



Background Paper



Scaling Up the Response for Children

East Asia and Pacific Regional Consultation on HIV/AIDS and Children
Hanoi, Viet Nam 22-24 March 2006

The East Asia and Pacific Regional Consultation on Children and AIDS is being jointly organized by the Vietnamese Commission for Population, Family and Children, Family Health International, Save the Children, UNAIDS, UNICEF, The U.S. President's Emergency Plan for AIDS Relief and WHO.

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Preface

“The countries of Asia and the Pacific stand at a crossroads, facing two diverging routes to the future. One route is ‘business as usual’. Though the easiest and cheapest route to take at the beginning, it ends up in rising levels of HIV infection and a toll far higher than the estimated 500,000 AIDS-related deaths that occurred in the region during 2004. The other route is one of determined prevention and care initiatives. Harder and more expensive at the beginning, it ends up stopping the epidemic in its tracks, and minimizing both its human and economic costs.”

– *A Scaled Up Response to AIDS in Asia and the Pacific*, UNAIDS, July 2005

This statement is especially poignant and true for the children of Asia and the Pacific. HIV/AIDS is taking a harsh and far-reaching toll on children. Increasing numbers of children in the region are becoming infected and dying, living with chronically ill parents and being orphaned, suffering stigma and discrimination that limit their opportunities and becoming more impoverished – all as a result of HIV and AIDS. This against a background where poverty, violence, trafficking and other abuses already leave many children vulnerable.

Leadership and resources for the fight against HIV and AIDS in East Asia and the Pacific are growing, but children are notably absent from the response agenda. Proven prevention, treatment, care, support and protection measures directed at children must be scaled up to ensure that this and future generations remain free from the impact of HIV and AIDS, able to enjoy their rights and to reach their potential as productive adults.

Scaling Up the Response for Children, the regional consultation on children and HIV/AIDS in Hanoi, Viet Nam, 22-24 March 2006 provides a key opportunity to put children on the HIV/AIDS agenda and mobilize an accelerated response in East Asia and the Pacific. This background paper is intended to stimulate thinking towards that end. We hope that consultation participants and other readers will reflect on the issues raised and bring forward new and creative ideas, resources and energy for working together to protect and benefit children.

Executive summary

Scaling Up the Response for Children – the regional consultation planned for 22-24 March 2006 in Hanoi – is the largest ever meeting to focus attention exclusively on the impact of HIV and AIDS on children in East Asia and the Pacific. Government representatives from countries throughout the region, donors and international agencies along with civil society partners and delegates under the age of 18 will come together to plan and commit to an accelerated response for children. The consultation offers a vital opportunity to place children prominently on the agenda for universal access to HIV/AIDS prevention, care and treatment and to mitigate the impact of HIV and AIDS on their lives. This background paper is intended to stimulate thinking on the key barriers and opportunities ahead.

HIV and AIDS are spreading fast in this region – faster in East Asia than anywhere else in the world.¹ Although the epidemic varies greatly across and even within countries, the growing threat is clear. Some countries, including Thailand, Cambodia, Myanmar and Papua New Guinea, face generalized epidemics with hundreds of thousands of children already affected. In China, Viet Nam and Indonesia, the epidemic is rapidly spreading and beginning to extend beyond marginalized groups, including sex workers and injecting drug users, into the general population. In other countries where prevalence remains low, aggressive action is needed to ensure that it stays that way. Throughout East Asia and the Pacific, 350,000 adults and children were newly infected with HIV during 2005.² Each new infection is a heart-wrenching personal story that one way or another causes harm and increased vulnerability for the children involved.

As a result of the growing epidemic, increasing numbers of children are becoming infected with HIV, living with chronically ill and dying parents, being orphaned, experiencing greater poverty, suffering stigma and discrimination and missing out on education and other fundamental rights and opportunities. Despite their suffering, children remain largely invisible in the response. Information is scant and inconsistent on children vulnerable to, infected and affected by HIV and AIDS in this region. Inadequate information may be leading to inaction and poor decision-making on the part of policy makers and practitioners. Programme coverage for children remains woefully inadequate.

Yet, there is hope. Global attention and resources are mounting for the HIV/AIDS response. The United Nations General Assembly on HIV/AIDS in 2001 and on Children in 2002 and the Scaling Up Towards Universal Access Initiative provide the mandate and the action agenda. HIV prevention remains paramount to ensure that the vast majority of infants and adolescents in this region remain uninfected through increased access to education, skills and services and expanded programmes for the prevention of mother-to-child transmission (PMTCT). The continuum of care integrating antiretroviral treatment with family-based care and support is proving essential for effective scale-up. Expanded legal and social protection for orphans and vulnerable children, including family-based alternative care, are urgently needed. Finally, aggressive efforts to address stigma and discrimination at all levels will be essential to achieving a scaled-up response.

