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## Positive Voices

Emerging
Governance
Issues
on
HIV and AIDS





Time to Act II

# Positive. Voices

Emerging
Governance
Issues
on
HIV and AIDS
in ASia







actionaid international

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## **Eoreword**

I congratulate the initiatives of Time to Act II report "Positive Voices – Emerging Governance Issues on HIV and AIDS in Asia", which is in continuation of the earlier report Time to Act in 2004. ActionAid International has identified key priority areas – HIV and AIDS is one of the six core themes and we work with HIV infected and affected people with larger mass based movements to advance them to work towards 'Universal Access to Care'.

This initiative is based on informing and informed understanding about causes and issues of HIV and AIDS from the perspective of governance and power relationship, unequal and unjust power equations. HIV and AIDS is also a political issue, warranting a political response from governments and the corporate sector. The role of civil society and non-government organisations is crucial in making change happen on ground. ActionAid is committed to galvanise synergy and facilitate co-ordinated action.

ActionAid International, Asia commits to place HIV and AIDS as a focus of our work to advance the rights of the most disadvantaged and vulnerable people, particularly their right to healthcare. Compassion and a humane response are necessary to deal with HIV and AIDS that has emerged as a public health challenge in Asia.

The issue of HIV and AIDS has socio-political, gender and cultural implications. There is a need to initiate organised action and concentrate public effort to fight the stigma and discrimination against people living with HIV. Changing this situation requires both societal action and public advocacy. We hope this report will contribute to such an effort.

I would like to congratulate the team Dr. G. Mahesh, P. Ravindranathan, Mukul Sharma, and all the contributors who made this report possible.

We look forward to your comments, support and solidarity to build a broader social and political movement to change this situation.

In Solidarity,

#### John Samuel

International Director - Asia ActionAid International

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## **Executive\_Summary**

At the HIV and AIDS regional meet of ActionAid International in August 2005, participants set out the mandate for the organisation's second report on HIV and AIDS. Its primary thrust was that AIDS is a political issue. The statement emerging from the meet further outlined its wider linkages – as an issue of people's rights, of human and economic development, dignity and well-being. It advocated intensifying the HIV and AIDS control efforts by addressing the political will of all concerned, with the objective of creating conditions that decrease vulnerability to HIV as well as ensuring access to means of prevention and treatment.

Despite relatively low levels of HIV prevalence, the problem still looms large enough in Asia. Estimated prevalence rates of 0.9 per cent in adults in India and 0.1 per cent in China signify its importance in two of the largest and rapidly economically growing countries of the continent. Asia is home to 60% of the world population therefore the epidemic here will have a massive implication globally. Some 8.2 million people are now estimated to be living with HIV in Asia, of which around 2.3 million are women. 1.2 million people were newly infected in 2005.

This report poses issues for shared thinking. How do we best minimise the suffering caused by the HIV and AIDS epidemic? The experiences, demands and aspirations of the affected people guide this effort.

#### Some Voices of Affected Men, Women and Children

- 'We want acceptance, understanding, and the removal of discrimination and stigma at all levels. Effective policy and decision making will help make that happen.'
- 'We want access to care and treatment for all opportunistic illnesses for PLWHA. We want free
  ARV treatment followed by supplements in nutrition. We deserve adequate care and support
  centres and groups for infected individuals, orphaned children, grandparents, and affected
  families.'
- 'We want access to more information on HIV and AIDS, and the opportunities to develop our capacities and skills so that we can help ourselves economically and socially, and live a positive life with dignity'
- 'We want a voice in policy and decision making so that we are not forgotten, so that we are considered when programmes and policies affecting PLWHA are being developed.'
- 'We do not always have the opportunity to be financially independent and secure. We are forced to rely on our families or husbands, and if they become ill, desert or abuse us, we must find a way to sustain our children and ourselves. Thus we want opportunities to develop our education, capacities and skills, and chances to generate an income.'
- 'We want to have lots of friends.... we want to share our fears and dreams with people around
  us. We want to study, play and laugh with other children in our school. We want to be included
  in all activities in our school.'
- 'When we are sick and can't attend school, we hope our teacher will not scold us for being absent. When we fall sick, we want a nice doctor to give us medicines that will make us well soon. We want health food that will make us strong so we won't keep falling sick.'

#### What is Needed to Respond to These Voices?

A Paradigm Shift: Thinking Differently

This report is based on the understanding that AIDS control cannot be carried on in isolation. The positive people's demands tell us that very clearly. The spread of HIV and the extent of suffering it causes is influenced by policies affecting all spheres of people's lives; economic, social, cultural and political. The extent of socio-economic development and the models adopted to achieve economic growth are crucial determinants. Colonial and neo-colonial structures of governance have generated conditions in Asian countries that make them vulnerable to HIV.

Commercial sexual activity and intra-venous drug use are the two major sources of HIV transmission in Asia. Chronic deprivation and acute insecurity, manifested in wars, internal conflicts, famines and other emergency situations, stoke the flames of the HIV epidemic. Both natural and man-made disasters bring with them an immediate and devastating additional danger – increased risk of HIV infection. Cross-border and domestic population movements could significantly contribute to the rapid transmission of STI/HIV. Trafficked women and children are highly vulnerable and are subject to multiple forms of exploitation. There can be no hope of controlling spread of HIV if the present dominant kind of inhuman economic 'development' is not stopped.

Two conceptual leaps appear necessary within AIDS discourse'normalising' the epidemic and reinstating the notion of 'social responsibility' in all relationships; the exclusivist approach will not do. The low levels of infection rates across Asia offer tremendous opportunities for concerted actions on several fronts in order to forestall further advances of the virus. This requires an approach to AIDS control that addresses HIV and AIDS as a form of social and human suffering, not as an issue of loss of economic productivity, of law and order, or of national security.

#### Generating Humane and Just Governance

The World Bank allocates large sums of money to fight HIV and AIDS; the money will only be available if the borrowing countries first agree to adhere to IMF loan conditions. These, however, will only aggravate the conditions that create vulnerability to HIV.

The Millenium Development Goals articulate the objectives for human development that can limit the vulnerability to HIV, dealing as they do with amelioration of poverty and malnutrition, improving child health and control of communicable diseases. Achieving the MDGs by improving the quality of life of people and not merely through technological fixes will make AIDS control efforts more effective. The right to food, to livelihoods with dignity, to comprehensive health care have to be the corner stones of qovernance.

right to food, to livelihoods with dignity, to comprehensive health care have to be the corner stones of governance.

In Asia, the region with the second highest need for AIDS treatment, the number of people receiving ART has increased three-fold from 55,000 to 155,000 in the past 12 months. However, the overall proportion of people in the region with advanced HIV infection receiving ART remains low, mirroring the global average of around 15 per cent. That means that around one million Asians with HIV who would currently benefit from ARV do not have access to the treatment.

The principal reasons of extremely limited access to ART is the high price tag of patented medicines and the limited functional capacities of health service systems, further being weakened by the policies of commercialisation of public services and corporatisation of the private sector. The delivery of ARV can succeed if there are 'functioning public health services that are generally accessed for curative care.'

The HIV control strategy has to be mainstreamed as a part of the wider strategy for disease control. The general health services infrastructure in several Asian countries is well developed although they may be functioning sub-optimally due to resource constraints and policy shifts. Current 'quasi-governmental' stewardship of HIV and AIDS control has to be re-examined by exploring the possibility of involving public sector health services in a larger way.

The TRIPS Agreement was a means to dampen the challenge to the monopoly of US and European pharmaceutical companies. The importance of this challenge will be obvious from the fact that Indian companies today offer a cocktail of anti-retrovirals at US \$200 per year in stark contrast to \$10,000 - \$12,000 charged by transnational corporations less than four year back.

Despite a number of internationally recognized codes of ethics to ensure the protection of human subjects in biomedical research, one still finds instances where the applicability of these has not been given importance. There have been incidents during the AIDS vaccine trial, which have led to further concerns about the involvement of humans in research.

Appropriate Knowledge Management is necessary for generating the right kind of research that will lead to holistic understanding of issues and then using it for planning of integrated approaches for AIDS control.

#### Financing of HIV and AIDS Control

Consideration of issues in financing of AIDS programmes raises larger questions about government spending on health service systems as a whole. A holistic support system, integrating preventive and promotive measures along with treatment with ARV has to be evolved. Rational use of ART as a part of comprehensive care of HIV positive persons and monitoring of ART by civil society is essential.

National budgets of Asian countries indicate clearly that while for some health has not yet acquired

the priority that it deserves, for others health seems to have lost priority. There is little hard data at the disaggregated level to use for analysis or for any planning or forecasting budgetary exercises for most Asian countries. Most of them are yet to prioritize the issues in resource allocation and disbursement for AIDS control.

Current government funding patterns show an encouraging trend: governments have been increasing their budgets. However, the challenge for Asian governments is to prioritize and accordingly increase their investment if they are serious about tackling the epidemic. There are also problems of leakages and non-utilisation of funds.

Private sector financing (including NGOs and employer based initiatives) constitutes a very minor proportion of total spending across the Asian region. The role of the public sector will remain critical in terms of prioritising investments both for and within the health sector, as well as in the signals that it sends to the private sector.

Out of contracts worth 3.4 billion the GFATM signed between 2002-5, only 1.6 billion dollars were disbursed. Donors and countries hit heavily by HIV and AIDS are now asking why funds are sitting lazy in the World Bank Safe. Except for Cambodia and Laos, per capita health investment by the Global Fund in Asian countries has been less than \$1per capita. In Cambodia and Laos it has been between \$1-\$3.

#### How Can This Paradigm Shift Be Made Possible?

People Living With HIV and AIDS themselves demonstrate the way forward; that collectivisation is the most effective tool of the marginalised.

Asian countries need to come together to think for themselves about the wellbeing of their people, especially the most socially vulnerable. They have to develop their own path of development, not be forced to accept the terms of the World Trade Organisation, the TRIPS agreement, the structural adjustment of their economies that suits global capital and increases disparities.

The Asian countries also need to come together to evolve their response to HIV and AIDS as suited to their disease profile, health services, social and cultural context. They must learn both positive and negative lessons from other countries of the region and outside, analysing all experiences critically for themselves.

Governance is the system of values, policies and institutions by which a society manages its economic, political and social affairs through interactions within and among the state, civil society and private sector. Processes of political, administrative and technical decision-making have to be rooted in the social context with a realistic long-term view.

## **Abbreviations**

AIDS Acquired Immuno-deficiency Syndrome APN+ Asia Pacific Network of People Living with HIV/AIDS APPACHA Asia Pacific Peoples' Alliance for Combating HIV/AIDS ART Anti- Retro Viral Therapy **ASEAN** Association of South East Asian Nations AZT AZIDOTHYMIDINE **CSDS** Centre for Studies on Developing Societies CSWs Commercial Sex Workers **EFV** Efavirenz (HIV-1 specific, nonnucleoside, reverse transcriptase inhibitors) **ESIS** Employees State Insurance Scheme GATT General Agreement on Trade and Tariffs GAVI Global Alliance for Vaccines and Immunisation GDP Gross Domestic Product GFATM Global Fund to Fight AIDS, Tuberculosis and Malaria GIPA Greater Involvement of People Living with HIV/AIDS GNP Gross National Product GNP+ Global Network of People living with HIV/AIDS HAART Highly Active Antiretroviral Therapy HIV Human Immuno-deficiency Virus HRG High Risk Group IAVI International AIDS Vaccine Initiative ICAAP International Congress on AIDS in Asia and Pacific ICMR Indian Council of Medical Research **IDUs** *Injection Drug Users* IEC Information Education and Communication IFIs International Financial Institutions ILO International Labour Organisation IR Indian Railways IMF International Monetary Fund MDG Millennium Development Goals MSF Médecins Sans Frontières MSM Men having Sex with Men MTPDP Medium -Term Philippine Development Plan NACC National AIDS Coordination Committee (Nepal) NACO National AIDS Control Organisation

NACP	National AIDS Control Programme
NAM	Non Alignment Movement
NCHADS	National Centre for HIV/AIDS, Dermatology and STDs (Cambodia)
NGO	Non Government Organisation
NSACP	National STD and AIDS Control Program
ODA	Official Development Assistance
PEPFAR	President's Emergency Plan for AIDS Relief
PHM	People's Health Movement
PLWHA	People Living With HIV and AIDS
PNAC	Philippine National AIDS Council
PRSP	Poverty Reduction Strategic Paper
RCH	Reproductive and Child Health
SAARC	South Asian Association for Regional Cooperation
SAIL	Steel Authority of India Limited
SAP	Structural Adjustments Programmes
STD	Sexually Transmitted Diseases
STI	Sexually Transmitted Infections
ТВ	Tuberculosis
TI	Targeted Interventions
TRIPS	Trade Related Aspects of Intellectual Property Rights
UK	United Kingdom
UN	United Nations Organisation
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNESCAP	United Nations Economic and Social Commission for Asia and the Pacific
UNICEF	United Nations International Children Emergency Fund
UNGASS	United Nations General Assembly Special Session on HIV/AIDS
UNTAC	United Nations Transitional Authority in Cambodia
USA	United States of America
UTI	Urinary Tract Infection
VAT	Value Added Tax
VCTC	Voluntary Counselling and Testing Centres
WHA	World Health Assembly
WHO	World Health Organisation
WTO	World Trade Organisation

Introduction

Time to Act:

Towards
a
Paradigm
Shift



View AIDS as an issue of Socio-economic development and recognise the need for contextually specific AIDS action.

- The problem is still large enough in Asia. Estimated prevalence rate 0.9 per cent in adults in India and 0.1 per cent in China signify its importance in two of the largest and rapidly economically growing countries of continent.
- **T**here can be no hope of controlling the spread of HIV if a certain kind of economic 'development' is not stopped.
- The vulnerability to HIV lies not only in the economic resources at hand; North America and West Europe should then have been immune to it. Also important is the nature of social relationships supported by the economic structure and the culture context.
- **T**he time has now come to relate AIDS control to the larger health service system.
- **Two** conceptual leaps in AIDS discourse appear necessary reinstating the notion of 'social responsibility' in all relationships, and 'normalising' the epidemic.
- Rational use of ART as a part of comprehensive care of HIV positive persons and monitoring by civil society is essential.
- **C**onsideration of issues in financing of AIDS programmes raises larger questions about government spending on health service systems as a whole.
- PLWHAs themselves demonstrate the way forward; that collectivisation is the most effective tool of the marginalised.

wenty years into global AIDS control initiatives, there are concerted calls for a paradigm shift. The Asian People's Charter on HIV and AIDS (2004), several other civil society initiatives as well as public health analysts have observed on the need to think of HIV and AIDS in a more comprehensive framework and accordingly, to do things differently. 'Asia may still be able to slow down and even stop the spread of HIV. But this calls for a paradigm shift of response strategies, political commitment and resource allocation.' This reflects the realisation that we have to think differently about HIV and AIDS as well as about AIDS action. Yet, we continue much as before, and the chief of UNAIDS speaks merely of 'scaling up' the present efforts. So the challenge is, how do we think about the issue 'outside the box'?

It is well recognised that AIDS is rooted in the social, economic, political and cultural context. But AIDS control policies rarely address these dimensions, at national, regional or global levels. This was the finding of the External Review Committee of the WHO's Global Programme on AIDS in 1992. Barnett and Whiteside came to similar conclusions in 2002: 'the main focus has been on the clinical medical, and behavioural levels, with scant attention paid to country programmes, ministries of health and government policies, to the broader factors which contribute to the risk of AIDS.<sup>21</sup> At the HIV and AIDS regional meet of ActionAid International in August 2005, participants set out the mandate for this second report on HIV and AIDS. Its primary thrust was that AIDS is a political issue, an issue of people's rights, of human and economic development, dignity and well-being.

The politics of AIDS arises both from its social determinants and from the way the approach to AIDS control is shaped. The dominant paradigm of AIDS action until now has had two characteristics. One, the isolation of AIDS from other problems affecting people's lives, and second, the absence of an understanding of the impact of international power equations on national and local perceptions and decision-making about actions for AIDS control. This report is based on the following assumptions about the politics of AIDS action that, we hope, will contribute to the making of a more comprehensive paradigm:

a) The vulnerability to HIV and AIDS and the effectiveness of AIDS control programmes are both dependant on the general quality of life, as well as the capacity of health service systems to provide comprehensive care. Both are outcomes of historical processes.

Focusing on AIDS-specific techno-managerial solutions (such as IEC material production, condoms, antiretroviral therapy or ART) is a market-oriented perspective that makes access to all these 'tools' of AIDS control the major issue. Linking AIDS action with the societal issues that shape people's quality of life makes it a part of the politics centred on the theme of social and economic development.

b) There is a contextual specificity of the epidemic and universal approaches to AIDS control will not work. Therefore the question to be addressed is, is there an 'Asian' specificity? What patterns of commonality and diversity can we see across the Asian sub-regions or countries? What is the appropriate thrust for AIDS action for Asia?

Accepting universal international prescriptions of 'best practices' for AIDS action uncritically and advocating their implementation is one kind of political response to the AIDS epidemic. A different political response is to consider contextual specificities and start by drawing upon local

'We have to think differently about HIV and AIDS as well as about AIDS action. AIDS is a political issue as well as an issue of political rights of human and economic development, dignity and well being...' ActionAid Asia regional meet in Dhulikhel, Nepal.

societal resources social, cultural and financialto plan for minimizing the vulnerability to HIV.

Adopting the latter of the political options on each of these points, that is viewing AIDS as an issue of socio-economic development and recognizing the need for contextually specific AIDS action, this report explores the situation in Asia to see historically which processes are likely to increase vulnerability of our societies to HIV and what the possible mitigating factors are that we can draw upon to build an adequate and appropriate response.

## Contextualising AIDS in Time and Space

AIDS has been a major cause of suffering in the world in the past 25 years. The biological disease agent, Human Immuno-Deficiency Virus (HIV) found a conducive social environment in which to thrive and spread in the last quarter of the 20th century. Starting from the western hemisphere it spread eastward to Asia. Sub-Saharan Africa proved extremely vulnerable to the onslaught, and today has over 7% of infected adults, with one-fourth to one-third of adults in several countries estimated to be infected and likely to die in the next 10-20 years. Fortunately Asia, which has almost 60% of the world's people in 45 countries, is not yet affected to this extent (see Table I). Data is now available on HIV sero-positivity for over two-third of the Asian countries, atleast for 2003 and 2004. Despite all its limitations, this provides some idea of the extent of HIV infection. UNAIDS has used the data to generate regional estimates for 2005, showing that the overall prevalence rate of HIV positivity among adults (15-49 years) in Asia is only about 0.4%. The epidemic has reached the highest levels in Cambodia (2.6 %) and in Thailand (1.5%). About half the countries in Asia have levels of 0.1% and below, that is, one fifth or less of the levels in North America and West Europe (ie. 0.5%). Only 5 countries have levels of 0.5% and above. Even in Central Asia where the epidemic is growing very rapidly, stabilisation has begun in some countries at well below this level.

The low level of positivity in Asian countries relative to other continents is reassuring, and points to conditions being significantly different in Asia as compared to Africa. While rates in Latin America are similar, the conditions leading to them are very different. What are the differences between Asia, Africa and Latin America? This is a moot question that requires to be answered if we are to understand the societal determinants of AIDS and identify the important points of intervention in each situation.

Even when shorn of the hype of the estimated magnitude of the epidemic, it is still large enough in Asia to require addressing as a major problem of people's suffering. Estimated prevalence rates of 0.9% in adults in India and 0.1% in China signify its importance in two of the largest and currently most rapidly economically growing countries of the continent. Also, disease processes in societies are extremely dynamic and changes in the agent, the environment and/or human resistance, can lead to dramatic shifts in the epidemic curve. Therefore, we need to heed the lessons learnt from experience of the epidemic until now. The following in-depth analyses illustrate the linkages between the social, economic, political, cultural and psychological conditions that generate the context for spread of HIV.

Table I: Global Regional Estimates of Prevalence of HIV Infection for 2005

Continent	Regions	Total Population		Prevalence of HIV in adults, in %	of HIV in women^^		Estimated HIV positive persons	
		Number (in millions)*	% of global^	Average (estmated range)**	HIV positive adults	Number (in million)**	Percentage of global total^^	
Africa	Sub-Saharan	751.273	11.62	7.2 (6.6-8.0)	52	25.8	64.06	
	North	154.666	5.70	0.2 (0.1-0.7)	43	0.51	1.27	
Asia	West	214.323						
	South	3533.691	54.66	0.4 (0.3-0.6)	24	8.27	20.53	
	SouthEast							
	East							
	Central	157.400	7.03	0.9 (0.6 -1.3)	27.5	1.6	3.97	
Europe	East	297.328						
	West	431.060	11.78	0.5 (0.3-0.7)	25.7	1.92	4.76	
North America		330.608						
Latin America		522.216	8.07	0.6 (0.5-0.8)	32	1.8	4.46	
Caribbean		39.129	0.60	1.6 (1.1-2.7)	46.6	0.3	0.74	
Oceania		33.056	0.51	0.5 (0.2 - 0.7)	52.07	0.074	0.18	
TOTAL		6464.750				40.27		

Sources:

Note: HIV prevalence data for North Africa and West Asia, Central Asia and East Europe have been clubbed together by UNAIDS and could not be disaggregated since country-wise figures are unavailable for 2005. Therefore data for Asia has been presented in three parts

West, Central and South-Southeast-East.

<sup>\*</sup>http://esa.un.org/unpp, \*\*UNAIDS/WHO (2005) AIDS Epidemic Update,

<sup>^</sup> data computed from http://esa.un.org/unpp,

 $<sup>{\</sup>it ^{\wedge}} \, {\it data \, computed \, from \, UNAIDS/WHO \, (2005) \, AIDS \, Epidemic \, Update.}$ 

Estimated prevalence rates of 0.9% in adults in India and 0.1% in China signify the importance of this epidemic in two of the largest and currently most rapidly economically growing countries of the continent.

Oranong Phaowattana, a village headwoman in Northern Thailand (one of the most affected regions in Asia), popularly known as Khru (teacher) Noi, had narrated to Ann D. Usher in 1993 the conditions that led to spread of HIV among her community members: "First, the forest died ...", she said. Khru Noi talked about how the forest once formed the fabric of people's lives, providing everything from food and shelter to spiritual meaning. But gradually, the forest began to disappear. The companies started coming in felling the big trees. ...At the same time, others were squeezed off their low-land farms to make way for dams, roads and expanded rice or cash crop cultivation, and followed the timber roads into the uplands."

She explained that Northern people used to derive almost everything from the forest. As the market economy reached the village and values from "the outside" became more dominant, people started consuming more buying radios, TVs, motorcycles, refrigerators. ... But as the forest died, so did the sources of cash income. As expectations grew, they became increasingly difficult to fulfil. Gambling, drinking, drug addiction became prevalent. Lacking official land title, many found it impossible to acquire credit from banks, and were forced to seek loans at exceedingly high interest rates from local moneylenders. Unable to pay off the debts, farmers were faced with the prospect of losing their land.

In this context, said Khru Noi, labour by young people became a commodity with significant value in the outside market. The men mostly went off to work in industrial factories and some of the women entered the sex industry. In the early years, children were frequently tricked into prostitution by conniving agents, or sold by their parents who were desperate for cashsometimes unknowingly. But increasingly young women left on their own, often with a strong sense of pride and duty towards the family. They were tempted by the big city, the attraction of the bright lights and excitement, the glamour shown by the media. The exodus was accelerated by many other factors as well, such as the Vietnam War and later, the growth of tourism. ... The culture adjusted itself to the economic necessity. Women who had worked for a time as prostitutes in cities in Thailand or abroad, came back to the north, married and settled down. They bought their families houses that were bigger and more colourful than their neighbours'; they donated money to enlarge and beautify temples. They supported younger siblings' education, and paid off debts to keep the land. ... This is how it came about," said Khru Noi. ....

1987 was Visit Thailand Year, the Thai government's all-out effort to put the country on the map for fun-and-sun-seeking vacationers. Over the course of that year, tourism became the country's number one foreign exchange earner, surpassing rice and textiles.... Indeed, 1987 appears to be the year AIDS tightened its grip." <sup>3</sup>

This description seems to fit so many population groups all across Asia today, with only minor variation in detail. There can be no hope of controlling spread of HIV if such economic 'development' is not stopped.

Conditions leading to Uganda's epidemic have been traced further back by Colleen O'Manique (2004) to land, labour and social policies of the colonial rulers. 'During the colonial period we see in Uganda the introduction of the system of migrant labour, and the economic development of some regions at the expense of others, causing significant societal disruption at multiple levels – from the personal to the regional. These processes further eroded women's position within their communities and precipitated the breakdown of the extended family system in some regions – the very system that is the supposed backbone of the contemporary community response to HIV and AIDS. The immediate post-colonial period further entrenched the conditions

that led to Uganda's high levels of HIV spread during the 1980s. .....(This is) not to paint a romantic picture of a rosy past – there were serious intra and inter-societal tensions in the region before the British arrived. In Bayart's words, Africa did not have to wait for the arrival of the Europeans before it witnessed the disappearance or weakening of its communities through conquest, economic decline, cultural assimilation, demographic weakening or ecological disaster. Nevertheless, the dislocations that marked the onset of colonial rule were radical and sweeping and did overthrow a more stable order.<sup>41</sup>

Thus, macro policies and conditions at national level, pandering to demands of international power wielders and viewed to be in the best national interest by the ruling elite, can generate environmental, social and economic havoc. The conditions created in existing communities can put their very survival at risk, especially for those with the least access to resources and role in decision-making. They are forced to compromise on some dimensions of their quality of life in order to survive. Further, as the societal dynamics change over time, the compromises made become part of the accepted way of life. Livelihood patterns are altered, lifestyles change, social relationships lose their earlier meaning, new forms of social interaction develop, norms and values change.

This seems to reflect the experience of large parts of Asia. The following recommendation of the Epidemic Update of the UNAIDS (2005), needs to be understood in this light, 'Bringing AIDS under control will require tackling with greater resolve the underlying factors that fuel these epidemics – including societal inequalities and injustices.<sup>15</sup>

Asia's challenge, therefore, lies in overcoming the impact of its colonial past and the present forms of neo-colonisation by global capital as well as correcting the inherent internal disparities and social hierarchies. Recognising this as part of the challenge for AIDS control is a necessary step for evolving more long-term approaches that are rooted in the societal context and its specificity.



Asia has the greatest poverty and some of the worst health indices. At the same time, the major national economies of the continent have had unprecedented and continuous growth over the last twenty years. So now the challenge is to invest in improving the quality of life of the majority. Learning from experiences of the kind described above, it is not only economic opportunities that have to improve for the majority; the nature of work, the family and community, human relationships and values have to be structured in ways that lead to all-round wellbeing.

The uniqueness of Asia lies in its still being largely rural (except for the Central and West Asian countries, which constitute approximately 10% of its population) and yet with fairly high levels of development of national systems and industrialisation. Africa, the other less urbanised

#### Asian Paradox

In spite of good growth in major national economies in the continent, Asia has the greatest poverty and some of the worst health indices. It is not only economic opportunities that have to improve the majority, nature of work, the family and community and human relationships and values have to be structured in ways that lead to all round well-

being.

continent, has less developed systems and what were developed was allowed to degenerate in the period of structural adjustment undertaken there in the 1970s'. Asia's strength thus lies in its multiplicity of resources and pluralism of cultures. It is the continent with the greatest number of ancient civilisations that are still part of the lived memory of the people. It has given the world all its major religions. It has a well-developed tradition of co-existence, of pluralism, of thought currents, lifestyles and worldviews; the atheist, the secular and the believer in diverse faiths live in the midst of a majority of practitioners of mainstream religions. It has celebrated and provided social space to the homosexual and women in prostitution, despite giving primacy to the faithful, lifelong, monogamous conjugal relationship. So, when Peter Piot, the chief of UNAIDS says, 'In order to prevent the spread of HIV, a combination approach is required. We need to promote abstinence, delay of sex, faithfulness and the use of condoms. No single approach will work. 'I is the most suited to the Asian cultural context. It is here that effective ways to implement the pluralistic approach must be adequately developed. Freedom of expression of individual and group orientations and preferred ways of life have to be respected, along with promotion of a sense of mutual responsibility in relationships, which are personal and yet social.

Peasant culture is shaped by its proximity to nature and well-recognised interdependence between human beings and nature, humans and humans, necessitating mutually responsible behaviour. Its uncertainties due to the vagaries of nature also lead to cooperation and pluralism in practice. Urbanisation and 'industrialism' detract from these positive social attributes, promote individualism, commoditisation and alienation between people, thereby increasing vulnerability to challenges such as HIV. Asian societies are attempting to mediate between 'tradition' and 'modernity', the urban and the rural, in their own way. How far they will be able to evolve liberative forms of social institutions will create the sustainable social bulwark against HIV and AIDS.

Required is a politics of the people with the vision of a comprehensive democracy; not merely a democracy in terms of the right of adult franchise, but democracy as a way of life that pervades the relationship of human beings with nature, society with the state and the market, employers and employees, individuals within their community and men and women within families and in friendship. AIDS action must contribute to the politics of building such a democracy across Asia and the world.

The status of women is lower than that of men in all societies across the globe, but the imbalance of power in the contemporary times is most marked in Asia. The view of women as objects to serve and fulfil family needs and male desires is dominant. The sex ratio is in favour of males in large parts of Asia, the practices of female foeticide, infanticide and high maternal mortality rates are its direct manifestation. For HIV and AIDS, the relationship existing across genders has increased vulnerability of the more 'powerful' males as well. The vulnerability of females is increasing secondary to that of the males, whether as wives, commercial sex workers or just sexual partners. The rapidly increasing economic disparity and societal shift towards a market orientation is leading to increasing 'supply' of human beings for exploitation on one hand and on the other, an increasing 'demand' for human services that treat them as commodities. It is most conducive to the spread of HIV, putting both men and women at risk. If such processes are not checked, the spread of HIV is impossible to limit on a sustained basis (except what limiting will happen through nature's own processes of host and agent adaptation between the virus and the human species). Whether it is the rapidly escalating numbers of migrant labour, of trafficked women coerced into the sex trade, or substance abuse such as alcoholism or drug addictions, they are all outcomes of structural violence, which the present national and international macro policies are accentuating.

The present phase of societal flux has the potential for change that renews our social institutions in egalitarian, liberating ways. Required is a politics of the people with the vision of a comprehensive democracy; not merely a democracy in terms of the right of adult franchise, but

democracy as a way of life that pervades the relationship of human beings with nature, society with the state and the market, employers and employees, individuals within their community, and men and women within families and in friendship. AIDS action must contribute to the politics of building such a democracy across Asia and the world.

### Relating to the International Politics of Development

Is the nature of development and HIV and AIDS discourse and action today conducive to such democratisation? The Millenium Development Goals (MDGs) and the Poverty Reduction Strategy Papers (PRSP) are the current international tools for increasing levels of development in the less industrially developed countries. While all such efforts are relevant for AIDS control, MDG 6 deals directly with reversal of the AIDS epidemic.

In spirit, the MDGs currently present the most humane face of globalisation, articulating very valid and urgent goals for societies to strive for. They are highly relevant for the peoples of Asia. But are they articulating the wider linkages? The MDGs are all inter-related and require that the quality of life of people be raised. Therefore, not only MDG 6 but meeting all the others will indicate that conditions for limiting spread of HIV among the poorest sections are being achieved. However, the strategies for fulfilling the MDGs are more focused on medical technological solutions rather than on the social relations perpetuating the inequalities and injustices. Clearly more and more comprehensive vision is required to meet the MDGs. Chapter 2 discusses this in greater detail.

The dominant global trends are contrary to achievement of the MDGs the structural adjustment policies, the WTO, the Health sector reforms, etc. but are tending to get entrenched. These forms of neo-colonial exploitation are undermining the agricultural base of the low-income countries. They are creating markets for sucking away the economic resources of the middle class and poor of all countries, with the objective of adding to the ever-escalating profits of the global capital. Between 1990 and 2002, world trade in services grew by 155% compared to 40% for agriculture and 97% for manufacturing. Despite two-thirds of the population still being engaged in agriculture in South Asia, the share of agriculture in national incomes has declined to less than 25% in the last two decades, the manufacturing industry has increased marginally to a little above 25% and services have escalated to over 50%. The services have been majorly those of business, telecommunication and finance, that is, those that are urban-based and have been backed by policy changes concerning participation of private domestic and foreign players'. On the other hand, subsidies given by the 'developed' countries to their farmers while disallowing them for the less industrialised countries, along with opening up of internal markets of agricultural produce to global trade in the poorer countries, is adversely affecting farmers as input costs go up and product prices crash.

Therefore, if the spirit of the MDG initiative is to be implemented, such macro policy initiatives will have to be countered. It has been estimated that a 1% increase in agricultural percentage of GDP creates a 1.61% increase in the incomes of the poorest 25% of the population

in 35 representative countries. In fact, agricultural development is crucial for achieving a number of development goals such as poverty reduction, improving food security and conserving natural resources. This will also limit the necessity of labour migration from rural to urban areas, one of the well-known risk factors for creating conditions conducive to spread of HIV.

The large informal industrial sector in Asian countries is also facing the negative impact of protectionist policies by the industrialised countries. For instance, 'Garments face a 25% and fabrics a 12% duty. In addition there is a 13% anti-dumping duty on bed linen. These duty rates have made Pakistani textiles and clothing extremely un-competitive in the European market from January 2005 onwards.<sup>10</sup>1

Governments of
Asian countries
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the majority
of their peoples.

Under the Trade Related Aspects of Intellectual Property Rights (TRIPS Agreement), which came into effect from 1st January 2005, a direct effect is a sharp increase in the prices of medicines in developing countries. Pressure from concerted protest by African countries and international activism resulted in the Declaration on TRIPS and Public Health. It has allowed some possible avenues of relief, but left unresolved the problems such as compulsory licensing that those having little manufacturing capacities would face in making effective use of the measures provided.

