

Getting it Right



**Case Studies on Paediatric HIV Treatment,
Care and Support in Thailand and Cambodia**



Scaling Up the Response for Children

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By Robert Horn

Cover photographs (from left to right):

- 1) Girl child from a residential rehabilitation and recovery centre, Cambodia:
Alessandro Di Meo/UNICEF Cambodia
- 2) Mother and infant at UNICEF's "Seth Koma" (Child's Rights) programme, Prey Keddey,
Kompong Speu Province, Cambodia: John Vink/UNICEF Cambodia/2003
- 3) Girl child from a residential rehabilitation and recovery centre, Cambodia:
Alessandro Di Meo/UNICEF Cambodia
- 4) Girl child at the Battambang paediatric care unit, Battambang Hospital, Cambodia:
Sedtha CHIN/UNICEF Cambodia/2009
- 5) Stateless boy playing with the toy in his village: Nonglak Boonyabuddhi/UNICEF Thailand/2008

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Preface

Paediatric HIV treatment and care is a relatively new phenomenon in East Asia and Pacific region. Although the HIV and AIDS epidemic first appeared on the continent in 1984, it was not until the mid to late 1990s that significant numbers of children infected with HIV and health care providers began turning up at hospitals in certain countries. By that time, several countries were making strong efforts at responding to this new health care crisis, but the responses were targeted at adults, as adults represented the first line of infection and the vast majority of those infected. By the late 1990s, however, it was clear that an epidemic among children was already underway in some countries, and in others it was looming on the horizon.

A few countries were able to make the leap from merely treating HIV-positive children for opportunistic infections to launching comprehensive programmes for paediatric HIV treatment, care and support. Among countries in the region, Thailand and Cambodia have invested in HIV paediatric care and are now making good progress in this priority area. In this report, two case studies of programmes that have yielded significant results for children in both countries are presented.

This report consists of two case studies of paediatric HIV programmes, one in Thailand and one in neighbouring Cambodia. While initially conceived as a compilation of “best practices”, those involved in these programmes preferred to label them as “good practices”, because while they believed their efforts were bearing positive results, no one could say with certainty that their methods and approaches were in fact the “best”. In the spirit of open-minded scientific and clinical inquiry, they acknowledged the possibility that there may yet be better ways to respond to the situation of HIV among children that they have yet to learn or discover. It is in that same spirit of open-minded inquiry that these two studies are presented.

Evidence from the first case study titled “Bridging the gap – Uniting to treat children with HIV in Thailand” showed that successful response must go beyond simply dispensing medication. Initial and long-term follow up including home visits to initiate treatment, monitor adherence including provision of psychosocial care and support for children and caregivers are a key to achieving success.

The second case study “Building from Scratch – HIV funds rebuild paediatric health care in Cambodia” has demonstrated that improving the physical facilities of paediatric wards and the general paediatric health care services have increased service utilization by the public. Furthermore, both case studies have pointed out that strong collaborative work with nongovernmental organizations (NGOs) and people living with HIV and AIDS (PLHA) groups are the essential ingredients for success and can be applied in many other settings.

It is hoped that the experiences and lessons learned in these two settings may prove useful for others engaged in, or planning to engage in developing national and local programmatic responses to paediatric HIV.

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Acronyms

AIDS	Acquired immune deficiency syndrome
ANC	Antenatal Care
ART	Antiretroviral therapy
ARV	Antiretroviral
CAN	Children’s ART Network
CBO	Community-based organization
CCC	Comprehensive continuum of care
CDC	Centers for Disease Control and Prevention
CDFC	Community development for children
CDHS	Cambodia Demographic Health Survey
CoC	Continuum of care
CPN+	Cambodian Positive People’s Network
HCBC	Home and community-based care
HIV	Human immunodeficiency virus
ICCO	Inter church organization for development cooperation, Netherlands
IDU	Injecting drug user
MCH	Maternal and child health
MMM	Mondul Mith Chouy Mith or Friends Helping Friends
MOH	Ministry of Health
MOPH	Ministry of Public Health
MSM	Men who have sex with men
NCHADS	National Committee on HIV and AIDS, Dermatology and Sexually Transmitted Diseases (Cambodia)
NGO	Nongovernmental organization
NPH	National Paediatric Hospital (in Phnom Penh)
OI	Opportunistic infection
PLHA	People living with HIV and AIDS
PHPT	Programme for HIV Prevention and Treatment
PMTCT	Prevention of mother-to-child transmission (of HIV)
RH	Reproductive health
STD	Sexually transmitted disease
STI	Sexually transmitted infection
TB	Tuberculosis
TNP+	Thai Network of People Living with HIV and AIDS
TUC	Thailand Ministry of Public Health – United States Centers for Disease Control and Prevention Collaboration
UNAIDS	Joint United Nations Commission on HIV and AIDS
UNICEF EAPRO	United Nations Children’s Fund East Asia and Pacific Regional Office
VCCT	Voluntary and confidential counselling and testing

