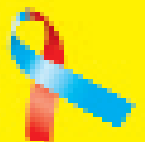




**East Asia:  
Children and HIV/AIDS**

**A call to action**

**UNITE FOR CHILDREN  
UNITE AGAINST AIDS**



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In the best interest of children and to protect their privacy UNICEF does not publish photographs of children who are HIV-positive or otherwise affected by HIV/AIDS except in those cases where the child's identity is protected or where the child and/or the parents/guardians have specifically authorized publication of the photograph.

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This child, who lost her father to AIDS, is one of many supported by UNICEF's children's care project.

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MƯỜI AN CH  
UNICEF

*UNICEF/UNAIDS Goodwill Ambassador Jackie Chan is working to fight against stigma and discrimination against and has called for more to be done to help HIV-affected children.*

# Foreword

HIV/AIDS has left virtually no country, rich or poor, untouched. The East Asia region is already witnessing some of the world's fastest growing HIV epidemics. Progress has been made, and leaders are beginning to match words with action. Yet there is much more to be done. Children are the missing face of AIDS, and failure to take account of their critical needs – be it prevention, treatment or care – will undermine the region's chance of reaching Millennium Development Goals.

HIV/AIDS is redefining the very meaning of childhood, depriving children and young people of care, love and protection of their parents, of information to protect themselves, of education and options for the future, and of protection against exploitation and abuse. All too often, children affected by HIV/AIDS are stigmatized and discriminated against, or slip through existing social welfare systems. And those children who are already infected are missing out on vital treatment and medical care.

The Global Campaign on Children and AIDS seeks to confront these challenges and renew the drive to meet the UNGASS targets as well as those made during the UN Special Session on Children in 2002. By forging a wide-ranging alliance with the governments, international and national partners, along with the civil society, and through leveraging resources, the campaign places children at the heart of the region's HIV/AIDS response, and thus, contributes to East Asia's efforts to scale up the response to HIV/AIDS.

It is fitting that the theme of World AIDS Day in 2005 is "Stop AIDS: Keep the Promise" – a reminder of the unfulfilled pledges we have made to children. With the Global Campaign on Children and AIDS, we have to chance to renew those pledges, and to finally meet them.



Anupama Rao Singh  
Regional Director  
UNICEF East Asia & the Pacific  
Regional Office



Prasada Rao  
Regional Director  
UNAIDS Regional Support Team  
for Asia-Pacific

In the time it will take to read this report, an infant in Cambodia will be infected with HIV through her mother. A girl in China will have lost both her parents to AIDS. Another child in Viet Nam will be forced to quit school and work the streets to support his AIDS-afflicted mother. In Indonesia, a teenage boy will have shot up heroin with a used needle or have had unprotected sex.

# Chapter 1:

## Introduction

HIV/AIDS is a communicable disease that not only threatens sex workers, their clients and drug users. It is a disease that has already devastated the lives of hundreds of thousands of children and adolescents in East Asia<sup>1</sup> and menaces millions more.

More than any other modern-day pandemic, HIV/AIDS insinuates itself into the lives of children through so many different channels and damages them in so many ways. And its effects are long-lasting. Not only does HIV/AIDS claim the lives of children, it is robbing them of their parents, siblings, relatives, friends, teachers, caregivers and other role models. For many children – all too often girls – HIV/AIDS is denying them of their education, their future livelihoods, and their place in society. HIV/AIDS is also exacerbating economic and social disparities, making those who are infected poorer, and marginalizing those who are affected further.

Unless action is taken now, the impact HIV/AIDS is having on children in the region will only worsen.

For now, East Asia has a narrow window of opportunity to halt the spread of HIV. Given the region's enormous populations, despite low national HIV prevalence, large numbers of men, women and children are living with or affected by HIV/AIDS. Even with an average 0.4 per cent prevalence, the number of adults and children newly infected with HIV in Asia was 1.2 million in 2004.<sup>2</sup> An incremental increase in prevalence would result in staggering numbers of HIV-infected adults and children.

But that window is starting to close. East Asia is witnessing some of the fastest-growing epidemics in the world, with the region's overall HIV prevalence rising by 24 per cent in 2004.<sup>3</sup> Many concentrated epidemics in the region, as seen in China, Indonesia and Viet Nam, are changing course rapidly and HIV/AIDS is seeping into the general population. The risk of escalating epidemics also looms over countries that had enjoyed initial success in tackling the disease. In Thailand, complacency is threatening the gains made by a series of comprehensive prevention campaigns in the 1990s that dramatically slowed the rate of HIV infections. Young injecting drug users in Thailand are still contracting the virus in high numbers and only 20-30 per cent of sexually active young Thai people regularly use condoms.<sup>4</sup>

East Asia is also rife with so many of the factors that set the stage for wider epidemics – poverty, ignorance, stigma and discrimination, fast-paced economic and social change, population mobility, trafficking of people and illegal drugs, gender discrimination, natural disasters and resulting displacement, and massive, entrenched sex industries.

East Asian countries now have two options in the face of the growing HIV/AIDS threat.

One is to cling to the status quo, maintain current interventions, and believe that HIV/AIDS will somehow stay put in the fringes of society. And as a result, witness far more than the almost 540,000 AIDS-related deaths recorded in Asia in 2004.<sup>5</sup> The other option is to embrace the tremendous prevention opportunities and step up efforts to confront HIV/AIDS. That means developing programmes that reach high-risk groups more effectively and stamping out deeply rooted stigma and discrimination, which only foster potentially fatal ignorance. An expanded response requires financial resources: In Asia Pacific region the availability of resources is expected to increase from US\$681 million to more than US\$1.6 billion between 2003 and 2006. Yet, spending available resources for HIV/AIDS in the region has been slower than in other parts of the world, even as the epidemic accelerates.<sup>6</sup>



An HIV/AIDS awareness billboard in downtown Ho Chi Minh City, Viet Nam

Above all, this option must place children at the forefront of a comprehensive HIV/AIDS response. It has been proven time and time again throughout East Asia that targeting children and adolescents and allowing them to participate can effect change and reverse trends. Young people grasp the message of prevention quickly given the right support. Surveys show teenage boys in Cambodia are far more likely to use condoms than adult men while male youths in Thailand are less likely to visit sex workers thanks to aggressive prevention initiatives.<sup>7</sup>

By putting children on the agenda, East Asian countries can avert the loss of thousands, if not millions, of lives. Studies estimate that the region can cut its annual AIDS death rate in 2010 by nearly 40 per cent and the total HIV prevalence by more than 40 per cent<sup>8</sup> if it pours more resources and efforts in prevention and treatment campaigns.

Despite the obvious benefits of getting young people involved and the fact that they bear the brunt of the pandemic, their voices and needs are all too often neglected by HIV/AIDS campaigns.

The Global Campaign on Children and AIDS, which is being launched worldwide on 25 October 2005, wants to rectify this omission by putting children back at the centre of the global HIV/AIDS agenda. As part of this campaign, UNICEF and its partners will create an alliance to push for programmes to:

- **Prevent** new infections among young people, particularly girls and women;
- **Prevent** mother-to-child-transmission of HIV;
- **Provide** adequate and appropriate paediatric treatment for children with HIV/AIDS;
- **Protect**, care and support orphans and children affected by HIV/AIDS;

For East Asia, the Global Campaign could not have come at a more critical time. This region's relatively low prevalence is not a sanction for inaction and indifference; it is an opportunity to be seized now. That means stopping children and adolescents from getting infected in the first place and equipping them with the knowledge to protect themselves and future generations.

So many communities in East Asia pride themselves on the emphasis they place on their children. But if this region truly believes that its children are its future, it must first ensure a future for them.

## The situation now in East Asia

East Asian countries are characterized by low overall national prevalence, yet with pockets of very high sub-national prevalence among certain populations. Cambodia has the region's highest national prevalence at 1.9 per cent. The epidemics in East Asia generally fall into three categories: Low-level epidemics signal prevalence of less than 0.1 per cent, as seen in the Philippines, Mongolia, and Timor Leste. Concentrated epidemics, which report prevalence of 0.1 per cent or higher, are found in China, Viet Nam, Malaysia, Indonesia and Lao PDR. Thailand, Cambodia and Myanmar are experiencing generalized epidemics with prevalence of one per cent or higher.

