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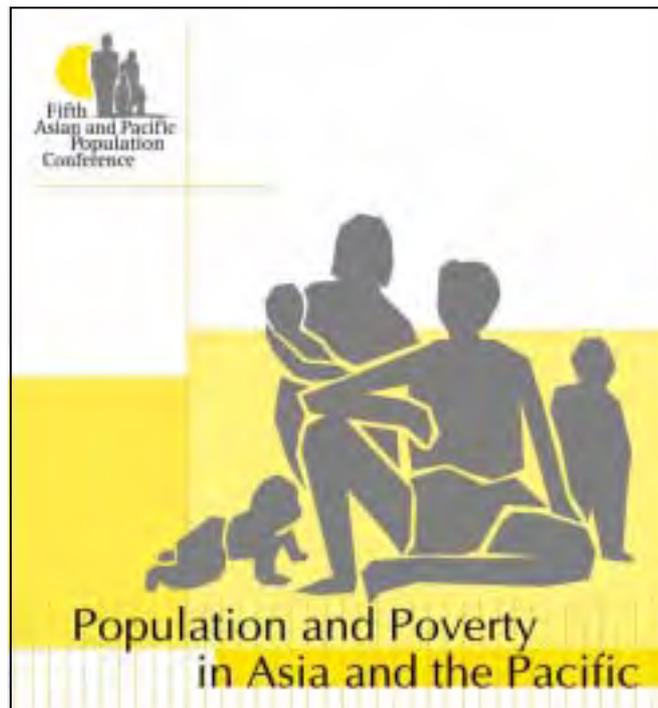
Working Paper on Reproductive Health

**HIV/AIDS PREVENTION, TREATMENT AND CARE:
REGIONAL SITUATION AND ISSUES
FOR CONSIDERATION**

by

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SUMMARY

The paper reviews the HIV/AIDS epidemic situation in the ESCAP region and discusses the existing country programmes dealing with this emerging epidemic. Based on experiences from several countries, especially Thailand where the epidemic has already reached its peak, the paper raises several issues with regard to the prevention, treatment and care. These are some of the challenges requiring urgent action to control the epidemic and to seek more cost-effective management in the implementation of the programmes.

In order to improve the effectiveness of the HIV/AIDS prevention programmes, it is essential that the public be given full and accurate information and knowledge of transmission and prevention, especially those groups that are most at risk. The paper suggests that STDs and HIV treatment services should be integrated into existing primary health services and that new preventive technology be developed to reduce the rate of transmission. Due to substantial movements of population across border, it is essential that greater attention be focused and concerted efforts be made in implementing HIV/AIDS preventive measures to effectively attain the hard-to-reach groups and highly mobile populations. It is especially important that these measures reach illegal migrant workers, including female sex workers who are trafficked across borders, who usually have little access to information, counseling and services. In connection to this, multinational collaborative programme against women and girl child trafficking should be strengthened as another effort towards HIV/AIDS prevention.

The main concerns on the effectiveness of provision of treatment usually centers around issues of coverage of treatment, accessibility to cheaper antiretroviral (ARV) drugs and availability of treatment of people living with HIV/AIDS (PLWHAs). The followings are some considerations deserving special attention.

In many countries, access to medical treatment for AIDS-related illness is still hard to reach for the majority of PLWHAs. More importantly, the availability of affordable ARV drugs to reduce viral loads remains a major obstacle. The challenges for the Governments are to find ways to ensure access to cost-effective prevention and

treatment and to provide non-discriminating health care to cover as many PLWHAs as possible, including infected migrant workers (both legal and illegal). The Governments should find ways to strengthen alternative treatment (herbal treatment, supplement diet, meditation for mental tranquility and other self-care practices) since it has become a necessity for PLWHAs in many societies to become increasingly self-reliant due to their lesser access to modern treatment (ARV and other medical services). In order to reduce mother-to-child transmissions, the provision of AZT (for both mother and child) should be seriously considered by countries where the HIV infections are more prevalent among pregnant women. The voluntary counselling and testing services should be promoted and made widely available. In this regard, NGOs can play a key role in ensuring non-discrimination and respect for human rights. For countries where the clinical trial of HIV candidate vaccine is planned, ethical issues on safety of volunteers and potential social harms must be carefully considered as top priority.

The community, including PLWHAs self-help network, should find ways to reach out and extend the assistance directly or indirectly to the PLWHAs who are living in hiding to have greater access to proper health-care service in a more equal basis. In addition, family and community should be strengthened through various approaches in order to be able to care for the PLWHAs who will become a heavy burden, especially among poor families. The community should learn how to develop a “strong community” and become more independent from outside assistance. The PLWHAs network and NGOs should also be encouraged to involve fully in all activities, from planning to the implementing stages. This principle is known as GIPA or Greater Involvement of People Living with HIV/AIDS. Under the new development of health-care approach, religious institutions and religious leaders in many societies become strong partners in providing care and spiritual supports for PLWHAs and the family in the most difficult time. Therefore, it is essential that these institutions are strengthened and developed to their full capabilities with an acceptable health-care standard to alleviate the burden of the Governments in providing care and support for those who are in need.

The issue of orphans and young children affected by HIV/AIDS deserve much attention since they are in a vulnerable position both in the family and in the community. In this regard, it is important to identify strategies to which the States, NGOs and the

community could extend their help to care for this group of children. Programmes to reduce social stigma and discrimination are also important. In order to provide a more effective family or community-based care programmes, it is recommended that systematic compilation of information and data regarding this issue should be undertaken. Lastly, it is urged to do more research on the “often neglected issue” of psychological care and support, especially among those who are at the terminal stage. The in-depth understanding of this issue would enable the PLWHAs and their families to cope with the life-threatening disease and access a better quality of life.

Introduction

The ESCAP region is home to approximately 62 per cent of the world's population. Since the mid-1980s, the unprecedented increase in the number of cases infected with the human immunodeficiency virus (HIV), which causes the acquired immunodeficiency syndrome (AIDS), in this densely populated region has become a global threat.

The Asian HIV/AIDS pandemic is highly dynamic. The risky behaviour and vulnerability, which promote, fuel and facilitate the rapid transmission of HIV, are present in virtually all countries of the region. Thus, the potential for its further spread is significant (Larson and Narain, 2001). Based on evidence from various sources, behaviours that produce the highest risk of infection in this region are unprotected sex (both heterosexual and homosexual) and needle sharing among intravenous drug users (UNAIDS and World Health Organization, 2001).