Understanding the context

Thailand and Cambodia were chosen as the subjects of the case studies on paediatric HIV for good reasons. They are among the four countries in East Asia and Pacific that have experienced the highest HIV prevalence (3.2 per cent among adults in Cambodia in 1998 and 2.1 per cent in Thailand in 1994-96). Their responses to the epidemic – both among adults and children – have been deservedly praised as success stories (prevalence has fallen to 0.8 per cent among adults in Cambodia, and 1.4 per cent in Thailand in 2007). It should be acknowledged, however, that these successful responses were neither smooth nor without setbacks at some points, and that constant vigilance will be required to ensure that positive results are maintained and advanced. Lastly, both countries are resource challenged, although to different degrees. Thailand is referred to as a “middle income” nation, but remains a developing country with great disparities in wealth, uneven infrastructure and service availability, and relatively weak social welfare systems. It is easy to find pockets of poverty in Thailand, and HIV is primarily an epidemic of the poor. Cambodia, recovering from decades of violent civil conflict, is among the poorest nations on earth. If these two countries, which struggle with resource constraints, have been able to mount an effective response, it is more difficult for other governments to argue that an effective response is too costly and beyond their means.

Although Thailand’s programme for paediatric HIV treatment and care was piloted in 2002, and Cambodia’s response to children with HIV first began to be formulated in 2003, the issue of children infected and affected with HIV and AIDS was not recognised as a truly regional issue until 2006. In March of that year, UNICEF convened the East Asia and Pacific Regional Hanoi Consultation on Children and HIV and AIDS. The meeting declared that children had for too long been “the missing face of HIV and AIDS”. A central goal of the gathering was to garner commitments to put children at the centre of national responses across the region.

One of the core dilemmas in effectively responding to the epidemic among children that was immediately apparent at the consultation was the lack of data on children and HIV across the region. According to UNICEF, 151,000 children in the region are living with HIV. In addition, about 30,000 women are HIV positive. Although a regional data hub on HIV and AIDS has been established in Bangkok, Thailand, data and information on children living with HIV are simply not available. Information holes still exist.

In 1984, Thailand became the first country in East Asia and Pacific where HIV cases were reported. It has an established sentinel surveillance system. Nonetheless, even in Thailand the number of children infected with HIV remains an estimate, in this case approximately 14,000. Because the epidemic began earlier in Thailand than in most other countries, it progressed and expanded to include children earlier than in most other countries. Infections among some children were already apparent in Thailand when Cambodia recorded its first adult HIV case in 1991.

The area in Thailand that serves as the focus of the first case study is the northernmost province of Chiangrai. It is no accident that the model for paediatric HIV treatment, care and support was developed there. The six provinces of the Upper North was the region of Thailand hardest hit by HIV. Chiangrai is a border province at the centre of the area known as The Golden Triangle, where Thailand, Lao PDR and Myanmar converge. Trafficking in drugs, people and other contraband flourish there, conditions that make the area a powerful incubator for an HIV epidemic. In 1992, the Upper North was home to 8 per cent of Thailand’s population, but more than 50 per cent of its HIV infections. By the mid-1990s, Chiangrai Prachanukroh Hospital, the regional hospital for the province, was dealing with 30-35 inpatient cases each month of HIV-infected children. There was little doctors could do except try to treat their opportunistic infections. A Prevention of Mother-to-Child HIV Transmission (PMTCT) programme launched in 1997-98 reduced the numbers of infected children slightly, but the problem was still serious.