But low prevalence often distorts the reality of the HIV/AIDS situation in the region. Because of the region's massive populations, low prevalence translates into large numbers of infected people. While China's prevalence is 0.1 per cent, it is home to more HIV-infected people than countries with much higher prevalence such as Brazil, Cote d'Ivoire and Ukraine.<sup>9</sup>

Low national prevalence also masks localized epidemics among high-risk groups in countries such as China, Viet Nam, Indonesia, Myanmar and Thailand. In some Indonesian provinces, the HIV prevalence among injecting drug users – many of whom are young – runs up to 53 per cent.<sup>10</sup> Prevalence has also skyrocketed among female sex workers. Even in isolated regions such as Mongolia, sex workers are increasingly infected. In Ulaanbaatar, 67 per cent of female sex workers reported at least one sexually transmitted infection, a proxy to HIV infection.<sup>11</sup> Moreover, young girls and women make up a large proportion of sex workers in Cambodia, China, Lao PDR, Indonesia and Viet Nam.<sup>12</sup>

Even within sub-populations, there are startling geographic differences. For example, in China, the prevalence among injecting drug users is over 50 per cent in some areas of Xinjiang, Yunnan and Sichuan provinces; but it is lower than 5 per cent in Jiangsu, Zhejiang, Inner Mongolia and Liaoning.<sup>13</sup> Meanwhile, the average prevalence among sex workers across China is 0.5-1.0 per cent. But results from a 2003 epidemiological survey indicated prevalence of between 3.3 per cent and 6.7 per cent at four national surveillance sites.<sup>14</sup>

If left unchecked, these sudden, sharp increases in HIV prevalence among sub-populations eventually spill over to general populations, a threat which is now being played out in Indonesia, Viet Nam and China. The spread of HIV among female sex workers is especially worrying because of the high demand for commercial sex among Asian men. Different studies have shown that a large number of men in this region – from every rung of the socio-economic ladder – frequent sex workers.

In fact, Asia's dynamic and vibrant economies could unwittingly feed into HIV incidence. Armed with more cash, more men are tempted to buy sex.<sup>15</sup> They then bring HIV home to their wives and girlfriends, who in turn transmit HIV to their babies.

### **Voice of the wife of a Vietnamese businessman**

"There is no injecting drug user in my family but I have been infected with HIV. It comes from my husband who is a director of a company. Nobody knew about his infection until he was at the point of death. I intended to have an abortion but my mother said I shouldn't do it. My child is now four years old, ailing all the time. (Crying as she speaks) When we go to the hospital for a health check, my child gets discriminated against. My child is so sad and disappointed but she has to wait for a long time before being treated and I still have to pay the hospital fee for her. This has been very difficult, but I am quite able to cope with everything but the attitude of the hospital staff toward me and my child."

*Source: The Situation of Families and Children Affected by HIV/AIDS in Viet Nam, UNICEF and Viet Nam's Ministry of Labour, Invalids and Social Affairs, April 2005.*

“Every holiday, I worried that I would not be able to return to school the following term.”

*Ar-Xiang, Yunnan province, China*

# Chapter 2:

## The Impact of HIV/AIDS on East Asian Children

One of the most distinctive characteristics about HIV/AIDS is the ripple effect it has on children and families. HIV among adults of working age has an impact on the lives of their partners, parents and children. And it is that impact on children that has not received the attention it deserves.

HIV/AIDS exacts a toll on all aspects of people's lives, especially children's. It inflicts not only physical pain on children, but emotional suffering. And that hurt does not just come from being sick or watching their parents and other loved ones die, it also stems from being forced to leave school, being compelled to work, being left unprotected, and most of all, being shunned or taunted. It also threatens their physical well-being as children face hunger when their parents fall sick or die. In this situation, food becomes one of their critical needs.

### Risks and vulnerabilities of children and young people in East Asia

HIV/AIDS is a young person's issue. Every day, a young person contracts HIV every 15 seconds. Globally, over 6,000 young people aged 15-24 are newly infected throughout the world and young people now make up 50 per cent of the world's new HIV infections. In addition, there are nearly 1,800 new paediatric infections each day.

As with other parts of the world, the virus is stalking East Asia's children and adolescents. By 2004, 120,700 children were living with HIV/AIDS in the Asia and Pacific region. Of those, 46,900 were newly infected in 2004 alone.<sup>16</sup>

In many East Asian countries, the profile of the newly infected is getting younger. Forty per cent of reported HIV infections in China are among people under the age of 30.<sup>17</sup> In Malaysia, 35 per cent of reported HIV infections occur among those below 29 years old.<sup>18</sup> In Viet Nam, 63 per cent of the people infected by HIV are under 30,<sup>19</sup> and young people between the ages of 13 and 19 are increasingly becoming infected.<sup>20</sup> Thailand sees 28,000 new infections a year, 50-60 per cent of whom are children and young people under 24.<sup>21</sup>

Not only is the face of HIV/AIDS in East Asia becoming younger, it is more likely to be female as well. As the region's epidemics shift from marginalized groups such as injecting drug users, sex workers, and men who have sex with men, more women of reproductive age are contracting HIV from their partners. Women are increasingly becoming infected in China, comprising 39 per cent of all HIV cases in 2004, up from 15 per cent in 1998.<sup>22</sup> In Thailand, which is already confronted with a generalized epidemic, around 70 per cent of the young people now living with HIV/AIDS are girls and women between the ages of 15 and 24.<sup>23</sup>

The feminization of HIV/AIDS and the younger age profiles of those getting infected signal devastating consequences for children in the region. Without programmes to prevent mother-to-child transmission, more infections among women of childbearing age mean more infections among newborns and infants.

But children in East Asia are not only exposed to HIV through their mothers. Despite East Asia's rapid economic development, poverty is still endemic throughout much of the region. Poverty coupled with insufficient child protection measures are placing more children at risk of living on the streets or working in the sex industry – situations that further increase their exposure to HIV. Vulnerable children and young

people also include those injecting drugs, engaging in labour and living in impoverished households as well as those out of school and affected by conflicts or natural disasters. Increasingly, some young people, including young men, engage in transactional sex in the Philippines and Thailand.<sup>24</sup>

Nearly 2.2 million children in Indonesia are child sex workers, child domestic workers, or children living or working on the streets – all means of earning money that heighten exposure to HIV.<sup>25</sup> In fact, 30 per cent of sex workers in Indonesia are children under the age of 18.<sup>26</sup> Teenage girls fill the ranks of sex workers in other Asian countries: 19 per cent of sex workers in Cambodia are younger than 20 while 29 per cent of sex workers in Lao PDR are under the age of 20.<sup>27</sup>

And child sex workers in East Asia have to deal with a clientele unwilling to use condoms. Clients in Asia often pay more money to have sex without a condom, or threaten to use violence if sex workers insist on using one.

East Asia's rapidly developing economies are also leading to unprecedented migration within and between borders. While migration for better job prospects is sound economics, the potential ramifications include increased exposure to HIV. For children, increased mobility may leave them with fewer family and community members to help guide them through life. In other cases, young people themselves are on the move, and are losing entire family and community support networks as a result. Economic development projects may also introduce HIV infection into previously unaffected communities. For example, a current project in Lao PDR to build a new transport corridor needs labourers in the short term, and will increase the presence of truck drivers in the long term. Both groups are potential "bridge populations" for HIV transmission.

Increasing numbers of children and adolescents are also injecting drugs – a risk behaviour that is fuelling some of the region's HIV/AIDS epidemics because of re-use of injecting equipment. In Jakarta, male high school students between the ages of 16 and 18 are far more likely to report taking illegal drugs than having sex or getting drunk.<sup>28</sup>

In East Asia, frequently injecting drug use and sex work overlap – a trend particularly noticeable in Indonesia and Viet Nam. Young injecting drug users do not just risk contracting HIV by sharing injecting equipment, many of them are selling sex to support the addiction – further exposing themselves and others to HIV infection. Studies in Viet Nam also show that many young sex workers turn to drugs in order to escape the painful reality of their lives or become sex workers to support the addiction.

Substance use and unprotected sex often go hand in hand. In the Indonesian port town of Pemangkat, nine out of 12 male teenagers, aged 15-18, said they had injected heroin before, and had shared needles

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### Problems with data in East Asia

Surveillance systems and data collection are not keeping pace with East Asia's growing epidemics, and this failure will create problems for future interventions. While HIV sentinel surveillance systems have been established in many countries, they are frequently limited in geographical coverage – a serious weakness in large countries with spread-out and mobile populations such as China and Indonesia.