In the early 1980s when the HIV/AIDS pandemic was becoming significant in the Western Hemisphere and Africa, only a few cases of HIV infection were reported in Asia. Relatively little attention was paid to HIV/AIDS by the population at large. However, the HIV/AIDS pandemic in Asia took a new turn in the 1990s. WHO estimated that HIV is spreading faster in parts of Asia than in other regions of the world. Some have predicted that the magnitude of the HIV/AIDS pandemic in this region in the twenty-first century could be much worse.

Based on UNAIDS and WHO estimates, at the end of 2001, 40 million adults and children around the world were living with HIV/AIDS. Out of this total number, 6.1 million infected persons were living in South and South-East Asia, while another 1 million were living in East Asia and the Pacific. This made the Asian and Pacific region the worst affected by the epidemic after sub-Saharan Africa where more than 28 million people have been infected (UNAIDS and World Health Organization, 2001). The spread of HIV in Asia is expected to accelerate if Governments fail to act with a sense of urgency, and if preventive action is taken too little or too late. In this regard, the Monitoring the AIDS Pandemic Study has warned that the recent increase in HIV prevalence in specific locations in Asia should be regarded as a serious warning of more widespread epidemics. The Study noted that the low current HIV prevalence rates in parts of Asia do not necessarily signify that these rates will remain low forever (POPLINE, 2001).

Evidence from behavioural studies suggested that the potential exists for substantial expansion of HIV epidemics in many Asian societies. Within the region, parts of South-East Asia have shown a pattern of dramatic increase (Brown, 2002a). The following four countries are considered in the advanced stage of the HIV/AIDS epidemic. India is the most adversely affected country; nearly 4 million HIV infections have been reported. Thailand, the first country in Asia to report HIV infections and to have

experienced an explosive epidemic, has seen a decline in the number of new infections owing to the implementation of a rigorous national AIDS prevention programme; however, about 2 per cent of pregnant women have been found to be HIV-positive. High HIV prevalence levels have been also detected in Cambodia where more than 3 per cent of pregnant women have been found to be infected; a successful intervention programme has somewhat reduced this rate. In Myanmar, where the HIV/AIDS situation is not quite certain, an increase in HIV prevalence has been evident among injecting drug users (IDUs), that is, from 17 per cent of certain groups in 1989 to 65 per cent in 1996. Approximately 20 per cent of commercial sex workers and 2 per cent of pregnant women are reported to be HIV-positive (Larson and Narain, 2001).

The second group of countries in Asia is still in a transitional stage, with recent evidence of rapidly growing HIV prevalence in specific populations and regions. These include China, Indonesia, the Islamic Republic of Iran, Japan, Nepal and Viet Nam. In China, where almost all cases of HIV/AIDS were previously transmitted through IDUs and unsafe blood transfusions, the epidemic is currently spreading through heterosexual contact. In China's Guangxi Province, 9.9 per cent of sex workers were found to be HIV-positive in the second quarter of 2000; by the fourth quarter of that year, the proportion rose to 10.7 per cent. Early UNAIDS and WHO estimates revealed that about 600,000 Chinese were living with HIV/AIDS in 2000. By the end of the following year, the numbers were estimated to exceed 1 million. In Indonesia, infection rates were rising rapidly following a decade of consistently low rates. The infection rates increased rapidly among blood donors, injecting drug users and sex workers. Indonesia has recorded an increase in HIV among sex workers from 6 per cent during the late 1990s to 26 per cent in 2000 in three major centres. In Ho Chi Minh City, Viet Nam, HIV infection rates among certain sex workers increased from virtually nil in 1996 to more than 20 per cent in 2000 (POPLINE, 2001; Brown, 2002a).

The last group of countries and areas, where extensive HIV epidemics have yet to be seen, include Bangladesh; Hong Kong, China; the Lao People's Democratic Republic; the Philippines; and the Republic of Korea (POPLINE, 2000; UNAIDS and WHO, 2001; Brown, 2002a; *Bangkok Post*, 3 July 2002). In the Pacific subregion, only a little information on HIV/AIDS is available. Although some HIV/AIDS cases have been reported to the authorities, the number was thought to be substantially underreported and to provide an incomplete picture of the HIV situation in that subregion. Nevertheless, there is the potential for a rapid transmission of HIV in the Pacific since many States are becoming tourist attractions (Lewis and Bailey, 1992/93).

Overall, the HIV/AIDS situation is serious. As stated during the Fourteenth International AIDS Conference held at Barcelona, Spain during the period 7-12 July 2002, "Asia holds the key to the future of the global epidemic. It is the home to two thirds of humanity and the potential for the spread of HIV in the region is high". This serious

situation calls for much stronger commitment and full participation of the parties concerned at all levels, which include the Government, the community and the family as well as the people living with HIV/AIDS (PLWHAs). The “deep denial” reaction, which still exists among many Governments in the region must be replaced by realism and acceptance of the fact that the rapid spread of HIV/AIDS is a real threat to human society.

Patterns of HIV/AIDS transmission

It has been quite evident that patterns of HIV transmission detected in many Asian countries follow Thailand’s epidemic; HIV transmission was first detected among homosexuals in 1984. Subsequently, the virus emerged among IDUs and later spread rapidly among commercial sex workers. In the mid-1990s, HIV transmission was recorded among the male population who were clients of commercial sex workers, before spreading to their regular partners. At a later stage, the transmission was especially high among pregnant women who transmitted the virus to their foetus or infant children (Weniger and others, 1991). In other countries, including Cambodia, Japan, Malaysia and Myanmar, there have been reports of HIV/AIDS spreading among men having sex with men. Many countries and areas have experienced the rapid spread of HIV through IDUs: Indonesia, Myanmar, Nepal and Thailand as well as India’s Manipur State and China’s Yunnan Province. As mentioned previously, Cambodia and Thailand had earlier experienced very high HIV prevalence rates among commercial sex workers, but this situation later subsided owing to the strong national preventive programme. However, HIV prevalence has been on the rise in many countries, including urban areas of China, India, Indonesia and Viet Nam. Currently, mother-to-child transmission (MTCT) has become a health threat among pregnant women in many Asian countries. This new emerging trend requires urgent action for prevention (Brown, 2002a).

