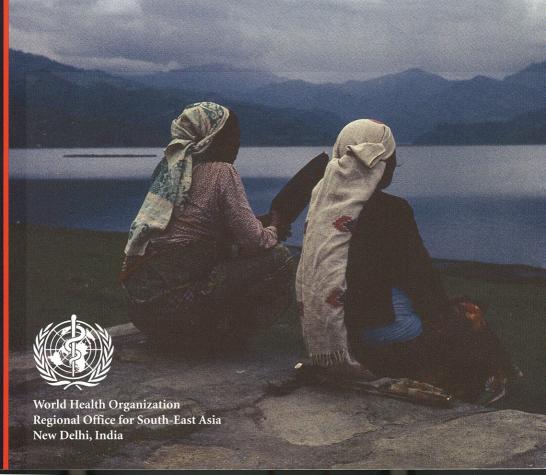
## **BEYOND 2000**

Responding to HIV/AIDS in the new millennium

Heidi J. Larson Jai Prakash Narain



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## Acknowledgements

Several persons have helped us in preparing this document.

Tim Brown and Daniel Tarantola provided valuable technical inputs; Jay Dowle and Karen Reynolds gave considerable editorial assistance; and Saroj Jha, Binod Mahanty and Purushottam Shrestha provided useful technical and editorial suggestions.

We gratefully acknowledge the contributions made by them.

Heidi J. Larson Jai Prakash Narain

June 2001

### **Foreword**

"Beyond 2000 – Responding to HIV/AIDS in the New Millennium" unfolds the story of AIDS in WHO's South-East Asia Region. The document focuses on how the epidemic has grown from a handful of HIV infections reported only from Thailand, in 1984, to over five million by early 2001. An extensively referenced account is also presented of the pattern of transmission, the vulnerabilities of different population groups and documented evidence of the socio-economic and health implications of HIV/AIDS in the Region.

As we step into the new millennium, it is appropriate to reflect on the progress made so far and to learn from the past as we plan for the future.

A number of lessons have been learnt over the last 15 years. The most important is that the control of AIDS calls for intensified multisectoral action backed by strong political support and community participation. The key role of the health sector is also well recognized as crucial to stemming the tide of the epidemic—an epidemic that is sweeping across Asia at a faster pace than anywhere else in the world.

Strategies for the new millennium as proposed in the document describe the approaches that countries of the Region must take if they are serious about slowing down the relentless spread of HIV infection, providing care and support for those infected and affected and alleviating the social and economic impacts of the epidemic. Accelerated efforts are clearly needed to build on what we now know works, to heighten and sustain national responses to the HIV/AIDS epidemic, and to bring about the necessary changes required, in policy as well as practice, without stigma or discrimination.

Dr Uton Muchtar Rafei Regional Director WHO South-East Asia Region

### **Acronyms**

AIDS Acquired Immunodeficiency Syndrome

ANE Asia and Near East

CSW Commercial Sex Worker

DOTS Directly Observed Treatment, Short-course

HIV Human Immunodeficiency Virus

IVDU Intravenous Drug User

NGO Nongovernmental Organization

PWA People With AIDS

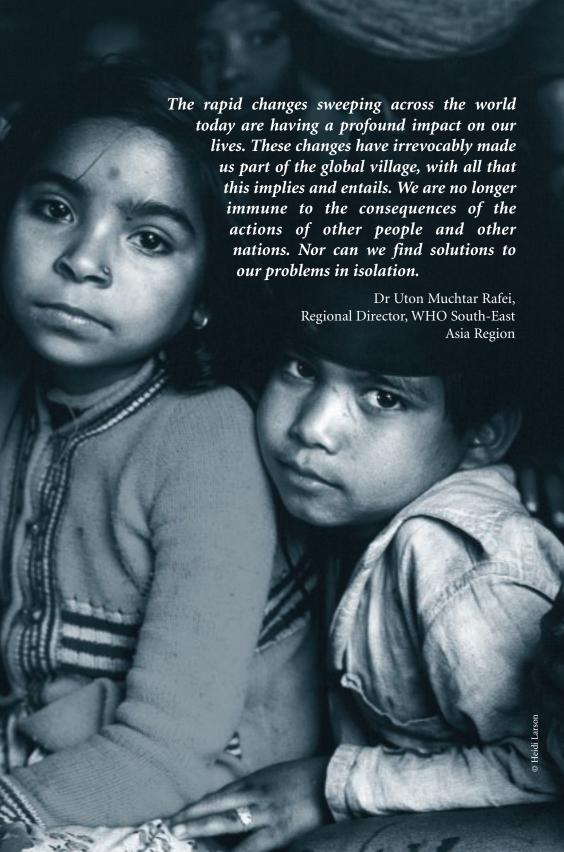
SEARO South-East Asia Regional Office STD Sexually Transmitted Disease STI Sexually Transmitted Infection

UNAIDS Joint United Nations Programme on HIV/AIDS

UNICEF United Nations Children's Fund UNFPA United Nations Population Fund WHO World Health Organization

### CHAPTER 1

# Introduction



Introduction 3

he story of AIDS is the story of an illness that is posing one of the biggest global challenges in the history of public health.

Three decades into the epidemic, there is still no vaccine and no "cure" for AIDS, the Acquired Immunodeficiency Syndrome. There is considerably more information available on how the Human Immunodeficiency Virus (HIV) which leads to AIDS, is spread, a wealth of "lessons learned" in implementing prevention strategies, and increased understanding about what constitutes effective treatment and care. The social and economic conditions that facilitate the spread of HIV are also well understood. Despite all we know, risk behaviour and risk environments persist and HIV continues to spread among individuals and across national and regional borders, the latest frontier being Asia\*.

With nearly six million people already infected in WHO's South-East Asia Region, the potential health and socio-economic impacts of AIDS in the new millennium is cause for serious concern. There is a compelling need to chalk out well-designed and effective strategies that will halt the spread of HIV and reduce the impacts of the epidemic in the Region. The challenges that face us are enormous. To address these, a more holistic approach to HIV/AIDS prevention and care is urgently called for.

The HIV/AIDS epidemic is deeply entrenched in several Asian countries in numbers that are escalating fast.<sup>12</sup> While Africa remains the worst hit region in the world, the rate of increase in the numbers of HIV infections is even higher in Asia. With more than 60 percent of the world's population, the Asian region needs prompt concerted action to avert the potential social and economic consequences of a more widespread epidemic.

While community-based responses to HIV and AIDS are still acknowledged as being the most effective means to change behaviour, supportive social, political and economic environments are also crucial to sustaining action at a community level. And, it is not just the socio-economic and political stage set at a national level that matter; policies and agreements made at intercountry and regional levels are critical to an effective response.

AIDS has not only crossed geographic borders around the world and within Asia, the epidemic has also challenged traditional cultural boundaries. Effective prevention involves address-

<sup>\*</sup>While "Asia" is used throughout the text, the key countries addressed are those covered by the WHO South East Asia Regional Office(SEARO): Bangladesh, Bhutan, DPRKorea, India, Indonesia, Maldives, Myanmar, Nepal, Sri Lanka and Thailand.

4 Introduction

ing traditional "taboo" areas in many cultures. Discussing sensitive issues around sexuality – critical to effective AIDS education – requires a change of traditional "cultures of silence" so that people can more openly talk about sex.

Due to the early association of HIV and AIDS with commercial sex, drugs and men having sex with men, the disease has also acquired a stigma that has been difficult to overcome. Those infected and affected by HIV and AIDS have faced discrimination and alienation. The early uncertainty about how HIV was spread and knowledge that it is a fatal illness with no currently available cure created considerable fear and consequent alienation of people living with HIV and AIDS as well as their close family members.

Today, the modes of transmission are clear. There is no mystery as to how AIDS is spread and the means to prevent transmission are well understood. It is the will to use the information that challenges us. With individual and collective vision and commitment, it is within our means to prevent further transmission, provide appropriate care for the infected and alleviate the impact of the AIDS epidemic. It is time to cross the borders laid by misinformation, fear and stigma in order to break down traditional "cultures of silence" around sexuality and take proactive, sensible and effective measures which can have significant socio-economic implications for the countries, cultures and communities in South and South-East Asia.

Beyond 2000 discusses the status and trends of the epidemic in South and South-East Asia; it looks at particular areas of vulnerability to the epidemic as well as potential impacts; and finally, based on lessons learnt at local, national and international levels, the concluding chapter sets out challenges and strategies to consider for the new millennium.

### CHAPTER 2

An
Overview
of the
Epidemic in
South-East
Asia

### 2.1 The global context

HO and UNAIDS estimate that at the end of 2000, 36.1 million people around the world were living with HIV – 2.5 million more than at the end of the previous year. During 2000, it was estimated that there were 5.4 million new HIV infections and 2.8 million deaths due to HIV/AIDS. Among the new infections, 600,000 occurred among children under 15 years old and more than 2 million were among women. Over 18 million people have died due to AIDS since the start of the epidemic including 3.6 million children. Nearly 14 million children have become orphans due to AIDS<sup>3</sup>.

The epidemic is now spreading rapidly in Asia, where new infections are increasing faster than anywhere else in the world. AIDS first appeared in South-East Asia in the 1980s. By 1997, over 65,000 cases of AIDS and an estimated 3.75 million HIV-infected persons were reported. By the end of 2000, WHO and UNAIDS estimated that over five million people living with HIV/AIDS in the region and more than 135,000 AIDS cases were reported.

Globally, India has the second highest estimated number of HIV-infected people of any single country, next only to South Africa. On the other hand, Thailand, the first country in Asia to report HIV infection and then experience an explosive epidemic, is now seeing a decline in the number of new infections due to an aggressive multi-sectoral national AIDS programme. The rate of

Figure 1 Adults and children estimated to be living with HIV/AIDS as of end 2000



Total: 36.1 million

Source: UNAIDS, AIDS Epidemic Update: December 2000

Number of cases 1,000,000 100,000 10,000 1,000 100 America 10 Europe 1 0 1989 1983 1985 1987 1979 1981 1993 1995 Year of diagnosis

Figure 2 Trends in reported AIDS cases by region

Source: WHO/SEARO, STD/AIDS and Tuberculosis Unit

HIV infection among all population groups is declining. Among military conscripts, for example, HIV prevalence has decreased from 3.6 percent in 1993 to 2.1 percent in 1996. Even more significantly, new cases of sexually transmitted infections (STI) treated at government clinics in Thailand decreased by 90 percent between 1989 and 1996<sup>5</sup>.