Political, cultural and social sensitivities are hindering data collection in this region. Because of stigma and sensitivity surrounding certain behaviours, many East Asian countries lack systematic tracking of populations long identified as being at risk, such as injecting drug users and men who have sex with men.

The same applies to children and young people infected or affected by HIV/AIDS. Not only do many East Asian countries lack adequate data on children already infected/affected, they are also not keeping track of the risk and vulnerability factors among children and young people.

Disagreement over who is considered at risk is also obstructing effective tracking. Moreover, few East Asian countries are examining young people's risk behaviours or knowledge about HIV/AIDS. Without this understanding, it will be almost impossible to devise effective programmes that reach children and adolescents. For instance, promoting condom use among young people has been proven to be an effective way of deterring HIV infections. But most East Asian countries are not identifying sexually active young people who might be practising unsafe sex and how to reach them with prevention education and services.

In order for future interventions to be effective, East Asian countries have to construct accurate profiles of children and adolescents who are vulnerable to drug use, unsafe sex and sex work, and thus, HIV.

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*Peer group educators in Indonesia*

an average of three times each.<sup>29</sup> All of them claimed to have first had sex between the ages of 12 and 14, and none had used a condom before. In Thailand, young people who drink or use methamphetamine are at high risk of HIV because substance use may impair judgment and result in having unprotected sex.<sup>30</sup> In Cambodia, among 11 to 18-year-olds who reported having had sex, 40 per cent did so after drinking alcohol.<sup>31</sup> Too often young people do not have the knowledge, skills or the confidence to obtain condoms or negotiate condom use, or simply lack access to condoms, further increasing their vulnerability to HIV/AIDS.

It is not just poor and exploited young people or children living in the streets in East Asia who are becoming more vulnerable to HIV. Political and social changes also lead to the breakdown of traditional values. Across Asia, young people are casting aside long-held attitudes towards pre-marital sex, and are becoming sexually active at earlier ages. A 2003 study in the Indonesian province of Papua showed that 12 per cent of the teenagers surveyed have had sex, some as early as the age of 10.<sup>32</sup> At least 25 per cent of teenage Many had sex before the age of 17 in Lao PDR,<sup>33</sup> and in the Philippines, a recent survey showed that at least 23 per cent of young people have had pre-marital sex.<sup>34</sup>

In Thailand, many girls are not only sexually active, some are also having casual relationships with multiple partners. A survey in 2004 among 6,700 female students in Thailand showed that 1,448 of them were sexually experienced. Around 80 reported that they have had sex with more than 20 casual partners.<sup>35</sup> Many are also reportedly engaging in transactional sex – having sex with mostly older men in exchange for gifts or money.

Adolescence is a time for young people to explore their sexual identities, so the fact that East Asian teenagers are having sex and having it at earlier ages should not be worrying. What is alarming is that sexually active young people are not protecting themselves. In a survey among young people aged 15-21 in northern Thailand, only 16 per cent of men and 11 per cent of women said they used condoms consistently with their regular partners.<sup>36</sup> Meanwhile, young people in China display uncertain knowledge about prevention methods. In a 2004 survey, when asked if they would take protective measures to prevent pregnancy and diseases if they were to have sex, 52.4 per cent said they did not know.<sup>37</sup> Meanwhile, 56.1 per cent thought they could prevent HIV by regular exercise, or through improved nutrition (25.6 per cent).<sup>38</sup>

More disturbingly, other studies have shown that less than 50 per cent of sexually active young men in Thailand and Indonesia used condoms during sexual initiation with, or regular visits to, sex workers.<sup>39</sup> Sex workers and injecting drug users in East Asia may be marginalized groups, but they are not isolated – they are in regular contact with the general population.

## **“Yes, Us!” Breaking taboos in Indonesia**

Confronted with apathy and social taboos, American David Gordon and his Indonesian wife Joyce Djaelani are tackling HIV prevention and drug abuse in the archipelago nation head-on.

David and Joyce run one of the few drug rehabilitation centres in Indonesia. Called Yayasan Harapan Permata Hati Kita – Our Children’s Hope – the centre is popularly known as YAKITA, an Indonesian play on words meaning “Yes, Us!” The centre is also spearheading an ambitious training programme for peer educators, targeted at young people from the greater Jakarta area and three other provinces, Bandung, Makassar, and Bali.

“The training programme is cutting edge,” says David. “And we’d like to expand the programme, fast! If we don’t, we won’t make inroads into the epidemic.”

Time may be running out. If efforts to stop the spread of HIV/AIDS are not scaled up immediately, the Indonesian Ministry of Health estimates that by 2010, there will be approximately 110,000 people suffering from AIDS-related diseases, or who have died because of AIDS, and another 1 million more may be HIV-infected.

“There are more than 6 million drug abusers in Indonesia,” says David, a former drug addict himself. “Of these, there are more than 300,000 intravenous drug users. In one district of Jakarta alone, official figures have recorded that 90 per cent of intravenous drug users tested positive for HIV.” He adds: “That really means they’ve all got it.”

Official government figures on the number of drug users are much lower, though most experts argue the exact number is not known.

One of the key aspects of the training program is breaking down long-held taboos against HIV and drug use. The centre houses 20 young recovering drug addicts at any one time, and is staffed by former addicts, many of whom are HIV positive. Because the training is held at the centre, the trainees work and live with recovering drug addicts and HIV-positive people.

Peer trainee Augustina Rahayu, 16, a student from Bogor says she had heard about HIV but didn’t know much. “Before, I was afraid of people living with HIV and I thought I could catch HIV by just being in a public place. Now I know so much more and I want to help infected people.”

To date, these young educators have brought the message of HIV prevention to more than 6,000 young people in schools, campuses, on the street, in hospitals, and even in military training barracks. In addition, the young trainers have taught more than 100 other young people through intensive three-day training exercises they have learned to conduct alone.

But there is much more to be done. Similar projects need to be established in other parts of the Indonesian archipelago, including the remote eastern province of Papua, which has a disproportionately high number of the country’s HIV cases.



*Yayasan Harapan Permata Kita (YAKITA) provides peer education and counselling for young people in East Java.*

Indonesia is at a crossroads – the epidemic could go either way. The government and the international community must take bold and sustained actions over the next two years before HIV infections can plateau.

Despite these obvious links, national interventions across Asia are failing to reach many of the most-at-risk populations that include young people because of continuing prejudices. As a result, prevention programmes are only reaching 5.4 per cent of the injecting drug users and one per cent of men who have sex with men.<sup>40</sup> Indeed, countries like Indonesia, Viet Nam and China are more likely to send injecting drug users to jail or drug rehabilitation centres, where the transmission of HIV is also a possibility. And not reaching these individuals with HIV prevention information and services has had its consequences.

### **What will happen to Fei?**

In five-year-old Fei's village, more than 600 people – half the population – contracted HIV through unsafe blood-selling – a practice that has devastated many communities in the Chinese provinces of Henan, Anhui and Shandong. The disease has already orphaned 29 children in the village.

HIV has struck almost all of Fei's family: Fei, her father, her grandparents and her little brother are all HIV-positive. With his wife already dead from AIDS, her ailing father is too ill to work in the fields and struggles to care for his children. He frets about their future.

"I don't know what their future will be when I die. My parents are also sick. The kids have AIDS, and the public orphanage won't take them in. Other relatives have healthy children, and they won't accept them either," he says. "I only hope the government will find a way to help."

*Source: CCTV, 23 February 2004.*

In Bangkok, HIV prevalence increased from 15 per cent to 28 per cent among men who have sex with men within a matter of two years.<sup>41</sup>

Even street children – a group widely acknowledged to be highly vulnerable to HIV infection – are slipping through the cracks. Prevention programmes are reaching only one in five street children in Asia and the Pacific.<sup>42</sup>

But prevention programmes in the region are not just overlooking highly vulnerable populations, they are also failing to reach children and adolescents in general. Although 11 countries out of 15 in the Asia and the Pacific region have national policies articulating the need to address young people, only four have actually implemented plans for comprehensive outreach programmes.<sup>43</sup>

## **Children orphaned by AIDS**

HIV/AIDS is not just endangering children's lives; it is killing their parents and other caregivers. Globally, 15 million children have lost at least one parent to HIV/AIDS.