HIV/AIDS prevention programmes

In responding to the HIV/AIDS pandemic during the previous two decades, each country in Asia has developed various intervention measures thought to be appropriate for the country’s social and cultural conditions, and available resources. Control measures implemented in most countries were aimed at reducing risky behaviour (drug injection, unsafe sexual contact, blood transfusion) practised among various target groups, and promoting safe behaviour (clean needle and syringe exchange, condom use as well as health education).

Within the region, Thailand has been praised for its rigorous and comprehensive preventive programmes. Among the many important factors contributing to the effective control and preventive programmes in Thailand has been the Government’s strong and continuous commitment to dealing with HIV/AIDS-related problems. Since the early 1990s, the Prime Minister has assumed chairmanship of the national AIDS Committee in

setting up HIV/AIDS-related policies. In the formulation of national policies during the previous two decades, three different phases of national responses to the HIV/AIDS epidemic (with regard to prevention, treatment and care) have gradually developed and have been actively implemented. Phase I used a health approach to monitor the epidemic's trend, especially among the so-called "risk groups". The health-oriented activities covered case reporting, control of sexually transmitted screening of blood for transfusion, treatment of opportunistic infections, awareness-creation campaigns and health education. Phase II, which used social programmes to deal with the social consequences of the epidemic, involved the public at large in activities such as the establishment of AIDS committees from the national to the grass-roots levels, promoting multisectoral collaboration, organizing a sentinel survey to monitor trends, and intensive campaigning on various preventive measures. Phase III involved efforts to engage civil society and foster community participation as well as build capacity for caring for vulnerable groups affected by HIV/AIDS and their families (Siraprasiri, 2002a).

Thailand has implemented various preventive programmes on a national scale: continuous, large-scale IEC campaigns on prevention; intensive health education; and promotion of the 100 per cent condom use in sex establishments. Various programmes on prevention and control have also been implemented among IDUs. However, the Government continues to be reluctant to implement needle and syringe exchange programmes, a situation which also exists in India, Malaysia and Myanmar. On the other hand, in order to reduce the transmission of HIV from mothers to children, the use of the antiretroviral drug azidothymidine or zidovudine (AZT) has been adopted by State hospitals throughout the country. In addition, other preventive measures have been also carried out, that is, total blood screening, counselling services at reproductive health clinics, anonymous clinics and comprehensive care services for PLWHAs. These preventive measures proved to be quite effective in HIV/AIDS prevention and control in Thailand, as the number of annual new infections was reduced from 143,000 in 1991 to approximately 25,000 in 2001 (*Bangkok Post*, 3 July 2002; Thaineau, 2002). Many of these preventive measures served as examples for many other countries to replicate and implement. The 100 per cent condom programme is especially widely known within the region; Cambodia has also adopted this strategy for prevention.

The success of programme implementation very much depends upon the amount of budget allocated for this purpose. In the case of Thailand, WHO initially allocated \$500,000 to the Thai Government in 1998; later, more funding support was provided by many other international donor agencies. However, the major part of the budget spent on HIV/AIDS prevention measures has been allocated by the Thai Government. For instance, a World Bank study (cited in Poolcharoen and others, 1999) revealed that during the period 1993-1995, Thailand annually spent about \$4.67 per capita for HIV/AIDS prevention and control activities; 72 per cent of that amount was from the Government, 16 per cent from NGOs and 12 per cent from international donors. The Government's

share allocated for these activities has increased over time from 58 per cent in 1998 to 96 per cent in 1997, while donations from outside resources have been declining because of Thailand's relatively advanced economic status (Poolchareon and others, 1999). By contrast, in large parts of Asia and the Pacific prevention programmes are poorly funded largely because many high-risk practices are frowned upon, if not criminalized (UNAIDS and WHO, 2001). Ineffective prevention and control could be one of the reasons for the rapid spread of HIV/AIDS epidemics in various countries of the region.

The negative impacts of HIV/AIDS spread on human well-being have also been strongly felt at the global level. Several attempts have been made to seek solutions. During the period 25-27 June 2001, the United Nations General Assembly Special Session on HIV/AIDS (popularly referred to as UNGASS) adopted the Declaration of Commitment on HIV/AIDS as a joint effort at the global level to fight against the HIV/AIDS pandemic. That Declaration, which states that prevention must be the mainstay of the global response, established a number of time-bound national targets (2003-2010) and various preventive measures, such as efforts to address risk factors, making available a wider range of information, education and communication (IEC) prevention programmes, and offering the public easy access to preventive services. Special focus is given to the young population (aged 15-24), migrants and mobile populations in the most seriously affected countries. The Declaration also calls for a reduction in HIV infection among infants (20 per cent by 2005 and 50 per cent by 2010). Further, the majority of pregnant women should have greater access to information, counselling and other preventive services so as to reduce the mother-to-child transmission rates (United Nations and UNAIDS, 2001).

Issues for consideration regarding prevention

Based on the review of the epidemic situation and experiences of many countries in the region, a number of lessons can be drawn with regard to HIV/AIDS prevention and programme implementation. In addition, there are several issues that need to be taken into consideration for improving the effectiveness of the programmes.

First, for countries where an HIV epidemic has just started, it is essential that full and accurate information and knowledge on routes of transmission and prevention be made known to the public, while avoiding the use of stigmatizing messages. In addition, prevention efforts should move quickly to provide effective coverage of the groups most at risk (Brown, 2002b). Many groups, especially the poor and those who live in the marginal areas, are still at high risk of being infected owing to their limited access to information and services, and their continued risky behaviour.

Second, to improve the prevention and treatment of STDs and HIV/AIDS, three major lines of action should be pursued: integrating STD and HIV services into existing

primary and community-based health services; developing new preventive technologies (female condoms, microbicides); and promoting gender equality in sexual and family relationships (United Nations, 2001a).

Third, for the most effective prevention programme, the country needs to closely monitor epidemic trends in order to be able to quickly adapt preventive programmes to changing transmission patterns. This issue of concern can be well illustrated by the Thai situation. Although Thailand has been successful in reducing new infection cases in recent years through an effective prevention programme, there have been some concerns that the epidemic could break out of its current pattern and spread further unless prevention efforts are adapted to new changes. It has been suggested that Thais remain at high risk of infection as a result of illicit drug injection among methamphetamine addicts and unprotected casual sex among adolescents (*Bangkok Post*, 3 July 2002). It is proposed that, in order to respond to the rapidly changing situation, all current preventive strategies should be carefully and continuously reviewed regarding their effectiveness. New strategies may have to be developed to deal with the changing problems. Additional and concerted efforts in preventing the epidemic will have to be made, while applying best practices among various target groups. Successful preventive strategies should also be scaled up (Siraprasiri, 2002a).