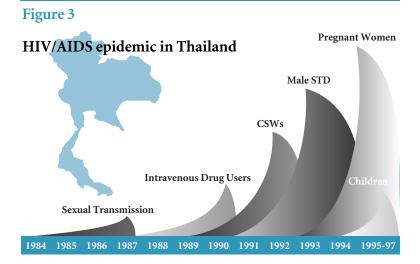
### 2.2 Patterns of transmission

Thailand's thorough monitoring of the epidemic, a model for other countries in the Region, reveals a sequence of "waves" of HIV transmission, which suggests a pattern of infection that other countries may experience.

- ♦ The first wave of the epidemic during the mid-1980s emerged among homosexual men through sexual transmission.
- ♦ The second wave of the epidemic was noted among injecting drug users. Between November 1987 and August 1988, the rate of infection among injecting drug users rose dramatically from 0 to 30 percent. Infection levels finally stabilized by the end of 1988 at 35 percent. In 1989, a national surveillance system was put in place to monitor infection levels

- and assess HIV prevalence among different populations around the country.
- ♦ The third wave of infection was observed among commercial sex workers (CSW). Thirty percent of the CSW population were HIV-positive by the end of 1993.
- ♦ The fourth wave of HIV infection was recorded among male STI patients, largely clients of the commercial sex workers.
- ♦ More recently, the fifth wave was evident from increasing HIV infection among the wives and girlfriends of the CSW clients. During 1994, as high as eight percent of pregnant women in Chiang Mai, Thailand, were HIV-positive.
- Finally, the sixth wave of transmission is now emerging among infants of mothers infected with HIV.

A similar pattern is emerging in parts of India. In Manipur state, the epidemic escalated quickly among injecting drug users. HIV infection among injecting drug users tested for HIV increased from one percent in 1988 to 56 percent in 1995. In 1996, some drug clinics reported HIV rates as high as 73 percent?. Among commercial sex workers in Vellore, HIV rates among sex workers increased from 0.5 percent in 1986 to 34.5 percent in 1990. In Mumbai, HIV infection increased dramatically from one percent in 1986 to 18 percent in 1990 and to 51 percent in 1996. HIV prevalence among STI clinic patients increased dramatically



AIDS AND HIV INFECTIONS IN THE SOUTH-EAST ASIA REGION (as of April 2001)				
Country	Reported AIDS Cases	Estimated HIV Infections among adults	Rate per 100,000 population	
BANGLADESH	17	13,000	16	
BHUTAN	1	<100	<16	
DPR KOREA	0	<100	<1	
INDIA	12,239	3,860,000	386	
INDONESIA	411	52,000	12	
MALDIVES	5	<100	<25	
MYANMAR	3,817	510,000	760	
NEPAL	383	33,000	66	
SRI LANKA	117	7,300	32	
THAILAND	156,309	740,000	1,345	
TOTAL	173,299	~ 5,000,000	>352	

from 2 - 3 percent in 1990 to 36 percent in 1994°. And, HIV infection rates in pregnant women in Mumbai are reported to be 2.5 percent<sup>10</sup> and nearly four percent among pregnant women in Pondicherry<sup>11</sup>. The latest round of sentinel surveillance in 240 sentinel sites in India show rates of HIV of more than 1% among pregnant women in six states, namely, Andhra Pradesh, Karnataka and Kerala, Maharashtra, Manipur, Tamil Nadu.

Myanmar has also experienced waves of transmission similar to Thailand. Injecting drug users were the first to experience a rapid spread of HIV infection. In 1989, 17 percent of injecting drug users were HIV-positive; in 1990 the level rose to 59 percent. By 1991, 71 percent of injecting drug users were infected with HIV. In 1993, the rate peaked at 74.3 percent and by 1996, the rate among injecting drug users was 65.1 percent. HIV rates among commercial sex workers increased from four percent in 1992 to over 20 percent in 1996<sup>12</sup>, while the prevalence among STI patients also rose from 1.9 percent in 1990 to 15.9 percent in 1991<sup>13</sup> and 18.6 percent by 1996<sup>14</sup>. UNAIDS reported in 1997 that two percent of pregnant women in Myanmar were already HIV positive<sup>15</sup>. The significant levels of HIV/AIDS in India, Myanmar

and Thailand mean that these countries are now at an advanced stage of the epidemic<sup>16</sup>.

Although the numbers of HIV and AIDS cases in other South-East Asian countries do not appear as high as India, Myanmar and Thailand, the situation in Indonesia and Nepal particularly among IDUs are causing increasing concern. Many cases go unreported in the Region and many are unaware that they are infected. The general trend in South-East Asia shows a pattern of dramatic increases that highlights the need for urgent action. Between June 1996 and June 1997 alone, the Region reported a 150 percent increase in the number of AIDS cases, and these are only the reported ones.

The Asian epidemic is highly dynamic and evolving. Given that risk behaviours and vulnerability which promote, facilitate and fuel HIV transmission are present virtually in all countries, the potential for further spread is significant. The window of opportunity is rapidly closing and action is urgently needed to stem the rising spread of HIV in Asia.

### CHAPTER 3

# Vulnerability Across Asia

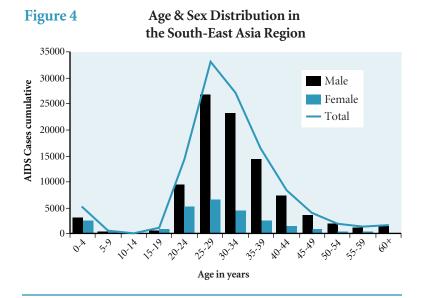
Asia's vulnerability to the spread of HIV is clearly evident, as high-risk sexual behaviour and sharing needles among injecting drug users are well-known modes of HIV transmission. Cultural taboos that surround sexual behaviour and talking about sex in many Asian cultures make information exchange and negotiating safer sexual practices a significant challenge. Poverty and low levels of education also contribute to a lack of awareness about HIV. Finally, highly mobile populations are more likely to engage in risk behaviour and can act as "bridges" transmitting HIV from one population to another.

Many factors can play a role in facilitating the spread of HIV and in determining the severity of a country's epidemic. In an East-West Center Report, AIDS in Asia: The Gathering Storm, three particular factors are identified: "the probability of transmission from one person to another; the size of the populations engaging in risk behaviour; and the rate of partner exchange, referring to either sexual partners or needle-sharing partners17." The probability of transmission is largely indicated by the incidence of sexually transmitted infections (STIs) in the population, ie. a high incidence of STIs means a high probability of HIV transmission from one person to another. This is partly due to the fact that STIs are an indicator of unprotected sex and partly due to the fact that people with STIs are physiologically more vulnerable to HIV transmission than those without STIs. Studies indicate that more than 50 percent of the world's STIs among adults were at one time recorded in South and South-East Asia<sup>18</sup>. Widespread unprotected sex and frequent partner exchange are realities across the Region that must be addressed.

### 3.1 Young people

"In many cultures, shame, fear and denial cloud discussion of the issue and adults to whom young people might naturally turn – parents, teachers, school nurses, community leaders – find it difficult to speak openly about STIs. Unfortunately, when youth finally approach the formal STI care system, they often encounter an obstacle course"19.

Over 50 percent of all new HIV infections occur among young people between 15-24 years old<sup>20</sup>. Nearly 50 percent of the developing world populations consist of young people in their sexually active "prime". Yet, religion and "morality" means they are often



denied access to important information and the sexual health services critical to their health and well-being.

Some young people are living in especially difficult situations, making them even more vulnerable to HIV infection. Those who are out-of-school, living on the streets, sharing needles with other drug users, engaging in commercial sex – sometimes forced into prostitution by their own parents – and those who are sexually abused are at special risk. Interviews and focus groups conducted in and around Bangkok with young people in difficult circumstances, their parents and social workers revealed a strong need for information and interventions<sup>21</sup>.

Young men having sex with men constitutes another marginalized group whose vulnerability is heightened by the lack of information and services available to them and directed to their concerns. Young women are more vulnerable than young men, for both physiological and socio-cultural reasons.

Sexually transmitted infections have significant implications for the vulnerability of young people to HIV. High rates of STIs among young people reveal the high levels of unprotected sex, which puts them at risk for contracting HIV. STIs are most frequent in young people aged 15-24, and 50 per cent of all HIV infections are among young people, most of whom contract HIV before they are 20 years old<sup>22</sup>.

Among those at greatest risk are street children. Some estimates suggest that there are as many as 100 million children and adolescents in the world who are working or living on the street, often in violent and dangerous conditions. These groups are some of the most vulnerable to HIV infection and, of course, to many dangers. For many, sex may be a means of securing money, affection, comfort, shelter or protection. And increasingly, street children are the victims of abuse by adults and those in authority<sup>23</sup>.

Young people are even more reluctant than adults to seek treatment for sexually transmitted infections. Many are embarrassed and fearful that their parents will find out that they are sexually active. Even if treatment for STIs is sought, young people, particularly in developing countries, are less likely to be able to pay for their treatment. Some go to traditional healers or obtain antibiotics from pharmacies without proper diagnosis. Incomplete treatment may alleviate the symptoms, while not curing an STI, which can still be transmitted to others and lead to complications such as infertility and increased vulnerability to HIV infection.

### 3.2 The status of women in the context of HIV/AIDS

Gender inequity, condoned both culturally and socially in parts of Asia, heightens the vulnerability of women and girls at many levels. Unequal access to education means that girls often have less access to important information to protect their health and well being.

Women are in "double jeopardy" as far as HIV is concerned. Not only are they more vulnerable to HIV but they are also caregivers when someone in the family gets infected and develops AIDS.

Cultural mores are more likely to allow men to have multiple sex partners and patronize commercial sex establishments while wives are expected to remain faithful<sup>24</sup>. New trends in the epidemic are revealing that faithful, monogamous wives are now becoming infected when their husbands bring home the virus<sup>25</sup>.

HIV infection among women who are not sex workers is increasing in India, and the likely mode of transmission is these women's husbands, according to a new study. Researchers from India's National AIDS Research Institute, Johns Hopkins University, and the National Institute of Allergy and Infectious

Disease investigated the spread of HIV infection in India. The researchers note that the infection rate among non-sex workers was "disturbingly high", considering their relatively low-risk.

Young girls are especially vulnerable to HIV – physiologically and socially. Physiologically, they are more prone to infection due to the vulnerability of the reproductive tract<sup>26</sup>. HIV transmission from male to female is more frequent than the other way around. Socially, young girls are more vulnerable to violence, abuse and increasingly sought after by older men as they are perceived to be less "risky" and unlikely to carry HIV.