Accurate figures on orphans are hard to come by in the region because of the difficulty in collecting data in low-level or concentrated epidemics. It is estimated that 1.5 million children in Asia and the Pacific have lost one or both parents to AIDS.<sup>44</sup> But the total number of orphaned children in Asia from all causes is much greater than regions with higher HIV prevalence. In 2003, there were 87.6 million orphans due to all causes in Asia, compared to sub-Saharan Africa's 43.4 million.<sup>45</sup>

Because of the slow rollout of antiretroviral therapy and inadequate scale-up of prevention efforts, the proportion of children orphaned by AIDS in East Asia will undoubtedly rise, even if prevalence remains low. By 2010, one out of three orphans in Thailand and one out of four orphans in Cambodia will have lost their parent(s) to AIDS.<sup>46</sup> Official figures in China show that already in 2003, 76,000 children had lost both parents to AIDS and between 150,000 and 260,000 children are projected to be orphaned due to AIDS by 2010. However, if China's prevention efforts falter, it could have as many as 10 million people living with HIV/AIDS by 2010 – a scenario that would dramatically raise the number of orphans. Indeed, although current projections show that Asia's total number of orphans will decline to about 80 million by 2010,<sup>47</sup> that, too, is based on the assumption that HIV prevalence will not sharply increase.

Orphans in the region are normally cared for by their relatives, but the HIV/AIDS epidemic is testing East Asia's age-old tradition of extended families. Many families are unable to give children orphaned by AIDS the love, care, protection and support they need. But as the number of orphans and children affected by HIV/AIDS increase, there is a need to have a comprehensive and integrated approach reflecting their diverse needs in care and protection. These children are frequently sent to aging grandparents in rural areas, who are ill-equipped financially and sometimes physically and emotionally to take care of their grandchildren. Elderly grandparents will need material support – especially food. The fate of these children is also thrown into question when their elderly caregivers pass away. In some instances, children in the care of extended family members are subject to different forms of exploitation, further raising their vulnerability to HIV.

## The impact of HIV/AIDS

Watching a parent die is always a shattering experience for a child, particularly when a father or mother wastes away in the kind of agonizing death that AIDS brings. HIV/AIDS also steals their most valuable source of protection, love and care.

But all children affected by HIV/AIDS feel emotional distress as the epidemic unravels their homes and undermines their sense of security. For children living with HIV/AIDS, the stigma and discrimination persistently associated with the epidemic in East Asia is eroding their self-esteem. Children living with HIV/AIDS witness their playmates being shooed away by other parents, or their friends deliberately avoid them. Stigma and discrimination also leave emotional scars on children who are not HIV-positive themselves. Participatory research with children affected by HIV/AIDS by Save the Children UK found that HIV-affected children in China were worried about being isolated or looked down upon by other people.<sup>48</sup>

They also said maintaining their emotional well-being was as important, if not more important, than meeting their basic material needs such as food and clothing. But all too often, the psychological pain and social isolation that children affected and infected by HIV/AIDS undergo is ignored.

HIV/AIDS also has a devastating impact on household incomes. Parents living with HIV/AIDS are often too sick to eke out a living, let alone pay for life-prolonging anti-retroviral drugs. In HIV/AIDS affected households, much of the income is spent on health-related and other associated costs such as funerals. The situation is not helped by widespread discrimination experienced by people living with HIV/AIDS in the workplace, with many HIV-positive people driven out of their jobs by their employers and co-workers. In Thailand, some companies order their employees to undergo HIV tests, saying they only employ “healthy” workers, a violation of the rights of HIV positive individuals to employment.

Faced with dwindling financial resources, children from AIDS-affected families are forced to leave schools in order to help their families with household duties or to earn money. A study in Viet Nam showed that 42 per cent of children from affected families worked, most often as labourers.<sup>49</sup> In Cambodia, a study found that one in five children from AIDS-affected families reported that they started working in the previous six months to support their families. Many also had to go without basic necessities such as food,<sup>50</sup> underpinning evidence that HIV-affected children often suffer from malnutrition.

### Easing Ar-Xiang’s pain

Ar-Xiang’s father died of AIDS when she was four years old, and her mother soon abandoned her. Fortunately, her aunt moved to Ar-Xiang’s village of Xincheng in China’s western Yunnan province to take care of her. Still, her aunt’s family has little money and life for them is very hard.

A bright and determined student, Ar-Xiang loves going to school. However, for years, the knowledge that the family’s precarious finances could put an end to her school days weighed on her mind. “Every holiday, I worried that I would not be able to return to school the following term,” she says.

One term, Ar-Xiang’s family was unable to pay for her schoolbooks, uniform and US\$3 per term tuition fee. That is when UNICEF stepped in, helping Ar-Xiang buy school materials. UNICEF is also helping Ar-Xiang and other children like her by training counsellors, who provide much needed psychosocial support.

Ar-Xiang wishes she could remember her parents more clearly. She is also haunted by memories of her father’s final days. At night, she often dreams about him, and he is always screaming in a dark room.

The UNICEF-trained counsellors encourage children orphaned by AIDS in Ar-Xiang’s village to express their feelings by drawing, singing, dancing, writing and talking. “These sessions really helped me to deal with feelings that were deep-rooted but that I had tried to repress,” says Ar-Xiang, who wants to become a doctor so she can help ease other people’s pain.



UNICEF/EAP00110

*A young girl does her homework outside while her mother works on household chores in rural China.*

Children orphaned due to AIDS face even bleaker prospects. Some orphans are often forced to work in the streets where they are in danger of exploitation, disease, and infection. A report in 2004 suggested that many children orphaned by AIDS in Indonesia end up on the streets.<sup>51</sup>

Many countries in East Asia also lack effective birth registration systems – more than 20 per cent of births in East Asia and the Pacific are unregistered.<sup>52</sup> Without birth certificates, children orphaned by AIDS run into serious difficulties in claiming inheritance. Birth certificates also provide proof of citizenship, and without them, children are also denied basic services such as education and health care.

HIV/AIDS also saps away this region's hard-won poverty reduction gains. Studies show that if current trends prevail, poverty reduction in Cambodia will slow down by 60 per cent every year between 2003 and 2015. They also show that every year between 2003 and 2015, an average of 5.6 million people will be impoverished by HIV/AIDS in Cambodia, India, Thailand, and Viet Nam.<sup>53</sup> Economic losses in Asia and the Pacific from HIV/AIDS epidemics could soar from US\$7.3 billion in 2001 to US\$17 billion a year by 2010<sup>54</sup> unless a comprehensive HIV prevention, treatment and care response is mounted as a matter of urgency in the region.

The financial burdens associated with HIV/AIDS are driving children out of school. In Viet Nam, 57 per cent of children affected by HIV/AIDS were attending school, sharply lower than the national average attendance rate of 90 per cent.<sup>55</sup>

And because of their perceived value as caretakers, girls are much more likely to be pulled out of school to tend to sick relatives or younger siblings, or to earn money for the family. In fact, even without HIV/AIDS in the equation, girls in East Asia are being denied of their right to an education every day. Six per cent more boys than girls in East Asia and the Pacific are enrolled in secondary schools.<sup>56</sup>

Unfortunately, poverty is not the sole reason why children infected or affected by HIV/AIDS are dropping out of school. Fear and discrimination are a major catalyst, with the parents of other students and officials blocking children infected or affected by HIV/AIDS from going to school. Other children are dropping out because they can no longer endure the teasing and bullying they suffer. In China, although the government recently abolished school fees for children orphaned by AIDS in some regions, some children are still reluctant to claim their free places because they would be easily singled out in communities fearful of HIV.<sup>57</sup> And some HIV-infected children are simply too sick to attend school because they lack proper treatment.

In East Asia, a region where education has long been valued, children who miss out on school miss out on more than basic education, they miss out on their futures. Indeed, children affected by HIV/AIDS often poignantly express their wish to remain in school. The ability to go to school and do well in their studies is one of the many concerns among children affected by HIV/AIDS in China and elsewhere.<sup>58</sup>

“...we run training and other activities to empower the local community to look out for themselves and their children. Now villagers report when a child is sick and take them to the right hospital if necessary.”