Fourth, movement across borders in Asia has accelerated where many countries share borders. Also, many countries' new economic policies encourage international trade, which usually induces more travel. Tourism is being highly promoted with less restrictive immigration requirements, inviting large numbers of visitors into countries of the region. More people move easily through the new roads and bridges built to link inter-country transportation networks. Among people who are on the move, there are thousands of illegal and unskilled labour migrants. In addition, cross-border movers, both short and long term, are unavoidably exposed to commercial sex services. This link opens the gate wide for the rapid transmission of HIV within and across the region. Such movers could create transmission bridges from borders to larger towns further inland, and accelerate the progress of epidemics. Therefore, it is essential that greater attention and concerted efforts be made in implementing HIV/AIDS preventive measures to effectively reach the hard-to-reach groups, such as highly mobile populations and migrant workers, especially illegal migrants who usually have little access to information, counselling and services.

Fifth, in recent decades, the volume of human trafficking of girls and women in the sex trade across countries within the Asian region and to other continents has been substantial and has become more evident. Vulnerable women movers could well be potential sources of HIV transmission. In order to fight HIV/AIDS across countries, it is therefore necessary for countries in the region to develop much closer collaborative programmes against trafficking in females.

Sixth, in connection with trafficking, some health education and AIDS prevention programmes have proved to be ineffective, especially among sex workers and male clients. It is even more difficult for sex workers who work illegally in foreign countries. Such women are at high risk of contracting HIV, since they have no ability to speak or understand the local language in order to negotiate condom use with foreign clients. In addition, these women have little access to health education and AIDS preventive programmes because of their illegal migration and employment status. Therefore, it is essential that various innovative prevention measures – such as using a non-verbal approach, for instance – be developed for these women to learn about prevention and be able to convince their clients to take measures necessary to protect themselves from being infected.

Seventh, for the effective implementation of preventive programmes, the strong commitment of the Government and sufficient funding invested in the programmes are crucial factors. Good examples can be seen from Cambodia and Thailand where prompt, rigorous and large-scale prevention programmes are holding the epidemics at bay (UNAIDS and WHO, 2001).

Treatment of HIV/AIDS infected persons

With regard to treatment, the UNGASS 2001 Declaration (item 55) recommended that national strategies should strengthen the health-care system while addressing factors affecting the provision of HIV-related drugs (antiretrovirals or ARVs), affordable pricing, and technical and health care capability. All countries are urged to provide the highest standard of treatment for HIV/AIDS (i.e., treatment of opportunistic infection, improve adherence and effective use of quality-controlled ARV therapy). National pharmaceutical policies and practices should be strengthened in order to promote innovation and development of domestic industries consistent with international laws (United Nations and UNAIDS, 2001).

The epidemics in many countries of Asia are now entering a new phase. Several hundred thousand people infected during the explosive start of epidemics are becoming ill and are undergoing treatment. The treatment of infections becomes a great burden for the country concerned, because HIV/AIDS requires long-term and effective medical care, periodical hospital-based care and trained manpower to provide comprehensive health-care services. For countries where resources are scarce, easy access to treatment and care remain very questionable and prohibitive for many PLWHAs.

For Thailand, reported cases of AIDS have increased over the years since the start of the HIV/AIDS epidemic in the mid-1980s. It has been estimated that in 2000 there were 60,000 HIV-infected persons who sought treatment from the health system, the total cost of which was approximately 37,000 million baht (approximately \$925 million). The

estimated direct cost for medical care per person per year was \$1,500. This cost does not include other indirect costs and the cost of antiretroviral drugs, which are not accessible to the large majority of infected persons. Not many PLWHAs can afford to pay for medication out of their own pockets. At the regional level, it has been estimated that the cost of HIV/AIDS treatment for countries in Asia could be as high as 4 per cent of the gross domestic product (GDP). Thus, this substantial financial burden requires well-planned management of funding allocations in order to provide the most effective outcomes (Kunanusont, 2000).

Opportunistic infections such as tuberculosis, pneumocystis carinii pneumonia, or cryptococcal meningitis are the most common illnesses among HIV-infected patients in need of immediate treatment. The medical treatment which is usually provided by hospitals or private clinics covers opportunistic infection treatment and prophylaxis as well as antiretroviral therapy. However, such treatment is not always available or sufficient in many countries. Judging from a 1997 UNAIDS survey of 22 university teaching hospitals (19 in Africa and 3 in Asia), these institutions had suitable diagnostic facilities and the correct drugs to treat only three conditions: pneumonia, pulmonary tuberculosis and oral thrush. For other HIV-related illnesses, the diagnostic capacity and drug supplies were so inadequate that a patient would have less than a 50 per cent chance of being correctly diagnosed and treated (UNAIDS, 2001). In Thailand, access to HIV/AIDS medical care has been made available since the early 1990s, and has gradually shifted to many new therapies over time. For instance, mono-therapy (AZT alone) was provided to PLWHAs during the period 1992-1995. Then, dual therapy (AZT+ddI [didanosine] and AZT+ddC [zalcitabine]) was provided during the period 1995-1996. The HIV Clinical Research Network (dual and triple antiretrovirals (ARVs)) was later implemented during the period 1997-2000. Since 2000, triple ARVs and the means for preventing and treating opportunistic infections have become more accessible. Thailand also set up strategies to expand access to ARVs in 2002 including drug price negotiation, generic drug production, in-house technique development for drug and laboratory tests, capacity-building for health-care personnel, infrastructure improvement and quality assurance, resource mobilization and health-care insurance integration (iraprasiri, 2002b). Currently, Thailand has a policy to provide all pregnant women HIV testing free of cost. If the test is positive, the woman is provided a short, antiretroviral regimen of zidovudine before and after delivery. For the newborn child, AZT syrup and a one-year supply of infant formula are provided to the mother to substitute her breast milk in order to reduce mother-to-child transmission. These therapies, however, are not yet available in most other Asian countries (Brown, 2002b).