The vulnerability of women to HIV transmission has further implications for the vulnerability of children, who have a significant chance of becoming infected at birth when their mother is HIV-positive. Anti-retroviral treatments can reduce vertical, mother-to-child transmission rates considerably, but in many cases the HIV status of mothers is unknown and such an intervention is not even considered. Another risk factor is breastfeeding. It is estimated that approximately one in five babies born to HIV positive mothers become infected during delivery and one in seven during breastfeeding<sup>27</sup>.

#### 3.3 Sex and HIV/AIDS

Unprotected sexual intercourse, whether men with men or women with men, is the most common way of transmitting HIV. Between 85-90 percent of new infections are transmitted through sexual intercourse<sup>28</sup>. Understanding the sexual behaviour of different sectors of the population is key to designing an effective response to the epidemic. While the commercial sex industry is often thought of as the highest risk area for contracting HIV through sex, a critical place for interventions is in the "bridging" population—the clients of sex workers who are the link or "bridge" for HIV transmission between the sex workers and the general population.

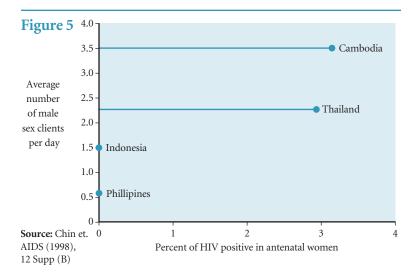
In the context of HIV epidemics, the notion of "bridging" refers to the group of people who connect high risk and low risk populations. Men who have sex with commercial sex workers and also with monogamous wives are an example of a bridging population. The larger the bridging group, the greater the risk of transmission into the general population.

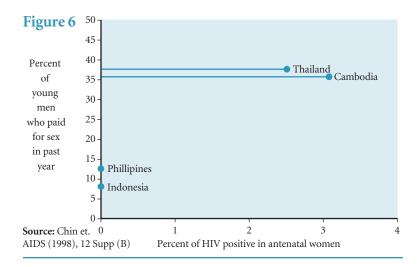
#### Commercial sex work

Across Asia, commercial sex workers are largely young. A survey in three urban areas in Thailand found 40 percent of the low-priced sex workers to be under 18. In two rural villages in northern Thailand, 46 percent and 71 percent of the sex workers started before they were 18 years old<sup>29</sup>. Young sex workers are at particular risk of contracting HIV as their social status makes them less able to negotiate the use of condoms and, biologically, they are more vulnerable to infection. Despite this, young female sex workers are often perceived by clients as being safer than the older sex workers who have been with more partners and are more "risky"<sup>30</sup>.

Many girls are forced into prostitution by their parents at an early age or simply taken advantage of by older men. According to the figures reported at the 1996 World Congress Against Commercial Sexual Exploitation of Children, one million children enter the sex trade every year<sup>31</sup>. In 1992, the Royal Government of Nepal estimated that there were close to 200,000 Nepalese girls and women in Indian brothels. Many young women are abducted or sold by parents, relatives or family friends in whom they had placed their trust<sup>32</sup>.

HIV spreads extensively in populations where the level of sex partner exchange is sufficiently high. The following figures present comparable data for two high HIV prevalence countries in Asia, Cambodia and Thailand and for two low HIV prevalence countries, Indonesia and the Philippines<sup>33</sup>.





#### These figures indicate that:

- (i) in the high prevalence countries, high sex partner exchange rates are combined with a high proportion of males engaging in sex with female sex workers. Conversely, in the low prevalence countries, there is low patronage of commercial sex and corresponding low sex partner exchange;
- (ii) there is a positive correlation between high sex partner exchange rates and high HIV prevalence rates, and
- (iii) HIV prevalence among antenatal women and the percent of young males who paid for commercial sex during the past year are both several times higher in the high prevalence countries than in the low prevalence countries.

While poverty is a key factor driving the commercial sex trade and the trafficking of young women, it is not the sole cause of prostitution in Nepal or anywhere else. Links between the social status of girls and women, growing consumerism, violence and crime and the erosion of traditional values are well recognized<sup>34</sup>.

It is not then merely poverty that drives individuals to become commercial sex workers. Family pressures to provide income, rape or broken marriages that leave women marginalized with few options for other income; and better earnings in the sex trade are all factors that motivate individuals to take up sex work. One study in Bali, Indonesia, revealed that even low-priced sex workers earn considerably more than civil servants. In Thailand, the average wages of massage parlour workers can be nearly 25 times the income of women working in other industries<sup>35</sup>.

The yearly income from farming is usually 2500 baht; while now these families get between 2000 and 5000 baht per month from the boys (working as commercial sex workers) alone. This builds up family expectations; they want a new house, a TV; there is no end to it. Life becomes associated with consumer goods...This is true of female sex workers as well though many of them are sold or forced into prostitution...according to the Director of ACCESS, "Some girls are bonded because their parents receive lump sum money from an agent in exchange of the girl. The family may be paid about 25,000 baht, and the girl has to work till she earns twice that amount.

A girl likes to return home to her village with honour and dignity... In recent times, thanks to the AIDS scare, a girl coming home sooner than expected is presumed to have HIV. If instead she has money, buys land, builds a house, and has cattle or buffalo, then she can go back with dignity"<sup>36</sup>.

These reasons are even more compelling when social systems are inadequate and do not provide needed support to individuals and families. Inadequate social welfare systems, vulnerable individuals and families and economic needs work together to make sex workers even more vulnerable to HIV.

### Sexually transmitted infections and HIV/AIDS

One of the key factors precipitating the spread of HIV is sexually transmitted infection. STI rates not only indicate the extent of unprotected sex, it is now known that an individual with an STI is more vulnerable to contracting HIV than an individual who has no other STIs. Aggressive STI prevention campaigns as well as prompt treatment of STIs are key to preventing the spread of HIV infection. In Bangladesh, for instance, a recent study revealed that 95 percent of the sex workers had contracted genital herpes and 60 percent had syphilis<sup>37</sup> – fertile ground for rapid HIV infection if such levels of STIs are not treated.

Other factors create a "risk" environment that can fuel a widespread epidemic. Certain occupations separate families for long periods of time, such as the military, transportation industry, fishing, and various forms of migrant labour. Workers in these

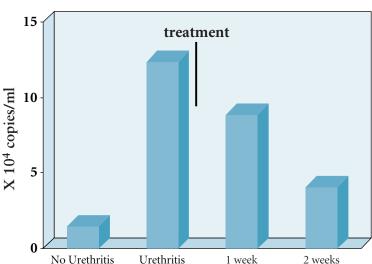


Figure 7 Median concentration of HIV-1RNA in semen among 104 men with and without urethritis (Malawi)

Source: Cohen MS et al - Lancet 1997; 349:1868-73

occupations are more prone to use sex workers and have multiple partners. And, with increasingly open borders in Asia and an economic environment that encourages cross-border relations and trade, aggressive measures need to be taken to prevent the further spread of HIV/AIDS throughout the Region.

#### The correlation between HIV and sexually transmitted infection

- ♦ The predominant mode of transmission of both HIV and other STI agents is sexual, although other routes of transmission for both include blood, blood products, donated organs of issue, and from an infected woman to her foetus or newborn infant.
- ♦ Many of the measures taken for preventing the sexual transmission of HIV and other STI agents are the same, as are the target audiences for these interventions.
- Access to STI clinical services are important for people at high risk of contracting STIs and HIV, not only for diagnosis and treatment but also for education and counselling.

- ♦ There is a strong association between the occurrence of HIV infection and the presence of certain STIs, making early diagnosis and effective treatment of such STIs an important strategy for the prevention of HIV transmission.
- ♦ Trends in STI incidence and prevalence can be useful early indicators of changes in sexual behaviour and are easier to monitor than trends in HIV seroprevalence.

In view of the strong association between HIV/AIDS and STIs, programmes to control HIV/AIDS now also focus on STIs through combined HIV/AIDS and STI programmes<sup>38</sup>.

### 3.4 The challenge of culture

Many dimensions of culture challenge HIV/AIDS prevention. The most commonly acknowledged obstacle – whether real or perceived—is the traditional culture of silence around issues related to sex. In most cultures in the region, sex is not talked about. Various initiatives, particularly among youth, have tried to break the silence and bring issues related to sex and sexuality out in the open, some more successfully than others. According to Dr Uton Muchtar Rafei, Regional Director, WHO South-East Asia Region, "It is most important that we find ways and means of dealing with these issues within the cultural and religious framework of each country."

Another key cultural constraint that challenges the response to the epidemic is an inherent gender imbalance between men and women, girls and boys. Men, for instance, are commonly granted sexual liberties, while women are expected to be faithfully monogamous. Traditional power relations between men and women also make women more vulnerable and less able to articulate their concerns and encourage or, even less-so, demand the use of condoms. Girls' more limited access to education also affects their access to important information about HIV and AIDS.

Traditional belief systems that surround sex and reproduction are also important to consider. Understanding prevalent sexual behaviours is key to designing effective prevention messages and services. Traditional approaches to treating STIs are also important to understand before introducing new approaches. In some cases, working with traditional faith healers may be a valuable strategy for communicating important information and advising on appropriate care to those who need it.

### 3.5 Drugs and HIV/AIDS

Needle sharing among injecting drug users is a high-risk activity that has fueled the spread of HIV and AIDS in a number of Asian countries. In China, the northeastern part of India, Malaysia, Myanmar, Thailand and Viet Nam, for example, the first rapid spread of HIV was among the injecting drug users.

Experience across Asia shows that the epidemic in a country or an area is often heralded by rapid spread of HIV among injecting drug users, who as a matter of camaraderie often like to share injecting equipment, fuelling rapid spread among their group members.

Since drug use is illegal and covert, these high-risk populations are particularly difficult to reach with interventions such as safe needle exchange and prevention education. It is also difficult to make accurate assessments of the extent of HIV<sup>39</sup>. It is clear, however, that injecting drug use and the related risks of HIV transmission is prevalent in all countries in the Region, although varying in scope from one country to the next.

### 3.6 Migration and HIV/AIDS

"Asia's trend toward urbanization and phenomenal economic growth encourages migration, both locally and internationally – and every new migration route is a potential path for HIV transmission..."

AIDS in Asia: The Gathering Storm<sup>40</sup>

Across Asia, borders are opening, new bridges and roads are being built, transportation and communication infrastructures are being strengthened and more people are on the move than ever before. Thailand, one of the wealthiest nations in the Region, is temporary home to nearly one million migrant workers from Cambodia, Lao PDR and Myanmar<sup>41</sup>.