*Nam Peung, Manager of AIDS Access*

## Chapter 3:

# The Way Forward

Clearly, the children of East Asia are not immune to HIV/AIDS and its impact. Hundreds of thousands of children in this region are already reeling from its effects. They are getting sick, losing their parents, leaving school and going to work at too young an age. And if interventions remain limited and uncoordinated, HIV/AIDS will cast its shadow on the lives of many more children.

However, East Asia still has a chance to stop HIV/AIDS in its tracks, if governments, NGOs, religious leaders, communities and individuals mobilize all their resources and begin focusing adolescents and young people *now*.

Of the four focus areas of the Global Campaign on Children and AIDS, prevention of new infections is perhaps the most crucial for East Asia to keep the region's current prevalence low. HIV prevalence is not destined to rise. Past experiences have shown us how to reverse the trend of increasing prevalence. Among the actions that East Asia can take are identifying and reaching out to individuals at high risk; promoting condoms and increasing access to them; expanding access among young people to information, education, skills and services; keeping girls in school; and expanding access HIV treatment and services focused on prevention of mother-to-child transmission, voluntary counselling and testing, and sexually transmitted infections.

Many East Asian countries already have prevention, treatment and care interventions in place, but they need to strengthen the coverage of their responses to reach a critical mass of people in order to reverse the course of the epidemic.

With many epidemics in this region on the brink of spiralling out of control, East Asia also needs to find ways to cope with the new waves: the rising number of children infected or affected by HIV/AIDS. HIV/AIDS violates children's rights in ways seldom seen with other communicable diseases. It also aggravates gender discrimination and widens disparities, and therefore, could disrupt this region's long sought-after social harmony and economic progress.

Underlying the four focus areas of the Global Campaign on Children and AIDS – preventing new infections, preventing mother-to-child-transmission, providing paediatric treatment, and providing protection, care, and support – are two key challenges.

First, East Asia must successfully end the stigma and discrimination linked to HIV/AIDS. Stigma and discrimination present the greatest obstacles to successful prevention, treatment and care interventions. They stop people, including pregnant women, from finding out their HIV status for fear of negative reactions from family members, neighbours and other community members. They drive children out of school. They impede access to health care for people living with HIV/AIDS. If East Asia is to succeed in staving off its HIV epidemics, acceptance and compassion must triumph over fear and ignorance.

Second, a grand alliance should be forged to meet the complex challenges posed by HIV/AIDS. Partnerships at every level are the key to responding this epidemic. Many have already embarked on projects and programmes to tackle HIV/AIDS. Yet much more needs to be done to place children at the heart of East Asia's HIV/AIDS response.

## Preventing new infections

The benefits of prevention information and education aimed at children and young people in East Asia cannot be overstated. Children and young people are at a point in their lives when behaviour patterns are being determined. They are quick to absorb new skills and knowledge. And as East Asian economies develop and mature, many children are receiving higher levels of education than their parents ever did, enabling them to pass on prevention information to adults. For instance, in an assessment of UNICEF's School-Based Healthy Living and HIV/AIDS Prevention Education (SHAPE) in Myanmar, a striking number of parents said they learned about HIV through their children.<sup>59</sup>

Despite the obvious benefits of prevention, knowledge about the basic facts of HIV transmission among young people in East Asia remains alarmingly low. More than two decades after the first HIV cases were reported in the region, a recent survey showed 63 per cent of young Filipinos believed they were immune to HIV.<sup>60</sup> In Indonesia, 61 per cent of girls between the ages of 15 and 19 knew about AIDS, but were not sure how to protect themselves from HIV. Although seven per cent of those living with HIV/AIDS in China are under the age of 20, one survey by the United Nations Population Fund found 50 per cent of a group of 2,500 15-20 year-olds could not name a single way of protecting themselves from HIV infection. There is even more cause for consternation in Timor Leste, where 79 per cent of women and 70 per cent of men had never even heard of HIV/AIDS.<sup>61</sup>

Ignorance about HIV transmission gives way to dangerous myths about the virus, particularly among girls and young women who are especially vulnerable to infection. Studies show that 70 per cent of young women between the ages of 15 and 24 in Indonesia incorrectly believed that a healthy-looking person could not have HIV.<sup>62</sup> In Viet Nam and Cambodia, nearly 40 per cent of young women believed this misconception, indicating that even countries with more coordinated national responses to HIV/AIDS are falling short.<sup>63</sup>

The myths also have the potential of perpetuating stigma and discrimination. Although attitudes towards people living with HIV/AIDS are changing in China, when asked if it was possible to contract HIV by sharing chopsticks with an HIV positive person, 69 per cent of 3,087 students between the ages of 12 and 20 answered "yes" or "do not know."<sup>64</sup> The same survey showed 42 per cent said it was possible to acquire HIV by eating with an infected person, while 51 per cent thought it was possible to transmit the virus through kissing. Nearly 65 per cent also believed they could get HIV from mosquito bites.

Even when there is knowledge, behaviour does not necessarily change. In a survey of injecting drug users in Indonesia, 100 per cent of the respondents knew that HIV could be contracted through used needles, but 53 per cent said they used someone else's needle during last injection and 83 per cent reported passing their needles to others.<sup>65</sup> This shows knowledge alone is not sufficient to produce behaviour change. A comprehensive prevention approach requires increased access by high-risk individuals, such as young Indonesian drug users, to a range of interventions, including voluntary counselling and testing, substitution treatment, clean injecting equipment, condoms and treatment for STIs.<sup>66</sup>

Why are prevention efforts in East Asia failing? Why are children and young people not acquiring the information and skills that they need to protect themselves?

At times, cultural and religious taboos hinder prevention efforts. Sex is often a prohibitive subject between children and their parents. Despite ample evidence that shows the contrary, some adults believe that frank talk about sex will only encourage young people to experiment with sex. Others may be too embarrassed to address the issue because they themselves do not know all the answers.

In a BBC World Survey on HIV/AIDS in 2003, only 47 per cent of Indonesians thought children should be taught condom use.<sup>67</sup> Other studies reveal only 26 per cent of young Indonesians living with HIV/AIDS received any information about reproductive health from their parents, and 83 per cent of those parents gave their children incorrect information.<sup>68</sup> Indonesian children and adolescents are not learning about sex in school either – the country still has a law preventing the inclusion of reproductive health and life skills in school curricula.<sup>69</sup>

Other children in East Asia are also missing the information and skills they need to survive. In China, in a 2004 survey conducted by the Ministry of Education, junior and high school students said school, extra-curricular activities, and peer education were the best forums for learning about prevention. But 80 per cent said they had never participated in any HIV/AIDS prevention education at school.<sup>70</sup> Even when reproductive health is part of the curricula, young people say they find themselves drifting during sex education classes because it is taught in a didactic, theoretical way.<sup>71</sup> Prevention education in



*A shadow puppet show designed to educate youth on HIV/AIDS is performed by local artists in Phnom Penh, Cambodia in 2000.*

Thailand is less rigorous than it was in the 1990s, and consequently, young people, particularly young women, often possess only a shaky knowledge of HIV/AIDS.<sup>72</sup> Gender discrimination in this region thwarts access to information for girls. Sex is often viewed as an inappropriate subject for discussion. And as mentioned before, girls are more likely to be withdrawn from school – a potentially effective outlet for knowledge about HIV prevention.

Traditional deference to elders is also preventing children and young people from asking their parents and teachers about sex. Faced with this reticence, children are turning to equally inexperienced or misinformed peers to learn about sex and preventive measures.

## What young people want

East Asian countries must overcome the challenges in providing children prevention information, skills and services if they are serious about tackling the HIV/AIDS crisis. Indeed, those who develop prevention policies and programmes need to look at the recommendations put forth by young people themselves.

In 2004, UNICEF held a series of consultations with young people in a wide range of countries, including Thailand, Indonesia, Cambodia and Lao PDR. In Thailand, which has chalked up considerable successes in HIV prevention, young people said they still did not have access to information, prevention skills and preventive services. They also said they wanted more guidance from educators as well as community and spiritual leaders.

These young people, who represented every section of Thai society, were clear about what they needed on the prevention front: better, more practical sex and life skills education; youth-friendly, confidential services; increased participation of religious leaders; easier access to condoms; and more support for families. Above all, they asked for a bigger role for themselves to play in prevention efforts. Child participation is a powerful tool in HIV/AIDS prevention, and UNICEF supports, and will continue to support, projects throughout East Asia – from peer education to after-school clubs – that get young people involved.