Campaigns against WTO and other such neo-colonial structures have also to be strengthened if Asia is to continue to remain at low to moderate prevalence levels for HIV infection. Governments of the Asian countries must take adequate stands. They can do so if they come together in mutual support to stand against international forces with negative impact on the majority of their peoples. We have travelled a long way on this path since the First Asian Relations Conference in New Delhi in March 1947. The Bandung conference and several others subsequently strengthened not only Asian solidarity but relations with other third world regions as well, especially Africa. The Non-aligned Movement also brought together countries across continents aspiring to charter their own paths rather than be aligned to the powers of either the first (West Europe and North America) or the second (East Europe and former USSR) world. ASEAN, SAARC and other such regional forums within Asia also articulated their aspirations for collaboration and solidarity. Consequently, economics and trade became not only bilateral issues but also regional and 'third world' or 'non-aligned world' concerns. The need of the present times is that forums such as the ASEAN and SAARC bring all Asian countries together to articulate the common interests of the majority, so that the negative consequences of the present globalisation are reversed and a positive globalism, moving towards freedom and a better quality of life to all, is fostered.

Also to be highlighted is that the vulnerability to HIV lies not only in the economic resources at hand; North America and West Europe should then have been most immune to it. Also important is the nature of social relationships supported by the economic structures and the cultural context. The placing of market values as the dominant worldview is currently undermining notions of mutual responsibility and ethical behaviour in any relationship. Rapid societal transformations are generating a situation of flux, where there is increasing lack of shared understanding of the basic norms guiding relationships. All these processes increase the vulnerability to HIV. Cultural changes must be welcomed, but societies should be able to mediate and develop on their own terms, not under pressure of ideas from the more economically and politically powerful.

What Pandit Jawaharlal Nehru said in his inaugural address at the First Asian Relations Conference (1947) seems to be appropriate once again: 'We stand at the end of an era and on the threshold of a new period of history. Standing on this watershed which divides two epochs of human history and endeavour, we can look back on our long past and look forward to the future that is taking shape before our eyes... A change is coming over the scene now that Asia is finding herself. We live in a tremendous age of transition and already the next stage takes shape when Asia takes her rightful place with other continents.... We propose to stand on our own two feet and to co-operate with all others who are prepared to co-operate with us. We do not intend to be playthings of others.'

We have to find solutions rooted in and appropriate to the Asian and its regional contexts. Starting with looking the problem through the eyes of our peoples and their lived reality, solutions have to move us forward in our struggle for a better life; a life lived with dignity and self-esteem, joy and pleasure, fun and laughter, cared for and with caring towards others. This has to be an inclusive dream, involving women as much as men, for persons with minority identity whether religious, ethnic or sexual, as much as for the majority groups. And yet, the communitarian spirit embodied in the collective entities of family, community, occupational and other groupings, have to be strengthened. Evolving relationships that mutually empower collectivities and the individuals within them, leading to a better quality of life, physical, emotional, and mental, is the societal challenge.



Assessing against this 'dream', how has AIDS action fared so far?

#### **Achievements of AIDS Control**

Over the last twenty years AIDS control efforts have been undertaken on a scale unprecedented for any disease. Though still not adequate, achievements such as the following need to be acknowledged and built upon:

- Awareness of the new disease has spread fairly rapidly, certainly wider and faster than for any other disease.
- National programmes are in place with more funding than for most other diseases
- Monitoring and evaluation, with involvement of civil society NGOs, activists and academicsas well as organised pressure from affected persons has led to concurrent modifications for strengthening the programme.
- Prevention measures have become multi-pronged from awareness raising about modes of transmission to empowerment for behaviour change, safe blood banking, prevention of mother to child transmission with a single dose of an ARV drug, treatment and support programmes for HIV positive persons have been undertaken.
- Safe-guarding 'human rights' of HIV affected groups and individuals has become a basic proposition across the world.
- Issues hitherto ignored have come into public debate, such as the conditions of women and men engaging in commercial sex.

#### The Gaps

However major gaps are identifiable, such as the following:

- Coverage remains an issue for awareness raising, surveillance, diagnosis, care, support and treatment in all locations but more so in rural areas
- Empowerment of large numbers can happen only through appropriate macro changes; but currently macro policies are generally moving in the opposite direction. Most AIDS control efforts do not address them or even linkup with others who are dealing with them.
- Some issues in AIDS control programmes are inherently difficult to resolve, such as the perspective on 'HRGs. Interventions targeted at the identified HRGs have been most effective in behaviour change, for instance in terms of increasing condom use. However:
  - The identified HRGs have also tended to get more isolated instead of getting mainstreamed and more socially accepted as human beings. Stigma has got attached to groups such as truck drivers where none existed before.
  - These TIs were short-term measures to protect those engaging in activities with high risk of transmission. However they do not lead to decrease in the activity itself. Without action at the level of macro policies, the fire fighting will always fall short of requirements.
  - The fact that women engaging in commercial sex and those women in marriage are in exploitative situations due to the patriarchal bias favouring male sexuality and rights, is lost sight of in the focus on Tls. We have to move beyond isolationist Tls to a common struggle, even while addressing the specificity of needs of special sections.
- AIDS has been viewed as a unique disease and responded to by isolating it from all other health interventions. This has allowed no learning from past experience of disease control to pass on to AIDS control policies and planning.
- Treatment and prevention have been viewed as two distinct activities, not recognising the unity of the two as a comprehensive approach to disease control.

The time has now come to widen the scope and relate AIDS control to the larger health system and to overall development. We need to think differently to evolve the paradigm appropriate for the diverse conditions prevailing in countries of the continent and within each country.

## Future Directions: Towards a New Paradigm

Two conceptual leaps in AIDS discourse appear necessary reinstating the notion of 'social responsibility' in all relationships, and 'normalizing' the epidemic. Then their implications for concrete action programmes will follow.

#### Social Responsibility as a Societal Value

'Care and support of PLWHAs and the practice of "Responsible sexuality" at individual level can be envisaged only in an environment where social responsibility is also evident in other spheres. The challenge is to develop an environment of social responsibility without constrictions

of creativity, diversity or individual freedom and well-being. Such a conceptualisation questions the very basis of present day globalisation. Any vision of 'Another Asia' can become possible only through tangible alternatives to dealing with people's problems." this was a statement endorsed at a workshop at the Asian Social Forum (2003), organised collaboratively by Swasthya Panchayat-Lokayan, Centre for the Study of Developing Societies and ActionAid India.

#### Rethinking AIDS as Social Responsibility

What will 'Social Responsibility' mean when knit together with Human Rights and Pluralism in the specific context of HIV and AIDS in South Asia? In the era of globalisation, can it help us rethink the responsibility of the following?

- the state towards well-being of its citizens,
- the public health system towards society for providing epidemiologically rational and socially contextualised, democratic programmes,
- the medical system and professionals towards patients,
- the media communicators towards socialisation processes and societal values.
- the community towards all its members, and
- the partners in interpersonal relationships, including sexual relationships.

Source: Priya, 2003, Rethinking AIDS as Social Responsibility, report of a workshop at the Asian Social Forum (2003), organised collaboratively by Swasthya Panchayat-Lokayan, Centre for the Study of Developing Societies, and ActionAid India

Promises made by national governments and international forums – such as of lowering Infant Mortality Rates and Maternal Mortality Rates, of providing Right to Food and Right to Livelihood with Dignity are premised on the idea of social responsibility of the state. They can lead to meaningful action and be fulfilled only if the idea becomes a societal value. Only then can our societies be protected from HIV.

#### Normalising the Epidemic: Reducing Exceptionalism

Most of all is the necessity of recognising people living with HIV and AIDS (PLWHAs) as 'normal' human beings who need to take some precautions, as all of us do for ailments that we may suffer from chronically. They need treatment whenever they are ill, as all of us do. When the disease becomes serious they need more intensive and lifelong treatment, as for many other chronic diseases.

This view of HIV and AIDS as part of 'normal' life takes root partly on its own when

familiarity with the disease grows. But if the AIDS awareness/IEC messages repeatedly speak of it as a unique disease and it is dealt with by an exclusive programme, the perception becomes that it is an exceptionally serious disease. This evokes fear and generates an isolationist attitude that discriminates against the infected persons in order to protect the rest of society from the disease.

The fact that HIV infection causes little or no ill health in a majority of the infected for long periods is important to make people see HIV positive people as 'normal'. The understanding that the conversion from HIV to AIDS can be triggered by 'stressors' and delayed with good nutrition, avoidance of chemical and emotional stressors, a positive psycho-social state and a low burden of communicable disease, allows for developing ways of dealing with the infection as a chronic disease. This emphasises once again the overall better quality of life, and a more comprehensive notion of patient management for HIV positive persons. It allows for a positive outlook rather than the doomsday prognosis that most doctors give them if they cannot afford anti-retroviral therapy (ART).

#### Monitoring Medical Technological Interventions and Research

Provisioning of ART through public health programmes is already off the ground in Asia, with added impetus from the WHO's 3 X 5 initiative and the GFATM. But rational use of ART as a part of comprehensive care of HIV positive persons and monitoring by civil society is essential to ensure optimal implementation. Besides access, people's interests require monitoring of drug resistance and side-effects. WHO is in the process of developing country systems for monitoring resistance to ARV drugs. But advocacy is still necessary for monitoring side effects. Clinical trials of old and new drugs are underway and their technical and ethical dimensions need social accountability. Revoking or diluting criteria of safety and effectiveness may be justified as fire-fighting measures, but cannot be of benefit in the long term.

Vaccine research could be a mirage due to the rapid mutation capacity of the HIV. Yet it has to be pursued in order to find a preventive technology. Despite a lot of discussion, the ethical guidelines for vaccine research for HIV, or for research in other preventives such as microbicides, are as yet unclear. Social monitoring of all such research is therefore essential.

#### Priorities, Governance and Financing

No final blueprint can be prepared for a successful programme for all contexts. Building up capacities at local levels to identify existing societal mechanisms to respond to HIV and AIDS and at the same time plan for the additional requirements of HIV and AIDS is the crucial issue for governance of AIDS control.

Financing of AIDS control efforts reflects the priorities of the decision-makers, and shapes the response of those receiving the funds. Consideration of issues in financing of AIDS programmes raises larger questions about government spending on health service systems as a whole. How much priority should the government give to HIV prevention and treatment as against other health problems? In countries with poorly developed health services, should the resources go into systems development or prevention programmes and ART? From within the budget for AIDS, what proportion should go to IEC, to blood banking, to treatment of opportunistic infections, care

and support, surveillance etc. and how much to ART? In an ideal situation all are necessary for appropriate use. But at a practical level, choices have to be made by weighing relative merits of each measure. In this context, several questions need to be explored at the international, national and local levels:

- Is the current planning for AIDS giving adequate attention to these dimensions of the health service systems?
- Are the current financing mechanisms suited to context specific and multi-dimensional planning?
- Is genuine decentralisation of programme and plan implementation happening, or possible, given the management perspectives currently operational?
- Is Greater Involvement of People Living with HIV/AIDS (GIPA) only a token concession or are the voices of PLWHAs of different class, caste, region or sexual orientation etc. actually finding a place in the conceptualisation of AIDS related policies, programme formulation and implementation mechanisms?
- Along with GIPA, how can the wider community be involved? One lesson that has emerged from Uganda and other African countries is that the community has a crucial role to play in successful efforts for prevention, care, support and treatment. The Asian countries seem to be lagging in this area. TIs and GIPA are much more in evidence than the involvement of other sections of society.

Since it is through the priorities and structure of AIDS control programmes and the planning processes that paradigms are given concrete shape, this report contains a separate chapter each for examining these issues of governance and financing of AIDS control. The first chapter provides an overview of the status in different countries and the social processes leading to the prevailing conditions. Chapter two deals with approaches to governance relevant for AIDS control in general development policy formulation as well as for AIDS control programmes while chapter three deals more specifically with issues of financing of AIDS control activities. Each of these three chapters end by summarising lessons and providing some directions for a paradigm shift. The last chapter highlights the experiences of those most affected, and what PLWHAs themselves demonstrate as the way forward that collectivisation is the most effective tool of the marginalised. It also provides examples of countries that have been successful in some measure in making innovative use of their own societal resources. Principles drawn from the planning processes of these countries can be used in other contexts as well. How comprehensively we can address the several linked challenges may test our ingenuity, but that is the political task AIDS requires of us.

Chapter I



Some 8.2 million people are now estimated to be living with HIV in Asia, including 1.2 million people newly infected in the past year. The number of women living with HIV has increased by 56 per cent since 2002, bringing the total number of women currently living with the virus to around 2.3 million.

Insecurity, manifested in wars, internal conflicts, famines and other emergency situations, stoke the flames of HIV epidemic. The destabilisation of Afghanistan after two decades of war has heightened the occurrence of HIV in that country

**B**oth natural and man made disasters bring with them an immediate and devastating additional danger – increased risk of HIV infection

**C**ross-border and domestic population movements could significantly contribute to the rapid transmission of STI/HIV

**T**rafficked women and children are highly vulnerable and are subject to multiple forms of exploitation

The low levels of infection rates across Asia offer tremendous opportunities for concerted actions on several fronts in order to forestall further advances of the virus. This requires a new approach to AIDS control which will consider HIV and AIDS as social and human suffering

The HIV control strategy has to be mainstreamed as a part of the wider strategy for disease control. The general health services infrastructure in several Asian countries are well developed although they may be functioning sub-optimally due to resource constraints and policy shifts

**C**urrent "quasi-governmental" stewardship of HIV and AIDS control has to be re-examined by exploring the possibility of involving public sector health services in a larger way.

**A** holistic support system is required to integrate preventive and promotive measures along with treatment with ARV.

Appropriate Knowledge Management is necessary for generating the right kind of research that will lead to holistic understanding of issues and then using it for planning of integrated approaches for AIDS control.

The spread of HIV and AIDS is continuing in many parts of Asia with varying degrees of intensity. Asia is not just vast but diverse, and HIV epidemics in the region share that diversity, with the nature, pace and severity of epidemics differing across the region. National HIV infection levels in Asia are low compared with some other continents, notably Africa. But the populations of most Asian nations are so large that even low national HIV prevalence means large numbers of people living with HIV.

The new millennium saw further worsening in the living conditions of the marginalised — the workers in general and women workers in particular — in different sectors due to forces of globalisation and neo-liberal policies. These policies have resulted in declining job opportunities for women in the formal sector, increasing the level of poverty in women. As a result, many women moved into cities looking for work in the informal sector. This may have increased the number of women in sex work, for lack of better economic opportunities. Studies indicate that there may be a relationship between macroeconomic policies and health outcomes including HIV and AIDS<sup>1</sup>.

It is against this scenario that one needs to locate HIV and AIDS and the programmes to control the disease. After almost two decades of AIDS control in the continent, a re-examination of the regional response is essential, especially given the widening disparity within the population as a result of the shifting macro-economic scenario in several countries of South Asia. One needs to ask if this calls for a paradigm shift in the regional response to AIDS focusing on the disease as a social suffering rather than an individual malady and on new approaches, programme priorities, financing, care and research.

## AIDS and the Global Gloom

In many countries, the impact of AIDS will be felt for generations to come. An estimated 3746 million people are living with HIV/AIDS in the world. Already, more than 20 million people have died from AIDS, 3.1 million in 2005 alone<sup>2</sup>. More than 4 million children have been infected since the virus first appeared. Of the 5 million people who became infected with the virus in 2005, 700,000 were children. This was almost entirely the result of transmission during pregnancy and childbirth, or through breastfeeding. Inaccessibility of health care services, non-affordability of ARV treatment and prevalence of socio-economic and environmental conditions conducive to contracting the disease are some of the persisting problems that result in high morbidity and mortality.

The most explosive growth of the epidemic occurred in the mid-1990s, especially in Africa. In 2005, Africa was home to two-thirds of the world's people living with HIV and AIDS, but only 11% of the world's total population. Today, about one in 12 African adults is living with HIV and AIDS. The epidemics in Eastern Europe and central Asia continue to grow and have even started affecting the societies at large. The number of people living with HIV and AIDS has increased almost twenty fold in less than 10 years in this region. AIDS claimed twice as many lives in 2005 as compared to 2003.

In the Americas, the most affected area is the Caribbean, which has the second highest

prevalence in the world after sub-Saharan Africa: overall adult prevalence rates are 23%. In Latin America, an estimated 1.6 million people are now infected. Most countries here have concentrated epidemics. Injecting during drug use and sex between men are the predominant modes of transmission. The predominant mode of transmission in the Caribbean is heterosexual sex, often associated with commercial sex work. In Central America, prevalence rates have been growing steadily and most countries there are facing a generalised epidemic. In the United States of America, 30,000-40,000 new infections occur every year, with African-Americans and Hispanics the most affected populations<sup>3</sup>.

Globally, unprotected sexual intercourse between men and women is the predominant mode of transmission of the virus. In sub-Saharan Africa and the Caribbean, women are at least as likely as men to become infected. Other important modes of transmission include unprotected penetrative sex between men, injecting drug use, and unsafe injections and blood transfusions. In many countries, including most countries in the Americas, Asia and Europe, HIV infection appears to be concentrated in populations engaging in unprotected sex (particularly in the context of commercial sex work or between men) and sharing of drug injection although there are indications that the infection is moving to the general population.

## Continental Collage

The spread of HIV in Asia began in the early-to-mid 1980s. Early infections could be traced to sexual contacts with infected persons residing outside the region, as well as some apparent further spread within the region itself. By the late 1980s, however, it had become evident that the transmission of HIV was increasing among several populations, at times with great velocity. Two sets of factors strongly influenced the course of the emerging epidemics in the beginning: participation in sex work and patterns of injecting drug use. However, despite focus on these groups, it is increasingly emerging as an epidemic with greater social, economic and political ramifications. The data however continue to be dolled out based on these specific groups.

By early 1997, South and South-east Asia accounted for an estimated 5.2 million (23 %) of the 22.6 million adults and children living with HIV in the world. About one third of adults living with HIV in the region are female. The estimated HIV prevalence in 15 to 49 year-old populations varies from zero (DPR Korea) to one per several thousand in most countries in the region, up to 2 to 3 per cent in Cambodia, Myanmar and Thailand.

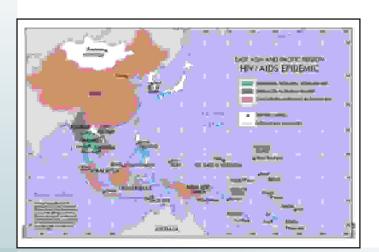
HIV epidemics in Asia and the Pacific are diverse, and show different trends over time. Against this backdrop, however, it is becoming increasingly clear that the intensity of HIV epidemics associated with sex work, affecting both female sex workers and their clients, is primarily determined by the daily or weekly number of sex partners (clients) per sex worker, the frequency of indulgence in commercial sex by men, and such other factors as the rate of regular condom use in commercial sex and the magnitude and quality of the response to the epidemics. Epidemics associated with injecting drug use have, in many situations, led to explosive outbreaks in the injection drug users (IDU) population and then to their sexual partners (e.g., in the late 1980s in Thailand; Myanmar, the Yunnan province of China; and the Manipur state of India, Vietnam and Malaysia).

Although HIV can spread rapidly among IDUs who share contaminated injection equipment, and then from them to their sexual partners, these epidemics have so far resulted only in limited spread of HIV to the heterosexual population at large. It may be assumed that, for a variety of reasons including social isolation of some IDU populations and their sexual partners from other communities, and/or stigmatisation to which they are subjected, there are only tenuous bridges between them and other sexually active adults. Strikingly, in Asia and the Pacific, HIV epidemics associated with commercial sex and those involving IDUs do not appear to fuel each other significantly. These epidemics appear to emerge and evolve almost independently from each other, as exemplified by the two concurrent HIV epidemics in Thailand, which were caused by two different subtypes of HIV, with minimum cross-over.

From a regional perspective, the magnitude and short-term trends of HIV epidemics are largely dependent on the extent of ongoing epidemics in a few countries: Cambodia, India, Thailand, Myanmar and, because of their population size, Indonesia and China. With a population close to I billion and multiple epidemic foci, India projects the image of a complex epidemic with infections moving to the general population including women and children.

Some 8.2 million people are now estimated to be living with HIV in Asia, including 1.2 million people newly infected in the past year. The number of women living with HIV has increased by 56% since 2002, bringing the total number of women currently living with the virus to around 2.3 million. AIDS claimed some 540 000 lives in Asia in 2004. The pace and severity of Asia's epidemics vary. While some countries were hit early (Cambodia, Myanmar and Thailand), others are only now starting to experience rapidly expanding epidemics and need to mount swift, effective responses (Indonesia, Nepal, Vietnam, and several provinces in China).? Other countries are still seeing extremely low levels of HIV prevalence, even among people at high risk of infection, and have golden opportunities to pre-empt serious outbreaks. These countries include Bangladesh, East Timor, Laos, Pakistan, and the Philippines.

On a vast archipelago such as **Indonesia**, where research has revealed ample opportunities for wider HIV transmission, the epidemic assumes diverse patterns. One in two injecting drug users in Indonesia's capital, Jakarta, now test positive for HIV, while in far-flung cities such as Pontianak more than 70% of drug injectors who request HIV tests are discovering that they are HIV positive. In seven Indonesian cities, an average 42% of sex workers had either or both gonorrhoea or chlamydia in 2003. Condom use ranges from irregular to rare. In 2002, fewer than one in five



sex workers operating out of massage parlours and discotheques in Jakarta said they used condoms consistently<sup>5</sup>. Among sex workers in brothel areas (a group that ought to be easier to reach with interventions), rates of condom use with all clients stood at a meagre 4%. The situation is even more troubling in parts of Indonesia's easternmost province of Papua, where HIV prevalence among sex workers in Sorong, for example, had reached 17% by 2003, over five times the national average for sex workers. There are strong

signs that the virus is spreading beyond sex workers and their clients. One recent serosurvey among adults in five villages found that close to 1% were HIV-positive<sup>6</sup>.

HIV has already become entrenched in lower-risk populations in several parts of **Myanmar**. Exceptionally large proportions of injecting drug users have acquired HIV. Between 45% and 80% of drug injectors have tested positive for HIV infection in sentinel surveillance each year between 1992 and 2003. HIV among sex workers rose significantly from around 5% to 31% over the same period. Meanwhile, the proportion of male and female patients at sexually transmitted infection clinics testing positive for HIV rose to 6% and 9%, respectively, in 2003<sup>7</sup>.

Thailand has been widely quoted as a success story on AIDS control in Asia. Thailand's advantage is the existence of a well-funded, politically-supported and pragmatic response. National adult HIV prevalence continues to edge lower, with the latest estimates putting it at 1.5% [0.82.8%] at the end of 2003<sup>8</sup>. Recharged commitment and revised strategies are now needed, however, to confront an epidemic that has entered a new phase. As many as half of new HIV infections occurring annually have been among cohabiting couples, as more women are infected by husbands who are (or were) clients of sex workers. Exceptionally high levels of HIV infection are being detected in parts of the country. In northern Thailand, 30% of drug injectors are infected with HIV, while median HIV prevalence as high as 51% has been found elsewhere. Yet, scant prevention resources are deployed on this front. The fact that injecting drug use is illegal should not block the path of effective action. A pragmatic approach — such as that adopted toward sex work in the 1990s — is much more likely to bring success. The same holds for men who have sex with men, among whom HIV prevalence as high as 17% has been detected.

Data from **Japan** show that HIV prevalence has risen steadily among male blood donors in that country, while staying relatively stable among women. This suggests that HIV transmission is occurring mainly among men who have sex with men, some of whom might also be transmitting the virus to female sex partners. In 2003, there were some 340 newly-reported HIV cases among Japanese men who had contracted their infection through sex with other men, just over three times the number of reported infections among men who report acquiring the virus heterosexually. Indeed, since 1999 there has been a rapid increase in the annual number of HIV infections attributed to male-to-male sex<sup>10</sup>.

HIV has now spread to all of **China**'s 31 provinces, autonomous regions and municipalities. Much of the current spread of HIV in China is attributable to injecting drug use and paid sex. However, sexual transmission of HIV from injecting drug users to their partners features prominently in China's epidemic. The Chinese government currently estimates 650,000 Chinese citizens to be infected with the AIDS virus. However, experts agree that these figures do not accurately reflect the actual number because China lacks the resources to carry out extensive surveillance in the countryside. Additionally, current surveillance protocols primarily cover only specific high-risk groups. Because of these limitations, it is estimated that only five per cent of HIV cases in China are reported. UN and World Heath experts believe the real figure lies between 1.5 and two million, and according to the Joint United Nations Program on AIDS projects China could have between 10 and 15 million HIV cases by the year 2010<sup>11</sup>.

**Bangladesh,** with a population of 136 million, had about 13,000 adults and children living with HIV at the end of 2002, according to UNAIDS estimates. However, since the first case was

detected in 1989, till December 2004, only 465 cases were officially reported. Of these, 87 have developed AIDS, and 44 have died. Significant underreporting of cases occurs because of the country's limited voluntary testing and counselling capacity. The HIV epidemic in Bangladesh is evolving rapidly although the overall prevalence rates are still low.

The estimated HIV prevalence in **Pakistan** remains low at about 0.06 per cent of the population. Cases have been reported from all provinces, with most of the infected persons belonging to the 20 to 49 years age group. Until very recently the majority of HIV infections and AIDS cases reported in the country were among migrant Pakistani workers who had been deported from the Gulf States. Heterosexual transmission accounts for the majority (37%) of reported HIV cases, with the next most frequent mode of transmission (18%) being related to infection through contaminated blood or blood products. The reminder of the reported HIV cases are linked with infection through injecting drug use (4%), homosexual or bisexual sex (6%), and mother to child transmission (1.3%).

There is no reliable data on the prevalence of HIV and AIDS in **Afghanistan**, which has an estimated population of 22 million. II cases have been reported to date. The main mode of transmission is believed to be blood transfusion and sharing contaminated needles during drug use. Little is known about the factors that influence the spread of HIV and AIDS in Afghanistan. There are many existing vulnerability factors including issues related to war and conflict that could fuel the epidemic, which require further investigation.

The five Central Asian Republics — Kazakhstan, Kyrgyzstan, Tajikistan, Turkmenistan and Uzbekistan — still have relatively low HIV prevalence. Nonetheless, recent sharp increases in the number of new infections, high prevalence in vulnerable populations, and these countries' position at the crossroads of the drug-trafficking routes between Asia and Europe suggest that they are highly vulnerable to a rapid acceleration of the epidemic. The number of newly reported HIV and AIDS infections in the region grew from 88 in 1995 to 6,706 in 2003, with most new infections occurring in Kazakhstan, Kyrgyzstan, and Uzbekistan. As elsewhere, however, the number of reported infections is significantly lower than the number of individuals infected. Among the republics, Uzbekistan is experiencing the most dynamic epidemic. In the last year, there were 2016 new infections, bringing the total to 5600.

In India too, the HIV epidemic is fuelled by social, economic, and cultural factors. Gender, poverty and caste issues are some of the important dimensions which need to be studied. This scenario adds to the burden of HIV care and support within the country and also hinders prevention processes. Globalisation, anti-poor policies and low expenditure for public health by the Indian government, has ensured that the primary health care system is already in shambles. The HIV and AIDS scenario certainly is also augmented by the fact that India has been a theatre for disasters and conflicts in the last decade. Increasing migration, conflicts and disasters pose a great threat to preventing the growth of the epidemic and in mitigating the impact of the epidemic on PLWHA and society in general.

India's epidemics are even more diverse than China's. Latest estimates show that about 5.1 million (the possible range is estimated to be 2.5-8.5 million people were living with HIV in India in 2003. Serious epidemics are underway in several states. In Tamil Nadu, HIV prevalence of 50% has been found among sex workers, while in each of Andhra Pradesh, Karnataka, Maharashtra

and Nagaland, HIV prevalence has crossed the 1% mark among pregnant women. In Manipur, meanwhile, an epidemic driven by injecting drug use has been in full swing for more than a decade and has acquired a firm presence in the wider population<sup>12</sup>. HIV prevalence measured at antenatal clinics in the Manipur cities of Imphal and Churachand has risen from below 1% to over 5%, with many of the women testing positive apparently being sex partners of male drug injectors<sup>13</sup>.

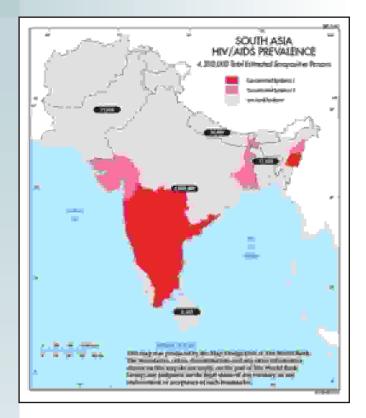
Like Manipur, the states of Maharashtra, Tamil Nadu and Andhra Pradesh have long-established HIV epidemics, but these are driven mainly by commercial sex. Available evidence suggests that prevention efforts in some of these states have done little to alter the epidemics' advance. Sentinel surveillance has revealed no significant drop in HIV prevalence among female sex workers in Mumbai, for example, despite decade-old safer-sex programmes for sex workers. It appears the programmes have been either too scattered or short-term to reach a large enough proportion of sex workers to make a difference. However the seropositivity rates in antenatal clinics have plateaued. Fortunately, India does boast some significant prevention successes, such as the drop in unprotected casual sex reported in Tamil Nadu. In 1996, 14% of truck drivers reported recent unprotected sex with a sex worker. By 2002, after concerted prevention programmes were introduced, that had fallen to just 2%.<sup>14</sup>

The collage presented above shows that the potential of forestalling the progress of the disease is considerable especially given the low prevalence rate in most of the countries. The governments within the region have realised this urgency and have taken concrete steps to develop a strategy for HIV and AIDS control. Most have to operate in a resource-poor setting despite significant flow of funds from donor agencies. Given the resource constraints, and the societal constraints such as a predominantly patriarchal system and the bias against women, some of the national responses reproduced in the section below could be partial in terms of success. The responses need to be sustained or streamlined for turning them into complete success stories.

# Challenging the Virus: Nations Respond

#### National Response to HIV and AIDS in Selected South Asian Countries

India: The 'first phase' of the World Bank project for the Indian National AIDS Control Programme lasted from 1992-1999. It achieved some of its objectives, notably an increased awareness. The second phase of the NACP began in 1999 and will run until March 2006. Under this phase, India continues to expand the programmes at the state level. Greater emphasis has been placed on TIs for high-risk groups, preventive interventions among the general population, and involvement of NGOs and other sectors and departments, such as education, transport and police. In brief, while the government's response has scaled up markedly over the last decade, major challenges remain in raising the overall effectiveness of state-level programms, expanding the participation of other sectors, and increasing safe behaviour and reducing stigma associated with HIV-positive people among the population. The Government of India is currently in the early stages of preparing for the third phase of the National AIDS Control Programme (NACP 3), for



which a multi-disciplinary design team has been constituted to lead the preparation. The design of NACP 3 envisages a complex consultative process including nationwide consultations with various national stakeholders, as well as international development partners.

**Sri Lanka:** In 1992, the Government of Sri Lanka initiated HIV prevention and control efforts through the National STD and AIDS Control Program (NSACP). Managed by the Directorate of Health Services in the Ministry of Health, the NSACP is being implemented in collaboration with provincial directors of health services, STD clinics, and the National Blood Transfusion Service. Since its inception, the NSACP has made significant

progress in improving STD services by refurbishing health clinics, meeting staffing and equipment needs, and establishing outreach camps. In addition, the programme has helped ensure blood safety through transfusion screening for HIV and upgrading of blood banks. This has raised the level of awareness and knowledge of HIV and AIDS among the general population.

However, the programme has limitations that need to be addressed urgently. Areas in need of strengthening include effective preventive interventions for highly vulnerable groups. This entails engagement of NGOs and other key sectors — namely, military, police, and schools — that are in the best position to reach populations at greatest risk. Stigma and discrimination against people living with HIV and AIDS and high-risk populations needs to be reduced. There is a need for monitoring and evaluation, including surveillance systems that capture biological and behavioural data, to help track the epidemic and inform policymakers and managers of effective programmes.

Afghanistan: The Government of Afghanistan has established a National HIV and AIDS/STI-control department, developed a five-year (2003-2007) strategic plan, and drawn up an annual plan of action to combat HIV and AIDS. Focal persons for HIV and AIDS have been assigned by the Ministries of Religious Affairs, Education, and Women's Affairs. It has been agreed that HIV and AIDS will be incorporated in the school curricula. Information, education, and communication materials have been developed and widely distributed throughout the country, targeting the general population. There are plans to conduct sero-prevalence studies among drug users and TB patients and to carry out behaviour surveys among these and other vulnerable groups, subject to the availability of required funds.

**Pakistan:** The mainstay of the AIDS Control Strategy in Pakistan is Prevention. The salient features of the strategy include gross enhancement of resources; decentralisation of HIV and AIDS control up to the provincial level through the development of provincial implementation units; and development of a comprehensive HIV and AIDS awareness raising strategy. The national policy also includes strengthening of a national HIV and AIDS surveillance system.

### National Response to HIV and AIDS in Selected East Asian Countries

Thailand: The government's determination to enforce condom use in brothels and to ensure wide access to HIV prevention campaigns through schools, the mass media, and the workplace have been the hallmark of Thailand's HIV and AIDS control strategy. From the early 1990s, the government worked in collaboration with brothel owners to ensure that the commercial sex industry did not become the main engine for a nationwide epidemic of HIV and AIDS. The HIV prevention programme also included a mass media campaign, workplace AIDS programmes, life-skills training for teenagers, peer education, and anti-discrimination campaigns. But of late there are some signs that the initial enthusiasm in AIDS control has perhaps been waning and that their effectiveness and relevance is compromised.<sup>15</sup>

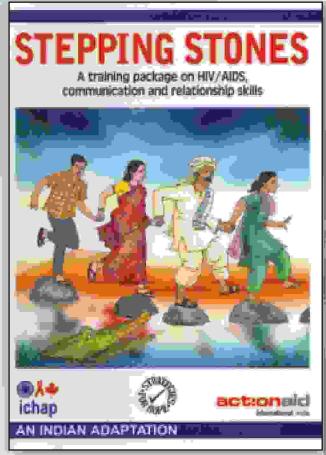
China: Following a joint survey with the WHO, the Chinese government estimated there were around 650,000 HIV infected people in China, including about 75,000 AIDS patients. AIDS is now reported in all 31 China provinces and autonomous regions.