Initiatives such at the "Friendship Bridge," linking Thailand and Lao PDR over the Mekong River, facilitate not only the exchange of people and goods, but unfortunately provide a new route for HIV and AIDS. Bridges and roadways alone do not fuel the epidemic, but research suggests that there is significantly more risk behaviour in border communities which are remote from usual legal and even cultural restrictions<sup>42</sup>.

The extent of this risk behaviour is apparent in the higher HIV prevalence rates in border provinces. In Thailand, HIV preva-

lence rates in border provinces with land crossings is nearly twice as high as in provinces without border access. In mid-1993, HIV prevalence averaged 6.2 percent in provinces with major land crossings, as compared to 3.8 percent in provinces without a land crossing. In 1995, Myanmar's sentinel surveillance also revealed a difference between HIV prevalence in border areas as compared to other areas without a land crossing. Over 15 percent HIV was reported in border areas as compared to less than 10 percent in other sites in Myanmar<sup>43</sup>.

Language barriers are another factor that puts migrants more at risk once they have crossed into a new land. Even those who might have made safe choices and taken precautions to prevent HIV infection may find themselves limited by communication skills in another country and be frustrated by difficult access to local resources and services such as buying condoms and seeking treatment for STIs.

A report on the situation in Merauke, a port city in Indonesia, revealed that the Thai fishermen's behaviour is more risky in Merauke than in the Thai ports, where the fishermen understand the language, the sex workers are mobilized to insist on condom use and condoms are readily available – support which is not available in Merauke<sup>44</sup>.

Some borders connect three or more countries, such as the southwest border of Yunnan, China. Yunnan Province has a border of 4,000 km with Myanmar, Laos and Vietnam and allows for considerable cross-border travel. The area of Yunnan that borders Myanmar hosts a particularly large population of injecting drug users, many of whom have become HIV-positive<sup>45</sup>. The fast growing rates of HIV infection due to IV drug use reported above, reveal a similar trend to the explosive spread of HIV among injecting drug users in Myanmar, discussed in the previous chapter. Such parallel epidemics suggest the extent of cross-border exchange and the crucial need for intercountry collaboration in designing an effective response.

### $\overline{_{ m CHAP}}$ ter 4

Health and Socio-Economic Implications of HIV/AIDS

There is no doubt that the health impacts of HIV and AIDS are severe and need considerable attention—both in providing care and in preventing further transmission.

The experience of the last two decades has demonstrated, though, that the impacts of HIV and AIDS reach far beyond the health sector. Education, employment and human rights are a few of the areas where HIV/AIDS can have a profound impact. This chapter will examine some of the existing and potential impacts of a widespread HIV epidemic in Asia.

#### 4.1 The economics of HIV/AIDS

"HIV is not only a burden on the health status of the nation but is also a major socioeconomic problem because of the loss of work and wages". Mr Salahuddin Yousuf, Minister of Health & Family Welfare, Bangladesh (1996)

A number of direct and indirect costs to individuals as well as to national health systems can emerge as a result of HIV and AIDS. The personal medical care costs of testing for HIV and HIV-related illnesses and treating opportunistic infections such as TB are examples of direct costs to the individual and family. Other costs, such as screening all blood prior to transfusion, public health information and AIDS research, while non-personal, are direct costs to the health system. Care and treatment of opportunistic infections is also a direct cost to the health system. Significant indirect costs also emerge as a result of lost production and incomes due to HIV and AIDS-related illness and death. The largest economic cost of a death due to HIV/AIDS is usually lost income, as those who die from AIDS are generally younger and in their most economically productive years<sup>46</sup>. Less quantifiable, but significant, are the emotional and psychological costs at individual, family and community levels<sup>47</sup>.

The economic impact of the AIDS epidemic is now acknowledged to be most significant at the level of family and community – especially among poor and marginalized groups – rather than at national, macroeconomic levels<sup>48</sup>. Research in Thailand, for example, found that more than half of the households surveyed had reduced their consumption by more than 50 percent to care for a family member with HIV/AIDS, 60 percent had used all of their savings for medical costs, 19 percent had sold property such as land, animals or vehicles, 15 percent had pulled their children

out of school to help at home and 11 percent had borrowed money to pay for medical costs and help maintain household needs. Overall, poor families became even poorer and lower middle-income households became poor ones<sup>49</sup>.

The impacts of HIV and AIDS appear to be more significant in some occupations than others<sup>50</sup>. Transport and fishing, the military, mining and construction are occupations in which workers are away from their family for extended periods of time and more likely to have multiple sex partners, putting them, and eventually their families, at risk of contracting HIV.

While the costs of the epidemic affect everyone, research reveals that poorer households are disproportionately affected both in terms of the likelihood of their being affected by HIV/AIDS and in their ability to cope with the resulting costs. The Thailand Ministry of Public Health reported, for example, that 60 percent of AIDS cases were among low-income labourers and agricultural workers<sup>51</sup>. Poorer households are generally less educated and less informed about HIV prevention, have less access to prevention methods, and have fewer resources to draw from when they are faced with caring for a family member living with HIV/AIDS<sup>52</sup>.

Sociocultural factors also affect a family's ability to care for a sick family member. Extended families, for example, are often better able to manage an illness in the household than nuclear-type families, due to their shared accommodation. The impact of illness on family income also depends on the nature of employment. Families who are self-employed can share work and cope with the loss of a productive family member more easily than others<sup>53</sup>. The extended family is one of the strengths of the Asian culture, which should be harnessed in both prevention messages and in providing care and compassion.

#### 4.2 Tuberculosis and HIV/AIDS

Globally, eight million people get sick with tuberculosis every year and nearly two million die of the disease. Thirty-eight percent of these cases are in the South-East Asia region with 1.4 million new infectious cases and 700,000 deaths occurring each year. Most of these cases are reported from five countries – Bangladesh, India, Indonesia, Myanmar and Thailand, which together contribute to 95 percent of the total. Between 56 percent and 80 percent of AIDS patients in the Region have TB, making TB the most common opportunistic infection associated with HIV.

One third of the world's population is infected with TB, although the majority of people who become infected with tuberculosis never develop TB disease, as the body naturally fights the TB bacteria which then remains dormant. HIV infection is the single strongest risk factor for TB infection to become active disease. The rate of progression from TB infection to TB disease is 10 to 30 times higher among individuals with HIV and TB than among individuals with only TB<sup>54</sup>.

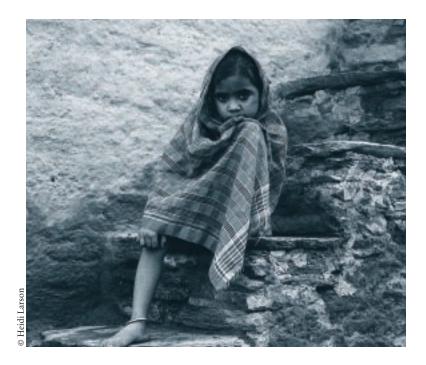
Studies are increasingly showing a close association between HIV and TB, each potentiating the effect of the other. Areas that have reported the highest rates of HIV are also reporting the greatest increases in TB cases. The same age group most affected by AIDS, 25-44 year olds, is also revealing the greatest increase in TB cases. HIV prevalence can also be higher among TB patients than among the general population as seen in Northern Thailand where HIV prevalence in 1994 was as high as 40 percent among TB patients compared to eight percent among antenatal clinic attendees<sup>55</sup>. Similarly, HIV prevalence during that period of time in JJ Hospital in Bombay was 16% among TB patients and 1.4% among pregnant women.

Although not all HIV-infected persons get TB, it is the most common and most important life-threatening opportunistic infection. TB can also accelerate the progression of HIV by accelerating the decline of CD4 counts and creating six-to-seven fold increases in the HIV viral load as compared to those without TB<sup>56</sup>.

The treatment available under the DOTS (Directly Observed Treatment, Short-course) strategy is effective in treating TB among people living with HIV/AIDS. If TB is not treated and cured, one infectious individual can infect an average of 10 to 15 other people per year. Aggressive HIV prevention can also contribute to slowing the spread of TB.

The implications of the dual epidemic for Asia are staggering. With two-thirds of the world's TB cases occurring in the Region and TB remaining the biggest killer of people with HIV and TB, the urgency to control TB in the Region cannot be understated. Aggressive early diagnosis and proper treatment of TB under the DOTS framework is critical to averting a widespread TB epidemic and large numbers of premature deaths.

The impact of the two epidemics (HIV and TB) on resourcepoor countries is already having significant social and medical implications, and already overstretched health services will have



to face a tremendously increasing demand if concerted action is not taken<sup>57</sup>.

### 4.3 The impact on children

By the end of the year 2000, over 13 million children globally will have lost their mother or both parents to AIDS, and 10.4 million of them will still be under the age of 15<sup>58</sup>.

In addition to the risks of children contracting HIV from an infected mother either at birth or through breastfeeding, or due to sexual exploitation during adolescence, the impact of HIV on uninfected children is also significant. Given the nature of HIV transmission, children risk losing both parents once one becomes infected with HIV. This increases the number of dependent orphans in families and communities already stressed by limited resources, compounded by the fact that those with HIV/AIDS are often the family members in their most productive years.

Resources available for basic health care, food and education are considerably more limited in families who have lost a family member to AIDS or who are caring for someone with HIV/AIDS.

In addition to the financial burden of caring for a family member with recurrent illness, the time available for basic household maintenance, cooking and childcare is reduced to take care of the ill family member. In these situations, children are also at increased risk of becoming malnourished.

In many cases, children are taken out of school in order to help care for a sick family member or help in a family business due to a parent's illness. Sometimes children of HIV-affected families feel forced to leave school because they are ostracized by their peers. Sometimes families can no longer afford even minimal school fees, books and transport needed for children to be able to go to school. Deprived of education, children's future employment opportunities are more limited, making them even more vulnerable to high-risk activities. With increased medical costs and decreased family income and resources due to parents' illness and death, children affected by HIV/AIDS are often forced to take to the streets and engage in unsafe behaviours to survive.

All children under the age of 18 living in today's world – whether they are themselves infected with HIV, affected by AIDS in their households or communities, or living in the shadow of HIV risk – are recognized by the United Nations Convention on the Rights of the Child.

The United Nations Convention on the Rights of the Child in the context of HIV/AIDS has outlined principles for reducing children's vulnerability to infection and for protecting children from discrimination because of their real or perceived HIV/AIDS status. This human rights framework can be used by governments to ensure that the best interests of children with regard to HIV/AIDS are promoted and addressed.