Young people in East Asia also want popular media to play a greater role in getting the prevention message across. MTV Asia has been an important partner with UNICEF in conveying prevention knowledge to young people in savvy, fun, accessible, and effective ways. In 2002, MTV Philippines teamed up with UNICEF to hold a music concert aimed at HIV/AIDS awareness raising. Months after the concert, a poll showed that 62 per cent of the attendees surveyed correctly remembered the event's main messages about safer sex, correct means of prevention, elimination of stigma and responsibility in relationships.<sup>73</sup> In Cambodia, TV spots featuring popular sports stars aired on national media have had a positive impact on the attendance of VCT services and the number of calls received by an HIV/AIDS telephone hotline supported by UNICEF.

Aside from providing prevention education and life skills to children and young people, East Asia must address the other causes of HIV risk and vulnerability, including gender discrimination and poverty. Child protection measures also need to be strengthened in order to prevent the exploitation and trafficking of children and adolescents in East Asia.

Over the long term, sending children to school and keeping them there is one of East Asia's best strategies against the HIV epidemic. On a more immediate level, prevention can be taught in classrooms. In the longer term, education instils self-confidence and imparts livelihood skills to children, especially girls, and reduces their vulnerability to peer pressure and risk behaviour. A series of youth surveys in Thailand, the Philippines, Indonesia and Hong Kong found that with girls and boys, aged 15-24, the more "connected" they felt to school, the less likely they were to take drugs, drink and smoke.<sup>74</sup> Finally, education helps young people make better-informed decisions as they transition into adulthood. To achieve universal education, East Asian countries need to expand basic education to include secondary schools. Basic education must remain free and compulsory and families need to understand the importance of educating girls.

### One nun's prevention campaign

It's noon, and the girls of the Bonsai Karaoke bar are relaxing before their day's work begins.

Products of Indonesia's extensive domestic sex trade syndicates, they have travelled to work as prostitutes in Sorong, a town on the northwest tip of Papua.

Hardened 17-year-old veterans make the rounds through the bars and logging camps of half a dozen similar Papuan frontier towns, servicing sailors, civil servants and soldiers. Others are fresh off the boat, barely out of school.



Sister Zita leaving a bar after her staff have finished taking pap smears and teaching girls about STDs and HIV/AIDS.

Buzzing among the young prostitutes in her crisp white habit, Sister Zita dispenses hugs, advice and foil strips of penicillin and ciprofloxacin to treat the venereal diseases that infect all the girls.

"I try to give them support and encourage them to look at their lives, to convince them to take a different path," Sister Zita says, an arm around the waist of Nona, a pudgy, blushing 14-year-old. "Mostly I'm just here for spiritual support, but we also provide many other services that deal with their immediate needs."

The coordinator of Yayasan St. Agustinos, a Catholic foundation that operates Sorong's largest independent medical clinic, Sister Zita has few qualms about distributing condoms despite her religion's doctrine against birth control.

"I want to be clear that I do not advocate their behaviour... or the use of condoms, but it's clear we're dealing with a killer disease and that there is no more effective and dependable way to control the problem," says Sister Zita.

While the foundation's clinic sees many different potentially fatal diseases, Sister Zita is particularly concerned about the spread of HIV/AIDS in Sorong.

Papua's 3 million people account for just over one per cent of Indonesia's population, but one third of the nation's identified cases of AIDS are found here, fuelled by the sex trade. Seventeen per cent of Sorong's sex workers, many of them children, are HIV-positive (UNAIDS, 2004).

As part of their UNICEF-supported outreach programme, St. Agustinos' staff visit each of the town's 28 karaoke bars once a month to test for and treat sexually transmitted diseases.

"We have no capacity to test for HIV/AIDS," Sister Zita says. "Even though we try to explain, these children don't understand the danger they are in. It worries me that there is no information."

Indeed, despite the free condoms, few of the girls will insist on their use when faced with a reluctant client. "Of course without a condom the gates should be locked, but show a little extra money and we'll give them the key," says one of the older prostitutes.

East Asia has advantages in its well-established school systems and the widespread desire for education among children and youth. East Asia has enjoyed decades of strong economic growth precisely because of its emphasis on education. But those advantages are starting to slip away, with disparities growing between those who can afford schooling and those who cannot.

Moreover, East Asian countries have to reach populations of out-of-school children, including children of migrant workers and displaced children, and children at high risk, such as children living and working on the streets and child sex workers.

## Preventing mother-to-child transmission

Although HIV/AIDS epidemics worldwide vary in nature, one of the most strikingly universal trends about HIV/AIDS in recent years is the increasing number of women now getting infected compared with men. According to the World Health Organization, women made up almost half of the 37.2 million adults living with HIV/AIDS in 2004.<sup>75</sup>

Part of the reason is physiological – women are more susceptible to HIV than men. Research has also linked gender-based inequality and violence, both pervasive problems in East Asia, to increased HIV vulnerability. Many women are not empowered enough to make the choices that would protect them from HIV infection, such as using condoms consistently or being able to refuse sex. A survey in Thailand in 2000 found that almost 40 per cent of women had been physically or sexually abused by a partner.<sup>76</sup> In such circumstances, condoms are seldom used. A culture of shame also cloaks sexual and domestic violence – many women in East Asia are reluctant to report abuse. Even when they do summon up the courage to report abuse, women often do not have the legal avenues to pursue justice. This is why combating gender-based discrimination and violence are important components in confronting HIV/AIDS.

Although men still make up the majority of people living with HIV in Asia, the percentage of women of reproductive age is growing steadily. The number of women living with HIV in Asia rose from 1.9 million in 2002 to 2.3 million in 2004, the sharpest regional increase in the proportion of women.<sup>77</sup>

And in East Asia, being married is not a guarantee against HIV infection. First, household surveys throughout Asia show that between five to 10 per cent of men visit sex workers.<sup>78</sup> And secondly, studies indicate many married men also have unprotected sex with other men – a major risk factor for their wives. Yet little is known about this population because of social prohibition. Thus, transmission between spouses is rising in Cambodia, Thailand and Myanmar.<sup>79</sup> More than a decade ago, around 90 per cent of HIV transmission in Thailand occurred between sex workers and their clients.<sup>80</sup> By 2002, projections showed that 50 per cent of new infections were taking place between spouses.<sup>81</sup>

Without any intervention, high infection rates among women lead to higher infection rates among infants. If left untreated, 15-30 per cent of HIV-positive mothers will pass the virus onto their children during pregnancy and delivery, while 20-45 per cent will transmit it through breast-feeding.<sup>82</sup> Yet, mother-to-child transmission can be avoided, once HIV infection is known. In fact, the risk of mother-to-child transmission can be cut down to less than two per cent in some instances when a range of PMTCT interventions is adopted.<sup>83</sup>

In 2004, around 155,400 women in Asia and the Pacific needed mother-to-child-transmission intervention.<sup>84</sup> But less than six per cent of women in Southeast Asia have access to public health services that could provide treatment to prevent the transmission of HIV to their babies.<sup>85</sup> Again, access to counselling and testing, coupled with stigma and discrimination deters many women from being tested in the first place, hindering effective treatment of HIV-positive pregnant women.

Supporting HIV-positive mothers and their children goes far beyond providing them with anti-retroviral drugs. It also means preventing new infections among women in the first place; preventing unintended pregnancies; encouraging safe delivery practices; giving advice on infant feeding; and providing care and support for the entire family.

The Global Campaign on Children and AIDS aims to bolster prevention of mother-to-child transmission programmes (PMTCT Plus) in East Asia, where many governments have stated their intentions of establishing nation-wide programmes. The “Plus” embraces prevention education and services, including counselling of couples, underscoring the importance of a comprehensive, holistic approach. All too often, PMTCT programmes in Asia also neglect the need for long-term treatment and care to prolong the lives of HIV positive mothers and children.

Thailand is one East Asian country that has followed the PMTCT Plus model with considerable success. Thailand, where HIV prevalence among the 900,000 women who get pregnant each year is around 1.4 per cent,<sup>86</sup> became the first resource-limited country to implement a national PMTCT programme in 1999. By 2002, access to services for preventing mother-to-child transmission was guaranteed and integrated into a new universal health coverage scheme, known as the "30 Baht" (less than US\$1) scheme.