The treatment of HIV-infected persons and AIDS patients is becoming more complicated where there is a high prevalence of tuberculosis, an opportunistic infection closely associated with HIV/AIDS. A recent report from WHO ranked Thailand as sixteenth among countries with the highest number of tuberculosis cases; India, China

and Indonesia were ranked as the top three countries plagued with this communicable disease. The situation in Thailand has become more critical during the previous 10 years when those testing positive to tuberculosis increased by 40 per cent. According to the Thai Ministry of Public Health, about 70,000 Thais or 113 per 100,000 population have been diagnosed with tuberculosis; the disease is especially prevalent in the northern and northeastern parts of the country. It has been speculated that the problem stems from an increase in the number of AIDS patients and alien workers (mostly working in fishing industries and farming) from neighbouring countries, especially from Cambodia, the Lao People's Democratic Republic and Myanmar, where tuberculosis is endemic. Bangkok and a few lower central provinces near the Gulf of Thailand are the areas most affected because large numbers of alien immigrants and AIDS patients are located there (*Bangkok Post*, 20 August 2002). It has been reported that the sharp rise in tuberculosis associated with HIV and the high prevalence of pneumocystic carinii pneumonia and other preventable opportunistic infections are clear evidence that many – if not most PLWHAs – are not receiving primary prophylaxis¹, even though these drugs are effective and low in cost (World Bank, 2000).

The very high costs of the ARV therapy programmes in combination with long-term medical treatment (maintenance therapy) have become a major burden on the health systems of most countries, and directly prevent the large majority of PLWHAs from gaining access to treatment. Currently, there are enormous variations in access to antiretrovirals in middle-income countries; in most of Asia, PLWHAs have only limited access to treatment (UNAIDS, 2001). As of July 2002, WHO estimated that in developing countries there were 6 million PLWHAs who urgently required affordable ARV treatment; by contrast, only 230,000 PLWHAs in the same group of countries had access to ARVs. This situation is due mainly to the lack of commitment of the parties concerned to provide life-saving drugs even after affordable ARVs become available (INTAIDS, 2002).

According to the first World Bank report in November 2000 on Thailand's response to HIV/AIDS, Thailand faces the enormous challenges of a severe HIV/AIDS epidemic, despite international recognition for performing well in handling HIV/AIDS problems. The report further stated: "With Thailand's level of income and its strong health infrastructure, it can again show access to treatment of opportunistic infections for people living with HIV/AIDS, both rich and poor". At the same time, the Government should improve access to, and facilitate reduced prices for, combination antiretroviral treatment for patients who can afford it and implement adequate safeguards to minimize inappropriate use of antiretroviral drugs (*Bangkok Post*, 17 September 2000).

¹Primary prophylaxis for opportunistic infections includes preventive therapy initiated when a patient's immune system has been weakened, before the onset of the opportunistic infection. Secondary prophylaxis is preventive therapy against recurrence of an opportunistic infection (World Bank, 2000).

In many countries, large-scale campaigns, protests and negotiations for obtaining cheaper drug prices have been intensively carried out through many different channels in order to help PLWHAs to gain greater access to ARV drugs. For example, in October 2002, some HIV-positive Cambodians demanded access to free antiretroviral medication. An estimated 500 of approximately 169,000 HIV-positive Cambodians are currently able to access free ARVs made available by Medicins Sans Frontieres and other NGOs. If others are to obtain them, they must buy the drugs at market prices, raging from \$150 to \$400 per month, which is prohibitive for the overwhelming majority of patients. PLWHAs in Cambodia live on average only five to seven years owing to the lack of adequate health and medical care; in comparison in neighbouring Thailand, HIV-positive persons may live 10 to 20 years (*Bangkok Post*, 2 October 2002).

The situation of PLWHAs in China is similar to that of Cambodia. The current monthly cost of treatment (\$233-350) is far too high for the vast majority of PLWHAs. At the time of writing this paper, the Chinese Northeast Pharmaceutical Group, which has produced AZT for export since early 2000, is expected to get approval from the Chinese Government to make AZT available to patients in specific AIDS hospitals. Domestically produced AZT could be made available for about a tenth of the price of imported versions (*Bangkok Post*, 17 August 2000).

In early 2002, the Government Pharmaceutical Organization (GPO) of Thailand introduced "GPO-VIR", a locally produced anti-AIDS drug proven effective in cutting viral loads while causing few side-effects. The drug is a combination of three antiviral drugs: stavudine, lamivudine and nevirapine. The drug cocktail costs less than \$30 a month, making it one of the cheapest antiretrovirals in the world. This low-cost drug is expected to relieve the economic burden of AIDS patients and give them greater access to antiretroviral treatments (*Bangkok Post*, 22 March 2002).

In addition to its attempts to produce cheaper ARVs, Thailand has been actively participating in several vaccine development programmes since 1993. Ten clinical trials of HIV candidate vaccines have already been undertaken, and the final results are expected in 2003 (Thaineau, 2002).

It is important to recognize that HIV/AIDS cases are often underreported. Those who do not have access to modern medication and hospital treatment because of economic hardship or their status as alien illegal migrants usually seek alternative treatments and other forms of health care, including herbal medicines, special diets and supplements, and meditation. While PLWHAs may gain some health benefits from alternative treatments, many have been taken advantage of by quacks or self-claimed healers who charge excessively high prices for their treatments. In this regard, the aforementioned World Bank report also suggested that the authorities concerned provide critical information about the costs and benefits of alternative treatment for patients.

Issues for consideration regarding treatment

There are several issues that need to be raised for consideration with regard to the provision of treatment and greater accessibility to cheaper antiretroviral drugs to prolong life and improve the quality of life of PLWHAs.

First, owing to limited resources and lack of trained manpower in health care systems and the weak commitment of Governments in many countries across the region, access to medical treatment for AIDS-related illnesses is not easy. In addition, the availability of affordable ARV drugs to reduce viral loads remains a major obstacle for the majority of PLWHAs. The challenge, therefore, remains for each individual country to expand its efforts to improve access to the means to prevent opportunistic infection and provide adequate treatment for all PLWHAs. The situation is far worse among the poor and unskilled – and often illegal – alien migrant workers who are actively moving in large numbers across borders to countries of destination. Most of these populations are not covered by any national health care programmes. Thus, Governments should adopt strategies that would ensure access to cost-effective prevention and treatment programmes as well as non-discriminating health-care services to assist HIV-positive migrant workers (both legal and illegal), at least on humanitarian grounds without taxing the country's budget.