### The United Nations Convention on the Rights of the Child in the context of HIV/AIDS<sup>59</sup>

- ♦ Children's right to life, survival and development should be guaranteed.
- ♦ The civil rights and freedoms of children should be respected, with emphasis on removing policies which may result in children being separated from their parents or families.
- Children should have access to HIV/AIDS prevention education, information, and to the means of prevention.

Measures should be taken to remove social, cultural, political or religious barriers that block children's access to these.

- ♦ Children's right to confidentiality and privacy in regard to their HIV status should be recognized. This includes the recognition that HIV testing should be voluntary and done with the informed consent of the person involved which should be obtained in the context of pre-test counselling. If children's legal guardians are involved, they should pay due regard to the child's view, if the child is of an age or maturity to have such views.
- All children should receive adequate treatment and care for HIV/AIDS, including those children for whom this may require additional costs because of their circumstances, such as orphans.
- ♦ States should include HIV/AIDS as a disability, if disability laws exist, to strengthen the protection of people living with HIV/AIDS against discrimination.
- ♦ Children should have access to health care services and programmes, and barriers to access encountered by especially vulnerable groups should be removed.
- ♦ Children should have access to social benefits, including social security and social insurance.
- ♦ Children should enjoy adequate standards of living.
- ♦ Children should have access to HIV/AIDS prevention education and information both in school and out of school, irrespective of their HIV/AIDS status.
- ♦ No discrimination should be suffered by children in leisure, recreational, sport, and cultural activities because of their HIV/AIDS status.
- ♦ Special measures should be taken by governments to prevent and minimize the impact of HIV/AIDS caused by trafficking, forced prostitution, sexual exploitation, inability to negotiate safe sex, sexual abuse, use of injecting drugs, and harmful traditional practices.

#### 4.3 Stigma and discrimination

The single most startling finding is that a high proportion of respondents have been at the receiving end of violence, apparently as a result of their sero-status – in the homes, in the community and elsewhere<sup>60</sup>.

Research throughout Asia reveals disturbing levels of discrimination in healthcare settings, workplaces and schools as well as in the neighbourhoods and communities of those living with or affected by HIV and AIDS. In a study conducted in India, 100 percent of the respondents said that they experienced discrimination in healthcare facilities once the diagnosis was confirmed. A further 37 percent noted workplace discrimination leading to financial difficulties<sup>61</sup>.

Discrimination extends beyond the level of social stigma and its emotional impact. In Thailand, one study found that households with an HIV-positive family member faced discrimination at many levels. Family businesses were not patronized, children of HIV infected parents were avoided and discrimination towards those related to a family affected by HIV and AIDS persisted beyond the death of the family member<sup>62</sup>.

While attitudes may be changing, albeit slowly, families are losing income because of discrimination and children are losing important years of education. A Provincial Health Office in northern Thailand noted that although there is compassion for those living with AIDS, discrimination persists in the workplace and at school because of fear and lack of information about the ways HIV is spread<sup>63</sup>. If such discrimination persists in a country with a relatively successful national AIDS programme and widespread awareness about HIV, the potential levels of discrimination in other countries in the region who are just starting to realize the extent of their epidemic is of serious concern.

## CHAPTER 5

# What Have We Learned?

IV/AIDS came late to Asia, compared to the rest of the world. But it has spread rapidly, especially in parts of India, Myanmar and Thailand.

Shaken out of its early years of almost complete denial and complacency, the Region rallied to establish national AIDS programmes, adopt rational strategies and launch innovative interventions to prevent the spread of HIV and care for those infected.

Of the several lessons learned from the experiences gained over the last decade, the following are highlighted:

#### 5.1 Political Mobilization is critical

One of the biggest lessons learnt, globally, as well as in the South-East Asia Region, is that national responses should not wait for HIV and AIDS cases to soar. Policies should not be delayed at a time when crucial prevention and care information and services are needed. Sometimes, prompt practical responses to the epidemic can actually mobilize policy-making.

#### **Prevention Works**

Lessons learnt from the countries of the region, reveal the following critical components of a national response:

- 1. Respond quickly to the HIV pandemic, mobilizing all sectors and all echelons of government;
- 2. Recognize and collaborate with NGOs and the private sector;
- 3. Involve vulnerable groups, including people living with HIV and AIDS, at every step of the policy and programme development and implementation;
- 4. Recognize the realities of sexual and drug-using behaviours that are likely to be much more prevalent in the current economic climate in Asia, and provide supportive social and legal environments that allow those at risk to access information, counselling, treatment (STIs and HIV/AIDS related illnesses) and means to adopt safer behaviour;
- 5. Extend information and education on sexuality, reproductive health and prevention of STIs and HIV to young people in and out of school BEFORE they become sexually active.

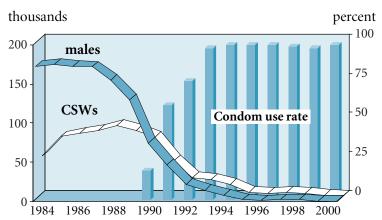


Figure 8 Number of STD cases and condom use rate among males & CSW (1984-2000)

HIV is particularly fuelled by situations of injustice and poverty and its impacts are felt well beyond the health sector. Another important lesson learnt is that a multisectoral response must be designed in the context of an overall development strategy to ensure its sustainability and effectiveness.

Thailand drafted its first national plan in 1987 and a three-year medium term plan (the first in Asia) in 1988. The Ministry of Public Health coordinated the implementation of the plan through the existing health care system. One of the successes of the Thai national programme is that it had the advantage of an already well-established and functioning STI surveillance and service delivery infrastructure which it could build on. However, the national programme was limited compared to the scale of the quickly growing epidemic.

True political mobilization in Thailand came in 1991 when the Prime Minister took over the chairmanship of the National Committee on AIDS and all ministries became actively involved. Funds allocated by the government increased 17-fold between 1990 and 1993, and a national AIDS prevention plan (1992-1996) was integrated into the seventh national five-year development plan<sup>64</sup>.

Although a number of activities were catalysed across sectors, a truly coordinated multi-sectoral strategy was not achieved at a national level until later. Only at a provincial level was multi-sec-

## Thailand's 100 percent

The government introduced this innovative programme in 1989, realizing that information alone, while important, would be insufficient to prevent the rapid spread of HIV. It had been observed that sex workers knew about AIDS and wanted their clients to use condoms, but were unable to enforce this. In addition, brothel and bar owners often pressured sex workers to meet their clients' demands—even if it meant not using a condom.

The authorities sought the cooperation of brothel owners, trying to persuade them to have their workers use condoms in all encounters, and if the customer refused, then to withhold services from them. An important part of the programme was to ensure that all owners of sex establishments in a particular area implemented the policy at the same time, so that customers could not threaten to go elsewhere.

Meetings were arranged in each province between health officers, police and local authorities and all sex establishment owners. The owners were educated about the severity of AIDS and the current situation in their province, and were urged to instruct their workers to use condoms, which would be provided by the Ministry of Public Health free of charge. They were also told that condom use would be monitored and that penalties for not complying include temporary or permanent closure of their establishments.

Condom use was monitored through interviews with male clients at STD clinics, collecting information from STD clinics outside the area,

toralism realised and implemented. One lesson learnt was that NGOs should have been "embraced" in the early stages of the programme. Several of the ministries who were allocated AIDS prevention budgets would also have benefited from better guidance in using the funds appropriately as they had no technical capacity or understanding of how they could best contribute to an AIDS prevention programme.

Partnerships are also key to an effective response. Public-private partnerships as well as multi-sectoral partnerships are crucial to effective response and for halting the negative consequences

## **Condom Programme**

monitoring STDs among sex workers, and monitoring the number of condoms provided to each establishment. The results have been highly encouraging. From an average 14 percent condom use among sex workers in 1989, the percentage increased to over 90 percent in 1995 and has remained stable since.

According to Dr. Wiwat Rojanapithayakorn of the Department of Communicable Disease Control, Ministry of Public Health, the 100 percent condom programme has succeeded because it was concentrated on a limited goal to the exclusion of questions of morality or the elimination of prostitution—the use of condoms in commercial sex. "Other countries would do well to consider this aspect when drawing up their own programmes," says Dr. Wiwat. "However, some particularly Thai conditions also contributed to the success, such as the existing strong infrastructure for STD services and the policy of tolerance and monitoring of prostitution." The programme was accompanied by a mass awareness campaign during a period of strong commitment from the Royal Thai Government, both of which were integral to the success of the 100 percent condom programme.

From AIDS Watch, News from WHO South-East Asia Region on STIs and AIDS<sup>65</sup>

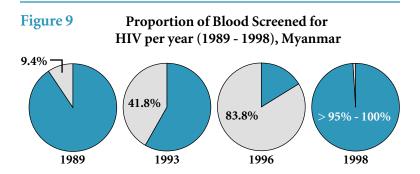
of the epidemic. Examples of successful partnerships and networks are in increasing evidence across the region, although still scattered.

Along Nepal's 435km main highway to India, which carries 80 percent of Nepal's imported goods, a network of local NGOs has mobilized to address high-risk activities along the highway. An NGO called General Welfare Pratisthan conducts outreach activities in collaboration with LALS (Lifesaving and Lifegiving Society) who provides technical assistance and training, including the development of peer education materials.

STI management packages were developed by the Nepal Medical Association and the Nepal Chemists and Druggist Association for syndromic diagnosis and treatment. Family Planning Association of Nepal clinics along the highway offer STI treatment and the Contraceptive Retail Sales Company coordinates social marketing of condoms. Other active partners include New Era, a research institute, which conducts baseline, monitoring and evaluation surveys, and Stimulus (a local advertising firm), which provides media support<sup>66</sup>. The value of a network of services such as these is not determined by the number of partners, it is effective coordination which identifies and capitalizes on the comparatives strengths of partners that has the most impact.

A strong public health infrastructure is essential. A substantial component of AIDS prevention and care relies on strong public health infrastructure in order to mount a more effective health sector response to AIDS. These include early diagnosis and treatment of sexually transmitted infections using the syndrome approach, blood transfusion safety, epidemiological surveillance and research and a continuum of HIV/AIDS care linking health institutions, community and home.

The National Blood Safety Programme in Myanmar which began in 1985, is a good example of a successful strategy to ensure blood safety in the entire country by strengthening the public health infrastructure. The Ministry of Health adopted five strategies to achieve this. These included regular replenishments of HIV test kits, recruitment of voluntary blood donors, referral to major blood banks, timely reporting and research for best practice methods. By 1998, 100% of all blood donated up to township level was screened for HIV<sup>67</sup>.



