pave the way to ensuring financial sustainability of the programmes.

The HIV/AIDS prevention and care programme is at a critical juncture. The Government of India is fully committed to preventing a catastrophic epidemic. Therefore a concerted effort will be made to accelerate, intensify and expand the national programme that has been implemented. At the same time immediate action will be taken to confront the key issues that increase susceptibility to HIV infection.

References

1. Bloom, David and Godwin, Peter (Eds): The Economics of HIV and AIDS: The Case of South and South-East Asia. Oxford University Press, New Delhi, 1997.

2. Basu, Alaka M., Gupta, Devendra B. and Krishna, Geetanjali: "The Household Impact of Adult Morbidity and Mortality: Some Implications of the Potential Epidemic in India." In: The Economics of HIV and AIDS. The Case of South and South East Asia. Ed. by Bloom, David and Godwin, Peter. Oxford University Press, New Delhi, 1997.

3. Sathiamoorthy, K., and Solomon, Suniti: 1997. "Socio-economic realities of Living with HIV. In: Socio-economic Implications of the Epidemic. Edited by Peter Godwin. UNDP Regional Project on HIV and Development, 1997.

4. The Male Declaration. Report, Ninth SAARC Summit. UNDP. Male, Maldives, May 12-14 1997.

5. Bharat, Shalini: Household and Community Response to HIV/AIDS in Mumbai, India. Tata Institute of Social Sciences, 1996.

6. Chela, C.M, Lal,Thakur, B.B.: Emerging Issues in HIV/AIDS Care in India. Unpublished report.

7. Wrap-Up: A YRG CARE Health Letter, vol. 1, No. 1, January 1997.

Bibliography

Piot, Peter, Islam QM., Sexually Transmitted Diseases in the 1990s: Global Epidemiology and Challenges for Control, Sexually Transmitted Diseases, 1994, vol. 21, No. 2, Suppl: 7-13.

Jayakrishnan, B: All-India Rapid Survey on Truck Drivers Halt Points: For STD/AIDS Prevention Among Intercity Truck Drivers. The Indian Institute of Health Management Research, Jaipur, 1995.

United Nations Development Programme: Annual Report of Development in India. New Delhi. UNDP, 1993.

Tamilnadu HIV Risk Behaviour Surveillance Survey: Baseline Wave - 1997. AIDS Prevention and Control Project, Voluntary Health Services, Chennai.

Merson, M: The HIV/AIDS Pandemic: Global Spread and Global Response. IXth International Conference on AIDS, Berlin 1993.

D'Cruz-Grote, Doris: Prevention of HIV Infection in Developing Countries. The Lancet 1996, vol. 348, 1071-74.

Decosas, Josef: HIV and Development in AIDS. vol 10, supplement 3, 1996.

Cornips, MJH: The Complexity of Dealing with HIV/AIDS in India: A Focus on Kerala State's HIV/AIDS Health Policy. 1997. Unpublished project report. Jawaharlal Nehru University, New Delhi.

Gupta, Indrani: Planning for the Socio-economic Impact of the AIDS epidemic: A View from India. 1997. Unpublished paper.

The Status and Trends of the Global pandemic. Final report. Official Satellite Symposium, 5-6 July 1996. XI International Conference on AIDS. 7-12 July 1996

Country Scenario Update, December 1995. National AIDS Control Organisation, MOHFW, GOI

Aide Memoire, World Bank Mid-Term Review, 1995.

USAID HIV/AIDS/STI Prevention and Control Activities in India: Assessment of the Status of the Epidemic, Current Programme Activities and Recommendations for the Future. February 1997.

Panday, CS et al. Economic Consequences of HIV/AIDS in India. National Medical Journal of India. Vol 10, No. 1, 1997.

India: the Road to Human Development. UNDP, New Delhi, 1997.

AIDS Prevention and Mitigation in Sub-Saharan Africa: AN Updated World Bank Strategy. April 20, 1996. Report No. 15569-AFR

Human Development Report, New York, 1997.

Interventions for Sexual Health. Project Memorandum, November 1995, DFID.