Second, the previously mentioned alternative treatments have become the treatment of choice for PLWHAs in many countries owing to their inability to access modern, effective treatments. An emerging concern over this issue is determining how these alternative treatments and health-care services can be strengthened so that they become more cost-effective and provide acceptable health-care standard services. An issue is how to manage and guide caregivers (such as traditional or indigenous healers and monks, for example) so that they strictly retain codes of conduct and maintain high moral principles in providing health care services for PLWHAs. Another issue is how PLWHAs and their families seeking alternative treatments could be adequately protected from being taken advantage of by unethical care service providers.

Third, the policy of using short-course AZT for pregnant women and AZT syrup for children, and the use of powdered formula to substitute breast milk to reduce the chances of viral transmission from mother to child proved to be successful in a few countries such as Cambodia and Thailand. Although these programmes may add some burden to the national budget, this means of prevention could well be considered by countries where the HIV infection has become prevalent among pregnant women as a means for controlling the spread of HIV.

Fourth, it has been suggested that voluntary counselling and testing is an important service for identifying those who can benefit from early treatment; thus, these

services should be promoted and made widely available. The aforementioned World Bank report found that, while voluntary counselling and testing is available in Thailand, the service is underutilized. In addition, the quality of counselling services and their links to care programmes has not yet been evaluated. Many PLWHAs discover that they have been infected only when their health begins to fail. Among the reasons for persons not seeking voluntary counselling and testing services are a lack of awareness or knowledge of how HIV can be transmitted and that measures exist to prevent transmission. Another reason could be the probable social stigma and discrimination they may face in revealing their HIV-positive status. In this regard, NGOs could play a key role in promoting non-discrimination and respect for human rights.

Fifth, for a country with a vaccine development programme or where a clinical trial of an HIV candidate vaccine is being considered, ethical issues regarding the safety of the volunteers and the potential for social harm and the violation of human rights must be carefully considered as a top priority.

Care and support²

With regard to care and support, the UNGASS 2001 Declaration (items 56-57) recommended that the country should develop and implement comprehensive care strategies to strengthen family and community-based care, provide and monitor treatment to people living with HIV/AIDS. Working conditions and capacity of health personnel should be improved as well to ensure the effectiveness of supply systems, the referral mechanisms and financing plans. In addition, psychological care for individuals, families and communities needs to be developed and provided (United Nations and UNAIDS, 2001).

The Report on Results of the Eighth United Nations Inquiry among Governments on Population and Development (United Nations, 2001) indicated that a large number of Governments worldwide have adopted measures to promote greater community participation in reproductive health-care services. Eighty-one per cent of Governments reported having undertaken measures to decentralize the management of public health programmes. Eighty-two per cent of Governments have formed partnerships with local NGOs, while 72 per cent of Governments worldwide have formed partnerships with private health-care providers. The inquiry results indicated high recognition of the importance of community participation in the process of providing health care.

² The major part of the discussion in this section has been adapted from “Home and community-based care for persons living with HIV and AIDS in Thailand: Lessons learned and future prospects”, a paper presented by Bhassorn Limanonda at the Fifth International Conference on Home and Community Care for Persons Living with HIV/AIDS, Chiang Mai, Thailand, 11-14 December 2001.

With regard to the HIV/AIDS pandemic, the burden of long-term care for large pools of PLWHAs has grown beyond the capacity of government health-care systems to cope with. Family and community involvement and participation have become the key concept to deal with care issues. Family and community-based care approaches currently are used as an important strategy for AIDS prevention and care in many countries. In this approach, the family and community are considered to be the most important basic social units to share responsibility in handling the consequences of AIDS and care for their own members at the grass-roots level. At the same time, the family and community should develop their own strengths in promoting an understanding and compassion for PLWHAs (Rau, 1994).

Care of a broader scope covers many elements including the following: policy, medical care (treatment of and prophylaxis against opportunistic infections, and antiretrovirals), nursing, laboratory services, pharmacological services, counselling, social support, self-help group activities, home and community-based care, alternative care and health promotion (Siraprapasiri, 2002b). More narrowly, care covers four important dimensions, according to the World Health Organization: medical care, nursing care, counselling services, and social and psychological support. It is believed that these four dimensions could be best carried out at home and in the community.

Family or home-based care offers several advantages over other care provision systems. Economically, home care generally costs less in comparison with hospital care, and places less of a burden on health personnel in caring for chronic symptoms over the long term. Mentally and psychologically, PLWHAs feel much better and are more comfortable when surrounded by their family members, especially at the terminal stage. Socially, family ties and relationships among family members are strengthened while the family is encouraged to take a role and share responsibility in providing care when their own members are ill. Community-based care under the main concept of civil society has been introduced as a key tool to solve AIDS-related problems and to provide care for PLWHAs.

However, it is important to understand that the introduction of family- and community-based care into the existing health-care system does not mean totally transferring all responsibilities or imposing the burden of care to families and the communities. Rather, it involves attempts by the Government to create more involvement of the family and the community in the caring process, and to provide moral support for PLWHAs.

Based on an extensive situation analysis in the four regions of Thailand (Limanonda, 2001), four basic elements have been identified as very important mechanisms in sustaining family and community-based care systems. They include the PLWHAs, the family and community, NGOs and the State or governmental

organizations. A full discussion on these dimensions, illustrating Thai experiences as a case study as well as identifying problems involved in each mechanism, is expected to shed some light on the issue for many other countries which are considering integrating family- and community-based care approaches into their health-care systems.

PLWHAs are the beneficiaries of the system and their potential should be tapped to run community-based care system. PLWHAs are more aware of their own vulnerability and have a much greater stake in the adequacy and appropriateness of the services provided. However, it is important to recognize that the health conditions of PLWHAs include physical, mental and spiritual dimensions and their potential is basically an important qualification that enables them to initiate and carry out activities which are most beneficial to them.

The spread of HIV/AIDS at unprecedented rates in six of the northern provinces of Thailand has forced entire communities to adjust themselves to live with the epidemic in a more harmonious manner. In the early period of the epidemic, the discrimination of the public forced PLWHAs to form self-help groups to support each other. Subsequently, with the full support of various governmental and non-governmental organizations, these self-help groups developed into a well-constructed network where the basic rights of PLWHAs could be protected in order to negotiate for their well-being. Over time, with greater understanding of the public towards HIV/AIDS, PLWHAs have been better accepted and better integrated into the community.