Understanding the context

In 2002, there was a breakthrough. AIDS ACCESS Foundation, a local NGO working with groups and networks of people living with HIV, approached Chiangrai Prachanukroh with an offer to supply antiretrovirals (ARVs) for a handful of children. The medications would be imported from India and funded by international donors through AIDS ACCESS. The doctor in charge of paediatric services, Dr. Rawiwan Hansudewechakul, hesitated. There was no guarantee the supply of ARV could be maintained, or that children would be able to maintain the 95 per cent adherence necessary for treatment to work. She was also apprehensive about working with a non-governmental organization (NGO), as there had been a history of tensions between NGOs and government officials in Thailand.

Dr. Rawiwan, ultimately however, had a visionary response. She and her team decided to pilot the treatment – and work closely with the NGO in doing so. A true partnership was established. AIDS ACCESS, working with local people living with HIV & AIDS (PLHA) groups, helped win the trust of HIV-positive patients, performed the important task of monitoring the home lives of the patients to ensure adherence, and contributed ideas and innovations to make the programme effective. “The NGO inspired us,” Dr. Rawiwan said. The partnership was the key to success. In the intervening years, the Thai government has made ARV available to all who need them under its universal health care coverage. The survival rate from among the 222 children living with HIV started on treatment between 2002 and 2004 at Chiangrai Prachanukroh was over 90 per cent. The approach to paediatric HIV care and treatment developed at Chiangrai Prachanukroh Hospital has now been scaled up to 12 of Thailand’s 76 provinces.

The model developed in Thailand for paediatric HIV treatment and care contributed to the success of the programme in Cambodia. A Cambodian team of paediatricians visited Thailand in 2005 to observe and learn from the Thai experience, and eventually adopted the Thai treatment protocols with some modifications. In 2003, however, when the head of Cambodia’s National Committee on HIV and AIDS, Dermatology and Sexually Transmitted Diseases (NCHADS), Dr. Mean Chhi Vun, was approached by Brown University about piloting the use of paediatric ARV formulas, he thought the task would be impossible. Although Dr. Vun had no doubt there were children living with HIV in his country, he had never seen one. So little data existed that no one had any idea how many infected children there were.

The heart of the problem was the state of Cambodia’s health care system. Unlike Thailand, which has a well-developed health care system and infrastructure, Cambodia’s health care system and infrastructure had been shattered during its era of conflict. Paediatric health care and services simply did not exist in many locations, and where they did they were often minimal. A central tenet of HIV treatment policy is to integrate HIV services into the general, or in this case paediatric health care system, rather than create a stand-alone programme. The dilemma in Cambodia was that there was essentially no paediatric health care system into which to integrate HIV care and treatment.

A visionary response on the part of UNICEF and the Clinton Foundation provided the solution. They allowed funds for their HIV programmes to be used to rebuild, restart and revitalise paediatric health care services. In many locations this meant funding the purchases of beds, mattresses, sheets, fans, and repainting and repairing wards. Boxes of medicines and essential equipment for general paediatric health care were supplied. At the National Paediatric Hospital in Phnom Penh, HIV funds supported the malnutrition ward and other wards where doctors often first spot children they suspect are infected with HIV.

At the provincial hospital in Battambang, Cambodia’s second-largest city, paediatric ward occupancy averaged 30 per cent before renovations in 2006. Since then, 80 per cent to 100 per cent occupancy is common and outpatient treatment numbers have skyrocketed. Similar increases have been recorded at other paediatric wards in other provinces. The Battambang programme is regarded as one of the most successful as far as reaching and treating children and families infected and affected by HIV because of the strength of the local NGO. Although not staffed by PLHA, that NGO plays a similar role to AIDS ACCESS in Chiangrai, conducting home visits and outreach to ensure adherence is being maintained.

One of the early tasks of launching paediatric HIV treatment and care in Cambodia was estimating how many children were living with HIV. With help in modelling from UNICEF and others, Cambodian officials concluded there were between 6,000 and 12,000 infected children with 3,000 in need of ARV. By mid-2009, 3,666 children in Cambodia were receiving ARV treatment, a clear sign of success of the programme.