The central government has allocated 800 million yuan to AIDS prevention this year. There is a significant increase from the 100 million yuan allocated in 2002. Of course, that China's leadership is even acknowledging that the problem of AIDS exists is in itself a milestone. A hard lesson that China learnt from the SARS epidemic in 2003 was that it cannot keep infectious diseases — SARS, AIDS or bird flu — a state secret. The Department of Disease Control at the Ministry of Health (MOH) is the primary organisation designated for China's efforts at preventing and controlling AIDS. It is also responsible, along with other related departments, for planning and implementation of the project for national AIDS prevention and control.

**Indonesia:** Indonesia launched a campaign in 2004 to combat HIV and AIDS, hoping to garner more public involvement in the fight. Efforts are also being made to reduce the prices of drug treatments for the poor living with the disease. Meanwhile, experts continue to urge that prevention programmes be targeted to those most at risk and be implemented on a national scale.

Vietnam: In April 2003, the Ministry of Health took the lead in coordination and consultation to develop a National Strategy on HIV and AIDS Prevention and Control for 2004-2010 with a vision up to 2020. Recognizing the danger of HIV and AIDS, the Vietnamese Government issued several ordinances, decrees and guidance as the legal framework for HIV and AIDS activities in Vietnam. They also included a 1995 ordinance on the prevention and control of HIV and AIDS and an instruction on guidance for the prevention and control of AIDS, as well as a government decree in 1996. The Prime Minister, in 1997, took some decisions regarding the tasks, authority and organisational structure of the National AIDS Committee and other AIDS Committees at different governmental levels and in different sectors. In 2000, he decided to establish the National Committee for AIDS prevention and for drug and prostitution control.

**Philippines:** The Philippine National AIDS Council (PNAC) is the country's lead agency in the fight against HIV and AIDS. The highlight has been the enactment of the Philippine AIDS Prevention and Control Act of 1998 (Republic Act 8504), a model for HIV and AIDS related human rights legislation. The entire process- the years of consultations, advocacy and lobbying, has been hailed as a 'best practice'. The legislation prohibits mandatory testing for HIV and AIDS and respects human rights, especially the rights of individuals living with HIV and AIDS.





# National Response to HIV and AIDS in Selected Central/Middle East Asian Countries

**Iran:** A national committee to combat HIV and AIDS, chaired by the Minister of Health, was set up in 1987. This committee provides policy guidance to the National AIDS programme. The National Strategic Plan, based on multi-sectoral collaboration and co-ordination, focused on prevention and has provisions for activities such as providing patients and community with information, educational material and communication; serological and behavioural surveillance; voluntary testing and counselling; blood safety and; HIV care, support and treatment.

The governments of Kazakhstan, Kyrgyz Republic, Tajikistan and Uzbekistan have started implementing HIV and AIDS strategies. A Regional AIDS Strategy prepared by UNAIDS in collaboration with Central Asian countries provided the framework for a series of country-specific plans. Kazakhstan, Kyrgyz Republic, Tajikistan and Uzbekistan applied for, and have been granted, funding from the Global Fund to fight AIDS, TB and Malaria (GFATM). In June 2004, the governments of Kazakhstan, Kyrgyz Republic, Tajikistan and Uzbekistan signed a Memorandum of Understanding committing to regional cooperation to prevent HIV and AIDS and to prepare a Regional HIV and AIDS Project to be supported by the World Bank. The Kazakhstan national HIV

and AIDS programme has three primary objectives: to stabilize HIV prevalence by preventing the spread of infection from high-risk populations to the general population; to reduce the growth of high-risk populations; and to ensure that at least 80% of HIV-infected individuals are covered by medical and social programmes.

Kyrgyzstan stands out in the region for its innovative and early response. Although lacking in funding, the government actively sought assistance from nongovernmental and international organisations. Its prevention plan, aims to reduce: the number of HIV-infected people, the spread of HIV, and the incidence of sexually transmitted infections through a range of specific interventions. The Tajikistan plan, first developed in 1997, includes the following elements, among others: a multisectoral approach, confidentiality in HIV and AIDS testing, integration of HIV and AIDS prevention and care into other health programmes, establishment of a national coordinating mechanism, and wide dissemination of information among youth and other at-risk populations.

# What Aids the Epidemic?

#### War and Conflict

Insecurity, manifested in wars, internal conflicts, famines and other emergency situations, stoked the flames of the HIV and AIDS epidemic. Factors of socio-economic deprivation get amplified in the event of a conflict. The destabilisation of Afghanistan after two decades of war has heightened the threat of HIV there. Prolonged, violent conflicts lead to sexual exploitation, increased social mobility, and destruction of healthcare infrastructure and rapid decline of the capacity of health care systems to monitor the health care needs of the population. Another facet of conflict scenarios is that they displace people on a huge scale, disrupting life, livelihoods, families and social bonding. Sexual relationships tend to change — willingly or otherwise — in such situations of flux and anxiety.

Conflict situations can pose an additional risk for girls and women as invading or stationed armies and militias often use sexual violence on local women as a means to humiliate the rival forces. Besides, war and occupation situations breed opportunities for paid and coerced sex in return for favours. For instance, the Russian army has acknowledged that since 1989 some 2,607 Russian servicemen have been confirmed HIV-positive, and one-third of its new conscripts were deemed unfit for service because of HIV or hepatitis.

Peacekeeping efforts can also lead to higher HIV vulnerability. For instance, in the UNTAC peacekeeping mission to Cambodia between 1991 and 1995, local NGOs reported that sex workers doubled their nightly number of customers. Studies of returning Uruguayan and American soldiers showed they were infected with a particular sub-type of HIV found only in South-East Asia and Central Africa.

Uniformed officers are particularly vulnerable to HIV and AIDS due to a number of factors, one of which is the young age of military personnel. The UNAIDS is now working with more than

75 countries worldwide to develop HIV awareness and prevention programmes for men and women. Recently, the UNAIDS joined the Ministry of Defence in **India** for designing and implementing a comprehensive HIV-prevention programme among military ranks. The programme includes awareness raising initiatives, peer education training and the integration of HIV and AIDS/STD-related topics into the curricula of military schools throughout India.

In **Thailand**, the military has recognised HIV and AIDS as a threat to national security. <sup>16</sup> "Reasons for higher rates include mobility, frequent casual sexual relations (particularly with sex workers), peer pressure, and alcohol and drug use". In Tajikistan's armed forces' HIV-infection rate is reported to be seven times as high as that of the general population. <sup>17</sup> Though not in such dramatic dimensions HIV among the forces has been recognised as a problem in many other Asian countries.

#### **Disasters and AIDS**

An emergency is a situation that threatens the lives, livelihoods and well-being of large sections of a population. It necessitates extraordinary action to ensure the survival, care, protection and adaptation of those affected. Both natural and man-made disasters bring with them an immediate and devastating additional danger — the increased risk of HIV infection. Disasters create chaotic conditions that accelerate the spread of the epidemic. The ways in which people have traditionally coped with famine and poverty are undermined by HIV and AIDS, which increases mortality and morbidity among those who may already be weak and malnourished.

Disast <mark>ers and AIDS: Conditions and Concerns</mark>
Loss of income, livelihood, homes, food, water, health care and education
Increased powerlessness leading to rape and sexual violence forces against civilians - most often exacerbated by impunity for crimes of sexual violence and exploitation
Severe impoverishment that often leaves women and girls with no alternative
but to trade in sex for survival
Mass displacement that leads to the break-up of families and subsequently
relocation into crowded camps for refugees and internally displaced people, where security is rarely guaranteed
The breakdown of school, health and communication systems usually used to
spread awareness against HIV transmission
Unaccompanied and unsupervised children and young people who have lost
family and community guidance, have no income and may be traumatised or simply bored
Limited access to condoms and treatment for sexually transmitted
infections



Given these conditions, HIV prevention, care and mitigation should be integrated into the multisectoral approach for disaster relief and rehabilitation programme. Adequate training, orientation and information should be provided to relief and rehabilitation workers regarding these conditions.

# The Migration Loop

Cross-border and domestic population movements could significantly contribute to the rapid transmission of STI/HIV. This is due to increased vulnerability of young people away from family and community support, limited access to STI services, condom supplies, and information.

Domestic population movements occur primarily for economic reasons. The nature of migration primarily reflects household subsistence strategies in the face of social, cultural, demographic and other constraints. Males predominate in most labour migration streams. But in a number of other cases, both men and women migrate together for work, especially among lower castes and tribals in India where constraints on women's participation in non-household economic activities are fewer. The pattern of labour migration (whether males alone, males and females, or females alone) is related to the social structure, the pattern of demand, and the nature of the migration process.<sup>18</sup>

Migration has often been referred to as an independent risk factor in the transmission of STDs and HIV and AIDS. The danger of this link is to blame migrants for the introduction or spread of such diseases in host communities. The advocacy to put mobility/migration in the HIV and AIDS agenda must therefore carry with it the responsibility of understanding the accompanying stigmatisation that attaches to migrants. It is therefore important to understand the social dimensions of migration from the point

of view of migrants themselves. The Colombo Declaration in 2002 recognised the need for developing a framework for dialogue at various levels to ensure appropriate recognition, protection and dignity of foreign migrant domestic workers. The experiences of foreign migrant domestic workers reveal that domestic work is still to be recognised as a socio-economic activity and valued accordingly. This leads to a serious lack of protection, vulnerability and exploitation. Multiple discriminations based on gender, race and class within the family, the community and nations, isolated and individualised conditions of work, and lack of protection and appropriate services and information increases their vulnerability to exploitation and violence and compromises their health and security.

It is also important to realize that social, cultural and economic structures take new forms and moral values, and that economic priorities and family networks change when people leave their native areas mainly for cities. Due to lack of awareness and separation from the family for an extended period, the migratory population is at great risk of being infected with HIV and AIDS by being exposed to conditions conducive to the disease.

**Sri Lanka:** Migration within Sri Lanka and to neighbouring countries is necessary for the economic survival of many households in both rural and urban areas. Thousands of women and men live away from their families as migrants abroad and as workers in the Free Trade Zones and plantations. Removal from traditional social structures, such as family and kin, has been shown to promote unsafe sexual practices, such as engaging in multiple sexual partners and in casual and commercial sex, as well as increase vulnerability of women and girls to sexual abuse.

**Nepal:** Nepal is another country where migration for sustaining livelihood may lead to conditions favouring the spread of HIV and AIDS. Seasonal and long-term labour migration to India and their implications for HIV and AIDS control strategy need to be studied in-depth for a better understanding.

China: It is estimated that the total number of migrants, both temporary and permanent, maybe as high as 200 million. This labour migration is a response to the government's economic reform process. More job opportunities, higher incomes, and a more attractive lifestyle are factors that pull people to urban areas. Many migrants are young, unmarried, and have more money to spend than they did in their home area. This makes young males likely to have casual sexual relationships, often with commercial sex workers. As most STI are notifiable diseases, migrants are often reluctant to seek treatment from public clinics for fear of discrimination, and losing their jobs.

In Beijing, around 34% of 2.3 million incoming migrant workers were women in 1997.

46% of them were unmarried. Of these women, the overwhelming majority was between 18-20 years old. Bearing in mind these demographics, it is easy to see a great need for reproductive health services. However, it is more difficult for migrants from rural areas to access health services in cities than for permanent urban residents. In a study among 146 young female migrants in 5 Chinese cities, it was shown that many cohabited with boyfriends. Most of them lacked the most basic knowledge about their bodies, reproductive health, STI, and only approached a family planning clinic if they needed an abortion and never for preventive counselling.

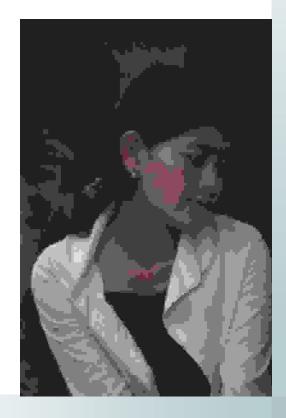
# Trafficking and the HIV Link

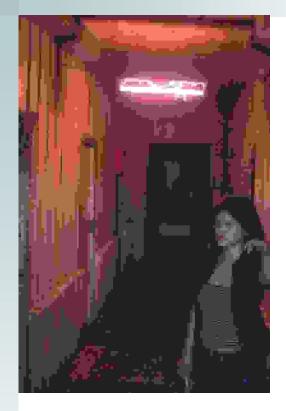
There is almost no accurate data available on cross-border flows because of the complexities in regulations, which vary from country to country. Only NGOs working in the field are able to provide data on this aspect. The combined estimates for Nepal and Bangladesh range from 500 a year to 10,00 girls to 5,000 and 7,000 girls being annually trafficked to more than 2,00,000 over a period of seven years. A UNDP study in 2002 showed that the average age of trafficked girls from Nepal to India fell from 14 to 16 years of age in the 1980s, to 10 to 14 years in 1994.<sup>20</sup>

The ADB report collated data on the number of women trafficked in Indian brothels

from various sources. NGOs reported that, of the I,000 to I0,000 women found in Kolkata brothels, 70 per cent were from Bangladesh. There are also I00,000 to I60,000 Nepali girls in Indian brothels, with about 5,000 to 7,000 girls being sold every year. Other estimates put the figure at 2,00,000 Nepalese women in Indian brothels. According to Reuters, 30,000 women in Kolkata brothels are from Bangladesh and another I0,000 Bangladeshi women are in brothels in Mumbai and Goa. The percentage of trafficked Bangladeshi women in brothels is I3.5 per cent in Kolkata, 0.2 per cent in Mumbai and 2.6 per cent in Delhi.<sup>21</sup>

Trafficked women and children are highly vulnerable and are subject to multiple forms of exploitation. Girls trafficked for commercial sexual exploitation are invariably made to entertain a large number of 'customers' a day. Even male children who are trafficked for labour or other exploitation face





sexual assaults from the powerful men who command and control them. Observations from studies show that:

- The victims of sexual exploitation are helpless about the mode, the method, type and time of sexual exploitation. Any objection or protest is likely to invite serious torture. Therefore, they have on option but to surrender to the exploitation. They are powerless before the exploiter.
- The exploiters, being in command and control, carry out all types of perverted activities and exploitation without caring for the comfort or feelings of the victim. It is the exploiters will and desire that prevails.
- In this kind of imbalanced power equation, the victims of sexual exploitation are often subjected to unsafe sex practices, causing UTI, STI, STD and HIV and AIDS.
- Despite the victim having been infected with HIV she is not given proper medical attention, and is made to continue in CSE till she becomes physically incapacitated. This continued exploitation is due to several factors. First, the brothel keeper would not like to announce that one of her inmates has HIV. This would affect her 'business'. Second, it would attach severe stigma to the entire brothel. Third, this would invite attention from NGOs, medical professionals and law-enforcement agencies which, in turn, would mean further discomfort for the brothel keeper. Therefore, the victim is forced to keep quiet and her exploitation continues.
- Among the rescued victims who are HIV-positive, the prevalence rate is very high among younger children. Perhaps, they are more vulnerable to being forced to accept unsafe sexual practices.<sup>22</sup>

Issues related to health in general and HIV and AIDS in particular need to be examined while addressing the problem of trafficking. It is a complex issue carrying cross-border dimensions. A comprehensive approach which recognises these complexities is therefore necessary.

# The Poverty Trap

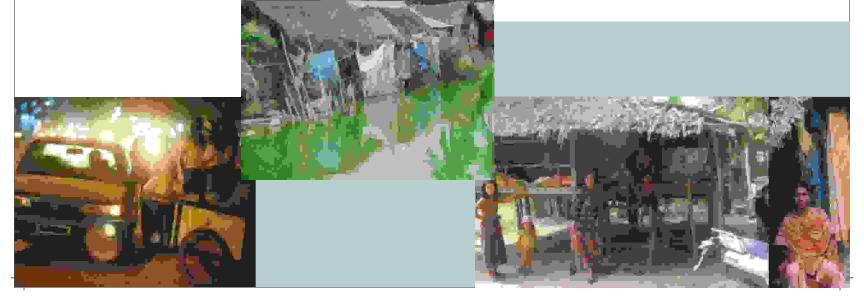
HIV and AIDS is biased against the poor and the marginalised. The disease and its impacts epitomize the sharp inequalities, fragmentation, denial of basic human rights and the process of marginalisation that exist in the world. HIV and AIDS targets the poor, and thrives under conditions of conflict, displacement and weak public health and social safety systems common problems in many Asian countries. The overwhelming burden of the epidemic today is borne by developing countries, where the disease threatens to reverse some important achievements in human development. It is estimated that 421 million people live with less than \$1.08 a day and 1,064 million with less than \$2.15 a day in South Asia.

There are two bi-causal relationships, which need to be understood by those involved in policy and programme development. These are:

- the relationship between poverty and HIV and AIDS which includes the spatial and socio-economic distribution of HIV infection and consideration of poverty-related factors which affect household and community coping capacities; and
- the relationship between HIV and AIDS and poverty understanding the processes through which the experience of HIV and AIDS by households and communities leads to an intensification of poverty.<sup>23</sup>

One needs to understand poverty as a multi-dimensional deprivation of capabilities rather than mere economic deprivation. The broad approach should include:

- the gender dimensions of poverty in particular that the poorest households are often headed by females and the women have to work harder and sustain the family;
- the intergenerational aspects of poverty the importance of seeing poverty as part of dynamic social, economic and political processes;
- the qualitative as well as quantitative measures of poverty giving appropriate weight to those aspects of poverty which delineate and define capacities and contributions by individuals and households to socio-economic and political processes, and how these are changed by the epidemic; and



• the ways in which the HIV epidemic alters the complex relationships between the poor and the wealthy – through changes in income and asset distributions brought about by the epidemic and an intensification of processes of social exclusion.

# Towards a New Paradigm

The low levels of infection rates across Asia offer tremendous opportunities for concerted actions on several fronts in order to forestall further advances of the virus. This requires a new approach to AIDS control is required which will view HIV and AIDS as social/human suffering, demonstrates and promotes social responsibility, as well as 'normalises' the epidemic. There should be an effort from scholars, activists, organisations involved in AIDS related work, and above all PLWHA themselves and to identify weaknesses, suggest changes and experiment with alternatives. This could cover the existing health services support, organisational strategies, funding mechanisms, care and treatment and research. While 'social Responsibility' has been demonstrated on the issue of HIV and AIDS control in some ways by government and civil society in most Asian countries, there is no attempt to 'normalise' the epidemic. It maintains an exclusivist identity and occupies a space that sets it apart rather than integrating it with other problems people suffer from. Two dimensions highlight the possibility of moving towards a paradigm shift.

# Health Services and Disease Control Strategies

One of the positive features of Asia relative to Africa is its well-developed health services infrastructure and availability of resources and professional and paraprofessional manpower. In this context, the HIV and AIDS control strategy has to be mainstreamed as a part of the wider strategy for disease control. The general health services infrastructure in several countries in Asia are well-developed although might be functioning suboptimal due to severe resource constraints. Mainstreaming the HIV and AIDS control programme through the general health services will help in controlling wasteful expenditure as well as in strengthening the public health services system in rural areas where the control programmes have to move in.

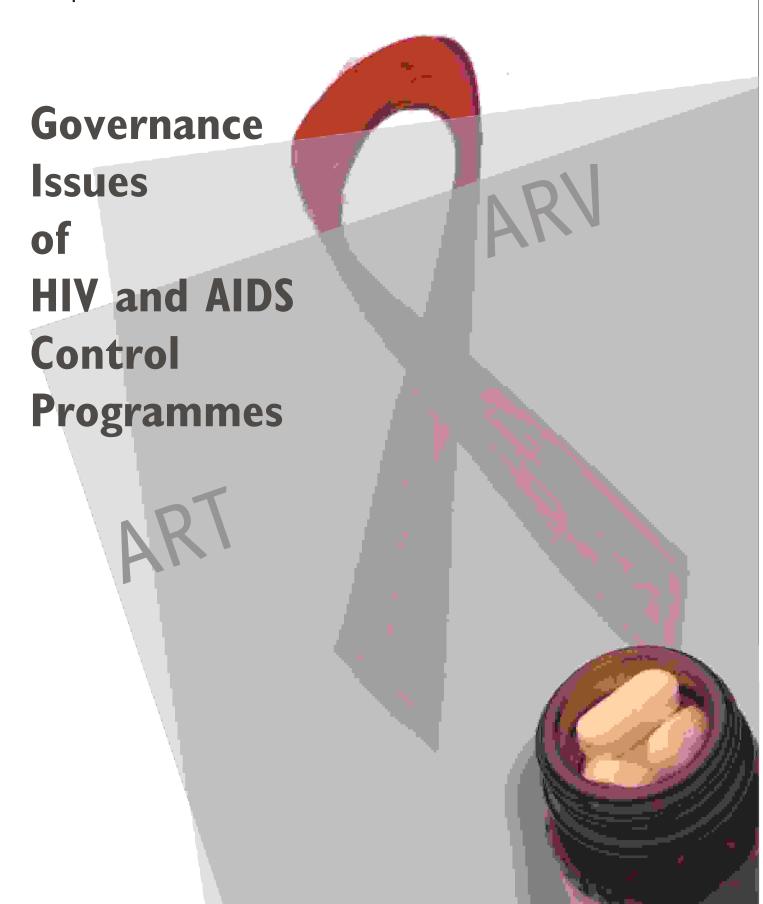
Current 'quasi-governmental' stewardship of HIV and AIDS control has to be reexamined by exploring the possibility of involving public sector health services in a larger way. Democratisation of health services and decentralised governance are pre-requisites for achieving the effectiveness of the programme. Such organisational re-orientation has to be combined with strengthening people-level organisations such as mutual-aid societies and groups.

A broader approach emphasizing a holistic support system is required which integrates preventive and promotive measures along with treatment with ARV. This should include well-defined policies for employment generation, educational planning and care for children of PLWHA as well as for the orphans. There are socio-cultural and economic specificities in the region which need to be recognised for developing a culturally sensitive, socially acceptable, economically feasible and epidemiologically appropriate programme for HIV and AIDS.

# Appropriate Knowledge Management

It is the failure to develop such a response that leads to several problems for AIDS control, including those of implementation such as reflected in the inability of country systems to absorb the available funding despite the chronic shortage of resources. Generating the right kind of research to provide the knowledge that would lead to appropriate policy and programme formulation is, therefore, crucial to present and future success. HIV and AIDS researchers face a number of challenges and Appropriate Knowledge Management is required. In the past, there was too much focus on behavioural research with emphasis on sexual behaviour. We now have a good data base on behavioural issues on which some of the educational programmes have been developed. On the other hand, socio-economic implications of AIDS have been poorly understood which could be an area to be focused for research funding. Similarly, Operational Research (OR) from an action point of view is essential considering the adhoc nature of control measures at present. Considering the proliferation of studies and information regarding HIV and AIDS, there is the need for optimum utilisation of such studies for policy-making. Making findings available for extensive discussion to a larger team of researchers with inter-disciplinary skills is an urgent step to draw their implications into designing future control strategies and research agendas. This is a major area of governance, the subject of the next chapter.

Chapter II



- The World Bank allocates large sums of money to fight HIV and AIDS; the money will only be available if the borrowing countries first agree to adhere to IMF loan conditions. These, however, will only aggravate the conditions that create vulnerability to HIV.
- Achieving the MDGs by improving the quality of life of people and not merely through technological fixes will make AIDS control efforts more effective.
- In Asia, the region with the second highest need for AIDS treatment, the number of people receiving ART has increased three-fold from 55,000 to 155,000 in the past 12 months. However, the overall proportion of people in the region with advanced HIV infection receiving ART remains low, mirroring the global average of around 15 per cent. That means that around one million Asians with HIV who would currently benefit from ARV do not have access to the treatment.
- Cambodia and Thailand are leaders among the Asian countries in providing for ART. The performance of the other Asian countries fall below the global average. India despite being a great exporter of ARV has an abysmally poor record of treating its own HIV positive population.
- The principal reasons of extremely limited access to ART is the high price tag of patented medicines and the limited functional capacities of health service systems.
- The delivery of ARV can succeed if there are 'functioning public health services that are generally accessed for curative care.'
- **F**ollowing the liberalisation and privatisation of state functions, health services are increasingly being outsourced to the private sector and NGOs.
- The TRIPS Agreement was a means to dampen the challenge to the monopoly of US and European pharmaceutical companies. The importance of this challenge will be obvious from the fact that Indian companies today offer a cocktail of anti-retrovirals at US \$200 per year in stark contrast to \$10,000 -\$12,000 charged by transnational corporations less than four years back.
- Despite a number of internationally recognized codes of ethics to ensure the protection of human subjects in biomedical research, one still finds instances where the applicability of these has not been given importance. There have been incidents during the AIDS vaccine trial, which have led to further concerns about the involvement of human in research.

National control programmes for HIV and AIDS are currently facing a double burden – planning and delivering preventive strategies, and, providing treatment and other forms of care for the clinical cases. One needs to examine the governance issues of HIV and AIDS control programmes as well as those of general development. WTO, TRIPS, 'Three Ones' and the '3 by 5' initiatives are all policy thrusts that directly impact the HIV and AIDS control initiatives. The global development agenda is currently articulated by the Millennium Development Goals (MDGs) – a set of internationally agreed development aspirations for the world's population to be met by 2015. Such global policy initiatives and commitments are crucial for determining successful control of HIV and AIDS. They create conditions that enhance or diminish vulnerability to HIV and are thus important for governance of the overall development.

There has also been an increase in the rights based approach and democratisation of the grassroots institutions. For instance, the Human Development Report 2005 is titled 'International Cooperation at Crossroads: Aid, Trade and Security in an Unequal World'. This succinctly summarizes both the potential and the environment in which various 'systems' and 'sub-systems' are operating as also the likelihood of successes or failures given the unequal nature of relationships. Three positives features that are crucial to the governance issues that confront HIV and AIDS programmes in the Asian region are:

- international cooperation has been on a global scale never seen before because of the killer nature of the disease.
- due to the lack of treatment or a vaccine attention has been focused on the social dimensions, bringing together social sciences and related disciplines in the generation of knowledge about HIV and AIDS and,
- the rights based approach has focused attention towards the needs of the positive people and particularly the demand for universal access to ART.

The discourse on governance is gaining importance in public administration. New models of public management are emerging in order to facilitate liberalization, privatisation and globalisation. While they ostensibly seek to strengthen health service systems and disease programmes, they have often resulted in the exclusion of weaker and marginalised communities. The U.N. Secretary-General Kofi Annan maintains that good governance is perhaps the most important factor in eradicating poverty and promoting development. While few dispute the significance of governance, there is much less agreement about how the concept should be used and what it really means<sup>2</sup>. The various definitions of governance in vogue include:

# The Context and Meaning of 'Governance'

**'Governance is** the system of values, policies and institutions by which a society manages its economic, political and social affairs through interactions within and among the state, civil society and private sector... (UNDP Governance for Human Development: An overview of Key Issues, 2000)

'We define governance as the traditions and institutions by which authority in a country is exercised for the common good. This includes, (i) the process by which those in authority are selected, monitored and replaced, (ii) the capacity of the government to effectively manage its resources and implement sound policies, and (iii) the respect of citizens and the state for the institutions that govern economic and social interactions among them.' (World Bank Institute)

'Governance means the process of decision-making and the process by which decisions are implemented (or not implemented).'

(United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP))

Governance therefore has a wide spectrum that can be interpreted broadly or defined too narrowly to measure merely indicators and outcomes. The UNESCAP definition allows one to map processes of decision-making and also why they do or do not get implemented. That, in essence, is the focus of this chapter in examining global and country level policies and forces that have a bearing on the framing and implementation of HIV and AIDS programmes in Asia. These include governmental and civil society initiatives.

# The Millennium Development Goals and AIDS

Governance of many major programmes and initiatives including those for HIV and AIDS is currently being seen through the MDG lens. The MDGs have come at a point when poverty and death remain inordinately high and the most basic needs of food, shelter, water, health and education are constantly being denied. The eight MDGs touch on the full spectrum of economic, social and environmental governance goals and incorporate a wide range of subsidiary goals. According to this declaration, the primary responsibility of attaining these goals lies with the nation states.

The MDGs have been variously described as "a historic commitment<sup>3</sup>" to "Most Distracting Gimmicks"! There has been little shift in macro policies that can convince one that these goals are being pursued seriously. The economic policies globally, are still going counter to them.

ActionAid International, in a global survey in 2005 that covered 7 Asian countries, identified the following key issues<sup>5</sup>:

- Small and marginal agricultural labourers are facing an unprecedented livelihood crises
- Acute and chronic hunger remains high
- Food security is low
- Women often face a greater crisis in these aspects
- Public health services are largely unaffordable and out of pocket expenditures are high

In this context the MDGs seek to deliver a package of services and programmes to improve access to technologies or to strengthen management systems. Without dealing with larger economic structures where the trend is to shift to the service sector and away from agricultural development, is it possible





to mitigate such conditions? Several concerns have been raised about MDG 6, which seeks to reverse the spread of HIV and AIDS:

- HIV continues to spread and increase in many countries.
- The programmes continue to remain weak in many countries especially where they are at a relatively early stage.
- Condom and needle exchange programmes have weakened following withdrawal by donors with 'moralistic political agendas'.
- Provisions for care, especially measures that go beyond ART, remain low.
- The poor state of general health services in many nations will be limiting the delivery of specific interventions.

# 'Moralistic Political Agenda' is a Serious Threat for Achieving MDGs

In May 2003, the U.S. Congress introduced an amendment to the Bush initiative obliging it to invest a third of the millions earmarked for prevention into projects whose only objective is chastity. This is yet another of the neoliberal paradoxes: the very promoters of economic policies that leave millions of people unemployed and force many women into prostitution are now the standard bearers of a sexual morality that the vast majority of the population finds impossible to fulfill in real life. But this does not stop them proclaiming it as the most effective way of combating the AIDS pandemic. Each country, culture, and right to maintain its own standards, rules, norms, taboos, and lifestyles.

**Source:** Bernardo Useche and Amalia Cabezas, "The Vicious Cycle of AIDS, Poverty, and Neoliberalism", http://americas.irc-online.org/am/2965 -IRC Americas Program Special Report, December 1, 2005

# The Impact of AIDS and the PRSP

Most of the developing nations take debts for their poverty reduction programmes from the International Monetary Fund (IMF) and World Bank – institutions that are essentially governed by select northern countries. Earlier the debt was provided on the basis of Structural Adjustments Programmes (SAP) that were supposed to benefit the debtor country. These policies were widely criticised for undermining national political processes, encouraging privatisation and barrier-free trade and causing widespread social and economic damage. In response to such criticism, the World Bank and IMF have adopted a new approach called the Poverty Reduction Strategy Papers (PRSPs), a set of medium-term development plans which poor countries are now required to implement in order to receive aid, loans and debt relief.

In a study conducted in 2003 by the Positive People Network of India with the support of

# The PRSP as a Tool: Undermines the Sovereignty of Governments

The IMF and World Bank promised that a Poverty Reduction Strategy Paper (PRSP) would set forth the government's own priorities, which, in turn, would guide operations, financed by donors and creditors. However, the sovereignty of governments is compromised because:

- The institutions have broken this promise. In practice, the World Bank's Country Policy and Institutional Assessment (CPIA) can be more influential than the PRSP in shaping key economic policies in borrowing countries. As noted above, the World Bank will require a government to remedy weaknesses in its CPIA rating in order to qualify for more financing or debt relief. Moreover, a government's budget targets, including the budget ceiling for the priority actions identified by a PRSP, must conform to the IMF's conception of "realistic" targets.
- Donors and creditors promote CPIA priorities as they play a major role in preparation
  of each government's PRSP. Indeed, the influence of external actors can
  overshadow the influence of domestic constituencies, even parliamentarians. The
  process of formulating PRSPs can displace more "homegrown" policy-making
  processes.
- CPIA-derived policy prescriptions can override the policy priorities of citizens and elected officials. Domestic constituencies are unaware of their government's CPIA ratings and the implications of those ratings for public policies.

**Source:** Judge and Jury, "World Bank's Scorecard for Borrowing Governments" (http://www.servicesforall.org/html/otherpubs/judge\_jury\_scorecard.shtml)

ILO, it was found that about 92 per cent of the respondents were in the age-group 19-40 years, the most productive age-group. This study also showed that expenditure on medicines and food increased as a result of an infected person in the family, and, expenditure on education and entertainment decreased, impacting quality of life of all the family members. Children were losing their parents due to AIDS which in turn put the responsibility of these children on the old grandparents who themselves were in need of support<sup>6</sup>.

Projecting even greater economic impact, two recent studies by the World Bank and the UNESCAP on South-east Asia's AIDS problems point out that AIDS, if not checked on time, may even result in the collapse of economies and governance systems<sup>7</sup>. There is no evidence yet of such an impending collapse in Asia. However, PRSP has been proposed as a way of breaking the vicious cycle between AIDS and poverty. Some of the African countries have incorporated AIDS in their PRSPs, 'wherein the people with the money tell the people without the money what to do to get the money.<sup>8</sup>'

# The Caution

PRSP is at best only a tool for mitigating the impact of abject poverty. It is neither a prescription for development nor a solution for HIV and AIDS. The international agencies allocate their lending on the basis of Country Policy and Institutional Assessments – a scorecard that ranks

countries on the basis of the policies they set in place. 'Good' policies that are given a high rating include:

- an average trade tariff of 10 per cent or less; no foreign exchange restrictions on long-term capital inflows
- equal treatment of foreign and domestic investors, and,
- the bulk of revenues coming from 'low distortion' taxes such as Value Added Tax (VAT) and property tax.

The policy scorecards are a form of conditionality in disguise. The seven wealthiest governments (G7) who dominate IMF decisions and influence most other foreign donors have an unjustifiable preference for low inflation in developing countries. While the World Bank allocates large sums of money to fight HIV and AIDS, the money will only be available if the borrowing countries first agree to adhere to IMF loan conditions, including those that keep inflation low (under 10% per year, or in many cases, under 5%). This means that poor countries with severe HIV and AIDS crisis will not be able to significantly increase public health spending as the loan comes with a low-inflation conditionality. In many cases, the loan will only cover the import of expensive anti-AIDS drugs, while expenses for medical services and infrastructure will be unavailable.