Unlike the situation in the six northern provinces of Thailand, in the central, northeastern and southern regions, there are many conditions that have obstructed or weakened the ability of PLWHAs to form social networks. PLWHAs were unable to reveal themselves owing to strong social stigma and discrimination, since the epidemic in these three regions exploded within a short period of time while the general public was unaware of it and unprepared for it. The situation was worse among illegal migrant workers (in the fishing and rubber industries) who concealed themselves because of their illegal status and inability to access adequate health-care services. Another obstructing condition for social networking among PLWHAs was the high level of mobility among the population (in the northeastern part of the country), or among fishermen (in the southern part) who normally had less education, lived in poorer conditions and had less access to health-care information and services.

The two basic social units, the family and community-based organizations, are believed to play a critical role in responding to AIDS-related problems. The participation or involvement of the family and communities in providing care for sick persons means much for the survival of the new system of caregiving. However, the effectiveness of the family- and community-based care approach depends on many factors, the most critical of which is the readiness of the family and community to cope with their own problems,

such as the burden of care provision, the cost of providing care and medication, the capability of coping with discrimination, the psychological effects associated with the illness and the eventual death of the ill member. Other important factors are regular support and supervision from health-care personnel at various levels as well accurate knowledge and positive attitudes towards HIV/AIDS among community members. To strengthen the ability of families and communities in combating HIV/AIDS, assistance is needed from all the parties involved. For instance, in order to empower the community, the TASO Community Initiative Programme in Uganda helped to identify needs and objectives, train community volunteers to be educators and visit homes to provide counselling and assistance with care, distribute condoms and refer people for HIV testing and medical treatment (as cited in Limanonda, 2001). This approach is widely used in many part of Africa. Thailand also adopted a community-based approach for AIDS prevention, initially setting up the programme in the northern region where the HIV epidemic was most severe.

The family is an important mechanism for shouldering responsibilities as a caregiver for PLWHAs, especially in the community, where the degree of discrimination against the PLWHAs is likely to be high. A study by Saengtienchai and Knodel (2001) well illustrates that providing care to HIV infected family members is a heavy burden, especially when the caregivers are elderly parents who have to care for their young sons or daughters. Care-giving tasks include assistance with the needs of daily living (preparing food, doing laundry, assisting the ill person in eating, dressing, bathing and using the toilet); assistance with health care (monitoring the ill person's current status, accompanying him or her to health service sites, staying with him or her at the hospital, seeking remedies and cures, administering medication at home); and giving moral support (calming the patient, providing encouragement and providing favourite foods). Besides carrying out these heavy tasks, the parents are likely to have gone through substantial stress and strain in care-giving, including those that are emotional, physical, social, financial and time-consuming. In addition, evidence from many places has clearly shown that families have faced a number of problems in providing care for PLWHAs. These problems deserve greater attention, and solutions should be sought to alleviate the burdens of care of the family.

Most families lack basic knowledge and higher understanding about HIV/AIDS prevention, transmission and treatment; yet they are indirectly "forced" to assume the role of caregiver for their ill family member.

Families lack necessary resources for caring, including the ability to buy high-cost medications, basic equipment for caring (such as antiseptic agents, rubber gloves for daily care and cleaning), and do not have sufficient access to a referral system when it is needed.

Families lack information on treatment and good sources of counselling, especially at times when the family and PLWHAs need emotional and spiritual support.

Not much attention has been paid to the needs of family members who act as caregivers, most of whom are women. Such caregivers are also in a vulnerable position since they have to carry out other burdens in the household in addition to providing care for the PLWHAs.

On the other hand, greater involvement of civil society organizations and participation of community-based organizations, such as women's groups, volunteers, religious institutions and religious leaders, self-help groups and members of the community) are considered to be key factors in combating HIV/AIDS epidemics. The question that remains to be answered is how to promote greater participation of the community concerned in caring for PLWHAs.

With regard to NGOs, basically, the role is to coordinate and supplement in order to fill gaps where governmental organizations are unable to provide health care services. Through the strong support of the Thai Government and international organizations, the NGOs working on HIV/AIDS-related problems in that country have increased rapidly from 23 organizations in 1992 to 184 in 1997. The number of AIDS-related programmes and activities also grew from 35 to 247 during the same time period. The national budget allocated to these NGOs also increased dramatically from 11.9 million baht to 90 million baht (Poolchareon and others, 1999).

With regard to State or governmental organizations, in the development of this new health-care approach, the Government should be a very important mechanism in setting up national policies concerning the control and prevention of HIV/AIDS as well as treatment, care and support of PLWHAs in addition to the allocation of the budgets necessary for the development and operation of HIV/AIDS control strategies.

Since the early days of the HIV/AIDS epidemic in Thailand, the Government has attempted to curb the spread of the virus through the declaration of the National AIDS Policy in 1987. Later, the National AIDS Control and Prevention Committee was established, as well as relevant coordinating agencies from the national to the subdistrict levels. Budgets allocated to AIDS programmes and activities have increased exponentially (except for 1997 when the country experienced a financial crisis).

Issues regarding care and support through the family and community

Currently, family- and community-based care has been initiated in many countries as alternative care strategies provided for PLWHAs through the basic concept of civil society and participation of the family and community in caring for their ill members. Based on Thailand's decade-long experience, there are a few issues relating to the operation of this new health care strategy which deserve attention from all the parties concerned.

First, quite a large number of HIV-positive persons still do not want to reveal their identity because of strong social stigma and a high degree of discrimination. The questions are how could the community, PLWHAs self-help groups and HIV/AIDS networks extend their assistance directly or indirectly to those who are in hiding? Is there any channel to enable PLWHAs, without revealing themselves, to have greater access to proper health-care services on a more equal basis with those who already have access?

Second, the HIV/AIDS epidemic is a long-term problem. In the new dimension of care, the family and community as caregivers should be relatively sustained. The main question in this regard is: how can the family and community be prepared or strengthened to be able to care for the PLWHAs, as this task will become a heavy burden, especially among poor families? Therefore, it is essential that the community should have learned how to develop into a “strong community”, and to be more independent from outside assistance. This would be of special value in the future when resources from the Government or other sources are no longer available or become inadequate in covering the costs of caring for the rapidly increasing number of families with PLWHAs.

To reach these objectives, the family and the community should be strengthened or empowered through various approaches, such as learning to be confident in their own wisdom; reorganizing the relationship structure within the family and community in order to encourage the members to think and to work as a group or as network; participating more in problem-solving processes; and learning how to manage or administer the new caring system most effectively within the limits of available local resources.