The programme provides free counselling and testing for HIV, ARVs to mothers and newborns, and 12 months of free infant formula. Women enrolled in the programme also receive counseling and support from doctors, nurses and social workers, who provide information about other diseases as well as HIV/AIDS.

### HIV/AIDS care in rural Thailand

Part of the infamous Golden Triangle of opium producing nations, the mountainous and remote province of Chiang Rai faces many problems, including high levels of drug cultivation, child trafficking and abuse, and poverty. Together, they have left a vicious legacy – one of the highest HIV/AIDS rates in Thailand.

More and more children are inheriting this legacy. Yo (not her real name) is one of them. At 15 years of age, she is HIV-positive, having contracted the virus from her mother.



UNICEF/Thailand/Few 2005

*A young girl who was given a watch by Aids Access so that she could more easily time the doses of her ARVs.*

In a meeting room of AIDS Access, a UNICEF-supported NGO, Yo recounts how she learned about her HIV status: "I started to get sick three years ago when I got herpes saucer on my face and hips." (Herpes saucer is a disfiguring opportunistic infection that can cause blindness.)

After a month of suffering, Yo was taken to a hospital. When the doctor heard that both her parents were dead, he decided to test her for HIV. In Chiang Rai, the death of both a husband and wife often means AIDS.

"The doctor said I had AIDS and I had to take drugs everyday," says Yo. "My grandmother borrowed money for the drugs and we are still paying off the debt."

Yo is now receiving help from AIDS Access, which aims to ensure access to anti-retroviral medicines and support for children affected by HIV/AIDS in an area covering 100,000 people.

"Local hospitals just don't have the capacity to treat HIV-positive children or go to check up on them at their homes," says Nam Peung, the manager of AIDS Access. "So we run training and other activities to empower the local community to look out for themselves and their children. Now villagers report when a child is sick and take them to the right hospital if necessary."

It was HIV-positive people in the local community who told Yo's family about AIDS Access. The NGO does not just dispense medicine, it also advises Yo and her family about how to look after her health and how to stick to the complicated anti-retroviral drug regimen.

AIDS Access also gives counselling and emotional support, which are just as important. "Since joining AIDS Access, my life has completely changed," says Yo. "I used to feel totally abnormal, but now I feel 99 per cent the same as other people. Here they help me a lot to concentrate on the future."

And the future is looking brighter. By building the community's capacity to run projects and raise funds, AIDS Access hopes that local people will be able to work on their own, freeing the NGO to move on to other communities in need. They are also lobbying with the government for AIDS care to be included as part of the national social security scheme. This may happen by the end of 2005, helping children like Yo stay alive without going into debt.

Yo has her own future plans, too. "I'd like to be a singer, but my voice is no good at the moment because I have a cold and I have been crying a lot. But I also want to be a volunteer here at AIDS Access – to visit people in their homes and look after children in hospital. I'd tell them no one is born to die – they are born to fight."

Because of the programme, nearly all pregnant women in Thailand are tested for HIV the first time they seek prenatal treatment.<sup>87</sup> The programme is also credited with halving the number of infants infected with HIV through their mothers. Without the programme, 5,000 babies a year were expected to be infected with HIV by 2003.<sup>88</sup> Now, about 2,000 infections among babies take place in Thailand.<sup>89</sup>

Other East Asian countries are stepping up measures. In December 2003, the Chinese government announced its ambitious “Four Frees and One Care” policy, which includes free voluntary counselling and testing, free drugs to HIV-infected pregnant women to prevent mother-to-child transmission, and HIV testing of newborn babies.

But the region has more work on this front. For instance, PMTCT programmes in Myanmar do not provide mothers with life-saving ARVs, and thus, ultimately creates more orphans.<sup>90</sup>

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### Recommended strategies to prevent mother-to-child transmission

- Preventing HIV infection in all people, particularly young women. Preventing women, especially those of childbearing age, from getting infected in the first place is the top priority. This strategy must involve educating women and men about HIV transmission and prevention, providing access to condoms, promoting women’s role in society and in households, and increasing men’s responsibility in stopping the spread of HIV.
- Preventing unintended pregnancies among HIV-positive women. This strategy involves boosting reproductive health services so that women, including those living with HIV/AIDS, have the means and support to avoid an unintended pregnancy.
- Reducing HIV transmission from HIV-infected women to their infants. This entails increasing access to voluntary and confidential HIV counselling and testing, antiretroviral therapy, or ART, safe delivery practices, and counselling and support on infant-feeding methods.
- Providing a continuum of care and support for infected women, children and families. This means delivering access to prevention, ART, early diagnosis and treatment of opportunistic infections, psychosocial, economic and social support to all members of the family, not just mothers and infants.

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### Providing paediatric treatment

While preventing new HIV infections is crucial in East Asia, the region also needs to treat those children who have already contracted the virus. Without appropriate care, up to 30 per cent of HIV-infected children will not see their first birthday while 50 per cent will not live past the age of two. High levels of malnutrition have also been detected among infected children.

In 2004, Asia and the Pacific had an estimated 120,700 children living with HIV/AIDS. Of those children, 34,500 children needed antiretroviral therapy, or ART.<sup>91</sup> There is scant data on how many HIV-infected children in East Asia are actually being treated, but available data from Asia and the Pacific indicate that less than one per cent of children who could benefit from ARVs receive treatment.

Some countries in the region are working towards providing ART to children, while individual actors across Asia are trying to treat infected young people. China’s “Four Frees and One Care” plan stipulates free ARVs for AIDS patients who are either rural residents or poor urban dwellers, and the country is working on developing ART programmes specifically for children. Thailand has recently stepped up access to treatment so that from January 2006 onwards, HIV positive people who require ARVs have access to treatment under the “30-Baht” (less than US\$1) scheme.

However, infected children seem to be missing from most national treatment agendas. For example, in Myanmar, a pilot programme was launched to provide ART to adults and children, but as of October 2004, only 10 children were taking part.<sup>92</sup> And China’s implementation of its treatment policy has been slow: Only 15,000 people are on ARVs in China and paediatric drugs are not yet fully available.<sup>93</sup>

Children with HIV in East Asia face the same problems as HIV-infected children elsewhere. First, sometimes they are mistakenly perceived as having short life spans, thus treating HIV-positive children has not been regarded as a priority. Second, ART for adults may not be appropriate for some children and paediatric formulas are lacking. Third, paediatric formulations are more expensive than adult ones. And where they

are available, children may be reluctant to take them because they are unpalatable or cause unpleasant side effects. Finally, not enough effort is placed in keeping parents alive and giving them adequate support in providing care for their children. Lack of follow-up is also a major area of concern in the region because parents might not give their infants the correct dosage of ARVs, which could eventually lead to drug resistance.

Programmes in East Asia also need to tend to the psychosocial issues that infected children experience. In addition, attitudes among health workers against infected children need to be addressed. Some health workers in this region refuse to treat HIV-positive children because they are afraid of contracting the virus. Consequently, insufficient number of counsellors and health care providers are trained in meeting the special needs of children infected with HIV.

The move to place children at the centre of the HIV/AIDS response will require strong partnerships with the ministries of public health and social welfare and planning, NGOs, communities and civil society to ensure access to treatment, protection, care and support.

Much more also needs to be done to lower the cost of paediatric formulations. Regional medical institutions and pharmaceutical companies, particularly those making generic drugs, play a crucial role in reducing the price tag. But it is also imperative that fairer trade rules are promoted, especially those regarding patents and intellectual property which prop up prices.

## Providing protection, care and support

Currently, fewer than 10 per cent of children orphaned or made vulnerable by HIV/AIDS are receiving public support in the world.

Along with providing paediatric treatment to HIV-infected children, East Asian countries must step up the protection, care and support of HIV-infected or affected children and their families, and indeed, all vulnerable children. HIV/AIDS is putting unprecedented pressure on communities and families, and without these safety nets, the children of this region are made vulnerable to abuse, violence, and exploitation.