National governments have a crucial and far-reaching role to play for children. In this region and all others, open and compassionate leadership has proven to be a fundamental element of success. Governments must take the lead in assessing the situation, setting targets and developing action plans, coordinating partners and sectors, mobilizing and channelling resources and establishing monitoring systems. Working across many sectors with a range of partners, governments in East Asia and the Pacific can mount an accelerated response that will make a difference for children.

Given all that is at stake, the regional consultation in Hanoi is not just another meeting. It is a crucial moment in the HIV/AIDS response that must be used to build a long-term collaborative process for the benefit of all children in East Asia and the Pacific.

The epidemiology of HIV and AIDS in East Asia and the Pacific

Approximately 130,000 people lost their lives to AIDS in East Asia and the Pacific during 2005 and over 350,000 adults and children were newly infected with HIV. Today, an estimated 2.5 million people in this region are living with HIV/AIDS.³ The vast majority do not have access to treatment, care or support.

The potential for further expansion of the epidemic is staggering. Due to the large populations in the region, low prevalence with even minimal increases translates into millions of people infected and affected by HIV/AIDS. If national responses remain the same, 2.7 million new HIV infections can be anticipated in East Asia and the Pacific between 2005 and 2010.⁴ Millions more will suffer economic, social and psychological harm as a result of the spreading epidemic.

Many different HIV and AIDS epidemics are underway in East Asia and the Pacific. Although low prevalence still predominates in this region, the epidemiological picture varies across and within countries. Some countries were hit early by the epidemic, including Thailand and Cambodia, while others such as Viet Nam, Indonesia and China, are now starting to experience rapid escalation of prevalence. East Asia is now home to the fastest growing epidemics in the world. Thailand, Cambodia and Myanmar all have generalized epidemics. Papua New Guinea is heading towards a severe epidemic most closely mirroring the epidemics found in sub-Saharan Africa, while Timor-Leste, the Philippines and others are still experiencing very low prevalence. Within countries too, there is wide variation in prevalence, with some sub-national areas and surveillance populations experiencing severe epidemics.⁵

Risky behaviours continue to fuel the spread of HIV and AIDS in East Asia and the Pacific. Injecting drug use, sex work and interplay between the two continue to be the primary driving forces of HIV and AIDS. In most countries, the epidemic is still largely limited to populations engaging in one or both of these risky behaviours. However, as injecting drug users, sex workers and their clients infect their spouses, other partners and children, HIV and AIDS begin to spread into the general population. The mix of risk factors currently in place in many parts of the region can quickly escalate a low prevalence or concentrated epidemic into a widespread, generalized epidemic.

Already, significant economic losses due to HIV and AIDS in Asia and the Pacific threaten to escalate if aggressive action is not taken. A study conducted by UNAIDS and the Asian Development Bank documented economic losses due to AIDS totalling US\$7.3 billion in 2001 and estimated that losses could exceed US\$18 billion annually from 2010, reaching US\$27 billion by 2015. The implications for poverty reduction and other development agendas are devastating. For example, HIV and AIDS could slow down the rate of poverty reduction by 60 per cent in Cambodia every year between 2003 and 2015.⁶

HIV/AIDS and children

One of the most tragic consequences of the HIV/AIDS epidemic is the harsh toll it is taking on children and their families.⁷ Many of the 580 million children currently living in East Asia and the Pacific experience vulnerability from one or more causes. These include poverty, violence, sexual exploitation, abuse, malnutrition, population mobility, economic stagnation and even the rapid economic growth and development now underway in some countries. Urbanization and the expansion of modern economies have been associated with increases in sex work, trafficking, injecting drug use⁸ and other risks to children while at the same time breaking down extended families and other social safety nets. The end result is that children are left less secure and more vulnerable to dangerous risks, including the spread of HIV and AIDS and their consequences. Children are affected by HIV and AIDS in a wide range of direct and indirect ways, all of which jeopardize their basic rights.

Children vulnerable to, infected and affected by HIV and AIDS

Rapidly increasing numbers of children under 18 years of age in Asia and the Pacific are:

- Losing one or both parents to HIV/AIDS;
- Living with chronically ill or dying mothers, fathers, or both parents;
- Becoming infected with HIV or at greater risk of infection;
- Experiencing deepened poverty as a result of AIDS-related illness in the household or the addition of orphaned children to be cared for;
- Suffering from stigma and discrimination because of their HIV status or association with a person living with HIV/AIDS; and
- Losing out on opportunities for education, health care and other basic rights as a result of their association with HIV and AIDS.