Third, in connection with the strengthening of the family and the community’s capability to manage their own problems, PLWHAs networks and NGOs as key partners in fighting the epidemic should also be encouraged to become involved fully in all activities from the planning to the implementing stages. This principle is known as “the greater involvement of people living with HIV/AIDS”, or GIPA (UNAIDS, 2001).

Fourth, as in many traditional societies, religious institutions and religious leaders in Thailand appear to play a significant role in providing care and giving spiritual support to PLWHA and their families. Many Buddhist temples or hospices founded by Buddhist monks have become the centre of last resort for ill and dying AIDS patients rejected by their own family or community.

Fifth, the issue of orphans and young children affected by HIV/AIDS deserves attention, since their population group is in a vulnerable position both in the family and in the community. UNAIDS (2001) has estimated that so far the AIDS pandemic has produced 13.2 million orphans worldwide, who before the age of 15 lost either their mother or both parents to AIDS. Although many of these children have died, many more have survived. These HIV/AIDS-affected children usually have difficulties in daily living

in their own community owing to social stigma and various forms of discrimination. They also often lack proper care within the family, especially when both parents died of AIDS.

In this regard, it is important to identify strategies so that the State, NGOs and the community could extend help to care for this group of children. Moreover, national resources may have to be set aside to support homes which provide care for HIV/AIDS-affected babies, orphanages and foundations, as well as day-care centres or even social welfare programmes for children suffering from the effects of HIV/AIDS. Social support is necessary to encourage friendly environments to reduce the social stigma and discrimination against these young children and orphans, and at the same time to integrate them into the mainstream of society so that they could lead a more normal life.

Sixth, the body of knowledge regarding family- and community-based care is generally lacking. No systematic compilation of information for reference or for knowledge-transfer exists. In addition, owing to limited research budgets and manpower constraints most of the research in the area of family- and community-based care for PLWHAs is usually small-scale and location-specific. Hence, the findings are less useful for the development or improvement of the system in general.

Seventh, one aspect of home- and community-based care which is largely neglected by most researchers is psychological care and support which is as important as physical care. Religious and symbolic activities could help to boost the morale of PLWHA, the ill who are at the terminal stage. This kind of spiritual support could be best provided by the family and the community close to PLWHAs.

REFERENCES

Brown, Tim (2002a). "The HIV/AIDS epidemic in Asia", *Asia-Pacific Population & Policy*, April, No. 60.

Brown, Tim (2002b). "HIV/AIDS in Asia", in, *The Future of Population in Asia*, (Honolulu, East-West Center Population and Health Studies).

INTAIDS (2002). "Campaign for more Yen for GFATM", a petition from the Africa-Japan Forum HIV/AIDS Working Group (August).

Kunanusont, Chaiyos (2000). *AIDS: Puzzle, Impacts and Responses in Thailand*, (Bangkok AIDS Division, Ministry of Public Health, J.S. Printing).

Larson, Heidi J. and Jai Prakash Narain (2001). *Beyond 2000: Responding to HIV/AIDS in the New Millennium*, (New Delhi, World Health Organization Regional Office for South-East Asia).

Lewis, Nancy Davis and Jodi Baily (1992/1993). "HIV, international travel and tourism: Global issues and Pacific perspectives", *Asia-Pacific Journal of Health*, vol. 6, No. 3, pp.159-168.

Limanonda, Bhassorn (2001). *Home and Community-based Care for Persons Living with HIV and AIDS in Thailand: Lessons Learned and Future Prospects*, (Nonthaburi, Thailand, Health System Research Institute).

POPLINE (2001). "Widespread HIV epidemic could hit Asia", *POPLINE*, December.

Poolchareon, Wiput and others (1999). *The Evolution of AIDS Control in Thailand: Best Practice for Development of Health Promotion Concept*, (Nonthaburi, Thailand, Health System Research Institute), (in Thai).

Rau, B. (1994). "AIDS and communities: Lessons for policy makers", *AIDScaptions*, Family Health International AIDSCAP Project, vol. 1, No. 2, May.

Saengtienchai, Chanpen and John Knodel (2001). *Parents Providing Care to Adult Sons and Daughters with HIV/AIDS in Thailand: UNAIDS Case Study*, Best Practices Collection, (Geneva, Joint United Nations Programme on HIV/AIDS), November.

Siraprapasiri, Taweessap (2002a). "AIDS prevention and control program", a paper presented at the meeting entitled "Preventive HIV Vaccine: Together We Can", organized by the AIDS Division, Ministry of Public Health, Bangkok, 23-24 August.

Siraprapasiri, Taweessap (2002b). "Care: Policy and strategies", a paper presented at the Workshop on Direction, Policies and Research Progress on Development of Health Technology on AIDS-Related Issues, organized by the AIDS Division, Ministry of Public Health, Bangkok, 15 May.

Thaineau, Vallop (2002). "Policy and direction of HIV vaccine research and development", a paper presented at the meeting entitled "Preventive HIV Vaccine: Together We Can", organized by the AIDS Division, Ministry of Public Health, Bangkok, 23-24 August 2002.

UNAIDS (2001). *Report on the Global HIV/AIDS Epidemic: June 2000*, (Geneva, Joint United Nations Programme on HIV/AIDS), (reprint), April.

UNAIDS and World Health Organization (2001). *AIDS Epidemic Update: December 2001*, (Geneva, Joint United Nations Programme on HIV/AIDS).

United Nations (2001a). *Population, Gender and Development: A Concise Report (ST/ESA/SERA/193)*, (New York, Department of Economic and Social Affairs, United Nations).

United Nations (2001b). Results of the Eighth United Nations Inquiry among Governments on Population and Development, (New York, United Nations), (January).

United Nations and UNAIDS (2001). *Declaration of Commitment on HIV/AIDS: United Nations General Assembly Special Session on HIV/AIDS, 25-27 June 2001*, (New York, United Nations Department of Public Information and Joint United Nations Programme on HIV/AIDS).

Weniger, Bruce and others (1991). "The epidemiology of HIV infection and AIDS in Thailand", *AIDS*, No. 5 (suppl. 2), pp. S71-S85.

World Bank (2000). "Thailand's response to AIDS: Building on success, confronting the future", *Thailand Social Monitor*, November.