In East Asia, the challenges in protecting children are particularly acute. As already mentioned, East Asia has a large absolute number of orphans from all causes, which may rise if HIV prevalence creeps higher. But the region's social welfare systems are not strong enough to accommodate the current number of orphans, let alone any future rise in the number of children orphaned by AIDS. Many East Asian countries also rely on institutionalized care, when family and community support is not an option. This practice is not in the best interests of the child. Children in institutionalized care are often denied the individual affection, care, and attention they need, and in the long run, their emotional and cognitive development suffers. Furthermore, the cost of institutional care is significantly higher than community-based care, which is why more countries are exploring alternatives to institutions.

Meanwhile, the social and economic changes convulsing East Asia have heightened existing threats to children, especially poor or marginalized children. The greater Mekong region is widely acknowledged as a major human trafficking zone, especially of adolescent girls. Driven by new money and demand, East Asia's inexhaustible and barely regulated sex industry continues to prey on the young. Widening income disparities mean more children and young people are compelled to work to help supplement desired lifestyles or shrinking family incomes. The growing ranks of economic migrants and their children are difficult to monitor. And as governments scale back basic services, children are losing access to health and education.

While stigma and discrimination hamper almost every aspect of HIV/AIDS interventions, they severely hamper efforts to provide protection, care and support to vulnerable and affected children. HIV-positive mothers in Viet Nam speak of their children being ignored by nurses or driven out of school. Some mothers living with HIV/AIDS in Viet Nam abandon their babies because of prevailing prejudices. Children orphaned or affected by AIDS in China dare not say "AIDS" aloud, calling it the "strange illness" or the "blood-selling disease" for fear of being targeted. More than 60 per cent of people in the Philippines say HIV-positive teachers should not be allowed to work. Even in Thailand, a country that has developed an impressive response to HIV, children affected by HIV/AIDS are often shunned or run out of their communities.

Some countries, such as Thailand and Cambodia, are pouring considerable resources into addressing the protection, care and support needs of vulnerable and HIV/AIDS-affected children. But others,

especially those with large populations like China and Indonesia, must step up their efforts, especially at sub-national level.

East Asian countries can take a number of measures to assist children and families affected by HIV/AIDS. One is to tackle stigma and discrimination – at the community level as well as the national level. East Asian governments are slowly moving towards this goal: In 2004, China passed a law banning workplace discrimination of people with infectious diseases while Cambodia passed an HIV/AIDS law that also prohibits discrimination of infected people. Such laws represent significant progress, but more needs to be done – not only by governments, but also by the private sector, schools, religious and community leaders.

A link must also be made between all child protection issues and the ones faced by children affected and infected with HIV/AIDS. HIV/AIDS, exploitation and poverty feed off one another to deny children their rights. East Asian countries have all signed the Convention on the Rights of the Child, and must ensure that their laws are effectively enforced to protect these rights. In addition, it is important for all East Asian nations to endorse and pursue the strategies detailed in The Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV/AIDS.<sup>94</sup>

On a more individual level, another measure is to lend more support to families, the first safety net for children. Again, keeping parents and caregivers alive is one of the most important steps towards protecting children, underlining the need to integrate the aims of protection programmes with ones devoted to prevention and PMTCT. Families affected by HIV/AIDS also hugely benefit from economic support, especially in the form of income generation projects or microfinance loans. Other means of family support include home care and medical and psychosocial counselling.

Communities are the next safety net. By promoting community-based programmes, we can ensure that vulnerable children not only stay in their home villages or towns, but also are actively being looked after by community leaders and members. Both Thailand and Cambodia have established a wide network of alternative and community-based care and strategies for HIV-affected children and others at-risk. For example, several programmes in Cambodia work with Buddhist monks to keep children in schools or provide other educational training, and ultimately, build a community's capacity to take care of these children. The monks play a vital role in reducing stigma and discrimination, and as a result, many of the children participating in the programme say they are accepted by their communities. Even in China, where the traditional emphasis has been on institutions, officials are exploring and promoting alternatives such as adoptions, foster care and small group family homes.

Finally, for each and every individual child affected by or vulnerable to HIV/AIDS, protection, care and support can take so many different forms. Children can be given scholarships and other material help to ensure they remain in school. School-based meals and other practical aid can help guard against hunger and malnutrition, and thus increase school attendance. Paying special attention to girls helps us defeat gender discrimination, and in turn, curtail HIV infection in the long run. Moreover, providing psychosocial counselling and support has proven to be immensely important to children affected by

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### **Key strategies in the Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV/AIDS**

- Strengthen the capacity of families to protect and care for orphans and vulnerable children by prolonging the lives of parents and providing economic, psychosocial and other support.
  - Mobilize and support community-based responses.
  - Ensure access for orphans and vulnerable children to essential services, including education, health care, birth registration and others.
  - Ensure that governments protect the most vulnerable children through improved policy and legislation and by channelling resources to families and communities.
  - Raise awareness at all levels through advocacy and social mobilization to create a supportive environment for children and families affected by HIV/AIDS.
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## A pagoda that's tops in prevention

When Cambodian schoolteacher Chun Sopheap discovered he was HIV-positive, the news spread quickly. Friends ignored the father of three, acquaintances scattered when he ate at the market and his children were ostracized. For Sopheap's wife, the shame was unbearable. She fled, leaving a rapidly ailing Sopheap alone with their children.

At his home in a district of Cambodia's north-western Battambang province, Sopheap recalls his fears while he lay ill and without hope three years ago. "I was worried about my children so I tried, I struggled, to stay alive," he says.

Sopheap's experiences are far from unique. But a UNICEF-supported programme aimed at educating people about the realities of HIV/AIDS and assisting them with home-based care is offering much needed hope to children and families.



UNICEF/HQ00-0112/Shehzad Noorani

*A health worker from Svay Rieng provincial hospital in Cambodia distributes AIDS awareness and prevention materials to young monks.*

The focal point of the programme is Battambang's Wat Norea pagoda, where a Buddhist monk, the Venerable Muny Van Saveth, began noticing in 1997 that the number of children affected by HIV/AIDS was soaring. In 2000, with support from UNICEF, he began training monks, nuns and laypeople in HIV/AIDS prevention and home care. His model was the successful Sangha Metta project first instigated by UNICEF with Buddhist clergy in neighbouring Thailand several years before.

Hundreds of trainees fanned out across communities to assist those infected and affected and to promote care and compassion for them. "I wanted to create Buddhist role models, to show real examples of monks who are helping their communities," Venerable Saveth says.

In Wat Norea's surrounding communities alone, the transformation has been profound. More families are staying together; and fewer children are left vulnerable to trafficking into Asia's rampant sex trade. "In the past when people were HIV-positive, the community discriminated against the family involved. Infected children could not attend school because other children were afraid of catching HIV. Children would not play together," Venerable Saveth observes. "Now, people have a much better understanding."

"Our work is very important because we can prevent young people from getting HIV/AIDS and families breaking down," says outreach worker Tae Kung.

Venerable Saveth is particularly encouraged that the programme works with the leaders of Cambodia's minority Muslim and Christian communities. "We don't talk about religious issues when we get together. We connect on issues in society and discuss how religion can respond, not by praying to any god, but by working practically," he says.

Wat Norea's programme has been used as a blueprint for 18 other pagodas in Battambang province, and Cambodia's Ministry of Religion and Cults is now expanding it to pagodas across seven other provinces. More than 7,000 households in Battambang have already received HIV/AIDS-related information.

For Sopheap, visiting Wat Norea turned his life around. The pagoda's monks and outreach workers began calling on him, bringing him rice and other basic needs. They also offered counselling. The staff educated Sopheap's community about what being HIV-positive meant and the stigma his family was suffering evaporated.

Sopheap's wife made a brief visit back and the monks invited her to an education workshop. Amazed at the difference in attitude towards her and her husband, she decided to return home.

Sopheap also started taking ARVs. With his health improved, he is optimistic.

"The monks still follow up, the staff visit and ask about my health. If something happens, they're there to help. I want to live longer, and this depends on the support of the community and the monks," Sopheap declares. "If they are there to support me, I can support myself."

HIV/AIDS, but is rarely available in this region. This support can range from memory books or boxes filled with photographs of their families to child-friendly schools and activity centres.

All children need love, friendship, security and laughter – and these children especially. After participating in a child-based research project, one child in China wrote in a letter: “Although I lost my parents I feel happiness and delighted at this time. It is the first time I feel so happy since my parents have gone.”<sup>95</sup>

## Endnotes

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