In East Asia and the Pacific, most children and adolescents vulnerable to, infected and affected by HIV and AIDS have become so as a result of their own or their parents' engagement in injecting drug use and/or sex work. However, the situation varies across and within countries and HIV and AIDS can quickly slip from marginalized groups into the wider population, putting all children at greater risk.

The response to children vulnerable to, infected and affected by HIV and AIDS in East Asia and the Pacific is greatly hindered by the fact that statistics on children infected and affected are not available in most countries. Rough regional estimates understate the problem but indicate that by the end of 2005, throughout East Asia and the Pacific, 31,000 children under 15 were living with HIV/AIDS, nearly 11,000 of whom were newly infected in the past year. Of these, 8,500 were in immediate need of antiretroviral therapy.⁹ Approximately 450,000 children had lost one or both parents to HIV/AIDS and at least that many were living with a chronically ill parent. Millions more are at high risk of HIV infection or have suffered impoverishment and/or stigma and discrimination as a result of their association with a person living with HIV/AIDS or an affected household.

The continuing effects of HIV/AIDS on children

"When I was 14, both of my parents passed away from AIDS. My mother was a prostitute. When they died, the pimp family with whom we lived drove me out. I had nowhere to go and sat on the road. There, I met with 'Mommy'. She gave me some encouraging words and took me to her house. When I turned 15, Mommy asked me if I wanted to work. Afterward, I got into this business."

– 18-year-old sex worker in East Asia¹⁰

Scaling up the response for children

There is growing recognition of the importance of children in the global HIV/AIDS response. National leaders committed to the protection and care of orphans and vulnerable children through goals set at the United Nations General Assembly special sessions (UNGASS) on HIV/AIDS in 2001 and on Children in 2002. In 2003, the global partners' forum on orphans and vulnerable children was established and consensus was reached on a response framework.¹¹ In 2005, UNICEF and its partners launched a global campaign for children vulnerable to, infected and affected by HIV and AIDS. Despite these commitments, children are barely visible in the regional response and action lags far behind the commitments made.

As resolved at the October 2005 United Nations General Assembly, the Universal Access Initiative includes a focus on orphans and vulnerable children:

*"We commit ourselves to: Developing and implementing a package for HIV prevention, treatment and care with the aim of coming as close as possible to the goal of universal access by 2010 for all those who need it, including through increased resources and working towards the elimination of stigma and discrimination, enhanced access to affordable medicines and the reduction of vulnerability of persons affected by HIV/AIDS and other health issues, in particular orphaned and vulnerable children and older persons."*¹²

However, children are not prominent in Universal Access planning documents and evolving country plans.

Although coverage data for children are limited, coverage estimates for especially vulnerable populations are distressingly low (see Table 1).

Table 1: Coverage of key vulnerable groups in Asia and the Pacific

Population	Estimated 2003 Coverage	
	Asia	Pacific
Coverage with prevention interventions		
■ Children living in the streets	22%	20%
■ Sex workers	19%	11%
■ Injecting drug users	5%	3%
Condom use during risky sexual acts	8%	
Pregnant women receiving HIV testing	8%	3%
Access to treatment with antiretroviral drugs	6%	12%
■ Among children ill with AIDS	<1%	
AIDS-affected households receiving home-based care	4%	

Source: UNAIDS, *A Scaled Up Response to AIDS in Asia and the Pacific*, July 2005.

At these rates, the countries of Asia and the Pacific are in grave danger of a heightened, more generalized epidemic with many millions of people affected. Children are especially vulnerable to the range of devastating affects.

Yet, there is hope. Leadership and resources for the response are growing. The cost of antiretroviral drugs has dropped significantly, making universal access to treatment a real possibility for low-income countries. Most importantly, 99 per cent of the population in this region remains uninfected, and proven interventions exist to prevent the spread and mitigate the impact of HIV and AIDS.

The action agenda

Four key areas of action for children vulnerable to, infected and affected by HIV/AIDS are: (1) primary HIV prevention, including the prevention of mother-to-child transmission; (2) paediatric antiretroviral treatment and clinical care; (3) supporting orphans and vulnerable children; and (4) reducing stigma and discrimination associated with HIV and AIDS. There is significant overlap among these areas and scale-up will require an integrated approach that addresses children and the whole family within their community context.

Prevent the spread of HIV

Prevention is the highest priority to ensure that children are directly protected from HIV. UNAIDS estimates that a scaled-up response could reduce new infections by half in Asia, preventing six million new infections by 2010.¹³ East Asia is home to some of the greatest HIV prevention successes in the world and can also benefit from lessons learned in other regions. To prevent children from contracting the HIV virus, two arms of intervention are required: primary prevention and PMTCT.