An incredible 96 per cent of PRSPs include fiscal stringency which prohibits government borrowings from the domestic economy. Despite evidence that it hurts the poor, further trade liberalization is evident in 72 per cent of PRSPs. 90 per cent of the PRSPs include privatisation, and nearly two-thirds specifically include water privatization or greater private sector involvement in water supply services. Two thirds of the PRSPs include investment deregulation. Despite these prescriptions developing countries are not growing economically. The helplessness is summed up by Dr. Sergio Spinaci, Executive Secretary of the Coordination of Macroeconomics and Health Support Unit, World Health Organisation:

"It is not easy within present budgetary constraints to invest more in health, especially if you have a large proportion of the budget invested in debt repayments and a macroeconomic policy focused on containing even minor inflation and setting rigid spending ceilings for the social sectors."

## Integrating HIV and AIDS in the PRSP

Studies reviewed from Africa (where much of the PRSP initiatives are located) revealed that<sup>3</sup>:

- there was initial attention on prevention e.g. targets, private sector involvement
- as more people develop AIDS, there is attention on treatment e.g. community-based care, provision of ART
- the PRSPs reviewed did not link up with the MDG targets, demonstrating a lack of connection between international commitments and national strategies
- the situation of orphans and other vulnerable children received very little attention
- mainstreaming has focused more on sensitisation and condom distribution rather than addressing the issue systematically at macro and institutional levels.



# Suggestions for Integrating HIV and AIDS in the PRSP

- 1. Exercise realistic caution: The current versions of PRSPs by and large do not integrate HIV and AIDS responses in ways that have clear targets, are costed, tied to national budgets, are subject to monitoring and are actually being implemented. The potentials are yet to be realised
- 2. Pay attention to harmonisation and accountability: If any funds are to be distributed in the scaling up, they should be subject to the effort to provide better coordination between donors, government and civil society. A practical approach that can have significant consequences would be to support improved monitoring, especially by local representatives.
- 3. Encourage civil society: Active civil society engagement in monitoring and evaluation, budget advocacy, linking the challenge of HIV and AIDS to the deeper issues of sustainable development, is essential.
- 4. Deal with all three dimensions of response: The activities of prevention, treatment and consequences must be more equally dealt with in order to avoid imbalances in approaches of integrating HIV and AIDS and the PRSP. Where prevalence levels are not so high, it is understandable that more attention is on prevention. But here too, a prevention approach that is multisectoral, moving beyond sensitisation and condom distribution, is essential. Moreover gender issues and the challenge of focusing more prominently on orphans and other vulnerable children must be central.
- 5. Promote better analysis of the two-way links and the structural issues:

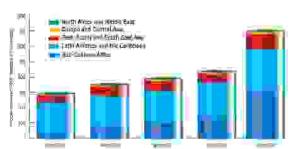
  Despite the PRSP speaking of HIV and AIDS as a cross-cutting issue it still relates to it primarily as a medical issue. Good socio-economic analysis brings up issues such as debt cancellation and act as pointers to the ways in which poverty is a consequence of policies such as imposed structural adjustment programmes.
- 6. Build capacity, utilise capacity: The experience of designing and implementing PRSPs has shown the obvious need for better capabilities to integrate HIV and AIDS into the programmes and better skills to monitor the implementation of these programmes. Much attention has been placed on building capacity. But has this capacity always been used effectively, e.g., in local research, in programme management, in political advocacy?
- 7. Call for and support better monitoring and evaluation: As mentioned often in the studies on PRSPs, there is a lack of clear targets in their setting out of programmes. The MDG targets do not appear as influential in design and implementation. This lack of clear targets makes monitoring and evaluation difficult and efforts are necessary to correct the imbalance

**Source**: Henriot J Peter. HIV and AIDS in PRSP: 'Some Practical Approaches'. Paper presented at the Seminar for HIV and AIDS Focal Points, Lusaka, Zambia, 1st June 2005

# **Anti-Retroviral Therapy (ART) and TRIPS**

UNAIDS and WHO report 'The AIDS Epidemic Update December 2005' has underlined the importance of bringing ART centrestage but certain conditions are necessary to enable this. Since end-2001, the number of people requiring ART has increased three-fold in low and middle income countries. In the best of situations, only one in seven requiring ART in Asia were actually getting the drug by mid-2005, compared to one in ten in Africa; clearly there is a huge unmet need. Successful treatment will pave the way for creation of an enabling environment for HIV prevention as well as increased testing, provided such services are available and accessible. Availability of treatment and enhanced community outreach can lead to more openness and reduction of stigma in societies where clinical cases are high.

#### **Distribution of ART Worldwide**



Source: WHO. 3/5 Dec 2004 report



## **Limited Access**

The principal reason of extremely limited access to ART until now has been the high price tag of patented medicines. In the environment of globalization, the products of rich countries were promoted as good quality products in the developing nations and treatment regimens of private sector or corporate hospitals as quality care and good practices. The efforts of the developing nations for economic development are often rendered futile due to unfair trade rules. The high cost of drugs is not due to limited production but due to the considerable margins that the already rich companies are expecting from the sale, the monopoly being perpetrated by the TRIPS Agreement.

The high cost of drugs is not due to limited production but due to the considerable margins that the already rich companies are expecting from the sale, and their monopoly being perpetrated by the TRIPS Agreement.

# **Implications for Developing Countries**

Laws that provide strong patent protection limit the ability of developing countries to enhance their science and technology capabilities and retard dissemination of knowledge. It was thus natural that many countries had domestic laws that did not favour strong protection to patents before the WTO agreement was signed. It was illogical to thrust a single patent structure on all countries of the globe, irrespective of their stage of development. These arguments were however systematically subverted during the GATT negotiations, leading to the signing of the

TRIPS agreement. The TRIPS agreement required countries like India to change over to a strong patent protection regime. A regime that would no longer allow countries to continue with domestic laws that enabled domestic companies to manufacture new drugs invented elsewhere, at prices that were anything between one twentieth and one hundredth of global prices.

Even before the TRIPS agreement was signed in 1995, Asian countries like the Republic of Korea, Indonesia and Thailand had succumbed to US pressures and amended their patent laws during the late 1980s or early 1990's to allow patents for pharmaceutical products. Thailand does produce cheaper drugs and provide it to people through an insurance scheme with minimal fees of 30-Baht. ART and testing and monitoring are given under some certain schemes. India was the last significant country to hold out and make use of the full 10-year transition period, but had to allow product patents by 1st January 2005.

There are several ways in which the TRIPS agreement impinged on the pharmaceutical sector and on the manufacture and sale of medicines. Article 27.1 entails that patent owners enjoy the same exclusive rights with respect to imported products as for products manufactured locally. This is contrary to what countries like India and Brazil allowed for – by making the local manufacturing of patented drugs mandatory. Such a provision has major consequences for the development of domestic industry in developing countries, as now, imports by transnational corporations are to be treated on par with local manufacturing.

The TRIPS Agreement was signed around the time when countries like Brazil, India and China were emerging as major centres for generic drug production. Today, an estimated 50% of drugs used to treat HIV and AIDS patients in the developing world are manufactured in India. The TRIPS Agreement was, thus, also a means to dampen the challenge to the monopoly of US and European pharmaceutical companies. The importance of this challenge would be obvious from the fact that Indian companies today offer a cocktail of anti-retrovirals at \$200 per year in contrast with \$10,000-\$12,000 charged by transnational corporations less than four years back.



# Profit Motives at the Cost of Life Saving Drugs

'Big Pharma' is a collective term used to describe the world's major pharmaceutical corporations, which are hugely influential in the control of the trade in medicine, and in shaping global trade rules and regulations. "Big Pharma boasts it is currently developing 73 AIDS drugs. Look more closely, and you will find that most of the firms doing this research are in fact receiving substantial government aid via publicly funded researchers with the National Institutes of Health! In other words, Big Pharma says it is doing R&D, but it actually is siphoning off taxpayers' money for much R&D on essential, life-saving drugs."

Source: Walden Bello. Speech delivered at the debate on patents, drug development, and HIV/AIDS at the XV International AIDS Conference, Bangkok, July 14, 2004. (http://www.focusweb.org/content/view/368/28/)

#### **Potential Escape Routes**

It has been argued that the TRIPS agreement has certain flexibilities that allow members to safeguard key areas of concern, especially related to public health. Of these, perhaps the most important is 'compulsory licensing'. This has the potential to break the monopoly that patents provide for. The requirement that a compulsory license should be authorised 'predominantly' for the supply of the domestic market, places constraints on exports of generic drugs by countries like India to less developed markets.

However the term 'predominantly' implies that some exportation under compulsory license can be allowed. A liberal interpretation may be that anything that is just less than half (say 49%) of a production under compulsory licenses can be exported. This is an important interpretation, as it has the potential to allow India, for example, to continue supplying on-patent medicines to Africa and Asia by getting them manufactured through compulsory licenses issued to Indian companies. However, it is unfortunate that while the TRIPS Agreement provides for generic production through compulsory licenses, there have been very few instances when the provisions have actually been used by a WTO member country to produce cheap generic drugs.

### **ART Becomes Available in Asian Countries**

Despite these adverse conditions, people living with AIDS in developing nations have started receiving ART. In Asia, the region with the second highest need for AIDS treatment, the number of people receiving ART has increased three-fold from 55,000 to 155,000 in the past 12 months. However, the overall proportion of people in the region with advanced HIV infection receiving ART remains low, mirroring the global average of around 15%. That means that around one million Asians with HIV who would currently benefit from ARV do not have access to the treatment. The additional seven million people with HIV in the region — who do not yet need ART or other care options — will each inevitably reach the stage where they also require AIDS-related care services in the coming years.

### Access to ART in Selected Countries of Asia (15-49 years age group)

Country	Need for Treatment in Dec. 2004*	People Receiving Treatment in Dec. 2004*	Per cent Receiving Treatment (%)
Cambodia	22,000	4,500-6,000	23.9
China	122,000	7,500-9,500	7.0
India	770,000	20,000-36,000	3.8
Myanmar	46,500	1,500-2,000	3.8
Thailand	114,000	45,000-55,000	43.9
Vietnam	27,500	500	1.8
All developing countries	5,800,000	700,000	12.1

Source: \* Estimates from UNAIDS/ WHO

Clearly, Cambodia and Thailand are leaders among the Asian countries in providing for ART. The performance of the other Asian countries fall below the global average. India despite being a great exporter of ARV has an abysmally poor record of treating its own HIV positive population – essentially a function of its public health facilities. The point is that while patents (or the absence of patent protection) are very important in determining access to anti-retroviral treatment, there are other critical factors that play a role in provision and access. Before the production of generic drugs, the antiretroviral therapy costed US \$700 per month. In 1993, an Indian pharmaceutical company, Cipla, started producing Zidovudine followed by Stavudine and Lamivudine, at a much cheaper price. Thus the cost of the drug came down to less than US \$5. Before the production of generic drugs the treatment cost was more than \$10,000 per patient per year – 40 times more than the US \$250 average price of such treatment.

# Access to ARV Drugs: How far and How near?

Generic competition has brought down the prices of first line AIDS drugs from US \$10,000 to as little as US \$ 150 per patient per year over the past five years. Local production in India, Thailand, and Brazil -possible because medicines were not patent protected there — has had effects far beyond the borders of those three countries. National AIDS programme in Brazil and Thailand have been successful because key pharmaceuticals could be produced locally at much lower cost. "But after hard-fought progress, we are now seeing the 'second wave' of AIDS drug pricing crisis", says Ellen 't Hoen, Director of Policy Advocacy with MSF's Campaign for Access to Essential Medicines. "The prospects of competition are diminishing because patent rules are being implemented by all but least developed countries. For example, second generation AIDS medicines are up to 20 times more expensive that older drugs, and when patients inevitably need to be switched to new regimes, their drug bill will shoot up."

Source: Access News November 2005 No. 12(www.accessmed-msf.org)

#### The Battle Continues

While the battle to ensure that the flexibilities in the TRIPS Agreement are allowed to be used by developing countries must continue, it is also necessary to understand that the TRIPS is

and shall remain an iniquitous agreement. The developing countries had argued precisely this in the Uruguay Round of GATT negotiations before the WTO Agreement was signed, and it is time now to return to this argument once again. The HIV and AIDS saga is a powerful reminder that patents and health care cannot be mixed together.

The Médecins Sans Frontières (MSF) expressed concern that access to affordable medicine for HIV and AIDS was becoming bleak (December 2005, Geneva)<sup>10</sup>. It expressed alarm at the decision of the World Trade Organisation (WTO) to amend the TRIPS Agreement based on a mechanism that has failed to prove it can increase access to medicines. The 2003 decision on production and export of generic medicines had long been viewed by MSF and others as cumbersome and inefficient. Newer medicines, such as second-line AIDS drugs, are priced out of reach for poor patients. MSF is paying 5 to 30 times more for second-line AIDS medicines to treat patients that need newer drugs. It called for delaying the amendment to ensure the possibility of testing and improving the current mechanism. The amendment has made permanent a burdensome drug-by-drug, country-by-country decision-making process, which does not take into account the fact that economies of scale are needed to attract interest from manufacturers of medicines. MSF has urged the WTO to provide evidence by the end of next year demonstrating that the mechanism it is putting in place can bring an end to the negative effects that full TRIPS implementation has on access to medicines.

### Concerted Effort to Achieve Universal Access to Treatment

The UN in September 2000, adapted 8 goals for a 'more peaceful, prosperous and just world' commonly known as the MDGs. One of the goals called for "Halting HIV and AIDS by 2015 and begin to reverse the spread". One of the key challenges has been to improve access to treatment for the 40.3 million HIV positive people in the world. In 2003, WHO along with UNAIDS set an ambitious goal to 'Treat 3 Million People by 2005'. In Asia, the region with the second highest need for treatment, progress has been significant with the number of people receiving treatment increasing nearly three-fold from 55,000 to 155,000 in 12 months. Yet, ARV is reaching only a fraction of people who need it because of many structural barriers.

While the target of treating 3 million by 2005 was not met it helped generate political commitment to improve access to treatment. In July 2005, G8 leaders, at the Gleneagles Summit pledged to increase official development assistance by \$50 billion a year by 2010 and have once again committed to "developing and implementing a package for HIV prevention, treatment and care with the aim of coming as close as possible to the goal of universal access to treatment by 2010 for all those who need it."" This commitment was reaffirmed by all the UN Member States at the 2005 World Summit. The UN General Assembly in its 23rd December 2005 resolution have requested the UNAIDS and its Cosponsors to assist in facilitating inclusive, country driven processes for scaling up HIV prevention, treatment and care to achieve universal access to treatment by 2010.

A multi partner effort, driven by the countries themselves to scale up universal access has been initiated at the behest of UNAIDS. It aims to identify solutions to the barriers that block comprehensive and integrated scale up of prevention, treatment and care. This universal access to treatment is not a programme in isolation it will also facilitate the achievement of other developmental goals as envisaged in the Millennium Development Goals.

A similar universal access to health was earlier visualised at Alma Ata in 1978. 'Health For All' by the year 2000 was declared there, but due to numerous hurdles existing in different countries this noble initiative was not successful. Similarly the recent joint initiative of UNAIDS and WHO of treating 3 million by the year 2005 was also not achieved. The initiatives of these two programmes were done without identifying any hurdles and obstacles, which could have possibly obstructed the implementation of these initiatives. The commitment to Universal Access builds on these past initiatives by recognizing the key structural barriers that hinder the achievement of the target. The barriers identified are as follows:<sup>12</sup>

- Constrained to ensuring adequate sustained financing, and therefore planning ahead, for scaled up AIDS responses;
- Too few trained few human resources, and health and social systems constraints;
- Barriers to reliable access to commodities and low cost technologies (e.g. condoms, injecting equipment, medicines and diagnostics)
- Stigma and discrimination, inequality, gender discrimination and insufficient promotion of HIV-related human rights.

The challenge now is for civil society activists to hold our governments accountable in addressing these barriers as they make progress to achieve the target of universal access by 2010.

# Issues of Vaccine and Drug Research

The vaccine research and implementation policies are spearheaded by the International AIDS Vaccine Initiative (IAVI) and the Global Alliance for Vaccines and Immunisation (GAVI). GAVI, formed in 1999 to replace the Children's Vaccine Initiative, is now funding research and development into vaccines for priority diseases, including HIV and AIDS. GAVI will also provide technical instructions to the Global Vaccine Fund, established in UNICEF for the purchase of newer vaccines. Initial financing has come from the Bill and Melinda Gates Foundation (which also funds the Children's Vaccine Program) and from the US government. The choice of suppliers and negotiations are also being done by these bodies with the result that local governments are completely being bypassed. Through vaccine development partnerships, IAVI will provide financial resources to move promising candidates through clinical trials to a point where additional resources and expertise may be attracted from large pharmaceutical companies. IAVI proposes to negotiate intellectual property and technology transfer agreements with such companies to provide:

- either, that a successful vaccine will be distributed at a given price,
- or, that the license can be made available to other manufacturers interested in doing so.

To cite an example, IAVI has signed pricing agreements with Alpha Vax Human Vaccines and the Medical Research Council in Britain, under which the companies can only charge for the cost of production, plus a maximum of 10 per cent in profit. If the vaccines can be produced at cheaper rates elsewhere, IAVI can force the companies to move their production to those countries. This applies to sales in developing countries only. Attempts to prepare vaccines for AIDS prevention are in full progress. What is interesting to note is the fact that though people in

developing countries are not receiving the antiretroviral therapy, they are preferred for the vaccine trials. Why is this so?

Communities living in developed economies are regular users of medicines; vaccine trial participants should ideally be using minimal medicines. As people living in the developing world do not have access to medical facilities, such participants are easily available. However, like any other trial, an AIDS vaccine trial too needs to abide by the ethical principles associated with involvement of human beings in research. Despite a number of internationally recognised codes of ethics to ensure the protection of human subjects in biomedical research one still find instances where the applicability of these has not been given due importance. It is generally agreed that if participants suffer injury as a result of the research, then those who stand to benefit from research, such as sponsor organizations, are obliged to compensate them. It has been argued that participants in HIV vaccine trials are likely to falsely believe that in the experimental HIV vaccine will protect them from HIV infection, which may lead participations to engage in increased high-risk behaviour. This in turn would put them at increased risk of HIV infection. Accordingly, HIV infection should be viewed as a harm arising from increased risk of infection and sponsors should provide high quality treatment for HIV infections acquired during trials. But who is going to shoulder the responsibility of life-long monitoring and treatment for the participants? This is yet another undecided issue, raising serious doubts about the ethics of these trials.

Despite a number of internationally recognised codes of ethics to ensure the protection of human subjects in biomedical research one still find instances where the applicability of these has not been given due importance. But who is going to shoulder the responsibility of life-long monitoring and treatment for the participants?

An effective vaccine is a social hope and a technological aspiration. It is relevant and essential that trials be conducted under diverse conditions. But governments should pro-actively take necessary steps before letting the drug companies experiment on their citizens. Indian Council of Medical Research (ICMR) has recently initiated steps to monitor technical ethical issues of clinical research trials in India that is currently one of the most favoured locations. Information about these ethical issues needs to be widely disseminated and discussed by civil society to ensure that they will adequately safeguard the interests of participants.

# Asian Civil Society Responses

The first case of AIDS in Asia was identified in 1984. The response of the Asian countries was slower than many other countries since the number of infections was relatively low and economic and social developments were national priorities. However, compared to many other public health problems AIDS did receive a faster and effective response. Besides the surveillance that started in several countries in 1985-6, and the official governmental programmes that started by 1987, a vast number of NGOs came up to respond to the epidemic. Starting from local initiatives they have come together to form networks for concerted action in Asia.

#### **APPACHA**

Asia Pacific Peoples' Alliance for Combating HIV and AIDS (APPACHA) was launched in Bangkok, during the XV International AIDS Conference and draws its core from the People's

Health Movement and its Charter from the Mumbai Declaration of the Illrd International forum for the Defence of Peoples' Health, which had preceded the World Social Forum 2004. The foundation of APPACHA emphasizes multisectoral alliances that brings together people affected and infected by HIV and AIDS, trade unions, women's rights movements, youth movements, faith based organizations, policy makers and other peoples' associations who share a commitment to combat the causes and consequences of HIV and AIDS. The alliance is currently

finding its foothold in India, Nepal, Bangladesh, Pakistan, Thailand, Cambodia, and Vietnam. With health and political activism coming together in Asia, one hopes that the world of HIV and AIDS sufferers becomes a healthier, more just and equitable world.

APPACHA pledges to spearhead various campaigns for the rights of people in resource-poor countries and demands action by governments in order to make ARV treatment available through comprehensive public health care services; to oppose changes in patent laws that could result in escalating drug prices; and to increase the budget for public health expenditures. The key to make APPACHA real is to ensure mobilization at the country level and be rooted in the realities of people's lives to form a strong and formidable alliance.

### APN+

Asia Pacific Network of People Living With HIV and AIDS (APN+), headquartered at Thailand, which is a subordinate body of GNP+ headquartered at Switzerland, was formed to give a platform to PLWHAs in Asia to raise their voice against the stigma and discrimination they faced, the violation of their rights and the physical and mental trauma they have to undergo. It is a social network for all infected by HIV and AIDS in Asia and the Pacific and is 'committed to improve the quality of life of people living with HIV and AIDS and to overcome the isolation of PLWHAs in Asia and the Pacific by extending the Network into all countries in the region.' Is

APN+ through its diverse works brings to the notice of the society the plight faced by the PLWHAs. APN+ in its report of 2004 has highlighted the discriminations faced by the PLWHAs. The report says that AIDS related discrimination is prevalent in every section of the society and that women are more prone to such discrimination. The report brings out the fact that the majority did not receive pre-test counselling before being tested for HIV and many were coerced for testing and were refused treatment after being diagnosed with HIV. Through such initiatives the APN+ is trying to increase the capacity of positive people to promote the adoption of national policies and programmes that protect their rights and reduce stigma and discrimination. <sup>14</sup>

Today, it is evident from the number of positive people's networks and the tremendous response they have received that their noble effort has not gone in vain. Regional networks of positive people have started all over. Due to this early determination today, people infected by HIV and AIDS are able to assert their rights, live life with dignity and have found reliable partners in different sections of society. Civil societies have joined their hands in confronting the



sections of society. Civil societies have joined their hands in confronting the mental trauma they face, which is harder to deal with than the disease itself.

Human Rights Groups and NGOs have come forward along with APN+ to advocate the universal access to treatment. The pressure applied by the positive people's network as well as these groups have resulted in ARVs being made available at a lower price. Under this pressure national governments and international organisations had made an attempt to provide ARVs to 3 million people by the year 2005. This initiative did not meet its target, nonetheless it was a positive beginning. Today HIV and AIDS positive people are seen with more respect and dignity. This is due mostly to the single mandate all the positive people throughout the world had to improve the quality of life of their brethren and the constant endeavour to further improve their position in the society. As Dr. Moody says, 'GNP+ will strengthen its work on access to treatment, care and prevention services for HIV+ people and their loved ones; scale up the building of coalitions; and strive for a strong united movement of PLWHA.' <sup>15</sup>

# People's Health Movement

People's Health Movement (PHM) is a collective effort of people's organisations, civil society organisations, NGOs, health professionals, academicians and researchers. PHM is trying to revitalise health and equitable development as top priorities as was promised by the 'Alma Ata Declaration' in 1978. PHM is of the opinion that comprehensive primary health care has been neglected for long and institutional mechanisms are needed to implement it.

It is also of the view that the structure of WHO and many health ministries are such that it reflects the dominant technical approach medically driven, vertical and top-down. PHM would like the WHO to transform itself and respond to the health challenges faced by the poor by avoiding vertical approaches, ensuring intersectoral work and involving people's organisations. It has also made a wide range of recommendations to WHO to ensure that health is easily accessed by all, and 'health for all' becomes a reality and not merely a privilege for a few.

ICAAP

The impact of AIDS in the future was realised in Africa. As a result, the International Congress on AIDS in Asia and Pacific (ICAAP) was formed before most countries had even detected any HIV infection. Over the years ICAAP has grown, covering various issues pertaining to HIV and AIDS. The Congress has played a very important role in keeping HIV and AIDS on the agenda as a global and regional concern and as a development issue. But, barring a few exceptions, the commitment of political leaders have been lacking. Political will is necessary in the public health domain including in the battle against HIV and AIDS. As signatories to the MDG, the countries have the responsibility of coping with AIDS. It has been proved by countries like Thailand and Brazil that it is possible to make a difference if the governments take necessary steps. In addition, the developing nations need to strongly support each other in matters that concern people's lives and national economies. It is thus important that countries participating in ICAAP take positions that are context specific and move beyond rigid frameworks like the 'Three Ones'.

# National Programmes

Despite the large NGO presence in AIDS control efforts, it is the governments, which can plan for and deliver educational messages and services at the mass level. With differences in epidemiology, state of health services, socio-cultural milieu and economy, the Asian states present a wide and varied picture. Yet, the national programmes have all essentially been vertical programmes. Global thinking, as opposed to local and contextual thinking, has dominated the AIDS control programmes as has been the recent trend for many other public health problems. While the HIV and AIDS pandemic necessitated an urgent response, many countries demonstrated knee-jerk reactions, perhaps in a bid to be over-cautious and impress the funding agencies. The 'Three Ones' has culminated from this vertical paradigm that seeks to straitjacket the programme globally. This section will highlight the key governance features in the national programmes in the light of their respective epidemiological situations.

### **Selected East Asian Countries**

China is confronting an emerging epidemic that is clustered among specific population groups including IDUs, CSWs, former plasma donors (and their partners) and two Provinces (Yunnan and Henan provinces and the Guangxi autonomous region). The rural population has been extremely vulnerable on account of low incomes and coping mechanisms have been marked by professional blood donation to unregulated private transfusion companies, sex work and large-scale migration. IDUs are particularly clustered in urban areas of southern China<sup>16</sup>. There were earlier criticisms that the national response was weak but recently there has been increased funding and a more transparent system. The health services have been criticised for catering largely to the better off in the urban areas. Village doctors who form the backbone of rural health services are usually left with very little resources. NGOs have been conspicuous by their absence because of rigid rules regulating their entry. The China HIV and AIDS Prevention and Control Action Plan (2001-2005) marks a new phase in political commitment. The 'Four Frees and One Care' policy currently in operation include<sup>17</sup>:

- Free treatment for all rural and poor urban PLWHA
- Free schooling for orphans and children of PLWHA
- Free PMTCT for women with HIV
- Free Anonymous testing for HIV.

China has made slow progress in realizing its 2003 pledge to provide free ART. HIV testing and counselling services remain underutilised; integrated prevention, treatment and care programmes are yet to be widely available.

In **Thailand**, the AIDS Control Programme has been marked by a high degree of political commitment, an IEC blitzkrieg and the '100% condom programme' . While HIV prevalence has been declining, there have been fears that decreasing prevention efforts may provoke a resurgence of HIV. Lower drug prices have led to increased ART coverage. It has been argued by some that the changes have been brought about largely through structural and societal-level changes, rather than just targeting individuals. The initial epidemic was attributed to the sex industry, which, though illegal, was mainstreamed to implement the preventive measures. But similar initiatives are absent for other groups like MSM and IDUs. Coercive action against them has

also been resorted to, violating the principles of human rights expected to underlie all AIDS control efforts.

With the HIV infection acquiring endemicity, large numbers of people will be requiring treatment, care and support. HIV and AIDS is now the leading cause of death among young adults and account for about twice the number of road traffic deaths. There is increasing concern that the centrally coordinated and directed response of the 1990s may not fit



the current context and diversity of the epidemic. More flexible responses are necessary that need to be decentralised to provincial levels. Low-cost generic versions of antiretroviral drugs are priced at about US\$ 300 per patient per year and are attributed to a good coverage of ART. However, health services and other supportive services require to be augmented. Alleviating economic impact for PLWHA was one of the goals of the National AIDS Plan but it is yet to be acted upon. Concern has also been expressed about increasing stigmatization, harassment and breach of confidentiality by the health system.

Sharing a long border with Thailand, Lao PDR has an overall low seroprevalence for HIV and AIDS but with two high foci areas. One of the 12 strategic programmes in the national health plan is the control programme for HIV and AIDS. Simultaneously the Lao National Poverty Eradication Programme is also being pursued so that Lao can exit the group of 'Least Developed Countries' by 2020. Allocation for health in the national budget has increased from 5.5% of the total budgetary allocation to 11% in 2005-06. The multi-sectoral National Committee for control of AIDS was established in 1998 and in the current year the National Strategic Plan for HIV and AIDS/STD draws to a close; the review of which will be an indicator of the nature of success of the programmes. A number of agencies are leading the programmes in different sectors - the Lao Red Cross runs the blood safety programme, the Ministry of Education runs the preventive programmes for schools and mass based organisations like Lao Women Union and Lao Youth Union in HIV and AIDS prevention activities. The poverty-focused health development plan under the National Poverty Eradication Program has defined a comprehensive set of goals and objectives for the health sector. The priorities are 'access with quality' and an emphasis on preventive health care. Laos is not one of the initial 3x5 countries because of its low seroprevalence; currently, treatment is being supported by an international NGO.

In Cambodia, despite a demonstrated decline in the prevalence rate, high rates of migration have been correlated with increasing prevalence among pregnant women in western areas bordering Thailand on account of a high rate of migration<sup>20</sup>. The HIV and AIDS programme is run by the National AIDS Authority and the National Centre for HIV and AIDS, Dermatology and STDs (NCHADS) established under the Law on the Prevention and Control of HIV and AIDS. Cambodia is also a signatory to the United Nations General Assembly Special Session on HIV and AIDS (UNGASS) targets, HIV related MDG and the 3 X 5 initiative. The Strategic Plan for HIV and AIDS and STI Prevention and Care for 2004-07 focuses on expansion of ARV services as a

and AIDS and STI Prevention and Care for 2004-07 focuses on expansion of ARV services as a new activity. The key HIV care targets in this plan are the expansion of the Continuum of Care programme to all ODs by end of 2007. The health services system is still in the process of being established in some ODs; ARV



provision is therefore being targeted in 36 key ODs with high HIV care needs. The NPRS, which complements the Socio-Economic Development Plan 2001-2005 has recognized the high costs of chronic life-threatening illnesses associated with HIV and their burden on poor families with Cambodians spending over 25% of their household income on health care. Despite these measures and the fact that Cambodia was one of the first countries to support the 3 X 5 initiative, the gaps identified by the Strategic Plan include monitoring of ART, preventing parent to child transmission, treatment of opportunisti infections and palliative care<sup>21</sup>.

In Vietnam, a large epidemic is considered imminent in the capital city of Ho Chi Minh City and the northern coastal cities of Quang Ninh and Hai Phong. The country has targeted to reduce the HIV and AIDS infection rate among its 82-million population to below 0.3 per cent by 2010, and keep it unchanged after 2020; the country's health care system will need to cope with an estimated 5000 to 10,000 new AIDS cases each year<sup>22</sup>. The current emphasis is on IEC with contents expanding into areas of virtues, lifestyle and behaviour, including encouraging youths to use the 'ABC' preventive approach and keeping away from drug addiction and prostitution. With large numbers of IDUs, joint efforts such as the border area needle exchange programme run in collaboration with China since 2002 are expected to bear results. With the strategies focusing mostly on prevention there have not been any specific and detailed guidelines on treatment and care for PLWHA. There has been no evaluation on the implementation and effectiveness of the current HIV and AIDS policies at central and community levels.

In Indonesia, the high profile 'Sentani Commitment' formulated in 2004 focused on<sup>23</sup>:

- promotion of condom use in every high risk sexual activity up to 50% in 2005
- reduction of prevalence among IDUs
- provision of ART to a minimum of 5,000 PLWHAs by the end of 2004
- reduction of stigmatization and discrimination of PLWHAs
- establishment and empowerment of provincial and district AIDS Committees
- development of a legal framework to facilitate HIV and AIDS prevention, care and support programmes.

Indonesia is facing an acute macro-economic crisis with increasing poverty and malnutrition and decreasing resources for the health sector; donor support is to the extent of 70%. A Social Safety Net programme to alleviate the health burden of the poorer sections of the population will provide subsidies for ARV drugs for impoverished PLWHA. The government is committed to providing access to subsidised antiretroviral therapy to everyone needing treatment, with the ultimate goal of ensuring universal access. Though most antiretroviral drugs have been registered in Indonesia they are not available in the dispensaries. Few generic antiretroviral drugs are registered. A state owned pharmaceutical is expected to produce and supply ART; the triple regimen is expected to cost about US\$ 564 per person per year.

The low prevalence in **Philippines** has been attributed to a good functioning system of routine screening for STIs along with other HIV prevention services for CSWs, circumcision (which reduces the al



risk of transmission), geography (no land borders) and relatively low number of foreign tourists<sup>24</sup>. The Medium-Term Philippine Development Plan (MTPDP) for 2001-4 sought to correct abject poverty conditions following the financial crisis of 1997. The Philippine National AIDS Council (PNAC) is the country's highest policy making and directing body and has

developed a multi-pronged strategy involving diverse bodies including churches and trade unions. Sustaining the low and slow character of the epidemic is one of the principal challenges being faced by the government among allegations by critics who suspect the data provided by the government. Currently, emphasis is being given to decentralizing the programme and mobilizing local responses

# Philippine AIDS Prevention and Control Act of 1998

The centrepiece of the national response to HIV and AIDS is the enactment of the Philippine AIDS Prevention and Control Act of 1998 (Republic Act 8504), a model for HIV and AIDS related human rights legislation. The entire process — the years of consultations, advocacy and lobbying, has been hailed as a 'best practice'.