#### 5.2 Communities must act

Community action results when there is true community participation and community mobilization. The term, "community participation" suggests the involvement of the whole community – an ideal situation, but not always realistic or even feasible. True community participation and mobilization will involve as many different players in the community as possible. Although there will always be diversity within communities, the challenge is to acknowledge the diversity and involve – to whatever extent possible – different sectors, bringing their different strengths and capacities together to achieve a common goal. In this case, the common goal is to prevent further transmission of HIV and provide care, where needed, without discrimination.

What is it about the participation of the community that keeps an initiative alive? One factor is a common language. When the language – verbal or non-verbal – comes from within the community, it is more likely to be understood and accepted. It is, in part, the cultural appropriateness and relevance of the language, but more importantly the use of local "jargon" that wins the ears and response of the community. Communities have a history of common experiences that need to be understood in order to effectively mobilize a response to HIV/AIDS. Communities know their history better than anyone else, and the most effective responses to HIV/AIDS build on "local knowledge".

#### Working with Islamic Leaders in Indonesia

A workshop supported by ANE and UNICEF, resulted in the Bandung Declaration (Nov. 1995) in which the leaders stated their recognition of the AIDS problem and addressed the need to not discriminate unfairly against PWAs, the need to reinforce family resilience and religious values, and the need for Islamic leaders to contribute to HIV/AIDS prevention as part of their religious practice. Islamic leaders at this and other forums have stated their willingness to promote AIDS and STI prevention through an approach based on traditional Islamic values such as chastity or purity, fidelity within marriage, and respect for the body through avoidance of alcohol and drug.

#### **Drug Users Adopt Safer Injecting Practices**

The Lifesaving and Life-giving Society (LALS) of Kathmandu began distributing sterile injecting equipment in exchange for contaminated equipment in 1991 among drug users in Kathmandu. The project began with one community health outreach worker and by 1994 this had increased to eight. Outreach workers also distribute sterile water, condoms and bleach and provide education, counselling and primary health care for clients. Staff are in regular contact with about 750 of an estimated total of 1,500-2,000 injecting drug users in the Kathmandu valley.

By the end of 1994, the project had facilitated 57,734 exchanges, rising from 4,506 (1991) to 30,000 (1994). A total of 48,386 client contacts were reported by the end of 1994: half of which involved syringe exchange and 6847 involved primary health care. Each year a sample of users is interviewed and tested (unlinked). A questionnaire (without any information which might identify clients) is completed by the community health outreach workers.

Findings reveal that HIV is not spreading among those in contact with LALS. Significant changes in self-reported injecting behaviour in relation to HIV occurred between 1991-3. There was more change among those users who had been in contact with the project from the start but change is also noted among those recently recruited to the project. This data suggests that LALS has had significant effect in promoting and supporting safer injecting practices among its clients, with some spread of this effect beyond those in immediate contact with LALS.

What is needed in the prevention of drug use associated with HIV transmission is the will to do those things which are known to work (including needle/syringe exchange and distribution and peer education) and to carry them out early enough and on a sufficient scale to have an impact. Confidentiality, anonymity and a non-judgmental and non-coercive approach are important features of the underlying policy for this kind of work. Once such a project becomes established, clients themselves become a source of support to others.<sup>68</sup>.

#### We understand that community responses need to be at the centre of national responses, but how to best stimulate, encourage, sponsor and sustain these?

There are different starting points for mobilizing communities, and the sequence of events which catalyze one community into action will not necessarily move another. The reality is that, among the "successful" examples of community mobilization, starting points have varied considerably and rarely follow a clear pattern "from start to finish". In some cases, the availability of resources catalyzed a particular group of people to mobilize themselves. In other cases an individual—or a small group of individuals — have mobilized whole communities to action because of some felt need or personal experience. Sometimes, an existing activity has expanded to address HIV/AIDS and an assessment of needs came later.

#### Universities talk AIDS

The first nation-wide AIDS prevention campaign launched in India in 1991 targeted student youth throughout the country. At the time, there were hardly any educational materials available and the information in the press was sensationalized rather than communicating the facts on prevention.

The Department of Youth Affairs and Sports, Ministry of Human Resource Development, initiated the nation-wide campaign using its voluntary student youth programme called the National Service Scheme (NSS). With its 1.1 million student volunteers across 158 universities, 6000 colleges and 2000 secondary schools, NSS was well-placed to reach youth across the country with important information on AIDS prevention.

One key element of the campaign was the participation of youth in the concept formulation, development of educational materials, planning and assessment. The students themselves came up with the theme of the campaign, "Universities Talk AIDS", recognizing that in a traditional society like India where parents, teachers and even text books are tight-lipped on the subject of sex, the first step to break the ice is by talking about the issue.

From a pilot project which focussed on training key NSS coordinators and student volunteers, the campaign went on to make whole colleges "AIDS Aware", and further to integrate AIDS education into the NSS training syllabi and programme curricula. As

the Programme Advisor of the NSS noted about the programme, "There is an information hunger (among students) which we wanted to address"<sup>69</sup>.

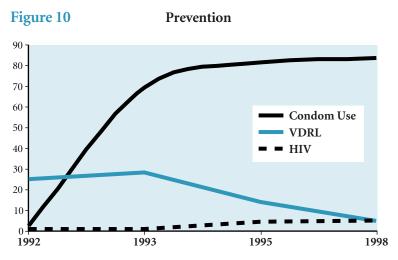
Public events such as drama performances or musical revues, which draw attention to HIV and AIDS, have been valuable in mobilizing communities. While public events and media have been a common starting point for promoting HIV/AIDS prevention and care in communities around the world, individual and personal interaction has also been increasingly recognized as an important means to mobilize community-level responses. Barbers, body builders, housewives, taxi drivers, rickshaw pullers, and seafarers are among a diverse range of networks that have been successful in mobilizing responses to HIV/AIDS. Personalizing communication, as well as making information clear and practical, is key to influencing behaviour change.

#### The Sonagachi Sex Workers Project

The Sonagachi Project targets an established red-light area of Kolkatta where an estimated 4,000 sex workers reside in nearly 370 brothels. In the project, education is delivered through peer outreach, clinical services are provided at a general and STI health clinic in the red-light area, and condoms are distributed by peer educators.

The success of the project has been measured in terms of reduced STI infection, increasing demand for condoms, and the increase in self-esteem among peer educators. The project has addressed a broad range of needs among sex workers including literacy, general health and immunization and has successfully promoted organization and self-help.

The project is based upon the principles of mutual respect and acceptance of sex workers, equality and participation in decision-making. Securing the trust and cooperation of power brokers and organizers of the sex trade have been of critical importance. A flexible and innovative approach to project implementation has contributed to the success of the project and expansion into new areas achieved through cooperation with additional partners. In order to secure clinic space, for instance, negotiations were undertaken with landlords, broker networks, political parties, police, private practitioners and gangsters.



Source: Sonagachi Sex Work Intervention, Calcutta, India

The decision-making structure of the project is multidisciplinary and includes government, NGOs and CBOs which are involved in implementation. Active involvement of CBOs ensures the participation of sex workers in decisionmaking. Decisions are reached by consensus through mutual consultation. Government representatives are committed to democratic functioning and are empathetic and sensitive to the ethos of NGOs.

The intervention is likely to be sustainable as sex workers are already managing their own activities, including the cooperative and the *Mahila Samanyaya* Committee. There is now growing independence and increased organizational capacity of target groups.

Responsiveness to changing needs—management as well as substantive—is critical to all HIV and AIDS strategies, but particularly relevant to community-level action. A community may be mobilized to spread awareness about HIV/ AIDS at one stage, and then be called upon to provide prevention and care services at other stages. Several experiences have shown that an effective community response may even need to address "felt" needs unrelated to HIV/AIDS in order to reinforce the sense of community critical to the HIV/AIDS response. One community case-study from India, for example, reported "we realized that only if we



took into account the women's own priorities could they develop the confidence and ability to improve their working and living conditions, and so be in a position to achieve better sexual health<sup>71</sup>." Similarly in trying to reach youth, it is important to build rapport with young people by addressing a broad range of their concerns. Issues surrounding sexual health will then be easier to approach. As Donna Kabatesi, the host of a Kampala radio show, Capital Doctor, notes, "Thoughtful youth educators also know that it helps to use a broad-based approach to STI education and counselling that takes other anxieties of young people into account<sup>72</sup>."

A community's experience of mobilizing to address less culturally and socially sensitive causes can be a valuable step to prepare a community to mobilize a response to the more sensitive concerns surrounding HIV/AIDS. Mobilizing for action for needs as basic as safe water, nutrition and employment, have set the stage for effective community responses to HIV/AIDS<sup>73</sup>.

"Initial contact with the community was made through a social worker from another NGO who had worked there earlier...through this person, GAP (Gujarat AIDS Programme) met brothel managers in Surat. Recalling the first meeting, GAP's Director said, 'We made them learn about the disease and asked them what they thought of it. The proposals then came from them. We asked, 'Do you need us or not? Are your children getting proper education? Do you want them to get a proper education? If you are suffering from a disease, do you want to go to a hospital? Do you have a school here? Do your children attend that school?"<sup>74</sup>.

When the India Health Organization's (IHO) field staff entered the red light areas of Mumbai, the community regarded them with distrust. Recalls one doctor, "They used to think we were police people. They were an exploited group, so why should they trust outsiders?" A perspective on the first interactions was provided by a sex worker who is now a peer educator, "When IHO workers first came here, I did not believe they were going to do anything good. I also rejected them saying, 'I don't want anything from you'. But they did not give up coming here and slowly we became friendly. They called me sister or mother and built a relationship. I had not heard these words from society. People only came for sex. This was new."

As one IHO member put it, "We went to them as brothers seeking their welfare and health." Recalled (another) one of them, "Initially they were afraid of us, not wanting of hear of condoms or AIDS... They were suspicious of men. We talked to them hoping to change their attitude. We took the girls' side.

"The delivery of other services such as STI treatment, condoms, counselling, sero-testing, and handling personal problems relating to work and lives of sex workers were thus placed within a larger framework of care and protection just as between siblings"<sup>75</sup>.

Challenges to community participation and mobilization, particularly in response to HIV and AIDS, are vast. The most frequently mentioned are cultural and religious constraints around addressing sensitive issues such as sexual behaviour and the counterproductive attitudes of discrimination and stigma against those with HIV<sup>76</sup>. Perhaps equally daunting, are the competing political agendas and power structures which affect resource allocation and information flow. At another level, an increasingly rec-

ognized challenge to community mobilization is making the transition from the initial start-up phase of an initiative to its ongoing management and resourcing.