Primary prevention

To avoid HIV infection, children, adolescents and their families require a combination of knowledge, skills and services. In East Asia and the Pacific, these essential ingredients are lacking, especially among those at greatest risk of infection. Knowledge about transmission and ways to avoid infection is not sufficient to change behaviour. Older children and adolescents at risk of infection require negotiation skills and access to a range of services, including voluntary confidential counselling and testing (VCT), clean injecting equipment, condoms and treatment for sexually transmitted infections.

Knowledge about HIV and AIDS is still alarmingly low

The basic facts about HIV transmission and prevention remain alarmingly low. More than two decades after the first HIV cases were reported, a recent survey showed 83 per cent of young Filipinos believed that they were immune to HIV. 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. A survey in China found that 50 per cent of 2,500 girls aged 15-20 could not name a single way of protecting themselves from HIV infection. In Viet Nam and Cambodia, nearly 40 per cent of young women surveyed believed that a healthy-looking person could not have HIV.¹⁴

Several challenges hinder prevention efforts in this region. Pervasive stigma and discrimination limit the reach and depth of prevention efforts. Risk factors, including injecting drug use and sex work, are hidden in society; therefore, individuals at high risk are hard to reach. Children living on the streets and children who are trafficked are also extremely vulnerable and often miss out on vital services, including HIV prevention. Religious and cultural taboos prevent parents and educators from addressing HIV/AIDS-related topics such as safe sex, condom use and harm reduction with children and adolescents. Financial resources for HIV prevention in East Asia and the Pacific are limited. Available resources are often spread thinly across the general population without targeted efforts to reach individuals at high risk with essential knowledge, skills and services.

To overcome these barriers, culturally appropriate, targeted education and service interventions designed with the input of children and adolescents must be urgently scaled up.

Reaching vulnerable adolescents with education, skills and youth-friendly services in Myanmar¹⁵

The isolated eastern border areas of Myanmar experience cross-border migration, trafficking, injecting drug use and sex work. They also neighbour high HIV-prevalence regions of Thailand and China. For all these reasons, adolescents living here are especially vulnerable to HIV infection. A programme supported by Save the Children UK focuses on out-of-school adolescents from ethnic minority and migrant communities to increase their knowledge and skills and improve sexual and reproductive health services.

In order to develop effective responses, cultural analysis with young people provided the entry point. Peer educators were recruited from a variety of populations, ranging from migrant labourers and sex workers to Buddhist monks and Catholic novices. Culturally appropriate curriculum was also developed for community midwives in the area to help them understand the needs of adolescents in relation to sexual and reproductive health and to encourage non-judgemental and supportive attitudes towards adolescents. One midwife explained how significant the training had been in changing her attitude:

“No one teaches adolescents about sex. We have been keeping silent on the issue because we think we should not teach them such dirty things. But children learn from adult videos... Adolescents are experimenting with sex because they don't know the consequence at all. That is why reproductive health problems among them become more and more common. Now I realize that it is our responsibility to provide proper information to them.”

As the programme has developed, it has been integrated with efforts to provide quality home-based care for adolescents living with HIV and AIDS, to reduce discrimination against these children and to combat trafficking, a significant source of child vulnerability in this area.

There are many routes to expand the reach of prevention interventions, and countries will have to find the appropriate mix of strategies. In Cambodia, HIV prevention interventions are being greatly expanded through VCT services at reproductive health centres.

Extending prevention to families through voluntary HIV counselling and testing in Cambodia¹⁶

In an effort to bring the fight against HIV and AIDS to the family, the Reproductive Health Association of Cambodia (RHAC), supported by USAID and UNICEF, runs a voluntary HIV counselling and testing (VCT) programme through its reproductive health centres. Counsellors provide information about HIV and AIDS and VCT services to all clients. Clients often come to the centres for other sexually transmitted infections that are themselves a risk factor for HIV and are spread through the same sexual behaviours that put people at greater risk for HIV infection. Clinic workers have been specifically trained to serve adolescents.

By providing counselling to those being tested for HIV, the programme is reducing infection rates and risky behaviour of clients and disseminating educational messages on reproductive health to families.

After counselling, female clients said that they feel more comfortable discussing topics such as stress and sexual history with their health providers and are more confident discussing birth control and HIV/AIDS prevention with their partners. The programme refers and encourages those who test positive to seek advice, health care services and treatment at HIV/AIDS care centres.

Preventing mother-to-child transmission (PMTCT)

Between 20 and 45 per cent of pregnant women living with HIV/AIDS will pass the virus onto their children during pregnancy and delivery or through breastfeeding.¹⁷ Newborns who escape infection are most often orphaned at a young age because their mothers have no access to care and treatment. As described in individual and focus group discussions with children affected by HIV/AIDS in Cambodia, the route of transmission begins with risky behaviour.