The legislation is often described as path breaking for it:

- Prohibits mandatory testing of HIV
- Respects human rights including the right to privacy of individuals living with HIV and AIDS
- Integrates HIV and AIDS education in schools
- Prohibits discrimination against people living with HIV and AIDS in the workplace and elsewhere
- Provides for basic health and social services for individuals with HIV

While the law provides a clear basis for policies and plans to address the problem of HIV and AIDS, its effectiveness is yet to be proven. Six years after its passage, the law has been inadequately implemented and put into action

Source: http://www.youandaids.org (UNDP)

### **Selected South Asian Countries**

The National AIDS Control Programme in India is managed by the NACO at the national level and the State AIDS Control Societies in the states. Despite a huge private sector, there is very little formal involvement. There are several epidemics in India with some states demonstrating a slowing down of the epidemic. Migration, poverty, commercial sex and IDUs (in some states) are diverse challenges for the programme. There is no mandatory testing except the armed forces; however, many Indians are being tested for HIV without their consent or knowledge in the health sector (largely, pre-operative check ups). Two states (Goa and Andhra Pradesh) are considering mandatory premarital testing for HIV through laws but should this occur, the existing infrastructure would fall grossly short of requirements. The public sector is expected to gear up to provide free ART but is constrained by high costs and a relatively weak public health system. Poverty reduction remains a key national goal; some states have adopted sector-wide approaches but this has been considered to have marginal impact on the HIV and AIDS control programme since it is a centrally



sponsored programme.

In Bangladesh, the epidemic is primarily among IDUs and to a less extent among CSVs. The economy relies on more than 1.5 million migrant workers mostly to neighbouring countries, including truck drivers, businessmen and labourers. These migrants, who spend much of the year away from their families, are considered to be at increased risk of

contracting HIV. There has been a focus on reducing high-risk practices among IDUs. Reduced use of non-sterile injecting equipment has been reported among those participating in needle exchange programmes. In the context of safe blood transfusion, the MDG Bangladesh Progress Report 2005 stated that:

'Although 98 blood transfusion centres have been set up throughout the country, a comprehensive policy and strategy to ensure safety of blood and blood products is yet to be finalised and implemented. There is need to establish the baseline information on the percentage of blood being screened in the 98 centres and in all the other facilities that carry out blood transfusion. Minimum standards and requirements for health facilities to qualify and be authorised to screen blood for HIV before transfusion should be defined by the National Policy and Strategy on blood safety.<sup>125</sup>

This is a matter of serious concern and needs immediate attention. A National Strategic Plan (NSP) for comprehensive and integrated action in response to HIV and AIDS has been developed. The NSP has formulated a Monitoring and Evaluation System that will strengthen follow up of MDG and UNGASS indicators. Interventions focusing on vulnerable groups are being scaled up, HIV and AIDS advocacy and blood safety campaigns are under way; a project on HIV and AIDS and the Adolescents and Young People is in progress.

In **Nepal**, the coordinating body for HIV and AIDS prevention and control is the National AIDS Coordination Committee (NACC), and recently, the National AIDS Council chaired by the Prime Minister has also been established. The programme implementation has been delegated to the National Centre for AIDS and STD Control and the external development partners. Approximately 65% of the resources necessary for the National Action Plan for 2005-6 have been

pledged by the external donors. There is no comprehensive package for ART and other requirements of PLWHA. With armed conflicts and households headed by women increasing sharply, a higher risk has been projected on account of possible unprotected sex for money. Large-scale migration to India and human trafficking for the sex industry are additional factors leading to vulnerability of the Nepalese population.

Sri Lanka is a country with a low prevalence of HIV



Programme is implemented in collaboration with provincial directors of health services, STD clinics and the National Blood Transfusion Service. The programme is marked by large-scale multi-sectoral involvement. Recognising that there is a potential for rapid spread, the programme is focusing increasingly on those practicing high risk behaviour. Large numbers of migrant women to the Middle East countries have returned with HIV infections. The situation warrants urgent legal provisions and sensitisation of recipient countries.

Devastated by prolonged armed conflicts, Afghanistan is one of the poorest countries in the world. Only a small proportion of the population has access to basic health services. There is acute shortage of health infrastructure and trained staff in rural areas. Most institutions are ill-equipped and unable to protect staff and patients from HIV or to treat opportunistic infections or prevent parent to child transmission. The poor state of blood transfusion facilities throughout the country is also of concern. The NGOs are playing a key role as of now and there is an urgent need to build up a national response.



Myanmar has 'one of the most serious AIDS epidemics in the region' with national prevalence close to that of Cambodia and Thailand. An estimated one million workers are migrants to Thailand<sup>26</sup>. The National AIDS Programme is run by the National AIDS Committee (NAC) that was constituted in 1989 and is a multi-sectoral body drawn from various governmental agencies and NGOs. There are signals that the 100% condom programme launched in 2001 is translating to benefits. In an effort to decentralize, the National Health Plan AIDS has formed committees at the state/division and township levels. A healthy living and AIDS prevention education project focused on schools is covering 1.5 million school children and intensive efforts are on to prevent parent-to-child-transmission. ART is currently provided through NGOs and the private sector. Large-scale efforts are necessary to scale up ART, including funding and expansion of VCTCs. While neighbouring Cambodia and Thailand have received millions of dollars as aid to fight the disease, few donors are willing to assist a regime that is widely accused of gross human rights violations. Myanmar's ruling junta insists that actual HIV infections are a fraction of those estimated by international agencies, claiming that reports of high HIV prevalence rates are being used as a political weapon to undermine the government's legitimacy.

#### Selected Middle East Asian Countries

The scale of the pandemic remains unknown in the Middle East since surveillance data is insufficient. In **Saudi Arabia**, relatively high rates of infection have been reported are through transfusion of contaminated blood and blood products. Nearly a third of the population consists of expatriates; fears of deportation lead to suppression of information. The National AIDS Control Programme is focusing on IEC campaigns through 2000 health centres and free ART is available in all hospitals. There are also four specialised clinics for referral services.

In Iran, the programme focuses on IDUs, with an estimated 50% of prisoners being detained

for drug use. The current emphasis areas include voluntary testing and counselling; telephone counselling is a major thrust area and IEC in public spaces is under consideration. 'Triangular Clinics' have been set up and these have been considered as 'best practice' in the Middle East and North Africa for controlling and preventing HIV and AIDS infection.

In Yemen, the National AIDS Programme was established in 1987. There is no comprehensive programme to cover vulnerable groups and surveillance systems are very weak. Yemen is in the process of recovering from an economic crisis and remains one of the least developed countries in the world. There is widespread stigmatisation of the disease among health care workers leading to under-reporting. No more than about 20% of blood donors in the country are currently being screened. Legislation on and regulation of transfusion services are urgently required. There are plans to scale up ART; I 300 people are expected to be treated by the end of 2005.

### Selected Central Asian Countries



It is generally agreed about the epidemiological situation of HIV and AIDS in Central Asia that<sup>27</sup>:

- there was large scale disruption following the collapse of the USSR; guaranteed employment ceased guaranteed employment ceased
- there was a rise in IV drug use and STIs
- there is lack of surveillance systems and therefore reliable data
- intravenous drug use is the principal route of transmission
- MSM is highly stigmatised and discriminated against; but their extent of contribution to the epidemic is largely a matter of conjecture
- Uzbekistan has the most rapidly increasing prevalence rate in the region
- Kazakhstan is also reporting increasing infections with intravenous drug and commercials identified as the principal routes
- the situation is comparatively better in Kyrgyzstan and Tajikistan
- coverage of HIV prevention programming is low
- only around 11% of people who need antiretroviral drugs are currently being treated

**Uzbekistan** has shown increased commitment in its response to the HIV and AIDS epidemic since 2000. The government has developed the Strategic Programme on Counteracting the HIV and AIDS Epidemic for 2003-06. More than 200 Trust Points have been opened throughout the country to provide counselling, testing and free syringes, condoms and information. ART through the public health system will only be beginning in 2005.

**Kazakhstan** has been undergoing health sector reforms that have facilitated a shift from curative to preventive medicine, promotion of primary care, decentralisation and stronger community participation. The government has recently come out with the commitment to fully support the  $3 \times 5$  initiative with a target to reach 80%.

There is no national policy yet in Kyrgyzstan on antiretroviral therapy, protection of human rights, confidentiality and voluntary counselling and testing. National antiretroviral therapy and care protocols are being developed. The Strategic Plan of the National Response to the Epidemic of HIV and AIDS in Kyrgyzstan was passed in 2000, and the Vice-Prime Minister chairs the National Multisectoral Committee on AIDS. The second State Programme on Prevention of HIV and AIDS and Sexually Transmitted Infections (2001-05) is currently in progress. It has one of the largest pools of IDUs; two pilot methadone substitution projects have been started, one in Osh and one in Bishkek; a needle exchange programme is also under way. Some elements of second-generation surveillance have been introduced that are expected to assess risks more precisely in the future.

In **Tajikistan**, it appears that escalation of the epidemics is currently in progress. The economic situation and health services are recovering from the collapse of the USSR. It is recognised that there is gross underreporting. The cost of antiretroviral therapy and pervasive shortage of trained healthcare providers are proving to be barriers to ART though the overall need is not very large. The programme is alive to the fact that the spread of HIV and AIDS in Tajikistan could be facilitated on account of sex work, migration and high unemployment among young adults.

Thus, while there is much diversity in the extent and details of the national response to the HIV and AIDS epidemics, there is a common thrust, similar to the worldwide approach to AIDS control. The broad picture and common issues emerging from it are easy to summarise.

### The Need for a Paradigm Shift in Governance

#### The Prerequisites for HIV and AIDS Control

- The current focus of shifts in AIDS control efforts is largely on universal access to ART. However, the target of treating 3 million HIV infected persons by 2005 in developing countries remains a distant goal despite recent increases in coverage. The delivery of ARV can succeed only if there are 'functioning public health services that are generally accessed for curative care.'
- A 'demand' for public health services can be foreseen as more and more people start accessing and demanding ARV. The health services system including the personnel will need to gear up for this challenge.
- Preventive programmes too still have a long way to go. While prevention campaigns need to continue without any dilution there is an urgent need to raise awareness about comprehensive treatment of HIV infected persons both among the community and the healthcare providers.
- However, if the spread of HIV is to be curtailed in any sustained manner, the narratives of the PLWHAs in the last chapter remind us once again of the urgency of generating livelihoods and access to food with dignity for the poor,

#### Governance of Development and Welfare

- Policy initiatives such as the MDGs and PRSPs represent a commitment to 'social responsibility' for people's welfare. However, the techno-managerial approaches espoused to pursue the objectives, and the lack of an integrated perspective, leave grave doubts about the possibility of their succeeding to any significant extent.
- The commitment to MDGs and PRSPs on one hand and further strengthening of economic policies of liberalisation, privatisation and globalisation that favour the global capital's commercial interests on the others, reflects the contradictions.
- TRIPS and WTO demonstrate the stronger face of such anti-poor global initiatives.

#### Governance of HIV and AIDS Control Initiatives

- The '3 X 5' and 'Three Ones' initiatives by UNAIDS too appear to be taking seriously the responsibility of governments for the welfare of HIV infected persons and control of its spread. But these initiatives demonstrate the techno-managerial thrust in current AIDS control efforts, again with neglect of the basic pre-requisites.
- The '3 X 5' initiative focuses attention on provision of ARV drugs without building up capacities of the health services.
- Governance models like 'Three Ones' tend to straitjacket programmes leaving little leeway to alter programmes according to local epidemiological or health service situations. Integration with the general health services is also very limited in most countries and the exclusivist image continues.
- The TRIPS agreement continues to be an obstacle to cheaper production of drugs. Despite provisions for generic production through compulsory licenses there are very few instances where this has been effectively used.
- Following the liberalisation and privatisation of state functions, health services are increasingly being outsourced to the private sector and NGOs. This has serious implications for concerted action in public health programmes of this size and nature.
- These arrangements suit the verticality of the programme but at the cost of missing out on planning and delivery appropriate to local contexts and utilisation of societal resources.

#### Appropriate Knowledge Management

- Knowledge generated by research studies with a comprehensive perspective that reflects the reality of people's lives has to be disseminated and used in policy and programme formulation.
- With the race for vaccine development intensifying, safeguards for the participants in the research and monitoring mechanisms have to be put in place.

#### The Challenge to Governance

- The Asian challenge is to demonstrate that effective systems can be developed for comprehensive services and optimum use of medical technologies, while simultaneously resisting the economic policies that favour global commercial interests at the cost of people's lives.
- Structures and mechanisms to understand and respond to community demands are essential.
- Will the governance structures of the various Asian countries, with their diversity of political structures, meet the
  challenge? The report card is not good, as this chapter shows. But there are glimpses of hope where collective civil
  society action presses for people's interests through concrete issues with a comprehensive perspective. The
  following chapter highlights the specific outcome of governance in terms of the financing of HIV and AIDS control
  efforts.



Most Asian countries are yet to prioritize the issues in resource allocation and disbursement – If prevention, care and treatment efforts continue to be as inadequate as at present, by 2010 yearly losses to the region are estimated to reach US \$17.5 billion as opposed to the estimate of US \$7.3 billion lost in 2001.

**P**rivate sector financing (including NGOs and employer based initiatives) constitutes a very minor proportion of total spending across the Asian region.

The role of the public sector will remain critical in terms of prioritising investments both for and within the health sector, as well as in the signals that it sends to the private sector.

**N**ational budgets of Asian countries indicate clearly that while for some health has not yet acquired the priority that it deserves, for others health seems to have lost priority.

Except for Cambodia and Laos, per capita health investment by the Global Fund in Asian countries has been less than \$1per capita. In Cambodia and Laos it has been between \$1 and \$3.

Out of contracts worth 3.4 billion the GFATM signed between 2002 and 5, only 1.6 billion dollars were disbursed. Donors and countries hit heavily by HIV AND AIDS are now asking why funds are sitting lazy in the World Bank Safe.

**C**urrent government funding patterns show an encouraging trend: governments have been increasing their budgets. However, the challenge for Asian governments is to prioritize and accordingly increase their investment if they are serious about tackling the epidemic. There are also problems of leakages and non-utilisation of funds.

There is little hard data at the disaggregated level to use for analysis or for any planning or forecasting budgetary exercises for most Asian countries.

he nature of financing of programmes and health services plays a crucial role in determining the structure and quality of the outcome and thus the capability of the health system to achieve its stated goals. Financing patterns also affect the behaviour of different stakeholders. Marked socioeconomic inequality and stagnant national health budgets call for immediate attention to financing issues that impact not only AIDS control programmes but health outcomes and development goals for the entire population as well.

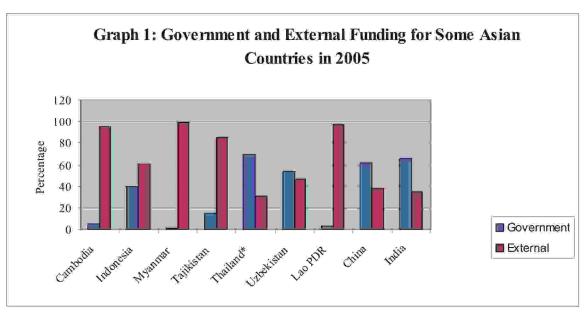
Unfortunately most of the Asian countries are yet to prioritise issues in resource allocation and disbursement. According to a recent study by ADB/UNAIDS, estimated losses in 2001 comprised over US \$7 billion in lost income and additional expenses borne by HIV and AIDS-affected households – overwhelmingly the result of the sickness and death of adults as well as US \$250 million in government spending on HIV and AIDS prevention and care. If prevention, care and treatment efforts continue to be as inadequate as projected, then by 2010 yearly losses to the region will equal US \$17.5 billion compared to the estimate of US \$7.3 billion lost in 2001. This they base on the projection of 10 million adults and children in Asia-Pacific becoming newly infected between 2004 and 2010; the annual death toll rising to 0.76 million by 2010, if there is a failure to immediately establish comprehensive and effective prevention, care and treatment programmes.

### Resources and Priorities

#### Financing Options - The Public Sector and External Funding

There are two primary sources of financing available for HIV and AIDS. One of course is what can be broadly classified as the tax-based public sector. External financing through grants and loans has emerged as the other major source of financing HIV and AIDS programmes across the developing world (Graph I). As of date, private sector financing (including NGOs and employer based initiatives) constitutes a very minor proportion of total spending across the Asian region. Out of pocket expenses of households (including user fees charged at public facilities) have on the other hand come increasingly into focus with mounting concerns for its negative implications for pro-poor financing. That user fees have adversely affected the ability of the poor to access public health systems is well established. Social and community based insurance systems have yet to address the concerns of HIV and AIDS patients in any significant way. To the extent that policies of liberalisation, privatisation and globalisation have led to the degradation of existing public health systems, these have implications for increasing costs of control efforts. There has been a steady weakening of state controls in several sectors, including health.

The Global Fund has emerged as a major funding source for most Asian countries. It relies on European countries and the US to provide two thirds of its resources. The remaining third is to come from the rest of the world, including Japan, Singapore, South Korea, Australia and New Zealand. The rich Asia Pacific countries have been lagging behind in providing their fair share of financial support to the Fund, contributing only 13% to date.<sup>2</sup>



**Source:** ActionAid Analysis 2005, based on CCM proposals at different rounds to the GFATM (Global Fund Website). \*The figures for Thailand are based on the financial commitment data reported for the period 2002-2006 in the CCM proposal to GFATM.



There is a lack of support systems among the Asian countries to fight against AIDS. It is clear that Asia needs more resources and it is justifiable that G7 needs to allocate more funds to fight AIDS. However, a question might be raised regarding the extent to which the better-off Asian countries have been able to achieve proper resource allocation within their own countries. Further, one may question what sort of support they have been able to provide to other poor countries in the region to fight AIDS. According to an Asian Development Bank (ADB) report, 'the region as a whole can well afford these investments. Even the peak resource need of US \$5.1 billion annually for the years 2007-2010 is just 4 per cent of current regional health expenditure and 0.2 per cent of regional gross national income (2001).'

A joint study by UNAIDS and ADB says, 'The region, and all of us, now have clear choices to make, with equally clear consequences. The problem is, in Asia, as in Africa, only a small fraction of those in need are currently receiving these lifesaving services. Increasing access to AIDS prevention and treatment will require a serious investment. Last year, \$1.5 billion was needed for a comprehensive response to AIDS in Asia, yet only \$200 million was spent by all public sources combined. This resource gap will continue to grow along with unmet needs. And by 2007, the funding needed for AIDS prevention and treatment services in Asia will rise to \$5.1 billion annually, or approximately \$2.00 per capita.'

#### **Prioritising Health Expenditure**

One observes wide variations in the per capita total health spending in different countries within Asia. It is a matter of concern that while a few Asian countries like Thailand have high per capita total health spending (at US \$ 71) others like India have spending as low as US \$ 23. There is also considerable variation in the contribution of public spending across these countries. A breakdown of health expenditure reveals that countries with higher expenditure by the public sector typically report higher levels of health outcomes. The HIV and AIDS situation is unlikely to be different from this broad picture. In order to ensure effective action, there is an urgent need for increasing health sector funding to remove bottlenecks in the existing health delivery system. Limited expansions of health budgets in general can also harm overall health sector goals, when within country national health schemes are seen competing with each other for funds. In India, for instance, malaria has got crowded out in the central budget allocation giving way to HIV and AIDS during the decade 1992-93 to 2002-03. While malaria moved from 66% of total outlay under disease control programmes to 29.3%, HIV and AIDS moved up from 5% to 34.3% <sup>3</sup>.

National budgets of Asian countries indicate clearly that while for some health has not yet acquired the priority that it deserves, for others health seems to have lost priority. The financial crisis in South-east Asia in the late 1990s worsened matters, leading to adverse consequences for social sector outlays in general, health being no exception. In most of these economies, the health system is yet to recover adequately to be able to deal with the increasing burden of disease. The MDGs' focus on two aspects of health communicable diseases and maternal and child mortality is one attempt to bring into prominence the importance of improving health systems. AIDS is one of the three communicable diseases that have been talked about in this context. To take the case of AIDS alone, fewer than 100,000 people are currently on ART in Asia and the Pacific, which is less than one per cent of those living with HIV and AIDS<sup>4</sup>. Even as the need for universal access to

Last year, the region's Gross Domestic Product (GDP) grew by 7.2 per cent, but this rosy figure has little bearing on most of the 1.5 billion population's quality of life, according to the UN report 'Human Development in South Asia 2004: The Health Challenge.' Two-thirds of the world's malnourished children are in South Asia, and although the adult HIV prevalence rate is below one per cent, in terms of absolute magnitude there are 5.2 million PLWHA, with an estimated 5.1 million of them in India. South Asia's health problems are worsened by a failing and under-funded public health sector. The region's governments spend about one per cent of GDP on public healthcare, while the average in developing countries is 2.7 per cent, and 6.3 per cent in developed nations.

ART is stressed, there are genuine concerns about the likely failure of the WHO and its collaborating partners in reaching the goal of providing 3 million people in poor countries with ARV treatment by 2005.

In June 2005, a UNAIDS report projected a funding gap of \$18 billion for HIV and AIDS in developing nations between 2005 and 2007. The projected estimates for funding made by UNAIDS in 2005, for the first time addressed the funding requirements for a longer term such as training of existing staff, recruiting and paying new staff, and provision of necessary infrastructure<sup>5</sup>.

Doubts have been raised about the extent to which macroeconomic policies as currently followed in many developing countries, provide scope for increasing outlays on social sectors. It is argued that the amount of public spending required on sectors such as health and education gets severely restricted by IMF led policies that stress macroeconomic stability through ceilings placed on the overall level of national spending. Tight monetary and fiscal policies, targeting lower inflation are seen as beneficial to economic growth. This in turn affects budgetary allocation on social sectors. However, while economists seem to agree that bringing down inflation from very high levels is beneficial, opinion on the relationship between low to moderate rates of inflation and growth stands divided. To quote from an UNDP source '...we simply point out that there is no strong evidence in support of the argument that very low inflation is either pro-growth or propoor'<sup>6</sup>. Civil society advocates argue for the need to explore alternative policy options that allow for higher levels of long-term public investments in sectors such as health and education, which in turn could take economies closer to the MDGs. Whether PRSPs will mean more money for health or not remains ambiguous. As one report highlights, the increases on social spending that the IMF allows for are nowhere near the levels projected to fight HIV and AIDS'. There are concerns that the current macroeconomic framework (supported by the IMF and the World Bank) simply does not allow countries that borrow foreign funds to increase public expenditures to the levels necessary to achieve the MDGs and effectively fight HIV and AIDS. Public discussions and debates about key fiscal and monetary targets and possible alternatives to dominant macroeconomic policy frameworks need to be encouraged.

## Investments-A Question of National Priorities

At the macro level, financing issues within the health sector would imply a comparison of the returns on money invested in an AIDS programme versus the returns from investing in other programmes within the health sector, including both programmes targeted at specific diseases (e.g. malaria, TB) as well as investments in overall health infrastructure. A related issue is the returns from investment in different components of the AIDS programme, which could be broadly classified into preventive and treatment aspects. At the micro or household level, the financing issues include three components – the expenses borne by households directly for the illness; the associated coping costs for the family members and finally, the direct income loss due to illness. Unfortunately, limited data availability at both the country and the household levels severely restricts cross-country comparisons on these heads of investment. However, broad country level

trends can be discerned from the existing data even as we voice the need for more systematic comparable country level information collection systems. At the household level, case studies and small surveys have also contributed to our understanding of some important issues. Most of the discussion in this chapter is based on a blend of country level trends as well as evidence from household surveys, large-scale databases still being a remote possibility.

A study by the International AIDS Economics Network examined the cost-effectiveness of different options for financing in India<sup>8</sup>. They found that provision of ARVs exclusively to those below poverty line was the most cost-effective, followed by provision to women who are detected HIV positive through the antenatal clinics along with their partners. The third and least cost-effective option was inputs to help patients adhere with IEC, lab strengthening, etc. There is obviously scope for improving on the study, for instance, it has been argued that the last of the options cannot be a separate option while it is an imperative for use of ARVs. Without sustained IEC for prevention, even Europe has seen a resurgence of HIV infections after ARVs were in use for some years. The point to note is however that such studies, which can contribute in planning for financial allocations, are a rarity.

UNAIDS projections on annual HIV and AIDS financing needs for the period 2004-07 (including 19 prevention activities, six treatment and care services, and three types of orphan support), reveal a more than doubling of financing needs over the period for both South and South-east Asia and the Asia-Pacific region. Global level estimates of resources needed for prevention and for care and treatment are at a ratio of 1.3:1 approximately. However, this of course masks specific country level requirements. In fact, Asian countries (including India) have often invited criticism for spending too little on IEC activities under national health programmes. The NACP in India is to an extent an exception to this rule, as evident from the table below. However, faced with HIV and AIDS in a resource-constrained situation, fire-fighting becomes a priority and general notions on preventive spending need to be carefully evaluated. The area of contestation is the budgetary allocation between preventive and curative aspects of AIDS funding. Ideally, the situation is expected to be country specific, and also dependent on the total amount of

The World Bank Table 1: Allocation of World Bank and Government of India Funding Across Components of the HIV and AIDS Programmes over the Period 1999-2005

Components	Allocation of Funds (in crores of rupees)
Targeted intervention for groups at high risk	265.6
Prevention interventions for the general community	389.1
Low cost AIDS care	163.3
Institutional strengthening	286.5
Inter-sectoral collaboration	50.5
Total (1999 - 2005)	1155.0

Source: Bhat and Saha 2004

Note: A large part of the targeted interventions comprises of IEC and condom distribution, i.e. prevention activities. It is evident that while 61% of the total funding is allocated for prevention (items 1, 2 and 5) and 25% for administrative costs (item 4), only 14% is allocated for treatment (item 3).

resources available. Opinion stands divided in countries such as India, where concerns for rapidly increasing access to ARVs have clashed with centrally driven priorities for preventive (mostly IEC) campaigns. Again low caseloads could further dilute the argument for urgency in spending on disease specific messages for AIDS when faced with gaps in funding. As long as pointed out by scholars the need for integration of treatment and care with prevention has been long overdue. In fact dichotomizing prevention and treatment is avoidable since diagnosis and treatment constitute one of the several levels of prevention. Most national health programmes include diagnosis and treatment as a basic strategy and the issue of prioritizing allocation between them arises from viewing treatment as comprising of ARVs only.

With the epidemic growing rapidly in Asia, most Asian governments have started to increase their national budgets to fight AIDS, although serious gaps in funding persist. With escalating intraregional tensions, government's face increasingly tough choices in making investment decisions. Fund allocations out of national budgets often take a back seat to expenses on heads such as defence. India and Pakistan are two of the largest spenders on defence in the world; countries like Vietnam and Cambodia have already faced the cost of conflict, while Nepal is battling internal strife. Security concerns head the priority list in China and Japan. As a result Asian governments are sometimes seen as reluctant to invest on people; South Asia in particular suffers from this syndrome. One indicator of this is that India invests nine dollars, Pakistan three, and Bangladesh two per person every year in basic education <sup>10</sup>.

Investment in health gets even lower priority. The basic issue of how decisions regarding within-country allocation of health sector funds are made is often not an easily comprehensible or transparent process. For instance, the central government in China has established a framework for allocating resources under the HIV and AIDS programme, with the population, social and economic status, as well as magnitude and trend of HIV and AIDS epidemic, all being weighed in allocating HIV and AIDS budget resources to provinces. However, there are reports of gaps in allocation and co-ordination at different levels, which have had adverse impacts on controlling the epidemic. This is a story that is common in other countries of the region as well. Some amount of flexibility in decision-making for financing health services at the local levels is also necessary as part of the strategy to cater to the needs of AIDS patients, as well as for preventive strategies. At the local level there could be substantial variation in needs and also unpredictability in operational

costs. Being tied down to a long-term plan of activities may not be a practicable approach in planning for such heads.

Although HIV and AIDS prevalence rates in Pakistan, Sri Lanka, and Nepal are low as compared to India at present, what is a matter of greater concern is that these countries suffer from the same maladies of low government health spending, weak health institutions and infrastructure and vulnerability to various illnesses, along with a weaker surveillance system. Hence, the financing priorities are similar, calling for higher public sector



investments in health care systems to facilitate successful delivery of HIV and AIDS programmes. Such investments would reap long term benefits in terms of both integrating HIV and AIDS patients into normal processes and also in improving overall health outcomes.

## Insurance and the Private Sector's Contributions

At the household level, private sector voluntary health insurance schemes can only work at the instance of specific government laws and orders.

> 'An insurance company in central China's Henan Province has launched a new policy that ensures the beneficiary a compensation of up to 300,000 yuan (\$37,050) in case of HIV infection. According to the new insurance programme of the Henan Province Branch of China Taiping Life Insurance Co., a policy holder will pay 12.9 yuan annual premium for an insured sum of 10,000 yuan in case he/she is infected with HIV during the year. Each policyholder can pay up to 387 yuan in annual premiums for a total insured amount of 300,000 yuan. Taiping Life was authorized by the China Insurance Regulatory Commission in early October to launch the HIV insurance programme nationwide, said Peng Dahua, an executive with the Henan branch.'

Source: (The Hindu, October 31, 2005)

However, the government can actively encourage (through partnerships) the financing of treatment at least for employees of private sector companies. Some limited evidence of this is seen in India, for instance. These include the big companies (Tata, Reliance, Apollo Tyres, Infosys, etc.) who have either entered into joint initiatives with the government or with some humanitarian organization. Several public sector (government and/or quasi government) organisations have also joined hands with NACO in fighting HIV and AIDS in various capacities and forms. Important among these organisations are Steel Authority of India Limited (SAIL), Indian Railways (IR), Employees State Insurance Scheme (ESIS), Defence Ministry, etc. SAIL has been organising and conducting different training and orientation programmes for doctors, school children and teachers. SAIL's activities have been concentrated largely around its different steel plants. The ESIS on the other hand, aims to reduce the spread of HIV among those ESI beneficiaries who are poor, marginalised and at highest risk of HIV infection, especially, migrant workers and industrial labourers. ESIS is also one of the few organisations, which provide antiretroviral drugs to AIDS patients from their own funds.

In short, it is obvious that for the large majority in the less developed world, the role of the public sector will remain critical in terms of prioritising investments both for and within the health sector, as well as in the signals that it sends to the private sector. However, priorities tend to get heavily impacted by the availability of funds, an issue of international importance in the context of HIV and AIDS control programmes.

# Politics of Funding and Global Uncertainties

In the global HIV and AIDS scenario, GFATM, AusAid, EU, DFID, USAID are some of the major donors funding for AIDS. Some corporate philanthropists (for instance the Bill and Melinda Gates Foundation) have also entered the scene. Most of the Asian countries have received assistance from these funding resources.

Despite G8 commitments on HIV and AIDS at the Gleneagles Summit, other recent events signal that financial support for controlling the epidemic may face an uncertain future. The GFATM has identified funding gaps of US \$700 million for 2005, US \$2.9 billion for 2006 and US \$3.3 billion for 2007. While donor contributions targeting HIV and AIDS programmes in the developing world have grown considerably in recent years, a funding gap of US \$18 billion remains for GFATM over the period 2005 to 2008.

The revised (UNAIDS, August 2005) estimates indicate global resource requirements of US \$15 billion in 2006, US \$18 billion in 2007 and US \$22 billion in 2008 for prevention, treatment and care, support for orphans and vulnerable children, as well as programme and human resource costs. The financial requirements for human resources and programme costs are preliminary, and

will form the basis for future refinement and improvement of estimates.



G7 countries have had a major influence on the global economy. The attainment of MDGs and the 3 X 5 initiative have suffered due to the lack of translating donor commitments into action. The G7 did not increase aid, at least not beyond the amounts agreed to three years earlier, although in 1970 all but one of them (the US) had committed themselves to providing 0.7% of their national income in aid. Thirty-five years later, the average G7 effort is only 0.26%, and even the top two G7 performers, France and the UK,

are well below the target<sup>12</sup>. The G7, which also exercises preponderant power on the boards of the international financial institutions, such as World Bank and IMF through their weighted voting systems, could, if it wished, cancel the unsustainable debt that is crippling the ability of the world's poorest countries to meet the promises of MDG and 3 X 5 targets. The recent initiative in Africa of waiving off the debts seems to be in a positive direction.

Most of the debt is held by the IFIs<sup>13</sup>. International aid is a key element of development financing. For many of the poorest countries, official development assistance (ODA) represents

financing. For many of the poorest countries, official development assistance (ODA) represents the largest source of external financing, supporting the country's education, health, public infrastructure, and agricultural and rural development. However, aid has often been used to

#### Aid for Greedy and Not for Needy!

Less than half of aid gets spent in the poorest countries, and only 10% is spent on basic services that are critical to achieving the MDGs.

40% of aid continues to be tied to overpriced goods and services from the donors' own countries.

80 official agencies are responsible for 35,000 aid transactions a year that are imposing a massive administrative burden on some of the poorest countries.

Aid conditions continue to impose donor blue prints, such as trade liberalisation and privatisation of essential services, with often devastating results for poor.



Table 2 provides country-wise funding and disbursement details of the Global Fund for some Asian countries. Except for Cambodia and Laos, per capita health investment by the Global Fund in Asian countries has been less than \$1 per capita. In Cambodia and Laos it has been between \$1 and \$3. Funding to fight AIDS in Asia is shadowed by the destruction of Africa. Donor communities are reluctant to fund Asian countries though the figures clearly show that the epidemic curve is rising in Asia. As far as the proportion of funding from government and external sources is concerned, in the two countries with the highest populations, India and China, the proportion of external aid is lowest with more than 60% of the funding coming from their own government sources. This is despite the fact that in Asia, India and China both have high numbers of people living with AIDS, along with Myanmar and Thailand. The absolute numbers have important implications in terms of the total costs of treatment.

External funding has its own problems – aid is often conditional, funds are not sufficient, and many come with their own global politics. The following statement mentioned in Vietnam's National AIDS Strategy indicates the burden and conditions that often accompany external funds, 'Although there has been close cooperation with the international community in HIV and AIDS prevention and control, but because of inactive use of resources, most of the international cooperation activities are fragmented, inefficient and could not live up to our requirements as well as the expectations of the international community".