"Frontliners found to its cost, like many other voluntary organizations, that the qualities of founders (commitment, enthusiasm, courage and determination) are often not the qualities best-suited to the people needed to lead and manage organizations once they have developed and grown."

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Other challenges, particularly when working with illegal commercial sex work and the drug trade, include the risks which participating in an HIV/AIDS programme might entail for commercial sex workers or injecting drug users who do not want to risk identifying themselves. Commercial sex workers are also likely to be hesitant to change their practice in ways that might affect their income.

There is no one formula for effective community mobilization. If there is a common denominator of all effective mobilization efforts it is a sense of opportunism – of capitalizing on people's energies and commitments, on available resources, and on situations that can help move a group of people – a community – to achieve a common purpose – a shared purposed understood by all.

## CHAPTER 6

## Beyond 2000 – Strategies for the New Millennium

#### 6.1 Challenges still with us

No country in Asia has responded quickly to the HIV/AIDS epidemic. This has been partly due to the slowly emerging nature of the disease and a lack of adequate surveillance, partly out of denial and partly due to competing national and political priorities. All countries have now developed national HIV/AIDS programme plans and have national committees, but the degree of activity and true political mobilization varies considerably across the Region.

Challenges ahead include overcoming the denial, blame, complacency and stigma, some of the biggest obstacles to an effective response. The South-East Asia Region is home to significant levels of high risk behaviours, including multiple sex partners and injecting drug use, which cannot be effectively addressed if they are not acknowledged.

For those who are aware and motivated to seek STI and other health services, including HIV testing and counselling, they are faced with poorly developed primary health care infrastructures in many areas of the Region, and vast segments of the population do not have access to quality health services. As increasing numbers of people living with HIV develop opportunistic infections, health systems will be further strained.

Other infrastructure constraints include weak information systems across the Region. HIV/AIDS surveillance activities, in particular, are yet to expand to provide accurate estimates of the extent of the infection in different geographical areas, the extent of co-infection with tuberculosis, and the prevalence of STIs. There is also a dearth of data on behaviour patterns and on the impact of Information, Education and Communication (IEC) activities.

Finally, political commitment is reflected in formulating legislation and policies with respect to HIV testing, confidentiality, anti-discriminatory practices, condom distribution, partnerships with NGOs and other sectors, dissemination of information through public media, and generally creating supportive — or "enabling" — environments for behaviour change. Resource allocation and training of personnel are seriously inadequate and need to be addressed to sustain effective programmes.

These persisting challenges need urgent attention in order to prevent the further spread of HIV and to provide testing, counselling and quality care for those infected and affected by HIV and AIDS.

#### **6.2 Strategies to consider**

Implementing effective prevention and care programmes calls for the development of feasible, doable and cost-effective strategies. These strategies need support from the highest political levels, from AIDS programme planners and managers, and from communities and individuals in order for them to be effectively implemented.

## Priority strategies for the new millennium could include the following categories:

- 1. Evidence-based planning: intensify surveillance and research;
- 2. Strengthen national capacities for a sustained response to the epidemic —

Enhance political commitment, Develop strong leadership, Strengthen public health infrastructure;

- 3. Heighten and expand community-level responses;
- 4. Build and sustain partnerships for multisectoral action;
- 5. Reduce vulnerability of the poor and the marginalized;
- 6. Create enabling environments for safe behaviour; and
- 7. Ensure access to HIV/AIDS Care and Support.

#### 1. Evidence-based planning: intensify surveillance and research

Good surveillance is essential for any effective HIV/AIDS response. Programmes need to operate from a true knowledge of their situation. Accurate information also serves as a mobilization tool for both resources and action, by keeping the problem up front.

Sound epidemiological surveillance systems are needed not only across the Region but also within each country. The HIV/AIDS epidemic is at different stages in different countries of the Region. Even within each country, there are marked differences in prevalence rates between provinces and districts. Surveillance is essential for determining the geographic spread of HIV infection and for monitoring its trends. Good surveillance also provides a valuable baseline against which to monitor any changes in the direction of the epidemic and to understand the impact of collective interventions. Surveillance data as well as behavioural research provides vital information needed to design a sound and comprehensive HIV/AIDS programme and to mobilize the political and social support and resources needed.

Research into the development of effective vaccines, affordable and effective antiretroviral drugs, microbicides and rapid STI, TB and HIV diagnostic tests are especially relevant and needed.

### 2. Strengthen national capacities for sustained response to the HIV/AIDS epidemic

#### Enhance political commitment

Demonstrated political commitment, leadership and support is vital for an effective HIV/AIDS response. Continued and sustained advocacy is critical to convince policy makers and opinion leaders on the need for clearly stated policies and resources.

In the South-East Asia Region, there are several platforms for effective advocacy activities. Regional associations such as ASEAN and SAARC, meetings of parliamentarians, meetings of health ministers and health secretaries and the annual deliberations of AIDS programme managers, all provide excellent opportunities to address policy makers, legislators, planners, managers and other key officials on the urgent need for well-resourced multi-sectoral HIV/AIDS programmes in their own countries, as well as through intercountry collaboration and cooperation. The role of NGOs in this effort cannot be overstated. Many NGOs in the Region have demonstrated advocacy skills in influencing policy through dialogue and debate on critical ethical and social issues, related to discrimination and fulfillment of human rights.

#### Develop strong leadership

As in the case of most other health programmes, success [or failure] in implementing AIDS control, often depends on the level and quality of leadership provided to the programme. When the

Prime Minister of Thailand took over chairmanship of the National Committee on AIDS in 1991, all ministries became actively involved. Funds allocated by the government increased 17-fold and a national AIDS prevention plan was integrated into the seventh national five-year development plan.

National capacities must be built to advocate for and develop strong leadership in charting bold policies, formulating technically sound and operationally feasible plans, mobilizing resources and launching innovative strategies.

#### Strengthen public health infrastructure

A strong public health infrastructure is essential for mounting an effective health sector response. Early diagnosis and treatment of sexually transmitted infections, blood safety, strong laboratory services, epidemiological surveillance and research and a continuum of care, linking health institutions, the community and the home are all needed in a strengthened health system. Strengthening national capacities for a sustained response to the epidemic will require technical assistance and training at all levels.

HIV/AIDS-related issues cut across various health programmes. Strategies to address HIV/AIDS in the context of other health concerns and at all levels of the health delivery system are essential. Maternal and child health, STI, TB, reproductive health, family planning, blood safety and health education programmes are particularly relevant to HIV/AIDS. As the TB/HIV dual epidemic advances across the region, HIV/AIDS and TB programmes particularly need to work hand-in-hand.

It is now well established that sexually transmitted infections, especially those which cause ulcers, greatly increase the risk of HIV transmission. Strategies to make STI services easily accessible to vulnerable groups, especially to women and adolescent girls, merit high priority. Appropriate and prompt treatment of STIs when symptoms are first reported is crucial. The syndromic approach to STI case management is well accepted throughout the Region. It is cost-effective and particularly relevant in resource-poor settings.

Ensuring blood safety is the responsibility of every government. In the South-East Asia Region, although much progress has been made, HIV infection still occurs due to unsafe blood transfusions. In order to ensure effective and efficient blood transfusions.

sion services, a national blood policy is needed which provides a strategy framework and directions for blood safety.

#### 3. Heighten and expand cost-effective community-level responses

Responsiveness to changing needs – management as well as substantive – is critical to all HIV/AIDS strategies but particularly relevant to community level action.

HIV/AIDS control programmes however well planned and designed at central levels remain ineffective unless they reach out to where people live, work, study and access health and other welfare services, including information services.

To facilitate such outreach, peripheral institutions at district and lower levels must be mobilized to participate fully in the national programme. A decentralized programme that provides districts, communities and the target populations the powers and responsibilities to plan, manage and evaluate their own HIV/AIDS programmes, is both strategically sound and operationally feasible. It also provides greater opportunities for intersectoral collaborations, NGO involvement and for communities to participate for its own welfare. Community participation also means building capacities in communities to advocate and bring about the political, social and economic changes, as well as to improved access to health and information services that will enable them to participate more fully in national efforts.

A community may be mobilized to spread information and education on HIV/AIDS at one stage and then be called on to provide prevention interventions targeted at populations with high-risk behaviour or to provide care services at other stages. Several experiences have shown that an effective community response may even need to address "felt" needs unrelated to HIV/AIDS in order to reinforce the sense of community critical to the HIV/AIDS response<sup>78</sup>.

True community participation and mobilization involve as many different players in the community as possible. There will always be diversity within communities; the challenge is to acknowledge the diversity, involve – to whatever extent possible – different sectors of the community, and, finally, bring the different strengths and capacities together to achieve a common goal – i.e. preventing further transmission of HIV and providing care, where needed, without stigma. Communities have a history of experiences together that need to be understood and learned



from, to effectively respond to HIV/AIDS. And, it is the communities themselves who know their history better than anyone else.

All appropriate educational and communication channels must be used to inform and educate and empower vulnerable groups to take appropriate action to protect themselves and their communities against HIV/AIDS. Improving capacities of communities will also involve leadership training and access to decision-making skills and other resources.

A social mobilization movement that engages peoples participation including those at risk, and which involves all relevant segments of society must begin. Such an approach will through a process of dialogue and negotiation build consensus for mobilizing community action to appropriately respond to the HIV/AIDS epidemic.

#### 4. Build and Sustain Partnerships for Multisectoral Response

"Outside the boundaries of the health sector lie an array of opportunities, sectors and systems, institutions and individuals, as well as organizations engaged in the cause of human development or crucial to it. These are all our potential partners for health"

Dr Uton Muchtar Rafei, WHO Regional Director, South-East Asia Region It is now widely accepted that AIDS is not merely a medical or health problem. It impacts on a broad range of human activity. Its economic, social and security dimensions have far-reaching effects on the dignity and quality of life of people. Given the nature of HIV transmission, which is particularly fuelled in situations of injustice and poverty and with the impacts of HIV and AIDS well beyond the health sector, a well-coordinated multisectoral response is crucial. Government and nongovernmental partnerships as well as partnerships across sectors are urgently needed to halt the negative impacts of the epidemic on human development in the region.

NGOs and the private sector have an equally critical role to play in an effective response. As discussed in the previous chapter, there are numerous examples of community-based responses and "lessons learnt" to draw from. The challenge is to identify appropriate, locally relevant interventions and experienced community based organizations to work with. It is also important to identify community based organizations with local credibility and strong management capacity that may not have experience with HIV/AIDS, but have the willingness and capacity to become involved.