“The father goes to town, he meets sex workers, and when he comes back, he gives HIV/AIDS to the mother ... the mother breastfeeds her baby and she has no medicine, so she gives HIV/AIDS to the child.”¹⁸

Supporting HIV-positive pregnant women and their newborns goes far beyond providing them with antiretroviral drugs. It includes providing VCT services, counselling HIV-negative women and couples on prevention, assisting HIV-positive women to make informed decisions about future pregnancies, encouraging safe delivery practices, giving advice on infant feeding, and providing care and support to the entire family.¹⁹ The priority and scope of a PMTCT programme however, will depend on HIV prevalence as well as available financial and human capacity.

PMTCT in low-prevalence settings

At the recent United Nations regional PMTCT task force meeting for Asia and the Pacific, a number of programmatic themes and recommendations were highlighted²⁰, including:

- Plans for PMTCT scale-up should be locally determined. Low-prevalence countries with limited resources may prioritize primary prevention (including counselling HIV-negative women and reproductive health support for HIV-positive women) over expanding the provision of HIV testing and antiretroviral drugs.
- All PMTCT programmes in low-prevalence countries should include a strong primary prevention component.
- More attention is needed on the quality of HIV counselling and not just availability. Adequate and appropriate training, counselling aids and incentives for counsellors are required.
- PMTCT programs need to be well-linked to treatment programmes and support initiatives for orphans and vulnerable children as part of a comprehensive continuum of care.

Increase access to care and treatment

Every day in East Asia and the Pacific, there are more children infected with HIV and in need of medical care consisting of highly active antiretroviral therapy, co-trimoxazole prophylaxis and/or other clinical interventions. These include young children infected through maternal transmission as well as adolescents infected through injecting drug use, unprotected sex or other risky behaviour. Current evidence suggests that the course of untreated HIV disease in young children is more aggressive than in adults, with 30 per cent of infected children dying by the age of one year and 50 per cent dying by the age of two years.²¹ Research in Thailand has demonstrated that paediatric antiretroviral treatment can be effective and safe in resource-limited settings, despite initiation of treatment during the advanced stage of the disease, and even though only generic and non-paediatric drug formulations are available.²² The prophylactic use of co-trimoxazole has been shown to reduce mortality in children living with HIV/AIDS by one third or more in some settings.²³ Guidelines have been developed for care, treatment and support of infants and children born to HIV-infected mothers in resource-constrained settings.²⁴

In countries with generalized epidemics, including Thailand, Cambodia, Myanmar and Papua New Guinea, scaling up treatment services for children and adolescents is an especially high priority. Yet only one per cent of the estimated 8,500 children in East Asia and the Pacific who could have benefited from treatment during 2005 actually received it.²⁵ Children are not receiving care and treatment because their HIV status is unknown, they are lost to follow-up or care and treatment services are unavailable. Older children and adolescents living with HIV and AIDS are not receiving treatment because most have not been identified as HIV-positive, stigma and discrimination limits their access to testing and treatment and/or they live in highly marginalized communities outside of the reach of most health services. Adolescents have different care and treatment needs as they may have particular psychosocial, disclosure and adherence issues.²⁶

Other barriers to providing treatment for children living with HIV and AIDS include stigma and discrimination from health workers, an attitude of hopelessness on the part of caregivers, the challenge and expense of paediatric diagnosis and laboratory monitoring, lack of availability and higher cost of paediatric formulations, difficulty with compliance and lack of support for parents and other caregivers who must follow through with the requirements of care and treatment. Despite these barriers, progress is being made in some countries and the numbers of children receiving effective treatment is beginning to increase.

Clinical care for children and adolescents: Lessons learned in Thailand and Cambodia²⁷

- Care should be family-centred to better meet the needs of parents or caregivers and children and adolescents. Family care improves adherence, is more resource-efficient, ensures all family members are treated and offers psychosocial support to the whole family.
- Paediatric HIV care should be mainstreamed into child health and HIV care programmes and guidelines.
- To reach children and adolescents in need of treatment and care, multiple gateways are needed, including PMTCT programmes, hospitals and community outreach.
- Availability of drugs and infrastructure, including laboratories, data reporting and referral systems, must be assured before scaling up treatment services.
- Effective service delivery requires a well-trained, motivated team of doctor, nurse, pharmacist, laboratory technician, counsellor and community workers.