It is also interesting to note that many donors are the members of CCM in many countries and it is obvious that they are influential in decision-making processes. For example in Nepal, there

Table 2: Global Fund Financing in Different Countries of Asia

Country	Rounds	Total Fund Requested (US\$)	Approved Funding (US\$)	Total Fund Disbursed (US\$)
Cambodia	1	15,714,629.00	15,714,629.00	9,706,758.44
	2	14,765,625.00	14,765,625.00	5,015,905.22
	4	36,546,134.00	8,794,982.00	2,824,061.00
Bangladesh	2	19,711,030.00	6,010,140.00	5,759,150.00
Afghanistan*	2	3,125,605.00	3,125,605.00	2,151,759.00
Myanmar	3	54,300,034.00	6,103,009.00	6,103,009.00
Pakistan	3	8,312,200.00	3,822,700.00	2,393,500.00
Vietnam	1	12,000,000.00	7,500,000.00	6,798,890.24
Yemen	3	14,764,061.00	2,715,720.00	1,353,759.00
	3	14,764,061.00	2,784,684.00	886,473.00
LaoPDR	1	3,407,664.00	3,407,664.00	1,800,283.00
	4	7,747,873.00	3,014,946.00	1,410,452.00
Indonesia	1	7,829,764.00	7,829,764.00	3,312,198.00
	4	65,035,569.00	31,129,618.00	8,123,871.00
Thailand	1	109,353,700.00	109,353,700.00	30,738,393.00
	2	81,348,535.00	14,079,270.00	3,929,004.00
	2	81,348,535.00	5,993,913.00	3,988,822.01
	3	1,371,348.00	911,542.00	275,140.58
China	3	97,888,170.00	32,122,550.00	23,764,424.00
	4	63,742,277.00	23,936,918.00	8,246,620.00

Source: ActionAid Analysis 2005 based on CCM proposals to the GFATM (taken from Global Fund Website)

was great hesitation from the donor communities while endorsing the 5th round GFATM proposal. Donors were of the opinion that Nepal does not need extra resources on HIV and AIDS and that there has been a large amount of budgetary allocation in Nepal. Some donors like USAID and DFID have supported many HIV and AIDS programmes in Nepal. Therefore, the issue they need to address are re-examination of the approaches and strategies adopted to deal with the problem.

In many Asian countries at times, the nominations for the CCMs and project selection have been political and the process of disbursement of funds is complicated. Although GFATM has also realised how complicated the systems and structures are, little has been done to address these problems.

Out of the 3.4 billion worth contracts the GFATM signed between 2002-05, only 1.6 billion

<sup>\*</sup>This is an integrated budget for AIDS, TB and Malaria





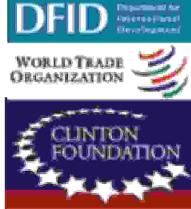
dollars were disbursed. Donors and countries hit heavily by HIV and AIDS are ing why these funds have been lying around in the World Bank safe. The main son behind this lies is the GFATM Comprehensive





Funding Policy (CFP). According to the CFP, the Fund can approve grants (for duration of 5 years) only if it has enough money in its account to fund the first two years. In other words, to sign a grant in 2005 the GFATM has to have already cashed from donors the amount that is to be disbursed until 2007.

Donors wanted to instil financial prudence to avert any possibility of failure to deliver what was approved due to lack of cash. The donors also wanted to avoid being forced by the GFATM rate of approvals to establish their contributions. Therefore, before determining the financial dimensions for any new round of proposals, the Fund is obliged to wait for all the donors to cash in. This is just the initial step. The launching of the Round to the approval of grants takes almost 6 months. After 3 years, donors still use the CFP to suit their own advantages: the money sitting lazy is considered to



be proven evidence of the Fund's limited absorptive capacity. The CFP policy has turned into a powerful tool to dismiss any increase in donors' contributions and to delay the disbursements of the limited promised amounts.

Following the recommendations of the GFATM Partnership Forum in July 2004, the Global Fund Director sought the advice of the private consultancy firm, Pricewaterhousecoopers, on the possibility of making the comprehensive funding policy more flexible by accepting donors' promissory notes in replacement of actual contributions. This reform would have allowed the Fund to simply approve grants on the basis of donors' pledges. The consultancy discouraged any move towards such increased flexibility. The consultancy noted that promissory notes are too risky for GFATM's financial stability: donors' promises are not reliable, they generally do not materialise. This conclusion was partly influenced by the fact that Italy did not release the amount of money promised in 2004. Ultimately, it then disbursed its 2004-05 contribution in June 2005.

Recently, the difficult financial situation of the GFATM has opened a new space to reduce the CEP. A board meeting in September was supposed to have approved 63 new 'technically sound' projects; it was obliged to 'temporarily' approve 37 proposals as there was not enough money, and hoped to force donor contributions before June 2006. It is unfortunate that the GFATM has been led to forcing donors to contribute to its needs rather than have donors contributing of their own accord.

The President Emergency Plan for AIDS Relief (PEPFAR) has been criticised in many countries. Activists from across the world are of the opinion that the selection of 15 African countries and one Asian country is politically influenced. The nomination of Vietnam from Asia has been controversial and AIDS activists are of the opinion that since India, China and other select India, which has twice the HIV and AIDS prevalence and 30 times the number of people living

countries are going through a serious crisis with millions of population at risk and already infected, the decision for selecting Vietnam was largely political. It has been reported that some lawmakers had called on the US President to select India, which has twice the HIV and AIDS prevalence and 30 times the number of people living with HIV as Vietnam, yet the decision went the other way.

The US has also been criticised for channelising most of its funding to its own international programme – the \$15 billion, five-year PEPFAR, which targets 15 countries rather than contributing to the main international effort, the Global Fund for HIV and AIDS, Tuberculosis and Malaria. Twenty per cent of the money released under the US emergency plan is earmarked for prevention. Of that 20 per cent, one-third is dedicated to programmes focusing on abstinence. Critics accuse the Bush administration of pushing its conservative worldview through this restriction <sup>14</sup>.

Donors can visibly influence the financial size of the fund and heavily influence the adequacy of its response. In a more subtle way they can influence the GFATM allocations through the Technical Review Panel (TRP) that scrutinises the proposal to be approved by the board. In selecting the 5th round proposals, activists around the world say that there has been a serious gap in acknowledging the facts of the epidemic and conflict and poverty related situations where HIV could destroy the economy and lives of people. The TRP that is supposed to be independent is too technical in view of the fact that tackling AIDS should be seen as a social, economic and health priority that has to go beyond limited technical boundaries. It is also worth mentioning that the recent decision of GFATM has compelled South Asia to consider itself as having been grossly neglected by GFATM.

# National Budgets: How Serious are Governments?

As mentioned earlier, South Asia in particular, spends very little of its national budgets on health. On the positive side, while most governments have started to increase their HIV and AIDS budget, the spread of the disease is far too rapid for it to be controlled by the current level and nature of initiatives. Most of the programmes in Asian countries are donor driven. The benefits reaching the grass-root level have as a result often been a matter of debate.

An analysis of total expenditure on health as percentage of GDP reveals that over the period 1997-2001, while this had been stagnating in India, Indonesia, Nepal, Pakistan and Thailand, it increased slightly in China, Cambodia, Bangladesh, Sri Lanka, Vietnam and Yemen. The central government expenditure on health as a percentage of total government expenditure over the same period indicates that the picture is more or less the same for these countries. The exception is China and Yemen, where the central government expenditure on health as a percentage of total government expenditure actually went down.

Out of pocket expenditures as a percentage of private expenditure on health showed a slight increase for China and Yemen, while this went down slightly or remained as is for other countries.

trends in financing show an increase allocation targeted specifically at HIV and AIDS control within health budgets.

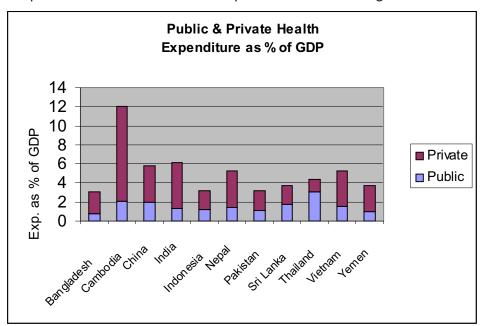
Table 3: Health Expenditure Indicators for Some Asian Countries for 2001

Country	Total Expenditure on Health as % of GDP	General Govt. Expenditure on Health as % of Total Health Expenditure	Govt. Expenditure on Health as % of Total Govt. Expenditure
Bangladesh	3.5	44.2	8.7
Cambodia	11.8	14.9	16
China	5.5	37.2	10.2
India	5.1	17.9	3.1
Indonesia	2.4	25.1	3
Nepal	5.2	29.7	8.1
Pakistan	3.9	24.4	3.5
Sri Lanka	3.6	48.9	6.1
Thailand	3.7	57.1	11.6
Vietnam	5.1	28.5	6.1
Yemen	4.5	34.1	4

Source: Human Development Report Estimates for 2002

Data on health expenditure as a percentage of GDP also shows wide variations between the public sector and the private sector expenditures across countries in the region (Graph 2). Thailand stands out in the region having a higher percentage of public expenditure than private expenditure on health. Cambodia is at the other extreme with a much higher share of private expenditure while in Sri Lanka the percentage expenditure is almost equal for the private and the public sectors. While in Vietnam, Nepal, China, India, Yemen and Bangladesh the difference in the percentage expenditure between the private and public sectors is more than 1%, it is much less in Pakistan and Indonesia. Of course, these differences have to be interpreted with caution, since the total level of health expenditures may be much lower than required, including those of the private sector for various socio-economic reasons. However, these do serve to indicate the extent to which the public sector is able to meet health expenditures, even at the current levels of health spending in the economy.

The minimum budget required to finance adequate levels of health in poor countries was estimated by the WHO Commission on Macroeconomics and Health to be US \$35 per person per annum in 2001. This can be contrasted with the findings from a study by Ooms and Hammonds that most PRSPs are based on the assumption that health spending will be much lower, even below US \$10 per person in some developing nations<sup>15</sup>. From a human rights point of view, this is not in keeping with the spirit of assuring a basic right to minimum health for all individuals in the less developed world. It remains to be assessed whether the Commission has over-medicalised problems with recommendation of irrational and wasteful measures and the PRSPs rely more on optimal use of medical services, or if the PRSPs are unduly conservative in their estimates.



Graph 2: Public and Private Health Expenditure as a Percentage of GDP

Source: Human Development Report Estimates for 2002

In February 2005, the United Progressive Alliance government of India, headed by the Indian National Congress issued the Union Budget for 2005-06. The government had earlier made huge promises in its National Common Minimum Programme. The budget was not a disappointment to the extent that education had moved up in priority, although the increase in budget allocation for health was marginal. NACP saw only 3 per cent increase. Compounding the low levels of allocation was the poor record on actual expenditure between 1999 and 2002 almost 35 percent of NACP's budget remained unspent. Often the funds are not utilised completely. It becomes imperative then to question the inability on the part of NACO to utilise funds. The overall focus of NACO is towards prevention of transmission. The programme focuses to a very limited extent on clinical treatment and other supportive services for patients, which consequently receives relatively less allocation. UNAIDS has also been implementing a programme (funded by AusAID) to provide a comprehensive response to HIV and AIDS specifically focused on north-east India.

It is also important to recognise the need for multi-ministry involvement if one desires to have a comprehensive approach towards tackling HIV and AIDS. In India, a positive step in this direction has been that the (current) Tenth Five-Year Plan mentions the crosscutting nature of HIV and AIDS. It has asked other ministries to earmark a separate budget and help combat the disease. The formation of the National Rural Health Mission takes a step in the right direction in that it seeks convergence across different vertical programmes through the district missions. However, the silence on the AIDS control programme in the proposed convergence scenario is worrisome.

There is a rapidly increasing budget for HIV and AIDS in China, both from external sources (such as DFID, USAID and the Global Fund) and from the central government in Beijing. International support from the Global Fund, the UN system, bilateral agencies and NGOs to China's HIV and AIDS programme has increased from \$31 million in 2003 to \$53 million in 2004

and this trend is likely to continue. In recent years, there has been significant increase in funding by government departments and agencies to strengthen the national response to HIV and AIDS. In 2003, in addition to an original commitment of \$14.5 million to HIV and AIDS, an extra \$33.7 million was added in order to provide free ART, care and support in areas hard-hit by the disease. China allocated US \$1.2 billion to HIV and AIDS prevention, treatment and care for 2003-04. Clearly the proportion of AIDS funds for treatment is much higher than those for prevention.

**Thailand** is a country that had been badly affected by the massive economic crisis of 1997 and is now considered as having been fairly well able to control the epidemic. In order to overcome the serious shortfall in financing the health sector, it strategically addressed the gap and tried to recover, unlike other South-east Asian countries which failed to recover from the adverse impacts of the economic crisis on their health systems.

In January 1990, Thailand announced its national policy to control and prevent HIV and AIDS. Government budgetary commitment to combat the disease also increased significantly from US \$425,453 in 1989 to \$2.56 million for 1990. The inception of the National AIDS Prevention and Control Committee with the Prime Minister as its Chairman in 1991 led to a rapid response to HIV and AIDS. All relevant government agencies were provided with funds to implement their own plans for confronting HIV and AIDS. During this period a lot of NGOs were involved in AIDS prevention and care activities throughout the country. Subsequently the budget outlay of the Royal Thai Government also increased significantly. The annual budget for 1996 was more than \$80 million. These efforts culminated in a substantive achievement in terms of a reduction in new infections from 143,000 in 1991 to 29,000 in 2001. Recently, the government created a policy to include the prevention and treatment of opportunistic infections into the 30 baht universal coverage health scheme. The inclusion of ART into this scheme is being explored. Thailand's national expenditure on health for the year 2000 was US \$6029.6 million out of which US \$33.79 million was spent on HIV and AIDS. Thailand continues to spend approximately US \$ 0.63 cents annually per person on prevention and treatment, over nine-tenths of it from public sector funds. The priority given to treatment and care in Thailand even before the advent of ARV is evident from the fact that treatment and care accounted for 62.24% of the share in HIV and AIDS programme spending over the 1990s (Teokul 2002)<sup>16</sup>. Overall HIV and AIDS expenditure in 2001 was 2.22% of health expenditure and 0.16% of government expenditure. In 2003, HIV and AIDS expenditure for persons living with AIDS in 2003 was US \$ 179 per annum while per capita expenditure on AIDS was US \$ 1.7".

In the last two years, the budget for HIV and AIDS in Vietnam has increased by about 33%. External partner's contribution has been instrumental in funding the health sector in Vietnam. The state has paid particular attention to investment in the HIV and AIDS prevention and control programme. Besides the state budget allocation, a number of localities have provided supplementary local budget allocations to this programme. Nevertheless, there are many localities which have not yet made any contribution to the HIV and AIDS prevention and control programme.

**Nepal**, a country going through internal political crisis, is also badly affected by the epidemic. Though the government of Nepal has expressed its commitments time and again, these have not been converted into ground realities. The National Centre of AIDS and STD Control has been a

low though compared to past years it has been increasing. AusAID has also been funding a programme to contain HIV and AIDS specifically among IDUs over the period 2000-05. Most of the programmes are supported by the assistance of foreign donors and INGOs. This has in turn raised serious issues of sustainability of the programme and its implications in addressing the epidemic in the long run. In the fiscal year 2005-06, His Majesty's Government of Nepal allocated NPR 313,901,000 (US \$ 4.2million) for the control of AIDS and STDs. The entire sum has been allocated as 'recurrent expenditure', that is, expenses of a general nature most of which goes to pay the salaries and regular expenses to run the administration. In Nepal, the National Centre functions as the only government institution that works for the prevention and control of HIV and AIDS inside the country. Most of the fund allocated under the HIV and AIDS head goes to this institution is responsible for the overall coordination of HIV and AIDS initiatives in Nepal. During this fiscal year, the Norwegian government is supporting the national AIDS and STDs centre with NPR 303,634,000 (US \$4.1 million). The government is contributing just 3.2 per cent of the total HIV and AIDS budget, as reflected in the government budget document.. Going by the estimates of UNAIDS that a total of 62,000 Nepalese are living with HIV and AIDS currently, and assuming that all the allocated budget (as reflected in the budget books) is spent on the treatment, care and support of people living with HIV and AIDS, the per capita HIV and AIDS budget in Nepal is NPR 5062.92 (US \$68.42). Unfortunately a major chunk of this budget is spent on administrative purposes. The centre also has the added responsibility to carry out other activities like creating awareness and the prevention and control of STDs and HIV and AIDS. Currently, it is said that only 175 people are getting ARV. In view of the fact that HIV and AIDS treatment requires antiretroviral drugs and highly active antiretroviral therapy (HAART) that costs about US \$600 per person in a year, it is beyond the reach of average Nepali people whose annual per capita income is less than US\$ 270<sup>18</sup>.

The Royal Government of Cambodia spends about \$900,000 on HIV and AIDS out of \$20 million, the total expenditure on health sector. The most cost-effective ways to reduce the spread of HIV are through prevention and protection. Cambodia's prevention efforts since the mid-1990s have focused largely on encouraging condom use among men when engaging in commercial sex and encouraging men to reduce their commercial sex activity. Additionally, the government launched a 100 per cent condom use campaign in collaboration with an NGO among brothelbased sex workers in 1999 which was modelled after Thailand's programme. This programme has helped tremendously in bringing down the infection rate among sex workers, military personnel as well as those engaged in risky behaviours. This decline in the prevalence rate was achieved with limited state funding. The government has framed a National Strategic Plan to combat HIV and AIDS comprehensively and multi-sectorally. In 2003 approximately US\$ 22 million was allocated for HIV and AIDS and STIs in Cambodia in the health sector; the government managed 26 per cent of this, USAID-funded NGOs 42 per cent and other NGOs some 27 per cent. This represents a steady increase in allocations over the years: US\$ 5 million in 1998, US\$ 13 million in 2001 and US\$ 15 million in 2002. Of these funds, the share allocated to care has also grown, from 14 per cent in 2001 to 22 per cent in 2003. In 2004 the amount allocated to HIV and AIDS in the national budget was US\$ 9,50,000.

The Government of **Indonesia** has invested a lot of money in its campaign against HIV and AIDS. During the fiscal year 2001, a total of US\$ 16,74,000 was allocated for HIV and AIDS. There has been a consistent increase in the HIV and AIDS budget over the years; it was US\$ 34,69,000 in 2002, US\$ 64,27,000 in 2003, US\$ 119,62,000 in 2004 and 2005. USAID works with the 005,

Government of Indonesia. USAID allocated US\$ 12 million in both 2004 and 2005 to combat HIV and AIDS and other infectious diseases in Indonesia. Much of USAID's work to combat HIV and AIDS in Indonesia is managed by Family Health International through the 'Aksi Stop AIDS programme.' In 2005, DFID committed an additional US \$ 45 million for Indonesia.

While observing the government funding patterns, the positive side is that governments have been increasing their budget; however the challenge for Asian governments is to prioritise and accordingly increase their investment if they are serious about tackling the epidemic. Problems of leakages and non-utilisation of funds also exists. But these are more a reflection of the nature of bottlenecks and lags in the funding disbursement and delivery mechanisms. While bilateral and multilateral efforts to increase funding for HIV and AIDS have led to significant increases in foreign aid levels, they have also raised crucial concerns relating to the bottlenecks in disbursement of aid and the absorptive capacity constraints of recipient governments. Problems of co-ordination among different funding agencies and increasing transaction costs of co-coordinating across multiple agencies can often make things more complicated.

# **Equity in Public Sector Processes**

Ideally, public sector financing should hold out the maximum promise for bringing in equity in financing to the extent that taxes are used for mobilizing resources from the better-off to finance health needs of the poor. Out of pocket expenses are at the other end of the spectrum being the most iniquitous. Recognition of the link between poverty and health outcomes implies that if the poor are a vulnerable group for AIDS, then, under the out of pocket system, they would be paying disproportionately more on health because of the higher probability of falling ill combined with a lower ability to afford treatment. As highlighted by the Macroeconomic Commission (2005), low public spending has led to inequity in access and distribution of public health services, the impacts of which are seen for poor households for catastrophic illnesses in particular. This builds a strong case for higher public sector spending<sup>19</sup>.

In the context of China, a report says, 'The national health system faces heavy constraints at the provincial and local levels, and has failed to effectively deal with the country's HIV and AIDS treatment needs. As part of the "Four Frees One Care" plan, local governments bear a heavy financial burden, added to their already heavy public health budget that are not covered by central funding. Weak financial controls impact the flow of funds to local levels, and a central government plan to provide AIDS treatment funding by relieving provincial tax payments (i.e. provinces are forgiven a certain amount taxes that would have been paid to the central government) has not resulted in sufficient funds being spent on HIV and AIDS.' The report further says, 'However, distribution of funds often suffers from a "planned economy" mentality among some administrators, with each province getting a slice of the pie regardless of the severity of the HIV and AIDS epidemic.' China still lacks in translating the strategy on the ground regarding the status and effectiveness of the programmes. While there have been a range of pilot programmes in all programme areas (prevention, VCT, care and support, and treatment) across the seven provinces, sufficient coverage to contain HIV and AIDS and mitigate its impact has not been achieved. Even

in Yunnan province, where there is a history of internationally supported programmes, coverage for risk populations is estimated to be less than 10%. These gaps are not due to funding gaps alone but technical and programmatic constraints as well. Few of the provinces have adequate sentinel surveillance, strategic planning processes or policy frameworks to support increasing coverage. Very few doctors are available with proper training in identifying and treating OI. As a result, many patients with OI may not be referred for HIV testing and those who are identified HIV positive often do not get proper treatment. Training of doctors has been conducted at national and local levels, but these have been limited in number and scope. Recognising the need for more training, some training activities have been initiated by Chinese health authorities.

Indeed, the need to treat those PLWHA who are co-infected with TB has already emerged as a major funding issue for government planners. The health ministry added EFV to the list of free ARVs in mid-2005, a sound medical decision, but lacks the political strength to mobilise the necessary resources to supply EFV nationally. The result is that many patients are either unable to access appropriate treatment or are required to pay for EFV themselves at more than US\$ 700 per year, far beyond the budgets of most Chinese PLWHA.

The expenditure pattern in Nepal also indicates that prevention has been the key area of work. Organisations lead by PLWHA have not been able to get these funds and except for few of them, others suffer from lack of resources even to run their organisation. NCASC has not been able to coordinate all the stakeholders. Although the government has been talking about mainstreaming, this has not happened as yet. In this context one can also highlight the governments' inability to manage GFATM second round support as the Principle Recipient indicates the government's lack of seriousness and its weak management and coordination systems.

In case of Cambodia also, as reported by the TREAT Asia Special Report 2004, the actual number of people in need of ARV was 22,000 while the estimated number of people receiving ARV treatment was only 3,400. In Thailand too, which is supposed to have been successful in addressing the AIDS epidemic, injecting drug users stand out as an example of how marginalised communities are still deprived from getting adequate resources.

In India, the government announced in December 2003 a 'treatment roll-out' programme through centres in each of the six high-prevalence states of Maharashtra, Tamil Nadu, Karnataka, Manipur, Andhra Pradesh and Nagaland. The programme would offer a fixed-dose combination of first-line drugs. The programme was started in April 2004. Initially, the government planned to put 100,000 people on ART by the end of 2005 but it will be lucky to reach that target by the end of 2006. Free ARV drugs — estimated cost at current prices is an average of Rs 1500-2000 per month for first line drugs plus essential tests — were to be made available to HIV positive pregnant women who visited government antenatal clinics, children under the age of 15 and adults with AIDS for care and treatment<sup>20</sup>. As of July 2005, just 10,255 people were on the programme, the government stated in parliament. Another 9,000 people are on ART through schemes for government employees and workers in the organised sector.

At about Rs 18,000 (US\$ 400) a year, the cost of privately-funded drug therapy remains out of reach for most people known to be affected and needing support. Activists and healthcare professionals also suggest that even the limited government programme is poorly conceived and

Table 4: Cost of Treating Opportunistic Illnesses of the Average Indian with HIV under Different ART Regimens (2002)

(1002)			
Lifetime Costs (US\$)	No ARV Treatment	Unstructured ARV Treatment	Structured ARV Treatment
Discounted at 0%	1200	1175	1100
Discounted at 10% at time of Treatment	814	660	494
Discounted at 10% at time of Infection	505	410	307

**Source:** World Bank Estimates (http://siteresources.worldbank.org/INTINDIA)

run. The treatment centres are in the cities, whereas the majority of people who need treatment live in rural areas and cannot afford to sacrifice daily wages and travel long distances for the drugs. Various tests are not free until the person is actually placed on the programme, putting ARVs out of reach of the poorest, who are most in need of free treatment. Even when tests are free, the machinery in government hospitals is often out of order, forcing patients to go to private diagnostic centres. There are reports that people are not properly informed of the drugs' side-effects and serious adverse effects, and that the drugs need to be taken regularly, life-long<sup>21</sup>. This is the reality at the ground level. The situation in many South Asian countries including China is similar. From a public health point of view there are several caveats to ARVs that need to be factored in. Further, the emphasis on ARV therapy has also led to the neglect of the other important components of comprehensive management of HIV positive persons<sup>22</sup>. ARV drugs are only a part of the expenditure and other components of ARV therapy and more comprehensive therapeutic regimens have attracted far less attention for funding.

In a resource constrained situation, both the manner and extent of utilisation of funds is important. In the Indian context, although NACO has been able to utilize the funds over time, the allocation has not been proportional across the years and hence a large leftover balance has been created. The broad pattern of expenditure of funds allocated to NACO shows that 'prevention' has been the important component of expenditure. This has accounted for more than half of the total fund allocated to NACO but care and support, a very important component in the control of the disease has received minimal attention and allocation. There are 475 Targeted Intervention projects in India. However, in 2003, there were no NACP funded Targeted Intervention projects in the states and Union Territories of Andaman and Nicobar Islands, Bihar, Dadra and Nagar Haveli, Daman and Diu, Delhi, Jammu and Kashmir, Lakshwadeep, Meghalaya, Pondicherry, Sikkim and Uttar Pradesh<sup>23</sup>. Further NACO needs to take on a stronger and more effective stewardship role, the programme needs further decentralisation, capacity needs to be strengthened at the state level, and management at all levels needs to focus more on results.

### For Whom the Bell Tolls?

#### Equity in Outcomes and Access for the Vulnerable

Most of the discussion has centred on the overall health sector and specific AIDS allocations from national governments and international donors. Far less has been done in terms of analysing allocations for social and economic groups within nations. Hence, most of the discussions on propoor financing have been based variously on theoretical, historical and altruistic considerations. There is little hard data at the disaggregated level to analyse or use for any planning or forecasting budgetary exercise for most Asian countries. Another common categorisation is to look at rural-urban divides. For instance, there is increasing evidence of a relatively faster spread than before among married, rural women in India. This raises a natural question – do we have means of tracking this information; and if so, can one adjust budgetary outlays accordingly. Similar concerns can be raised in terms of reaching groups such as children, particularly those from marginalised groups. Concerns such as these are however, neither new to the public health system nor unique to HIV and AIDS control programmes in most developing countries.

Poor households in many Asian countries have not been able to access the services and the cost of living with HIV is increasing. Though there is some flow of money in the name of different programmes, it has not yet been able to address the gamut of problems that PLWHA have to face. The situation is similar in many Asian countries like Vietnam, Nepal, Pakistan, Indonesia, Bangladesh, India, China, and unfortunately it is the poor who suffer the most. For instance, ARV can cost anywhere from US \$300, to US \$5,000 per year, excluding the costs of related services, tests for viral load, CD4, CD8. This will be an impossible expenditure for most Cambodian families, given that the per capita income of Cambodia is only US\$ 263 per year. Without AIDS, families in Cambodia are already incurring health costs of around US\$ 30 per capita, of which US\$ 22 per capita is spent on medication. The non-availability of ARV treatment to large numbers is an urgent indicator of the need for mechanisms that facilitate increased funding for AIDS control programmes.

#### **Pricing of ARV**

There are various ways in which the issue of prices of ARVs in Asian countries can be addressed, including elimination or lowering of taxes, minimising the costs added by middlemen and lowering costs of overheads. The Global Fund could also be asked to offer a subsidy on these drugs to poor countries. Constructive employer actions, either on their own initiative or in collaboration with governments, can go a long way in scaling the costs at which these drugs can be made available, depending on the patient's ability to pay. Institutionalising such joint initiatives through law (such as that on social security or labour welfare) could go a long way in making treatment more affordable, even if some have to pay for it. But, this in turn requires more initiative on the part of funding agencies. At the global level encouraging competition among pharmaceutical companies should push manufacturers towards charging prices that reflect marginal costs rather than average costs, which tend to be higher. Monopolistic overpricing of drugs has to be controlled by some global consensus. Studies have shown that average prices tend to be lower in countries where larger proportions of the population are better informed about drug prices (UNAIDS 2003). While the case for continuing advocacy, negotiation and activism for lowering

drug costs is not to be disputed, there is an equally strong case for focusing on the high costs of diagnostics used in AIDS care that add a large financial burden to the treatment costs. There is a global responsibility to promote and disseminate information. This can have an impact on lowering drug or diagnostic prices, both by more rational use of these technologies and by lowering their cost. The non-affordability of ARV and inaccessibility to comprehensive care combine in creating conditions that lead to high morbidity and mortality due to the disease.

#### **Household Coping Costs**

The AIDS related treatment and funeral costs were found to be exorbitant and (similar to TB costs), likely to be catastrophic for poor rural households in sub-Saharan Africa and Thailand, absorbing 50% or more of annual income. Research in Tanzania and Thailand also found that medical spending on AIDS deaths was higher than for non- AIDS deaths because of the long duration of the disease. In Thailand, 35% of the households with an AIDS death felt a serious impact on agricultural production, leading to a 48% reduction in family income. In Thailand, with one of the most successful anti-AIDS programmes, an UNESCAP study points out that the expense of caring for an AIDS patient can be devastating. In Thailand's Chiang Mai province, families report spending on average US\$ 1,000 a year in direct medical care costs - the equivalent of half the average annual household income in the region. In the Chiang Mai study, incomes of a third of AIDS affected households fell by 48%.

For most Asian countries, the existing gaps in funding basic AIDS treatment imply that there is little spending on what has been termed as the 'care economy' (UNAIDS 2004). Financial support

Table 5: Socio-economic Impact of HIV and AIDS from a Case Study in Vietnam

Household Coping Strategies	% of Households with PLWHA
Borrow money from friends	36.0
Cutting down on food consumption	28.8
Borrow money with interest	27.2
Decreasing health expenditure of other household members	25.6
Selling assets, including production means	20.8
Elderly going out for earned job	17.6
Selling land/house	5.6
Children being taken from school	3.2
Children being sent out for earned job	2.4
Sending children away for foster care	1.6
Receive loan from credit programs	1.6

**Source:** Socio-economic Impact of HIV/AIDS in Vietnam: A Preliminary Note, http://www.undp.org.vn/undp/docs/2003/seimpact/seimpacte.pdf,

for meeting coping costs of families affected by AIDS, income generating programmes, improvement of access to credit facilities or the provision of special loans at low interest rates have remained largely peripheral to national AIDS programmes. Microfinance institutions can play a significant role by not merely providing access to relevant and affordable financial services to the poor households, but also through appropriate financial risk management activities, which help households, cope with financial problems. Such institutions need to be encouraged as part of the care economy, probably through policies that actively encourage a collaborative approach between such an institution and HIV and AIDS control organisations<sup>24</sup>.

#### Research: Investing in the Vaccine

It is difficult to say with any certainty how much funding it will take to develop an effective vaccine, given the many unknowns in developing new health technologies (IAVI 2005). The problems are compounded by the fact that reliable and extensive information on expenses incurred or planned on AIDS-related research by the public sector is virtually absent in the region, although such research is on in some countries. India for instance has reportedly begun its first-ever Phase I clinical trial of two HIV vaccines. An IAVI (2005) study identified 20 countries that had provided public sector funding for HIV vaccine Research and Development. India and Thailand were the only two Asian countries featuring in the list. Both countries were spending under US\$ I million in 2002.

Thus, while there is an undercurrent of excitement and optimism about ARV and the vaccine (as and when it comes), it is worth reiterating the need for more funding for improving the health system as well. A functional and comprehensive health services system will be crucial in ensuring universal access to ARV, ensuring that treatment and 'care' reach all those who need it.

#### **Summing Up**

- Weak health care and delivery systems, marked socio-economic inequality and stagnant national health budgets call for immediate attention to financing issues that impact health outcomes in general and AIDS control programmes in particular for the vast majority in Asia.
- Asian countries are yet to appropriately prioritise issues in resource allocation and disbursement. If prevention, care and treatment efforts continue to be as limited in effectiveness as at present, by 2010 yearly losses to the region will equal US\$ 17.5 billion.
- GFATM has no doubt become one of the major funds to fight AIDS and has been supporting
  AIDS initiatives in many Asian countries. However, its processes have not always been
  apolitical and can get complicated. For instance, the CFP policy has turned into a powerful
  tool to dismiss any increase in donors' contributions and to delay the disbursements of the
  limited promised amounts.
- There are genuine concerns that the current macroeconomic framework in many countries
  does not allow countries that borrow foreign funds to increase public expenditures to the
  levels necessary to achieve the MDGs and effectively fight HIV and AIDS. More debate and
  discussion on possible alternatives to dominant macroeconomic policy frameworks is
  necessary.
- Need for more systematic and comparable country level information collection systems to better understand costs borne by HIV and AIDS affected households – coping costs, illness related costs, and direct loss of income due to illness. There is also a need to examine the impact on national economies on some realistic basis in diverse settings of HIV prevalence, economic structures and health service systems.
- Need for higher, long term public sector investments in health; public sector financing is the best path to ensuring equity in access and distribution of health services for the poor when affected by an illness such as HIV and AIDS.
- Non availability of ARV treatment and its prohibitive costs is an urgent indicator of the need
  for financing mechanisms that could help in achieving universal access through AIDS control
  programmes. Reduction in prices of ARVs, investing in improving the health delivery system
  and more spending on the 'care economy' are important components of a successful
  programme.