Collaboration and communication among all sectors at a community-level is invaluable. In a background document for the 47th World Health Assembly, whose theme was "Community Action for Health", the importance of "political support" and "empathy with ALL parties concerned" were stressed as key elements "likely to contribute to successful community action"<sup>79</sup>.

"When we went out with the agricultural sector, community development people or the education sector, people paid much more attention. We had a team there to help whatever problem they had. We talked together, worked together, helped together and solved problems together.

"Formerly we did not recognize the importance of collaboration. We thought that we could work by ourselves. When AIDS came we realized that it is impossible to work alone."

Dr. Aree, Phayo Provincial Health Office, Thailand

#### 5. Reduce vulnerabilities of the poor and the marginalized

Poor and marginalized populations are particularly vulnerable to HIV infection. The South-East Asia Region harbours nearly 40% of the worlds poor. In formulating national programmes, the needs of such groups must receive high priority and strategies developed to address those needs. Access to basic health and STI services is crucial along with other HIV/AIDS prevention and care services such as voluntary counselling and testing.

The poor and especially poor women and young people need to be supported to become proactive in seeking and demanding services to protect and promote their health. Policies must be put in place to ensure equitable access to services.

#### 6. Create enabling environments to support behaviour change

HIV/AIDS is not merely a technical challenge. It is also a political and social challenge. Behaviour change will not occur without a significant change in the social and political environment in the wider society. Unequal gender and power relations, taboos on frank and open communications about sex, and stigma and discrimination are particularly significant obstacles to an effective response. If stigma and fear around HIV/AIDS persists, the epidemic will remain hidden. Only clear, candid information about how HIV is and is NOT transmitted will alleviate unnecessary fear and discrimination.

While information is critical to behaviour change, there is substantial evidence to show that information alone is ineffective in changing behaviours. Integrated approaches involving advocacy, education, voluntary counselling and testing, provision of condoms and STI services have met with considerable success. In the South-East Asia Region, the 100% condom use programme in Thailand and the Sonagachi Sex Workers Project in India are examples of how HIV infection and other sexually transmitted infections could decline after the implementation of such integrated approaches. Involving all relevant players in order to create an enabling environment for safer choices, including not just the sex workers, but the brothel owners and local police, was also crucial to the projects' success.

Successful intervention projects have shown quite clearly that when target populations are involved right from the stage of programme planning and across the implementation and evaluation

## Principles for creating supportive environments at the workplace:

- 1. HIV/AIDS screening as part of an assessment of fitness to work is unnecessary and should not be required.
- 2. For persons already in employment, HIV/AIDS screening, whether direct (HIV testing), indirect (assessment of risk behaviour) or asking questions about tests already taken, should not be required.
- 3. Confidentiality regarding all medical information including HIV/AIDS must be maintained.
- 4. There should be no obligation on the employee to inform the employer of his or her HIV/AIDS status.
- 5. Persons in the workplace infected, or perceived to be infected, by HIV/AIDS must be protected from stigmatization and discrimination by co-workers, unions, employers or clients. Information and education are essential to maintain a climate of mutual understanding necessary to ensure this protection.
- 6. Employees and their families should have access to information and educational programmes on HIV/AIDS as well as relevant counselling and appropriate referral.
- 7.HIV-infected employees should not be discriminated against; this means that they should have unreserved access to and receipt of standard social security and occupationally related benefits.
- 8. HIV infection by itself is not associated with any limitation on fitness to work. If fitness to work is impaired by HIV-related illness, reasonable working arrangements should be made.
- 9. HIV infection is not a ground for termination of employment. As with many other illnesses, persons with HIV-related illnesses should be able to work as long as they are medically fit for available and appropriate work.
- 10. In any situation requiring first aid in the workplace, precautions should be taken to reduce the risk of transmission of blood-borne infections, including hepatitis B, and standard precautions will be equally effective against HIV transmission.

stages, the project is more likely to succeed and sustain. The Sonagachi experience is an example of affected populations taking up the responsibility of educating their own community through peer education.

An important lesson learnt is that most of the effective interventions carried out remain confined to a small area. Therefore, urgent and rapid "scaling up" of such interventions, in terms of population coverage, is essential for the programmes to have significant and nation-wide impact.

Other obstacles to creating an enabling environment should also be addressed. Lack of access to preventive measures such as condoms, marginalization of high-risk groups and lack of healthy recreational outlets, including sports facilities for youth, can negate many of the expected outcomes of AIDS programmes. A broad strategy to create a sustainable supportive environment to facilitate behavior change and provide accessible services is essential.

#### 7. Ensure access to HIV/AIDS care and support services

With the rising numbers of people living with HIV and AIDS in the Region, comprehensive care and support is an essential component of any national AIDS programme. HIV prevention and care must go hand in hand. Effective HIV/AIDS programmes will ensure a continuum of care across various levels of the health care system, from hospitals to village health posts and to care given by families in homes and by supportive networks in the community.

#### **Issues Beyond Drugs**

Experience world-wide shows that a combination of three or four anti-retroviral (ARV) drugs including one protease inhibitor, has a powerful effect. It cannot only reduce the number of HIV-associated infections a patient might develop, it can also delay the progression from HIV infection to AIDS and prolong the lives of those with AIDS. However, one major constraint has been cost.

While there is a need to mobilize additional resources for drugs, it is important to consider longer term implications for countries to become self-sufficient, rather than dependent on external resources. The broader issue of generic manufacture and compulsory licensing within TRIPS — Trade Related Aspects of Intellectual Property Rights — must also be considered. Provisions made under TRIPS allow signatory States in the event

of national emergencies, such as the HIV/AIDS epidemic, to pass national laws enabling them to produce or import less expensive versions of internationally patented drugs.

All possibilities and strategies to enhance access to ARV drugs should be explored. For example, governments should look at national policies and make a rational selection of drugs, waive import duties and, most importantly, strengthen health infrastructure for making voluntary counselling and testing (VCT) services available and set up a system for monitoring the rational and appropriate use of these drugs. International organizations in collaboration with drug manufacturers and countries should examine the provision of compulsory licensing of drugs under TRIPS, to make these more responsive to country needs; agree on differential pricing for developing countries; and consider favourably the parallel importation of drugs. Improving access to drugs should be part of a broader strategy to strengthen health services.

Finally, accelerating access to ARVs could help facilitate access to other essential drugs, particularly for HIV-associated infections, such as tuberculosis, pneumonia and diarrhoea, as well as life-saving drugs for malaria. The focus on drugs for persons living with HIV/AIDS should be holistic and not restricted to ARVs. There are many people whose quality of life would be greatly improved if early and adequate treatment was made available for opportunistic infections. ARVs are important and every attempt should be made to increase access to them. However, drugs for opportunistic infections are already within reach and no patient should be denied their right to treatment.

## CHAPTER 7

## Conclusion

s we enter a new millennium, we are still faced with an ever-growing AIDS pandemic. We also have in front of us Lan opportunity to use two decades of global and regional experience to turn the course of the epidemic around. While our understanding about HIV and AIDS and what constitutes an effective response has increased over the past two decade, we are still faced with an ever-growing AIDS pandemic. HIV infection continues to spread, especially among those with high-risk behaviour and among those that are vulnerable, such as women and young people. Bold steps must be taken to honestly acknowledge and address the status of the epidemic, ensure adequate resources and establish needed policies and programmes. Thailand has already demonstrated that it is possible to change the course of the epidemic with a concerted multisectoral national response. Even Thailand, though, is still learning and responding to new challenges as they emerge, such as the increasing spread of HIV among presumably "low risk" housewives. Men who have sex with men is also another area of concern — a forgotten epidemic — that needs further research and response.

There are many borders that need to be crossed to truly address HIV and AIDS. National plans must consider the impact of rural-urban and intra-regional movement of people across geographical borders and provide relevant, understandable information and services. Sectoral borders need to be crossed and the comparative strengths of different sectors mobilized. Age and cultural borders need to be crossed. Young people, who may have been denied information on sexual issues for cultural reasons, must now be given access to critical information that can affect their health and well-being. Young people should also be recognized as key advocates for healthy behaviour and not merely recipients of information. Traditionally sanctioned gender borders limiting women's access to education and information as well as opportunities to express their views need also to be renegotiated in light of the epidemic.

"The AIDS epidemic will not diminish until discrimination, including persistent gender bias and inequity is eliminated. The protection of the rights of girls and women is critical in the context of AIDS, especially their right to set the terms of their own sexual activity, including its safety, and to refuse sex altogether. And the responsibility of boys and men to respect these rights needs strong emphasis"<sup>81</sup>.

It is clear from the many lessons learnt that there is no single strategy or solution that can be used across countries. There are "elements" of success and "tools" that can be gleaned from different country experiences which can contribute to designing effective strategies as we move further into the 21st century. A crucial determinant in the development of appropriate strategies will be the country's thorough understanding of its own problems through a realistic assessment of both the current situation as well as the future trends.

According to the report of the UN Secretary-General reviewing HIV/AIDS "in all its aspects" in preparation for the June 2001 Special Session of the General Assembly on HIV/AIDS:

"Twenty years of fighting the AIDS epidemic have resulted in a growing understanding of what constitutes effective action. Truly effective action is underpinned by the principles set and the lessons learned from the current global and national-level responses".

### Fundamental principles guiding a successful response to HIV/AIDS are:

That gender inequalities fuelling the epidemic must be explicitly addressed;

That prevention methods, life-saving treatments and the results of scientific breakthroughs in prevention and care must be made broadly available on an equitable and affordable basis to all;

That people living with and affected by HIV/AIDS must be actively engaged and supported in their efforts to address the epidemic in communities around the world;

That national Governments working with civil society must provide the leadership and means required to ensure that national and international efforts respond to country and community needs, *and* 

Successful responses are linked to respect for human rights.

One of our greatest challenges is to honour the right to health. We can do this by mobilizing political will and commitment – not merely words of enthusiasm, but true commitments of financial and human resources to national AIDS programmes; by providing technical expertise to support the commitment to health; by addressing issues faced by the poor and other vulnerable groups in the populations; by mobilizing public awareness and

action at all levels; and, by catalyzing legislation and widespread information that ensures non-discrimination of those affected by HIV and AIDS beyond all borders.

"In the vision that I have of the future, I see ethics prevailing, to ensure health as a fundamental right of every citizen of the world, regardless of race, colour, economic or social status."

Dr Uton Muchtar Rafei, Regional Director WHO South-East Asia Region

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