Protect orphans and vulnerable children affected by HIV and AIDS

Prevention and treatment are only part of the response needed for children. Millions of children are adversely affected by the HIV/AIDS epidemic because they have lost a parent or other caregiver to AIDS or are living with a chronically ill adult. Setting a common definition for children orphaned and made vulnerable by HIV and AIDS has been an important challenge for high-prevalence countries. The standard definitions outlined below have been adopted by the United Nations and are essential for assessing progress towards global goals and making cross-country comparisons.

Monitoring definitions of children orphaned and made vulnerable by HIV/AIDS²⁸

A child orphaned by AIDS is a child aged under 18 years whose mother, father or both parents have died from AIDS.

A child made vulnerable by HIV/AIDS is a child who:

Has a chronically ill parent;

Lives in a household with a chronically ill adult;

Lives in a household with an adult death in the past year; or

Lives outside of family care (in an institution or in the street);

And any other context-specific vulnerability indicators:

In low-prevalence countries, a number of non-HIV/AIDS related childhood vulnerabilities predominate. These may include poverty, malnutrition as well as various rights abuses. In this context, locally extended definitions of vulnerability are crucial to reduce both inclusion and exclusion-based discrimination and ensure better programming and outcomes for children.

Children orphaned and made vulnerable by HIV and AIDS may suffer a number of deprivations, including: economic hardship; lack of love, attention and affection; withdrawal from or interruption of school; psychological distress; loss of inheritance; increased abuse and risk of HIV infection; and stigma, discrimination and isolation.²⁹

The *Framework for protection, care and support of orphans and vulnerable children living in a world with HIV/AIDS*³⁰ defines current agreement on five programming strategies while emphasizing that the impact of HIV and AIDS on children varies considerably from one context to another. "There is no model or specific set of interventions that can be prescribed for all communities, countries and regions. For this reason, within each country, the mix of strategies and actions will vary according to locally identified needs, capacities and priorities."³¹ The five broad programming strategies are:

1) Strengthen the capacity of families to protect and care for orphans and vulnerable children.

Ensuring that orphaned children are provided with the most family-like care environment and that institutional care is used only as a last resort or temporary measure is a priority for many countries. However, families that take in children often require some external assistance, including, for example, material support, investment and training to build economic resilience, psychosocial support and help with succession planning.

2) Mobilize community-based responses to support affected families.

Community initiatives are providing much-needed support for orphans and vulnerable children in East Asia and the Pacific. Faith-based initiatives, such as the Sangha Metta Project described later in this report, involve pagodas, churches or temples and may offer outreach, psychosocial support and temporary or day care for orphans and vulnerable children.

3) Ensure equal access to essential services for orphans and vulnerable children.

Of particular importance are birth registration, education and health services. Ensuring that all children are registered at birth is important for their identity and access to social welfare services. Stigma and discrimination as well as financial and other barriers often prevent orphans and children made vulnerable by HIV and AIDS from staying in school and/or accessing much-needed health services. A quality basic education is one of the most effective ways to keep children from engaging in risky behaviours and acquiring HIV infection.

4) Provide government protection for the most vulnerable children.

As described more fully below, governments have the ultimate responsibility of protecting the rights of orphans and vulnerable children.

5) Raise awareness to create a supportive environment for all children.

Efforts to reduce stigma and discrimination and engender compassion for children affected by HIV and AIDS will improve results in HIV prevention, care and treatment and all of the framework strategies.

Reduce stigma and discrimination

*"Children know that when people know a family member is infected with HIV, the whole family is affected, and that they cannot find a job in the future and no one will want to marry them."*³²

Stigma and discrimination associated with HIV and AIDS is deeply entrenched in culture and society and permeates every aspect of the response. HIV and AIDS, orphanhood, poverty, sex work and injecting drug use are all targets of stigma and discrimination. Sex workers and injecting drug users are shunned by society and therefore especially hard to reach with needed interventions. People at risk are unwilling to seek testing, treatment, care and other services for fear of being ill-treated. Children orphaned or made vulnerable by HIV and AIDS are often isolated and may lose out on opportunities for education, health care and other essential services. They may be unwelcome by relatives and other potential caretakers because of their association with HIV/AIDS.

Efforts to combat stigma and discrimination must also be pervasive. A mix of strategies implemented through multiple channels at all levels will be required. Successful efforts have included government leadership, legislative and policy reform, outspoken people living with HIV and AIDS, local leaders and celebrities, multimedia campaigns and community mobilization.

Building community support and reducing stigma: The Sangha Metta Project³³

The Sangha Metta (Compassionate Brethren) project was initiated by a lay Buddhist teacher in 1997 to extend the traditional role that monks and nuns play in community social welfare to include HIV prevention, care and support activities. Stigma was challenged through the intervention of monks in communities of northern Thailand in many ways, and the following results were achieved:

- HIV-positive children previously denied admission to school were re-admitted.
- Grandparents who removed their grandchild from her HIV-positive mother's care returned the child.
- A young HIV-positive woman rejected by her family is now back home receiving care and support.