Thus there is an obvious necessity to generate more resources for health and use them optimally, rationalise priorities, technological choices and administrative structures. Putting in the public domain analyses of the financial allocations for general health care, HIV and AIDS control as well as prioritisation within the programme can go a long way. A more informed debate on prioritisation, on optimisation of technological choices and on structures of administration, can strengthen the governance of HIV and AIDS control as well as health services development. It will also enhance the capacity of social action groups to translate the needs and aspirations of those affected by HIV and AIDS into socially responsible policy issues and demands. The reality of the lives of PLWHAs, articulated in the following chapter, must underlie all such policy debates to create humane financing systems.

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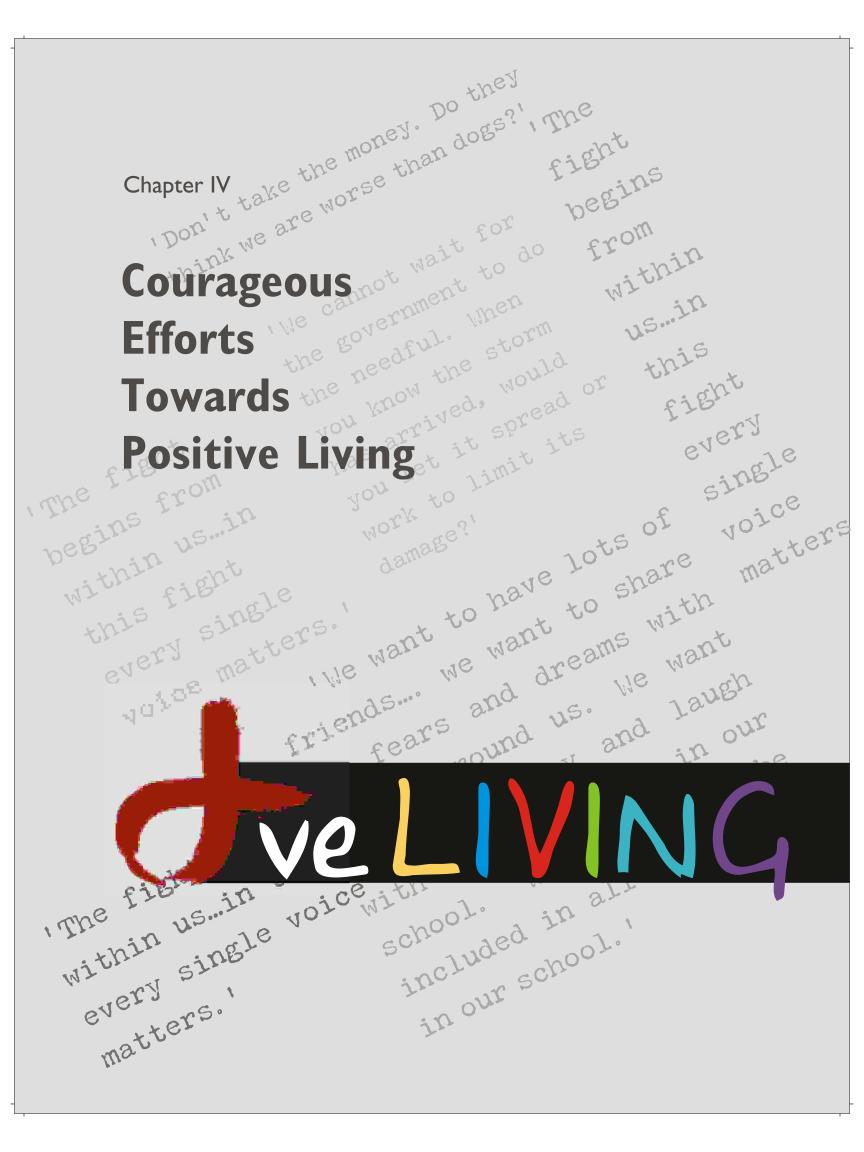
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and every community.



'We want acceptance, understanding, and the removal of discrimination and stigma at all levels. Effective policy and decision making will help make that happen.'

'We want access to care and treatment for all opportunistic illnesses for PLWHA. We want free ARV treatment followed by supplements in nutrition. We deserve adequate care and support centres and groups for infected individuals, orphaned children, grandparents, and affected families.'

'We want access to more information on HIV and AIDS, and the opportunities to develop our capacities and skills so that we can help ourselves economically and socially, and live a positive life with dignity'

'We face a unique set of problems as HIV positive women in Asian society. We want access to care, treatment, and support services as PLWHA who are individuals, mothers, wives, sisters, and daughters struggling to meet our ends in this patriarchal society.'

We want a voice in policy and decision making so that we are not forgotten, so that we are considered when programmes and policies affecting PLWHA are being developed.'

'We do not always have the opportunity to be financially independent and secure. We are forced to rely on our families or husbands, and if they become ill, desert or abuse us, we must find a way to sustain our children and ourselves. Thus we want opportunities to develop our education, capacities and skills, and chances to generate an income.'

'We want to have lots of friends... we want to share our fears and dreams with people around us. We want to study, play and laugh with other children in our school. We want to be included in all activities in our school.'

'When we are sick and can't attend school, we hope our teacher will not scold us for being absent. When we fall sick, we want a nice doctor to give us medicines that will make us well soon. We want health food that will make us strong so we won't keep falling sick.'

Life is bleak and existence itself a misery for HIV affected people in Asian countries. Denial, stigma and discrimination, lack of policies or legislations, poverty, gender inequalities including violence against women, conflicts, disasters, emergencies and poor governance all play a crucial role in the spread of the epidemic in the region. The epidemic also has differential impact on men, women, children, sex workers, sexual minorities and injecting drug users, particularly from the poorer sections of the society. Reports suggest a large proportion of the population continue to be unaware of their HIV positive status. Notwithstanding the fact that experiences of individuals are diverse, with different levels of discrimination and support, the impact of the epidemic follows similar patterns across Asia. Responses too are fairly similar though diversity emerges due to differences in forms of governance and social structures. Stigma and discrimination is the bottom line, many a times leading to a life of physical and mental solitude of PLWHA, despite the commitment to protect the human rights of the PLWHA made by the World Health Assembly in 1988. The suffering of PLWHAs is further aggravated by lack of political will and irresponsible leadership, which still focuses on the need for prevention of this 'dangerous' epidemic, and ignores the care and support needs of persons living with the virus.

However, in the middle of this negativity, there arose pressure across the globe from among PLWHA for human rights, acceptance and a life of dignity. In 1994, at the Paris AIDS Summit, 42 national governments declared that the principle of GIPA is critical to ethical and effective national responses to the epidemic. Since then the GIPA principle has been promoted as a cornerstone of HIV and AIDS prevention, care and support. Networks and organisations of PLWHA have played a key role in changing the tide of prevention and care efforts in countries. Though rare, positive responses have come from governments and non-governmental organisations.

This chapter looks at the issue of HIV and AIDS from the perspective of PLWHA and other AIDS activists. The aim is to help reduce stigma and discrimination and to promote and encourage positive living as a way of life. The initial section captures the inhuman faces of the epidemic from harassment to persecution in order to reiterate and remind ourselves of the human rights violations that continue against PLWHA by the civilised world. The second section highlights the passionate and committed efforts of individuals in claiming their rights and leading a life of dignity. The role of networks in giving dignity to PLWHA and their families is discussed in detail, further illustrating the right to self determination and meaningful involvement of PLWHA in AIDS programmes. Successful attempts by NGOs, media and governments across the region and globe particularly Uganda, Brazil and Thailand are highlighted as a way forward. The chapter concludes with a Charter of Demands in the hope that all people of Asia will be able to take advantage of this Window of Opportunity'!

## Voices of People Across Asia: A Common Canvas

#### Woman with HIV: A Life of Torture and Solitude

'The position I hold in the society being a woman hinders every move I want to take. My husband, despite knowing about his illness, married me. If I had known condom would save me then at least I would have tried that. The society in which I live has confined me with barbed wire'

Jhumoor, Dhaka, Bangladesh



#### Forced to Grow Up: The Extreme Vulnerability of Children

'An alcoholic father and poverty pushed me out of my home to a relative's home at a very tender age. I was initiated by a cousin into having sex with men at the age of 12. Need for emotional support and money pushed me to continue engaging in sex with men. A year ago, with counselling from Abhaya, an ActionAid Project, I took an HIV test, and found that I was positive. I feel very depressed as I have no support system from within the MSM community and from the outside world.'

Mahendra, India

#### The S- Word: When Sex is Considered Taboo

'It is a very tough situation for someone with HIV in Pakistan. There is a lot of stigma and discrimination not only in the general community, but also in doctors' attitudes. When a person goes to the hospital, he faces discrimination. He fears seeking treatment because the doctors often ask embarrassing questions in an insensitive manner like 'how many times have you had sex with females'. When a person faces such questions, he feels fear, shame, and a sense of guilt. People are reluctant to go to the hospital, because they are afraid their status will be told to their family and friends.'

Eid Muhammad Shamas, Pakistan

#### Drugs Ruined My Life and I am Scared

'I contracted HIV from my husband who was a drug addict. I always put some scent on his altar to pray for him. Although I hate him, I still feel pity for him. I always feel tired for no reason. There is no one to take care of me when I'm sick. I just stay in bed on my own. My son is my only motivation for living. He is three years old. I'm not courageous enough to take him to a medical centre for another HIV test. I'm scared of the ruthless truth, which I won't be able to stand. My son and I live by ourselves.'

Quach Thi Mai, Vietnam

#### Why Do I Suffer when Other Children Play?

'I don't like to stay home and I feel
very lonely. I get angry when my mother
comes late from work. I get up at 6.30 am
and take my medicines everyday. If I don't
take medicines, I know that I will die. I
also miss my father, especially during parent
teacher meetings at school. I think of what happened to my
father; and my mother and I too have HIV. Then, I start crying.'
Naveen, 8 years old, India

#### How Can I Save My Son Without Any Money?

'We have done all we could do. We sold many appliances in the house for his drug and HIV treatment. I look after him when he's sick, waking all night to sit beside him. I do not know what methadone and ARV are, but if I did, I would hope in vain, because I am sure that there is no way we can afford those medicines. The death of my young son is coming very soon. Who can tell us what I should do to save his life?'

70 year old mother of 36 year old Vu QuangVy, Vietnam

#### A Vicious Circle of Poverty and HIV

Living in a rural area with little money and other economic opportunities, and an ailing mother, I ended my education after the 4th standard, and at 16, landed in the city of Phnom Penh to find employment, where I ended up as a sex worker. As a sex worker, I was subject to unprotected sex, multiple gang rapes, physical abuse, cheating and theft. I found myself to be HIV positive and since then I have worked as a beer girl. I live with a man whom I cannot marry, because his family does not approve. He is currently unemployed so I must earn the money to support him. My husband does not know I am HIV positive, and even though I am tired at the end of the day, he still demands sex from me. He blames me for being tired, but is not willing to leave me. It is not enough to tell people the danger, it is important to try to change the system that creates the problem. We feel tired with this situation, but have no choice.'

Serey Phally, Cambodia

#### Not Knowing any Better: Sharing Needles is Common

'I always feel tired, and I can't work in the fields. I haven't been to the doctor as I don't have any money. I'm scared of infecting my little children. I have heard if we spend time with other people we can't be sure how the disease is passed on. I've heard you can infect

people through eating with them.' Sha Wang's friend in the village bordering Myanmar says 'We just use each other's needles freely' And sometimes, when people throw away needles, I'll pick them up and use them again. We

don't know if it's dangerous. We're not scared to use them. We need money to buy new needles and we don't have any money.'

Sha Wang, China

#### Fear and Discrimination Kills, Not HIV

'When my husband and I were diagnosed HIV positive, I didn't tell my family or his about it. After his death when I informed my in-laws about my status, they accused me of causing their son's death. I explained to them as much as I knew about HIV and AIDS, but they would not listen. I became very depressed. Within six months, I could see that my health was getting worse, and I felt that listening to them was killing me faster than the virus'

Kiren, Malaysia

#### Poor People can only Dream of ARVs

'I do not worry much about myself, but my daughter, who is 4 years old now, weighs only 11 kg. She falls ill very fast with severely disordered digestion and suffers from skin disease. Presently, she drinks 200 ml of milk per day, but cannot eat anything. She takes tens of pills but none of the pills are to treat HIV and AIDS.' I heard about ARV on television, but poor people like us can only dream of it. My little daughter is all I have in this world. If she is able to live, then I want to live. Otherwise, why should I...?'

Nguyen Thi Bien, 30 year old Mother, Vietnam

#### Swallowing Big Tablets is so Difficult

'My ARV pills are as big as 20 paisa coins, and I find taking such medicines the hardest! I am sick so often, and last year I failed my exams, and was very upset. It was my mother and teacher who supported me. I love going out with my family, and look forward to all meetings at the support network MILANA, because I have so many friends there.'

12 year old Ramya, India

#### Political Instability Increases Vulnerability to HIV

'Nepal's situation is very poor. The political situation and the security situation is bad. The security presence is so strong in Nepal now. In Kathmandu, it is everywhere. Every street has a checkpoint and patrolling, so the *metis* (feminised males) and sex workers going in the night for sex or for earning money or something get checked and raped or blackmailed or cheated by security forces.'

Sunil Pant, Nepal

#### Injecting Drug Use and Street Children

'I was often treated with cruelty by my paternal uncles, and that became the main reason for me to run away from home years ago, and I am now living on the streets of Lahore. Street children have sex with anybody and it does not matter how many people they have to deal with in a day. The only important thing is the amount of money, which they need to buy their daily "medicine" (hashish).'

18 year old Amir Sohail, Hyderabad, Pakistan



'The memory of how they writhed with pain at the end of their lives still haunts me. Can you imagine within one year my son, daughter-in-law, daughter and son-in-law died of HIV and AIDS? My wife and I are in shock. The tragedy started when my son-in-law was found to be a drug user. At that time, he did not know that he had HIV and he injected my son with the same syringe of opium, when my son had a severe stomachache. Consequently, the catastrophe happened for the two innocent younger women their wives. Over the first 2-3 years of infection, my sons and daughters received neither medicine, nor care, nor advice of doctors on HIV and AIDS disease. They silently passed away; one by one.'

70 year old Tran Van Dap, Vietnam

#### Generic Medication: The Need of the Hour

'Care and treatment have to be set as priority. People come around voluntarily when you say there is treatment available. Some health workers never talk about ARV, because there's an issue of not knowing about it, and it is so expensive. This makes people who are ready to access ARV more depressed.'

Joshua Formentera, Phillipinnes

#### **Subtle Discrimination**

'In Japan, HIV discrimination is more subtle. Social welfare is available for Japanese patients with HIV. But I live deep in the countryside, and if I apply for benefits, everybody in the community will know about my infection.'

Nancy, Japan

### People Fight for Rights: Stories of Extraordinary Courage and Determination of Individuals

Yet in this often grim scenario for PLWHA in Asia, there are glimpses of hope, and possibilities for change. There are people with extraordinary courage and determination leading the way in fighting exclusion and injustice. They are also empowering PLWHA to reclaim their fundamental rights and entitlements. A few demonstrations of some of these spirited individuals and institutions are cited below.

#### A Young Widow Fights for her Daughter's Right to Education

'You are educated. You should know what you are doing to my daughter is discrimination.'

Hajira never went to school and cannot read or write. At the age of 16 her parents got her married, and she became the mother of two children: a daughter and a younger son. Hajira and her children were entirely dependent on her husband's income.

When her husband contracted HIV and then died of AIDS, Hajira came to know of its horror. She realized with fear that it was possible that she too was HIV+ along with her children. She and her children underwent tests. She was positive and began to undergo counselling. She waited with tremendous fear for the results of her children. The results showed her children to be free of the virus.

With her husband dead, Hajira and her children became destitute. Her in-laws asked her to leave, and her parents would not take her in. Her sister's family had to keep them in their home. Although thankful for some support, Hajira was not happy to be a burden. She worried about her children's future. Her single-minded aim became to make her children educated and ensure their future financial security.

Through Hajira's relentless efforts, her daughter was selected for admission into a residential school run by a trust for poor children of her community. Hajira was very happy, that her daughter not only would be fed, but she would also, unlike her, be educated. After this initial good news came the blow. The authorities of the school found out that Hajira was positive. They refused to admit the child into school because her mother had AIDS. Hajira could not understand this. Her daughter was HIV negative. Hajira tried to convince the authorities, but in vain.

Hajira says 'I was shattered. I pleaded with them, but they did not listen to me. They thought I was lying. So I took my child to the school to show them how healthy she was. They did not believe an illiterate woman like me. So from the doctor I got a letter that stated my daughter was not HIV positive, and that HIV cannot spread from someone who is not infected.'

Hajira fought for three and a half months with support from doctors and social workers. It was a time of great difficulty. She cried to the authorities, 'I am illiterate, but you are educated. You should know what you are doing to my daughter is discrimination.' Finally the authorities gave in to the pressure and readmitted Hajira's child into the school.

Hajira's is not an isolated case. There are many children being denied education because of stigma. Recently, spurred on by such cases and pressure from activists, the Ministries of Education of Karnataka and Andhra Pradesh States have issued orders that no school in the state shall discriminate against children affected by HIV. In case of violation, schools can lose affiliation or face punitive action.

### Collectivising Women in Nepal to Fight Stigmatisation by Communities



'The fight begins from within us...in this fight every single voice matters.'

In Janata Basti, Itahari, Nepal, some women are called witches. After their husbands died, the society believed that they were witches and had taken their husbands' lives. The women are usually shunned and ill treated by the people, but they have now come together to fight against the injustice done to them. They are taking collective action against any person who mistreats them. The person responsible to bring the women together is thirty year old Preeti.

Preeti is an uneducated woman from a remote village in Taplejung, eastern Nepal. To get herself out of her own misery and turn her own misfortune into positive action that benefits other d found they were all HIV positive.

woman has been a long journey for Preeti. Her husband died from AIDS. She was left alone to fend for their two children. Preeti found out about her husband's HIV status only after his death. He never told anyone. He kept it a secret, perhaps because he feared stigma and discrimination. She got herself and her children tested, and found they were all HIV positive.

Her husband had taken the easy way out by keeping quite about it. What was she to do? At first she blamed her husband. Then she became deeply depressed. She thought she would die immediately. Why not end her life herself rather than wait for death? Then she looked at the innocent faces of her sweet children. What was their fault? For them, she needed to keep going.

The first thing Preeti had to do was to find out what was HIV all about. She came to Itahari and talked to the social worker. She learnt how to live her life positively and with dignity for the sake of her sons. She then returned to her home in Taplejung, but she was not satisfied. She wanted to do something for people like her. She thought, 'Because of the stigma and discrimination we become marginalised. We live and suffer quietly. We are forced to form a silent group. This should change. Positive people should overcome this and cease to remain silent ...'

She decided that she would turn her thoughts to action. She would do something, especially with women who are always dominated by the Nepali patriarchal system. She left home and went back to Itahari where she joined an NGO.

Today Preeti, is an activist of ActionAid Nepal. She conducts literacy and awareness programmes for women. She shares her experience and talks about the different issues of HIV and AIDS. She heads the group of widows in Janata Basti who have suffered from the death of their husbands.

She says, 'the fight begins from within us...in this fight every single voice matters. If an uneducated, positive woman like me with two positive children can bring herself to the frontline, all others can. Therefore, let us speak up and strengthen our solidarity in the fight against HIV.'

## A Rare Success Story of One Man's Fight for The Right To Employment in India

'I qualified for the post, but the state denied me my right. The state was unjust. I was determined to fight.'

From the town of Shimoga in Kamataka, Ramesh completed his graduation and then sat for the entrance examination for the post of Sub Inspector. He says, 'I always wanted to be a police officer. When I came to know I had passed the exams and was selected for the post of constable, my family was overjoyed. I had to only pass the medical fitness exam to join the police force.'

Ramesh is a tall, well-built and healthy man. He passed the physical exam with ease; however, his blood samples showed him as HIV positive. The police overlooked Ramesh's overall fitness, and cancelled his selection because he was HIV+. 'My future fell apart before my eyes. Out of the 55 selected, only I was rejected. I could not believe this had happened to me. In the beginning, I just wanted to die. I could not sleep and I began to fall ill. My parents and sister were very worried. But it was not my fault. I knew that I had done nothing wrong, and to bear this injustice quietly was wrong. I decided to fight. I filed a case against the police in the Kamataka Administration Tribunal with the help of the Lawyer's Collective.'

After the case was filed, however, there was nothing more Ramesh could do but wait. While his case dragged on in court, Ramesh's day to day life became an unimaginable struggle. 'The attitude of

people changed overnight. Close friends kept a distance; that hurt very much. Often the doctors and nurses shunned me and life become unbearable. My family was dependent on my income. I needed money. There were also medical expenses. The pressure made me depressed. Thinking back, I realized I must have contracted HIV when I did a small scale business of washing and filling waste hospital bottles with battery acid, but I had to look ahead. I needed a job. I took a loan and bought a vehicle. I began to earn money by transporting goods. I went for counselling at the NGO Abhaya and joined KNP+ (Karnataka Network of Positive People). My main support were my parents and sister who stood by me throughout. It was a very difficult time for them also, but their love and support gave me strength. In 2005, five years after the case was filed in a landmark judgment, the Karnataka Administration Tribunal ruled that the cancellation of the selection of the applicant to the post was in total violation of Articles 14 and 16 of the constitution and that the action of the state was illegal, arbitrary and unconstitutional. The tribunal quashed the order of the Superintendent of Police terminating the appointment of Ramesh. Further, a circular issued in March 1994 by the Director General and Inspector General of Police that deemed an HIV positive citizen unsuitable for civil service was also quashed. Ramesh had won against the state.

Although happy with his victory, Ramesh feels there is a long way to go regarding the attitudes of people. He says 'What happened to me can happen to anyone. We need to be courageous. We do not need pity. The only way we can truly live normal and productive lives is through the support of society and state.'

## A Woman from Pakistan Helps Others Overcome Stigma and Discrimination

'We cannot wait for the government to do the needful. When you know the storm has arrived, would you let it spread or work to limit its damage?'

It's impossible for someone to guess that 35-year-old Shukria Gull has been living with HIV for almost a decade now. The lively personality and an ever-smiling face belong to a courageous woman who refused to give in and waged a campaign against the stigmatisation of those affected by HIV and AIDS.

In mid 1995, Gull's husband was admitted to one of the country's premier hospitals in Lahore for treatment of an unidentified illness. It was a medical student who suggested a blood test that eventually identified the cause of illness as AIDS. The staff at the blood bank initially refused to give the test results, and sought blood samples from Gull and her two children. The subsequent tests found Gull HIV positive, but fortunately her children were not affected.

'They simply handed me the results saying that my husband was going to die soon and I was also infected. They had no idea about counselling the family and gave us no information whatsoever as to how to deal with the situation. The outcome was that I took the results to the hospital staff, who wasted no time in shifting my husband to the worst room available. They stopped all treatment and started waiting for him to die. Even the senior most doctors at the hospital would examine him while standing several feet away behind a partly open door.'

Gull's husband had spent several years in Kenya and had returned two-and-a-half years before he died. The news of his death found its way into newspapers and further stigmatised the family.

The changed attitudes of the people close to Gull and the concern for the future of her two children

forced her to seek as much knowledge about HIV and AIDS as possible. There was no place in Lahore, she says, from where she could get any information about the illness and even doctors were not aware of the facts. 'When I asked the doctors how my children would be safe from HIV, he advised me to apply antiseptic to my hands to kill germs every time I go to the toilet and I did so for a long time,' says Gull. 'Coming from a traditional Pathan family I was not supposed to meet men or travel alone,'" says Gull. 'Yet, I took things into my own hands and ran the family embroidery business for two years to earn a livelihood.' She also travelled to Rawalpindi on a number of occasions seeking information about HIV and AIDS and to learn about ways to keep herself healthy.

Gull has been actively involved not only in raising the awareness level of others but also providing counselling services to newly diagnosed persons. 'During the past few years I have seen so many places all around the country, and have led awareness campaigns in Balochistan and Sindh on HIV and AIDS. Since the government even today practically does nothing for people like us, I still am working on my own resources and doing what the government departments should have been doing.'

She has formed two groups of HIV positive patients in Karachi and Lahore, and reveals that none of the members of her groups are registered with the government or national AIDS programmes for fear of stigma. She sums up her efforts, 'We cannot wait for the government to do the needful. When you know the storm has arrived, would you let it spread or work to limit its damage?'

## A Couple Together Claim their Rightful Place in Society

'He says that if he knew that he had HIV and it was so serious, he would definitely not have married an innocent girl like her. Now, I don't care about anybody other than her.'

Salim is in love with his wife. He says, 'we have passed through so many hurdles together and suffered so much. We had no money. We struggled for days even for one meal; but all that pain brought us closer. Now we are happy.' Salim's wife is HIV positive. He says, 'Because of my ignorance, my wife got HIV and I want her to lead a good and happy life.' Salim's is a story of a rough and tough life before he found love.

The oldest son in the family of four children, Salim lost his father at the age of 12. He ran away from home, went to Bombay and worked in a hotel and also as a porter. He lived with three friends in a slum, and would drink, smoke, watch pomography, and visit sex workers. He lived with and later married the daughter of a sex worker. After she died during childbirth along with their child, he continued his old activities.

Once, when Salim had his blood tested because of an accident, he was found to be HIV positive. But nobody told him about the infection and how serious it was. He returned to Davangere and became an autodriver. Salim continued his old habits but when he lost his mother and his relatives arranged his marriage, his life changed.

His new dimpled wife was Rukhsar. She was bubbly and childlike. She loved talking and interacting with people. Salim was happy. But then, Rukhsar got pregnant. She fell constantly ill. She was admitted into hospital for treatment of TB. Here Rukhsar was tested and found HIV positive. Their baby died. Salim came to see his wife in the hospital. She was all alone. Their relatives, even her parents, had abandoned her on knowing her positive status. Salim was angry, but when the doctors told Salim about Rukhsar's illness, Salim realised then that he had given it to her. The couple left Davangere and went to Bangalore and even contemplated ending their lives in despair.

Salim and Rukhsar lost their second child. But this time, unlike earlier, they got counselled at the Bangalore hospital. Rukhsar started attending family support network meetings, and Salim would accompany her when he could. Slowly, Salim and Rukhsar began regaining their lost confidence. The network people suggested they go to Davangere where Rukhsar too could work. The couple took a long time to take a decision and finally decided to return home.

Rukhsar joined an HIV-AIDS project as a field worker. They were trying to start a new life together, when Rukhsar's work became an issue: a woman working outside the home! Their relatives and community people complained to Salim that he should stop her from coming home late, visiting and talking to sex workers. At first, Salim listened to them. But eventually he also took up work there as a peer educator. He found it difficult to do this kind of work, but slowly got used to it, and understood its importance.

Now Salim has changed a lot. His temper is under control. He wants to work for people living with HIV and AIDS. He does not bother about his relatives' or friends' comments on Rukhsar's work. He asks for their support, or else he asks them to stop interfering in their personal lives.

Salim wants his wife to lead a happy life. He says that if he knew that he had HIV and it was so serious, he would definitely not have married an innocent girl like her. Salim says, 'Now, I don't care about anybody other than her.'

## A Woman in Nepal Fights for Her Property Rights

'I had nothing: no house, no money, no property, no rights, no identity and no clue what to do about my situation. I did not give up.'

Pushpannjali Shrestha says, 'Women are particularly affected. Once their husbands die of AIDS, they are rejected by their husband's families, denied property and left with practically no resources to fend for themselves.' Pushpanjali's husband was a drug addict. He died of AIDS, passing the virus on to her. She says, "Only people living with HIV and AIDS know the pain and psychological trauma that they go through when their status is disclosed to society. When my husband got HIV and developed AIDS, I used to curse him and was always angry with him. Then I got the illness. I felt what he must have felt when his HIV status was

disclosed.'

Pushpanjali understood her husband's plight but the pain and trauma of being an HIV victim in her case was doubled due to her also being a woman. 'I was left alone after my husband's death. I had nothing: no house, no money, no property, no rights, no identity and no clue what to do about my situation. I did not give up.'



She also faced the other problem women often face, ignorance about official matters: 'Before my husband's death, I knew nothing about the citizenship certificate and marriage registration. I was totally dependent on him, used to be least concerned about all these things,' says Pushpanjali, 'But, after my husband passed away, I had to struggle hard for getting the citizenship certificate to fight for my right.'

Her fight was not an easy one. It involved making many trips to the ward office and being ill treated by the employees there. It also involved trips to the police station to track down absconding relatives. She persisted and finally won her case.

Pushpanjali set up an example in her country for others to follow. She now works as a counsellor in an NGO. She has completed 6 months' training in journalism. After the training, she wrote her own success story, and it was published in the national daily of Nepal. She is probably the first Nepali woman to fight for her rights to property despite being HIV positive. She is determined to do her bit to change the way society looks at the people living with HIV and AIDS.

## A Wife Fights for Justice in Marital Relationship

Bhagini is the third daughter of Narasimha Rao and Lakshmamma, a poor rural couple whose two older daughters got the status of 'second wife' in a society where downy decides who they can marry. When it was Bhagini's turn, ensuring she gets the first wife's status became a question of family prestige. So, when a 'good' proposal came, it was with a lot of pride and pleasure that her parents gave her away to Krishna Rao.

In her fifth month of pregnancy, Bhagini tested HIV positive and having completed her schooling where she learnt about HIV transmission, she demanded to know whether her husband had also tested positive. But the doctor who tested both of them declared that Krishna Rao was negative. Bhagini's parents were horrified and her father in law refused to accept her back in his house. Bhagini stayed with her parents and was surprised when her husband continued to have unprotected sex with her on regular visits. He also gave her articles on care and support for people living with HIV. She bore the painful stigma and discrimination meted out at the government hospital to give birth to a lovely baby.

Then her husband said, 'Let's divorce to satisfy my parents. I will continue to visit you and support you.' Bhagini was shocked and refused to give her consent despite coercion and threats. Though afraid, she did not change her stance and argued, 'You are the source of my infection. So, you cannot get away from the responsibility of taking care of me and my baby by holding a false statement that you are negative.'

When Bhagini was summoned in court, she demanded that for her to give consent, her husband should get tested for HIV in a government run VCTC and produce the results in court. For the past three years she is fighting what she believes is her husband's false declaration. 'It is not just financial support that I am seeking. I want justice,' she says as she takes care of her four year old and her aged parents. 'I have never found my lack of higher education and the financial crunch a limitation for positive living.'

## Informed Consent Leads to Remarriage and Public Acceptance in China

'On April 24th, two people living with HIV, together with their newly-wed and uninfected spouses took part in a meeting with the media entitled 'Love Under the Sun' in Wuhan, China.'

Both positive people come from Dazhi City. One of them is 48 years old and contracted the virus along with his wife, when one of them sold blood at a hospital in Henan in 1995. His wife died in

2001 and he has known his new wife since the two of them were children. Separated since for many years, they fell in love after renewed contact and received their marriage certificate from the Dazhi Civil Affairs Bureau on April 6th.

The other positive person is a thirty year old woman. She and her late husband were infected after selling

blood some years ago. Four years ago, AIDS took her husband's life. When she went to work in Wuhan, she befriended a young man working at a construction site. The two of them registered their marriage in March this year.

The deputy director of the Hubei Provincial CDC, Li Hanfan said, 'We do not encourage AIDS carriers to marry healthy people because they can pass on the virus to their partners, and also to any children through mother-child transmission. But we do give them the relevant information and take preventive measures in order to lower the risk of transmission as much as possible.' At a time when talking about AIDS can still cast a shadow in many places, the fact that people living with HIV can marry healthy people, shows that people's understanding of HIV and AIDS is improving and fear of the disease has been reduced.

According to an official from Dazhi City, the relevant parties held a joint wedding ceremony for the couples on April 28th.

Source: (Xinhuanet Wuhan, 24 April 2005) Reporters; Li Changzheng, Xu Zhengdong (http://www.china-aids.org/english/News/News414.htm)

#### Women in Cambodia find Friends in their Fight for Survival

'Sometimes I think it is the road all women must face in life, misery and hardship and then survival. We are the women that are forgotten because we are survivors.'

It is the attempt to survive in a society that provides almost no option for poor women like me that causes us the most pain and discrimination. We are blamed for husbands being unfaithful, and we are taught HIV prevention by NGOs so the rest of the community can remain safe from us. It is an unjust world!

My name is T.R. I am 32 years old and I come from Kandal Province in Cambodia. My father was in the army but died when I was I 0. My mother is a farmer. I didn't study because my family is poor and I am the oldest daughter. When I was I 6 years old, I was married off. My parents arranged it for me and we never argued about it. I worked and fed my husband. He often drank and yelled at me.

Since my husband went away about 5 years ago, I tried to make ends meet for my child and me by selling flowers at the Phnom Penh market. I now work as a sex worker because I know I can earn more money. I need money to support my family and pay for my child's education. I still sell oranges and baby ducks. (Men buy oranges for a higher than normal price and can touch me.) Sometimes, I go to sleep with clients. My parents, siblings and community don't know that. When I got sick, my sibling who stays outside the country had to send money to help me. Too many of us get sick and often cannot think of going to a medical facility, because we would have to ask relatives for money. It is very



expensive. Poor people rarely have the money to seek good health treatment, and our health is all privately operated.

Twice, I was gang raped. The first time, they raped and hit me until I had a broken leg. The second time, they raped me and took all my money. Both times that I was raped, the men didn't use condoms. I was not a human being for them. I am also not a human being to society, and you can only be a human being if you have money. I know being a woman and a poor woman in a poor country means being at high risk.

For two years now, I have been living with HIV. It was difficult to deal with this news. I felt sad and worried, but now I'm OK. I joined a study group and a leadership group to teach others about this so it does not happen to other women; although, we all know how easily it can happen.

I still have to survive so my livelihood has not changed; if I had a choice I would not have chosen this in the first place. If the client doesn't use condoms, I use female condoms. Now I worry about my child's future. If I die what will happen to my child? I know this is the story of many women today. For this reason too, I have been participating in women's groups so I can tell others not to blame themselves. I help them to understand this system that first makes us vulnerable and then discriminates against us.