The model has been expanded to Myanmar, Cambodia, China, Lao PDR, Viet Nam and other Asian countries. It has also been used successfully with Christian, Hindu and Islamic leaders and an interfaith network is being established.

The national process

Across the globe, HIV and AIDS success stories share a common backdrop of open and strong national leadership. In East Asia and the Pacific, Thailand and Cambodia achieved significant reduction in incidence with an aggressive multi-faceted approach driven by bold government and community leaders. Governments that are silent on HIV and AIDS or exercise stigma and discrimination against people affected by AIDS fuel the epidemic and its worst consequences for children.

Governments have the ultimate responsibility to protect children and ensure their well-being.³⁴ They have a central role to play in all aspects of the HIV/AIDS response. Key areas of national responsibility include assessment and monitoring, planning, coordination, legislation and financing.

Assessment and monitoring

An initial situation assessment of children and youth vulnerable to, infected and affected by HIV and AIDS can assist governments and partners in acquiring a common understanding of the factors that fuel vulnerability and identifying opportunities for prevention and mitigation. Urgently needed throughout the region are better estimates of the number of children vulnerable to, infected and affected and qualitative information on the circumstances of these children. Several countries have assessed the situation of children³⁵, but the definitions used, quality and scope of these assessments varies. Assessments need not be national in scope, but can focus on the most affected regions and communities. Assessments should be more than a technical exercise carried out by a single party. Collaboration led by government but including children and young people and other key partners will enhance design; results and analysis and will heighten awareness and commitment among stakeholders.

A situation assessment gives only one snapshot in time. Government also has responsibility for ongoing monitoring of progress for children vulnerable to, infected and affected by HIV and AIDS. Common indicators have been developed for national HIV/AIDS prevention programmes for young people³⁶, for the prevention of HIV in infants and young children³⁷ and for orphans and vulnerable children.³⁸ A monitoring system that collects reliable and consistent information over time is essential for understanding the impact of HIV and AIDS on children, planning and monitoring policies and programmes, national and regional advocacy and for providing focus for the different sectors and partners involved.

Efforts to systematically monitor programme effectiveness and quality must also be strengthened and expanded. Identifying and disseminating best practices and lessons learned will contribute to continual programme improvement and expansion and better outcomes for children.

Action planning and policy development

As part of the 'Three Ones' strategy³⁹, UNAIDS recommends the establishment of one comprehensive HIV/AIDS framework or action plan. Although many countries have developed national HIV/AIDS plans, the issues surrounding children are rarely emphasized. The development of country-specific plans and targets for Scaling Up Towards Universal Access provides an important opportunity to ensure that children are made more prominent on the response agenda.

Government policies provide the framework for any national action plan. Policies that permit or encourage discrimination hinder the HIV/AIDS response while policies that promote open dialogue and access will accelerate results for children. The "Four Frees and One Care" policy introduced in China during 2003 aims to provide free antiretroviral drugs to people living with AIDS in the rural areas and the urban poor, free VCT, free drugs to prevent mother-to-child transmission, free schooling for children orphaned by AIDS and care and economic assistance to the households of people living with HIV and AIDS.⁴⁰ After years of silence and stigma, this unprecedented move is providing the potential for a truly effective response in the world's most populated country.

Coordination of a multi-sectoral response

UNAIDS also recommends the establishment of one national AIDS authority to maximize and coordinate the inputs of various stakeholders. With so many different sectors and organizations working for children (e.g. social welfare, education, health care, community and faith-based organizations, etc.), it is important to have a coordinating body that focuses specifically on children. This structure may be a sub-committee of the national HIV/AIDS authority or an existing committee with a broader child welfare mandate that is closely linked to the HIV/AIDS authority. An example of the former comes from Cambodia, where the Committee on Children is run by the National AIDS Authority and includes government ministries, UN agencies and non-governmental organizations.

Legislation to protect children

Most countries have several pieces of legislation that relate to the rights, protection, care and support of children. As is now underway in Viet Nam,⁴¹ existing legislation needs to be reviewed and revised to reflect current international standards and address the challenges for children posed by HIV and AIDS and other sources of vulnerability. Most importantly, there must be effective structures for the implementation and enforcement of legislation.