## Networks Lead the Way: Stories of Collective Efforts of People through Networks to Bring about Changes

## Sex Workers Unite in their Stand Against the Politics of Funding

'Don't take the money. Do they think we are worse than dogs?'

In early May, when the government of Brazil rejected US \$40 million in American AIDS financing because of restrictions the United States would have imposed on groups that work with prostitutes, Rosanna Barbero gave a quiet cheer. She had been there before.

Barbero is the head of Women's Agenda for Change (WAC), the leading advocacy organisation for sex workers in Cambodia. WAC teaches the country's many

prostitutes to organize and to improve their working conditions, and it has spun off a sex workers' union that now claims 5,000 members.

Starting in 2001, the US Agency for International Development supported Barbero, with about US \$73,000 over three years. Then in 2003, Congress mandated that any organisation receiving USAID assistance declare that it "does not promote, support or advocate the



Postic Remodel Sex Work

legalisation or practice of prostitution." Technically, WAC doesn't do any of this, but in practice, it would have had to break with the sex workers' union. Barbero went to the union's elected leaders five women and two srey sros, or transvestite/transsexuals to ask what they thought she should do.

"They said don't take the money," she recalls. "I remember one said: "Do they think we're worse than dogs? How can they tell us all this time that we have to stand on our own two feet, and now suddenly say they can't work with us?"

When Barbero, 40, a diminutive Australian first came to Cambodia in 1992, she was doing research for her thesis in Asian studies. She found that peacekeepers and aid workers affiliated with the United Nations were fueling a sudden explosion in prostitution.

When women have nothing, they have to sell sex. WAC is a nonjudgmental, antiauthoritarian sanctuary for these women. Its headquarters, a double-decker barge moored on the Tonle Sap River, was previously a floating discotheque. Now a visitor might find anywhere from a half-dozen to 50 women sitting in a circle on the dance floor, holding a meeting. Some might be prostitutes discussing how to avoid being raped, while others might be laid-off seamstresses brainstorming about a campaign against Levi's. (WAC also works with garment workers.)

WAC is widely seen as the most effective organisation in its field in Cambodia. Along with the sex workers' union, WAC helps sex workers protect themselves from violent clients and predatory policemen. And it helps them reach out to hospital workers so they are not refused when they seek treatment for sexually transmitted diseases. If Barbero had taken USAID's anti-prostitution pledge, she would have sacrificed the quality that her constituents most value: a willingness to accept them as they are.

As USAID forces the pledge upon anti-trafficking and anti-AIDS organisations, an increasing number are starting to protest: in May, 2005, 171 NGOs signed a letter opposing it.

**Source:** Extracted from The Question of Rescue By MATT STEINGLASS; The New York Times. (http://www.nytimes.com/2005/07/24/magazine/24ENCOUNTER.html)

#### An Ostracised Community Fights for Equality and Human Rights

#### 'If one has courage only then can one survive.'

D. Noori, President of the South India Network of Positive People (SIP+) is a hijra, a transsexual, living with HIV and AIDS. 'I have wiped out from my brain that I am HIV+. I have deleted that fact from the computer in my head. And I just lose myself in my work. I was diagnosed as HIV positive in 1987. The doctor told me I have 2 years to live. Here I am going strong even after 18 years,' she says with pride.

Noori has achieved a great deal over the years. She is the Founder President of South India Network of Positive People (SIP+). She set up SIP+ in August 2001 with just 26 members because 'even after working with so many NGOs for over 10 years, I was always pointed out as a hijra and not as a woman! I felt the need to set up a people's institution irrespective of gender. Of course, all that I learnt from other NGOs especially INP+ has helped us a great deal.'

The network today consists of a total of 1700 positive people who come from all groups including transsexuals, MSM, commercial sex workers and people from the 'general population'. A group of 17 hijras actively work in SIP+, and funding support is currently available from 7 agencies. Program activities

cover awareness building, counselling for positive living, nutrition and ART for children and mothers, skill development and support for augmenting family income.

'Counselling through home visits has helped reduce harassment of daughters-in-law and atrocities on positive children. It also helped prevent suicides and made people avoid irresponsible sexual behaviour. We are also very happy to have helped 11 couples to start a new life after marriage and the message is that people living with HIV can get married and live normal lives and also have

children with support from society and services from the health sector.' Says Noorie. 'A number of leading newspapers have reported the weddings as a welcome step and

stigma by families is reducing in Tamil Nadu.'

'Speaking of the hijra community, a "different" child is ostracised even by parents and often shown the door and survival sex takes over.' With no love or family support, young transsexuals enter the isolated world of the structured hijra community in India. In some places you have the guru-chela system and in other places you have the maa-beti system. Noorie adds 'Awareness and education is crucial. The guru-chela system is more difficult to enter into because the chelas will only do what the gurus tell them. It is necessary therefore to make the gurus aware about safe sex and responsible behaviour and then the others will follow.' Through relentless efforts, things have improved and in many places the sex workers have adopted safe sex practices.

Noori feels a very important factor that would reduce the prevalence of HIV and AIDS is the provision of alternate income. 'Only if the people are drawn away from sex work will change occur in a larger numbers.' Towards this aim SIP+ helps develop skills in preparation of toys, greeting cards, envelopes and bags, condiments and clothes to wear. Also, people are helped to get loans for setting up a small business.

Access to ART for all who need it is another focus and many like Noorie need level II and even level III regimens that are not provided by the Indian government. 'This has to come or else we will die. I know the fight for our rights is long and difficult but as long as we are alive, there is hope,' says Noorie.

Pointing to her red ribbon earrings and necklace, she smiles. 'It helps spread awareness. When I am travelling, passengers ask me what the ribbon design is about and then I start educating them about HIV and AIDS.'



## A Support Group in Pakistan Lobbies for Access to Medicine

'NLACAG is the place PLWHA in Pakistan rely on to get ARV drugs.'

I am Nazir Masih, 45 years old, the Founder and Chief Coordinator of New Light AIDS Control Awareness Group (NLACAG) formed by PLWHA in Pakistan.

I have been living with HIV for the past 13 years, and during this period I faced discrimination and stigma from my family and society. I had been working for 10 years in Dubai when problems started in 1987. I went through blood transfusion after a major accident. I recovered, but in 1990 I had to go through a HIV screening test to renew my visa. I came back to Pakistan after giving my blood sample and a few days later received a letter from hospital authorities in UAE declaring me HIV positive! This meant that I could not go back to UAE again.

In Pakistan, I went through complete blood tests from a Lahore lab, and doctors took almost Rs. 200,000/- for treating me. I had to sell my house to pay them, and after six months of treatment I was told that I was perfectly all right. I went to Hong Kong for a job but there I got a boil on my finger. It wouldn't heal and I had to come back to Pakistan.

This time when I went for a blood test, the lab technician immediately announced me as an HIV positive in front of every body present in the lab. I was shocked with the report as well as attitude of laboratory staff. Next morning I was shocked when a few journalists visited my house, took snaps of my family and me and published them in Jang, a national daily. Doctors advised my family to separate my bed, clothes and utensils. It was humiliating and since then, my wife and children too had to face all kinds of stigma and discrimination from relatives and society in general.

I was spending my life in sheer tension and desperation when one day I met Dr Abdul Rasheed (Ex. Associate Professor of Institute of Public Health). He counselled me and advised me to lead a normal life. His words eased my pain and distress and encouraged me to begin a new phase of life with enthusiasm and passion.

Establishment of NLACAG is result of my effort to make people aware of this epidemic as well as provide counselling and all other possible help for people living with HIV. The government of Pakistan promised to provide ARV to 500 HIV positive people till the end of 2005 but so far no progress has been made. NLACAG is the only place PLWHA rely on to get ARV drugs.

## Families Support Each Other in Coping with HIV and AIDS

'Take in the music and songs that soothe... soothe the pain of hopelessness and loss.

Sing your heart out because you have hope for the future.'

MILANA meaning 'mingling together' is a family support group of People Living with HIV and AIDS based in Bangalore. Starting with just 4 members who had little to look forward to, the large group of over 380 today is dynamic and vocal and singing its way to positive living. The songs reinforce MILANA's belief that all people living with HIV and AIDS deserve the same rights, including the right to live with dignity and respect, the right to be treated as equal members of society, and the right to have their basic human needs fulfilled. Through its advocacy programmes, MILANA fights for the rights of people living with HIV and AIDS.

The MILANA choir sings in Kannada and a favourite song is 'Bani, Bani Mithrare, Hoganna Namma Milana ke (Come friends, lets go to MILANA, let us all learn, and gain knowledge and find solutions to reach our goal).'

All the songs composed by MILANA members echo the spirit of togetherness, acceptance and offering a helping hand to any one touched by the virus. The message is about not being

judgmental, about love and the triumph of the human spirit against all odds. The songs are emotional and motivating and stress that there is no problem, no physical condition that we cannot rise above, together. 'It is a voice of hope for people like us, the songs give us courage and hope,' says Meena, a member of the choir.

Members from 235 families, a majority of who are young widows with children, support one another in this forum by learning and sharing experiences of living with the virus. MILANA promotes positive living, self-reliance and reduction of infection rates through HIV and AIDS education, prevention and care. A holistic approach to the care and support of people living with HIV and AIDS through counselling, educational, nutritional and medical support, self-help groups, income generating activities, support groups, wellness management and positive-living programmes has made a

big difference. Since a majority of the members are illiterate and belong to the lower socio-economic strata of society, skill development for income generation is crucial. 'Our first attempt at income generation through sale of file covers, bags and mobile pouches was a sell out', says Amudha with pride tinged with relief. 'Now we have the confidence to try other options of earning to help support our children and ourselves.'

MILANA also strongly advocates the reintegration of positive children into caring communities and loving families to enable them to get education and healthcare. Jyoti Kiran, the mother figure to all says 'When they need medicine, it must be provided. When they are sick, they have a right to be cared for. When they die, they must be able to die with dignity, surrounded by love. All programmes and activities must be based on rights: the rights of these children, enshrined in the Convention on the Rights of the Child.'

Young mothers, grandparents and fathers with children on ART also form a parent's support group that meets to discuss coping skills and the way forward. 'It is always cathartic when I share my experience with others,' says Chandrika, a peer counsellor with a fair idea of Olsand medical treatment because she earlier worked in a care home. 'We need to come together to not only fight for our rights, but also to see our children get ART and lead near normal lives. We are among the best people to talk to others about HIV and can definitely help prevent its spread.'

MILANA members are also extending assistance to people living with HIV in two other districts of



A Farmily Support Net work

## Intravenous Drug Users are in the Driver's Seat and Spearhead Art in Thailand

'I felt we had to become more active, a force for change instead of just for support.'

Thailand has 750,000 people with HIV, I 50,000 who need urgent treatment. The government has mounted a bold plan for people to get HIV drugs. But Prime Minister Thaksin's treatment campaign may never have got off the ground without the courageous work of ordinary Thai people with HIV.

Paisan Tan-Ud, a skinny, intense 37-year-old, was diagnosed 12 years ago at a drug addicts' recovery centre. He was first chair of the TNP+ (the Thai network of people living with HIV and AIDS) and now heads his own organisation, the Thai Drug Users' Network (TDN).

'I was part of the group that set up the Wednesday friends' club at Chulalongkorn hospital, Thailand's first support group for people with HIV, in 1991. I saw so many friends dying or living in fear, I felt we had to become more active, a force for change instead of just for support. In about 1999, shortly after TNP+ started, we saw what was happening in the west and decided to focus on treatment. Without treatment, there is nothing for us.'

Paisan says doctors regarded them as bad people for catching HIV and had no means of treating them. 'We told them we would die without information. We started training people to train their doctors. Now things are moving fast. The government wants an HIV comprehensive care centre in each of the 800 public hospitals, each with two people living with HIV on staff. They have already set up over 100 centres. But it's going to be complex getting people on to ARVs. I haven't heard much about how they are going to encourage people to come forward for treatment.'

A crackdown on drug users has made it harder for patients to come forward. Drug users do not want to identify themselves. But Paisan has never feared exposure or bowed to stigma. The drug users' network was born at the Chiang Mai 14th International Harm Reduction Conference in April 2003. At the height of the government-sanctioned murders of drug users, the network mounted a continuous vigil outside the conference, silent witnesses to the terror around.

'Other organizations said we should call ourselves the former drug users' network. We said "No. We are who we are".'

On 4 December 2003, the network demonstrated outside the royal palace during the King's birthday celebrations to attract the attention of His Majesty, King Bhumibol Adulyadej, and ensure Thaksin kept his word.

Any visitor to Thailand knows how the King is revered. He never makes his views public but what the King says is followed. Word is, he told Thaksin to curb his addiction for killing drug users, and to concentrate on treating them instead.

Source: Extracted from Paradise Regained by Gus Cairns. Website www.positivenation.co.uk

## A Bangladeshi Official Becomes a Powerful Advocate for HIV Prevention Programmes

'Wherever I go, I share my experiences of what I have seen and learned. It is crucial that we be proactive about stopping the spread of the epidemic for the sake of all Bangladeshis.'



Because there is a low prevalence of HIV and AIDS in their country, many Bangladeshis believe that they are not at risk for the disease. But Ferdous Ara Begum, Joint Secretary of the Ministry of Women and Children Affairs for the People's Republic of Bangladesh, now knows otherwise. 'Now is the time to break the silence about HIV and AIDS,' she stated recently. 'This is a silent killer that spreads at geometrical speed. It can destroy a nation very quickly.'

A key strategy to help prevent the spread of HIV, in any country, is to spark a dialogue about HIV and AIDS at the policy level while building champions of HIV prevention within government ministries. Training in HIV and AIDS, field visits and an exposure visit to Thailand in 2002 opened Ms

Ferdous Ara's eyes to the possibilities for prevention in her country. 'I began to see that if Thailand can control its HIV and AIDS epidemic through high-level commitment and an efficient strategic programme, Bangladesh can, too. I realised that it is possible to save Bangladesh from this deadly disease through a calculated effort and a massive awareness campaign.'

Bangladesh has the key ingredients needed to respond successfully to the threat of an HIV epidemic: a nationwide network of effective NGOs and a long-standing history of successful government collaboration with these organisations. Ms Ferdous Ara returned from Bangkok and started to use the information she had gained to mobilize the government and NGOs to collaborate and effect change. She introduced information about HIV and AIDS and sex trafficking issues into the curriculum of a programme aimed at vulnerable groups that benefits about a half million extremely poor women each year. In addition, the Ministry of Women and Children Affairs, with assistance from UNICEF, initiated a nationwide campaign to raise awareness about HIV and AIDS. 'Our Minister, Ms Khurshid Zahan Haque, MP, says that HIV and AIDS is a development problem and a gender problem,' stated Ms Ferdous Ara. 'Therefore, it is imperative that we educate our people about the danger of HIV and AIDS and risky behaviour.'

A resources team has already arranged workshops and seminars to sensitize parliamentarians, policy makers, and government officials about the issue. In addition, the team is meeting in many districts with vulnerable groups, including university and high school students, truck drivers, slum residents, transient people, and street children, to educate them about HIV prevention. 'Wherever I go, I share my experiences of what I have seen and learned. It is crucial that we be proactive about stopping the spread of the epidemic for the sake of all Bangladeshis,' said Ms. Ferdous Ara. With her newfound commitment to this cause, she is working to access additional financial resources from the GFATM for a programme called Migration Mobility and HIV and AIDS. Following on this successful project, Engender Health continues to work in partnership with the government of Bangladesh to prevent HIV.

Source: Extracted from website of Engender Health, 2005; www.engenderhealth.com

## The 'Dharan Positive' Network for Drug Users in Nepal Proves to be a Dream Come True

'I now work to fulfill my dream that nobody will die because of lack of medicines.'

In the beginning of 2002 when nobody would dare expose themselves as HIV positive in families and in society, Naresh Lal Shrestha a 40 year old drug user was undergoing treatment for drug addiction in Kirat Yakthung Chumlung (KYC) Punarjiwan Kendra. Hailing from Hetauda in eastern Nepal, he had been taking drugs for 15 years. It was not his first time at a rehabilitation centre. He had earlier been admitted five times and gone back to drugs every time. This time, Naresh learnt that he was HIV positive. He attempted suicide because his own family and society excluded him completely, and he also faced

attempted suicide because his own family and society excluded him completely, and he also faced discriminated at the local hospital. Yet his wife encouraged him to live and promised to be at his side in his struggle.



It was then that an NGO Punarjiwan Kendra for the first time launched the Right Based Programme for drug users and PLWHA with support from ActionAid Nepal. This time, Naresh committed to quitting drugs completely and becoming an ideal for PLWHA. Spreading awareness about drugs and HIV in the community in the eastern Nepal, Naresh openly accepted his HIV status. He also organised school awareness programmes and spoke to the media, risking stigma and discrimination in a traditional society. His efforts brought together many people living with HIV and it became a challenge to organize a PLWHA group called 'Dharan Positive'. 'Though they were HIV positive, they were still using drugs,' Naresh shares. Gradually, he started to inspire people to avoid drugs and sought support to create the environment to rehabilitate them. 'My dream came true when all the members of Dharan Positive recovered from the drug abuse,' recalls Naresh.

Today, PLWHA in the eastern part of Nepal have united in an umbrella organization called Eastern Association of People Living with HIV and AIDS. Naresh has become a lead activist and is also the team leader of the Right Based Programme for People Living with HIV, funded by ActionAid Nepal. 'We still have a lot to do,' he says. 'Most days of the months are spent attending the funeral of my fellowmen because they are dying without getting proper medicine and care and support. I now work to fulfill my dream that nobody will die because of lack of medicines.'

#### Local Governments Take the Lead in China

'Authorities are responding to Children affected by HIV and AIDS in Henan Province.'

'Daddy died three years ago because of the disease called AIDS.' Taohua is a skinny I I year old girl with a ponytail. She is shy but articulate. 'First he had headaches. Then he got very sick and went to see a doctor, but he just got sicker. My mom wanted to buy some medicines, but our family was too poor. My daddy didn't want my mom to spend the money.'

Taohua's family grows wheat, peanuts and fruit trees. They cannot afford any chickens or pigs. They live in a sleepy village in the middle of the vast flatland of Henan Province. The massive wave of urbanisation in coastal China has not yet reached here. But HIV and AIDS have.

In the early 1990s, several blood collection centres were set up near Taohua's village. Many villagers sold blood to supplement their incomes, happy to earn money for each visit. In order to help them recover from blood loss so that they can sell blood again quickly, other plasma was pooled together from various blood sellers and pumped back into all the sellers' veins. The plasma was not tested for HIV viruses. As a result, HIV spread quickly in this conservative rural area where drug use and extramarital sex are rare. According to official statistics, more than 10,000 HIV and AIDS cases were reported in Henan Province in 2003.

Like Taohua, some 130 children in her village have already lost one or both parents to AIDS. In

SHUANGRAO

Henan Province, more than 2,000 children have been orphaned by AIDS, most of them between the ages of 6 and 15 years. Some of the children too are HIV positive. If the surviving parent is too sick to take care of his or her children, the youngsters generally live with their grandparents, or at a local welfare centre.

UNICEF China, along with other UN agencies and development partners, formed a UN theme group

on HIV and AIDS to urge the Chinese authorities to make HIV and AIDS a top national priority in 2003. In 2004, China's State Council established an HIV and AIDS Working Committee chaired by Vice Premier Wu Yi. The government banned blood trading and safe blood programmes were put in place.

As part of the support package, local governments in Henan waived school fees for children affected by HIV and AIDS, while also providing training to schoolteachers. Other measures include: free screening test and confirmation test for anyone who wants to be tested for HIV, all clinics, hospitals and health workers are required to use disposable needles and syringes for all injections, efforts to prevent parent-to-child transmission of HIV, road construction in villages affected by HIV and AIDS to help stimulate local economy, provision of water to every household to maintain good sanitary conditions, and make agricultural work easier for HIV and AIDS affected families and exemption from a variety of local taxes for PLWHA and their family members.

During a monitoring trip in March 2004, UNICEF China's chief health expert Dr Koenraad Vanormelingen was impressed by the progress made since his last visit six months earlier. 'With relatively small financial input and technical support from UNICEF, the local authorities have taken a number of significant actions. I can see the difference already.' The Henan authorities recently put together a tenyear plan of action to deal with the disease.

Source: Extracted from a report on Henan Province, China, 11 June 2004, UNICEF Website.

#### Children are Peer Educators for Awareness in Pakistan

'If we don't tell people about this virus, it will spread very fast.'

At the age of 14, Yasin Malik a child labourer, decided to go to school and leave the car workshop he was employed in the Gawal Mandi area of Rawalpindi in Pakistan's Punjab Province. He had discovered that he could be at risk of abuse from the older engineers and HIV and AIDS. 'I used to see them having sex with the boys in the workshop. They had no choice but to do it with them and they didn't use protection,' he said. 'I know you can die from AIDS and I'm so glad I have leamed about this.'

Malik is one of the more lucky boys. Others are forced to work because their families are just too poor and cannot support them. He made his decision after being educated on HIV and AIDS under the 'YES programme' run in Rawalpindi by the Pakistani NGO, Amal. Up to 3,000 children in Rawalpindi are educated under this programme every month by other boys in the area, who are trained to spread the word about HIV and AIDS.

Using 14 boys in the area as the key educators, the message was spread quickly and effectively. Every educator taught five boys, who in turn passed the information on to others in Gawal Mandi. In addition to this, a project to educate youngsters on HIV was also being run in five schools in Rawalpindi alone, two of which are for girls. An aid worker maintained that raising awareness in preventing HIV and AIDS was crucial in a country where roughly 60 per cent of the population was illiterate and misconceptions like having sex is fine but masturbation is not makes children more vulnerable to exploitation and thus infection.

Usman Ali Butt, aged 17, is the leading educator in the workshop area, where some 500 boys are employed. 'We tell children what HIV is and how they can protect themselves, by using cassettes and books,' he said. 'If we don't tell people about this virus, it will spread very fast,' he asserted.

In a country where youth makes up 23 per cent of the population, getting the message across to children has also become a priority for the government's national AIDS control programme. NGOs are making a special effort to reach out to conservative areas, where children are at most risk of being infected by the HIV virus. Projects focused on raising awareness are beginning to sprout across the country. The AIDS Awareness Group (AAG) in the Punjabi city of Lahore is educating children aged between 12 and 19 in schools. Over the years, some 3,000 children have been informed under the programme. 'Each time a session is held, children are chosen from the class so that they can talk to other children and spread the message about safe-sex and the dangers of drug abuse,' the head of AAG, Kushi Lal, told IRIN from Lahore.

The response from families when tackling such issues has not been too obstructive, according to AAG staff. 'About 90 per cent of the parents have agreed to our way of educating the children, so there has been only a small margin that has disagreed with this approach,' he said.

Source: Extracted from YOUANDAIDS Portal of UNDP 2005; Tuesday, November 15, 2005. (Original source and disclaimer: This feature is sourced with permission from IRIN, a UN humanitarian information unit, but may not necessarily reflect the views of the United Nations or its agencies).

## Behaviour Change Communication Leads to Sustainable Community Responses

'Stepping Stones should be taken and shared in every house in every community.'

Stepping Stones (SS), a training package on HIV and AIDS, gender, communication and relationship skills, grew out of the need to address vulnerability of women and young people when it comes to decision-making about sexual behaviour. Developed by Alice Welbourn and a team originally for Africa, 2000 organizations in 100 countries today use SS, ActionAid's renowned approach to HIV prevention. Designed to enable people to explore issues that affect sexual health with great sensitivity, this participatory tool for behaviour change among communities goes a long way to prevent and control STI/HIV and AIDS.

The principles and approach of SS is based on the belief that:

- The best prevention strategies are those developed by community members
- Peer groups need their own time and space to identify and explore their own needs
- Behaviour change is effective and sustained when all members of the community are involved.

All work is based on people's experiences and facilitated through role-playing, drawing, singing etc.

No formal education is needed and everyone can take part. Peer groups usually based on gender and age or marital status work together. A logical sequence and progression of sessions addressing all issues of sexuality, HIV and AIDS fits in with the 'fission and fusion' structure of the workshops. This structure enables two things:

It creates time and space for discussion of personal issues in comfort of peer groups and also creates a public platform for unequal power groups in a community to address issues.

Designated 'Best Practice' by UNAIDS for its emphasis on empowering women, SS has been successfully adapted for use in India. It is being implemented by youth organisations in India to encourage behaviour change. 'One session was stopped by a policemen who thought we were encouraging promiscuity among teenagers', says 19 year old Deepak, a peer trainer from Centre for Youth Development Activities (CYDA) in Pune. 'Because I had been trained in SS, I was able to calmly convince him of the need for HIV awareness among youth,' he adds. CYDA has taken SS to youth groups in 17 districts of Maharashtra and the demand for trainers and training programmes has risen sharply. 17 year old Sangeeta from a small tribal village in Amaravati is regular participant in their village where the Youth For Change-Stepping Stones (Y4C-SS) process is on. One day she said, 'A distant relative of mine convinced my parents and took me along with him promising me a good job in Amaravati. He took me home and tried exploiting me sexually, but firm resistance from my end, which I learnt through 'assertive skills' scared him and saved me.'

Indo-Canadian HIV and AIDS Project (ICHAP), an organisation that has collaborated with ActionAid to adapt the package to the Indian context, is implementing SS in over 80 villages of Bagalkot district in Kamataka. Desirable changes in the community are becoming visible. In Berur village, the SS groups have been able to advocate the use disposable needles to the Panchayat to get the PHC (Primary Healthcare Centres). In other villages, women's groups have been able to take up issues of alcoholism, child marriages and polygamy that harm the community. The SS group is involved in resource mobilisation, referrals, condom distribution, identifying and helping vulnerable people and campaigning for health camps. People are now far more aware of health-related matters and seek early diagnosis and treatment. Relationships have strengthened among couples, within families and communities.

'...in my estimation one of the most valuable recent additions to the quite scantly written material available in the area of community mobilisation...UNAIDS has included this resource package among the "key documents" recommended for use in innovative community mobilisation programmes' Noerine Kaleeba, UNAIDS, Switzerland



Uganda

Uganda's approach to HIV and AIDS has been remarkably successful despite major problems like poor access to health facility, political conflict between rebels and government-backed militia, and falling GDP. Characterised by political openness and leadership, the Uganda example has potential to be adopted by other countries suffering under a high burden of HIV prevalence.

In 1986, Uganda's Health Minister announced that there was HIV in the country. In that same year, the President toured the country, telling people that it was their patriotic duty to combat HIV. This was a brave approach that paid off. The President also encouraged input from numerous government ministries, NGOs and faith-based organisations. He relaxed controls on the media and a diversity of prevention messages spread through Uganda's churches, schools and villages. The message about HIV and AIDS was effectively communicated to a diverse population by the government and by word of mouth. Much of the prevention work occurred at grass-roots level, with a multitude of tiny organisations educating their peers, by people who were themselves HIV positive. Breaking down of the stigma associated with AIDS, and a frank and honest discussion of sexual subjects that had previously been taboo was encouraged.

Most importantly, community involvement by the government very early in the epidemic encouraged Ugandan people to help themselves in the fight against HIV and AIDS. One of the first community-based organisations to be formed was TASO, The AIDS Support Organisation founded as early as in 1987 when there was still a great deal of stigmatisation of people with HIV. TASO now provides emotional and medical support to HIV Positive people and their families.

Source: http://www.avert.org/aidsuganda.htm

#### Thailand

Thailand was the first country in South and Southeast Asia to be hit by AIDS in 1984. The initial policy response was limited until 1991 when Prime Minister Anand Panyarachun, made AIDS prevention a high national priority and urgent and effective steps were taken to stem the epidemic.

Excellent use of media through a massive public information campaign on AIDS had messages aired every hour on the country's 488 state-owned radio and television stations. Every school was required to have AIDS education classes.

The hugely effective '100 per cent condom programme' was initiated. This programme aimed to enforce consistent condom use in all commercial sex establishments. Brothels that failed to comply could be closed. Repressive policies like mandatory reporting of the names and addresses of AIDS patients were also repealed.

Every segment of Thai society was involved in AIDS prevention including the medical community, teachers, monks, sex workers, the government, private organisations, and also the military. By 1999, AZT was being used in most hospitals in Thailand to reduce mother to child transmission.

The number of new HIV infections has reduced from 140,000 in 1991 to 21,000 in 2003. Visits to commercial sex workers have been reduced to half, condom usage has increased and STDs have decreased.

Source: http://www.avert.org/aidsthai.htm

#### Brazil

Brazil is the one country in the world that has successfully managed to cut its nationwide HIV-prevalence rate of 1.2% in half and mitigate the impact of the epidemic on society at the same time. Brazil's programme has been extraordinarily successful not only in decreasing deaths due to AIDS, but also in reducing the HIV prevalence rate and in producing financial benefits for the country. This programme did not happen overnight, but was part of a systemic, multi-sectoral, decentralised approach. Brazil's actions set a great example for other countries attempting to curb the epidemic.

From its inception, the programme in Brazil has been based upon the philosophy that access to healthcare is considered a constitutional right; hence HIV care and treatment are provided for free, balanced with prevention activities. However, this combination of care and prevention is not sufficient to explain the success of the programme. Much of the success has been achieved because the government chose to act very early in the epidemic. The essential components are:

- The Brazilian government showed **strong political leadership** and mobilised the civil society by forming partnerships with grassroots and non-governmental organisations at all levels to ensure that the HIV and AIDS education and awareness messages would reach traditionally hard-to-reach high risk groups. Action was taken early on in the epidemic.
- Brazil implements a multi-pronged HIV and AIDS **prevention strategy**. Condoms are promoted even while delayed sexual activity is advocated and clean needles are handed out to injection drug users and transmission from the mother to the baby is being prevented and blood transfusions are done in a safe manner.
- Universal access to free ARV therapy in Brazil was made possible through a combination of locally manufactured drug supplies and lower negotiated prices for those drugs still under patent protection. It has also threatened compulsory licensing.

To do the above, in 1997, Brazil's public health system was revamped. Part of the programme included healthcare capacity building programmes conducted at various levels. In addition to building the physical infrastructure and systems required for treatment of HIV and AIDS, Brazil trained its healthcare workers to diagnose and treat HIV and AIDS and related opportunistic infections.

As a result of this comprehensive program, the HIV prevalence rate in Brazil has halved and AIDS death rates have dropped 60-80%, mitigating the impact of the epidemic on society, opportunistic infections have dropped significantly, decreasing healthcare expenditures, the incidence of TB has been reduced by 80%, and there has been a seven-fold reduction in hospital admissions. In addition to the value of these health benefits on individuals and on the Brazilian society, the Brazilian government estimates that their comprehensive HIV and AIDS program has produced actual financial savings of more than 2.2 billion USD over 5 years in reduced hospital and ambulatory care costs. While the epidemic has not been halted yet in Brazil, data suggest that it may be manageable now. Brazil's success can be an example for other countries.

Source: 'Brazil: The Success Story' by Marie Charles, MD, MIA; Columbia University, NY, USA; website www.iceha.org.



The PLWHA are fighting for their survival and their dignity. Their efforts teach lessons for improving quality of life against all odds. The voices and stories of the PLWHA in this chapter highlight:

- The need for collective action
- The need for assertion of our right to self-determination
- The need to innovate in each context, making maximum use of all available resources and

opportunities while constantly striving to expand them

• The need for comprehensive approaches incorporating issues of livelihood, food security, social relationships, and health care.

It is the responsibility of nations to recognize the voices of despair, of courage and hope of people living with HIV and AIDS highlighted in this chapter. This responsibility should lead to actions that promote and uphold the rights of PLWHA. It is in the interest of nations, communities and individuals to learn lessons from the struggles of PLWHA and develop systems that can provide comprehensive treatment, care and support to those affected by it.

# Charter of Demands for PLWHA

'This Charter has emerged out of ActionAid India's work with MILANA. We Demand, the Right to Inclusion, Right to Access to Comprehensive Care and, Right to a Dignified Life.'

## We All Say

'We want acceptance, understanding, and the removal of discrimination and stigma at all levels. Effective policy and decision making will help make that happen.'

'We want access to care and treatment for all opportunistic illnesses for PLWHA. We want free ARV treatment followed by supplements in nutrition. We deserve adequate care and support centres and groups for infected individuals, orphaned children, grandparents, and affected families.'

'We want access to more information on HIV and AIDS, and the opportunities to develop our capacities and skills so that we can help ourselves economically and socially, and live a positive life with dignity'

#### Women Say

'We face a unique set of problems as HIV positive women in Asian society. We want access to care, treatment, and support services as PLWHA who are individuals, mothers, wives, sisters, and daughters struggling to meet our ends in this patriarchal society.'

'We want a voice in policy and decision making so that we are not forgotten, so that we are considered when programmes and policies affecting PLWHA are being developed.'

'We do not always have the opportunity to be financially

independent and secure. We are forced to rely on our families or husbands, and if they become ill, desert or abuse us, we must find a way to sustain our children and ourselves. Thus we want opportunities to develop our education, capacities and skills, and chances to generate an income.'

### Children Say

'We want to have lots of friends.... we want to share our fears and dreams with people around us. We want to study, play and laugh with other children in our school. We want to be included in all activities in our school.'

'When we are sick and can't attend school, we hope our teacher will not scold us for being absent. When we fall sick, we want a nice doctor to give us medicines that will make us well soon. We want health food that will make us strong so we won't keep falling sick.'

'We want to know more about our infection and how we got it and why we cannot get children's medicines for this.'

'We want our parents to be with us always.'

As Nelson Mandela said in July 2004, 'In the course of human history, there has never been a greater challenge than HIV and AIDS. History will surely judge us harshly if we do not respond with all the energy and resources that we can bring...'

In conclusion, HIV and AIDS have to be viewed differently for countries in Asia. 'Normalizing' HIV and AIDS in attitudes and actions, practicing 'social responsibility' in all spheres, and doing 'appropriate knowledge management' are essential components for creating a 'humane governance' that can contribute to HIV and AIDS control that is responsive to the voices of the affected.

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