Legislation that protects children vulnerable to, infected and affected by HIV and AIDS includes:⁴²

- Promoting and ensuring access to confidential, voluntary HIV counselling and testing;
- Prohibiting discrimination in health care, schools, employment or other areas based on actual or presumed HIV status;
- Providing placement and guardianship for children who lack adequate adult care;
- Ensuring women's rights to own property and hold jobs;
- Protecting the inheritance rights of orphans and widows;
- Protecting children against abuse, neglect and sexual contact with adults;
- Eliminating the worst forms of child labour;
- Eliminating barriers that keep children from attending school or accessing health care;
- Protecting children who live on the streets;
- Developing policies that encourage and support family-based placements for children without adequate family care;
- Establishing specific standards for alternative care of children without family support, including steps to prevent separation of siblings, first preference for family-based placements, use of institutional placements as a last resort and temporary measure, and the involvement of children in decisions regarding their placements.

Financing to ensure an adequate and sustained response

Although East Asia and the Pacific have benefited from the global growth in financial resources for HIV and AIDS, the increase in spending in the region has been slower than in other parts of the world, even as the epidemic accelerates. Except in Thailand, most of the money spent on care and treatment comes directly from AIDS-affected households, many of them already desperately poor. Public expenditure on prevention programmes in the region during 2003 covered only 20 per cent of needed resources. Given the current level of under-funding, the growing backlog of prevention, care and treatment needs, and the level of resources required to mount and sustain a comprehensive response, current and projected funding is woefully inadequate.⁴³

No regional estimates exist for the proportion of funding that is channelled for children vulnerable to, infected and affected by HIV and AIDS. Given the inadequacy of overall spending on HIV/AIDS in the region, the notable absence of children from the response agenda and the extremely low coverage of interventions, it can be assumed that children's needs are significantly under-funded. Even where HIV/AIDS funding is directed to children, it may be spread widely across the general population and not reaching those children and adolescents at greatest risk.

HIV and AIDS pose an immediate crisis and a long-term challenge for children. Each year, a new cohort of children is exposed to the risk of HIV and AIDS, so aggressive prevention efforts must be maintained, even in situations of very low prevalence. In Thailand, earlier successes in reducing prevalence may soon be reversed as prevention efforts lose momentum. When a parent or other caregiver is infected with HIV, the impact on children lasts over many years, and age-appropriate support is needed throughout their development. Treatment itself is a lifetime commitment. For these reasons and more, governments and donors must adopt a long-term framework as they plan to accelerate financing for children and HIV/AIDS.

Key themes and recommendations

The HIV/AIDS epidemic poses grave and growing consequences for children in East Asia and the Pacific. The know-how and potential exists for an effective response to prevent further spread and to mitigate the impacts of HIV and AIDS on children.

Scaling Up the Response for Children, the East Asia and Pacific regional consultation on HIV/AIDS and Children is a unique and groundbreaking opportunity for national delegations from a wide range of countries to collectively strategize and commit to increased action for children vulnerable to, infected and affected by HIV and AIDS. Sessions and discussions will focus on many of the themes and recommendations that recur within this document. Specifically, delegates will consider the following:

Country-specific planning – The HIV/AIDS epidemic and the circumstances of children vary greatly across the region and within countries. Available resources do not permit countries to take on all aspects of the response with equal force nor does the epidemiology warrant such an approach. National delegations and their partners will be asked to consider relevant priorities and strategies for their countries.

Increasing access to prevention, care, treatment and support – The Scaling Up Towards Universal Access initiative offers a process for setting targets and designing action plans that include children. Country delegations will consider how to best achieve a scaled-up response for children vulnerable to, infected and affected by HIV/AIDS.

Improving the evidence base – The regional response is greatly inhibited by a lack of good quality, consistent data on children vulnerable to, infected and affected by HIV and AIDS. Current estimates are widely thought to underestimate the scale of the problem and may be leading to poor decision-making and resource allocation. Situation assessments and monitoring systems are urgently needed to better understand and respond to the needs of children.

Resource mobilization – National delegations and regional partners must work collectively to mobilize more resources for the response to HIV/AIDS in general and for children in particular. Prevention remains the greatest hope for this region, and resources available fall far short of estimated needs in the coming years. Clear strategies are needed to increase the resource base and sustain it over the long term.

Engendering compassion – Consultation delegates represent a powerful force in the fight against stigma and discrimination surrounding HIV and AIDS. The sooner countries open up a public dialogue on HIV/AIDS and come to terms with the issues that must be addressed to halt the epidemic, the better the chances of protecting children. Delegates will be challenged to consider ways in which they can influence attitudes and reduce discrimination against children and their families infected and affected by HIV and AIDS.

The regional consultation will challenge participants to think collectively and creatively on the many obstacles and opportunities and to reach consensus on moving forward. The true measure of the consultation's success, however, will be in what is achieved for children throughout the region after the closing ceremony.

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