Using HIV budgets to fund general paediatric services was controversial. UNICEF's overarching goal, however, is to improve the lives of all children. In temporarily broadening the scope of the HIV programme, that programme has delivered more to all of Cambodia's children than could have been expected. While it was an appropriate response in Cambodia, it probably would not be justified in most other settings. Cambodia is unique in that 80 per cent of its government budget comes from donors. The country does not have the means at this time to achieve at national scale what UNICEF had achieved in selected sites. Most other governments are not in a similar situation, and so bear the responsibility for providing paediatric services. This will also eventually be the situation in Cambodia. While help from UNICEF and others may be needed to maintain paediatric services for some time, Cambodia's economy is growing and its government will eventually have to assume the responsibility for providing and maintaining these services and facilities.

On the other hand, the similar models employed in Thailand and Cambodia, in which partnerships with PLHA groups and NGOs were the foundation for success, could be applied with good results in many other settings. The main constraint in applying this model is that some governments do not permit the formation of NGOs or civil society groups. It could be argued that those countries may be putting themselves at a disadvantage, not just in mounting an effective response to HIV, but potentially to other public health issues and crises. For public health to be effective in serving the public, it must involve the public. In general health, NGOs, and in the case of HIV, PLHA, can provide a powerful link or pathway to the public for government and health officials. That point has been proven by the success of the paediatric HIV responses in both Thailand and Cambodia.

Bridging the gap

uniting to treat children with HIV in Thailand

Executive summary

Thailand has been referred to as epicentre of the HIV epidemic in Asia. In 1984, it was the first country on the continent where HIV cases were detected and the epidemic began to expand. By 2000, nearly a million Thais had been infected with HIV since the beginning of the epidemic, and 289,000 had died of AIDS-related diseases. As the epidemic matured it moved beyond members of most-at-risk groups. Increasing numbers of women became infected, and ultimately increasing numbers of children. An estimated 14,000 children in Thailand are infected with the HIV virus. Within Thailand, Chiangrai and its sister provinces in the Upper Northern region, were particularly hard hit by the epidemic. They comprise a border region marked by injecting drug use, migration, people trafficking and a commercial sex industry. Those conditions provided an effective incubator for an HIV epidemic. By 1992, 50 per cent of all Thailand's HIV cases were in the Upper North.

In the mid 1990s, Chiangrai Prachanukroh, a public hospital in Thailand's northernmost province, began admitting a steady stream of children to its paediatric ward who were infected with HIV. As health care workers in Chiangrai struggled to respond to the epidemic among children, they received some unexpected help in the form of a donation of antiretrovirals for children from AIDS ACCESS, a foundation established in 1991, and dedicated to responding to the HIV epidemic in Thailand.

Doctors were skeptical and initially reticent about partnering with an NGO due to a long history of conflict and tension in Thailand between government and civil society groups. However, the prospect of receiving medications that could effectively treat HIV in children persuaded Dr. Rawiwan, the head of the paediatric department at Chiangrai Prachanukroh Hospital and her colleagues to put aside their reservations and work with AIDS ACCESS. It wasn't long before they realized how invaluable PLHA and NGOs were when it came to treating and caring for children infected with HIV. All the children maintained 100 per cent adherence. The key was partnership. PLHA volunteers and AIDS ACCESS staff worked with doctors at the hospital to win the trust of the children and their families. They took on the responsibility of visiting the children at their homes and alerting doctors to any situation that might negatively affect treatment. And they used their knowledge about successful treatment programmes gained through PLHA groups and networks to brainstorm with public health workers and devise strategies, methods and innovations to support treatment adherence among the children.

To make the programme work, health care workers and PLHA groups had to work together to find solutions for a range of challenges and difficulties including, elderly and illiterate caregivers with limited capacity to keep children on their medications, psychosocial problems among children and adolescents, and infected children from minorities and hill tribes for whom language barriers, cultural differences and documentation and identification were issues. Their success, achieved through teamwork, in helping children and their families maintain treatment adherence and survive has led them to believe they have an effective approach to paediatric HIV treatment and care. Since initiating the programme, Chiangrai Prachanukroh has treated 488 children infected with HIV and achieved a survival rate of 90 per cent. Suddenly, children whom Dr. Rawiwan once described as having no hope, now had hope for the future, hope for living a healthy life well into adulthood.

The model consists of five steps:

- 1) clinical screening for ART initiation and family preparation for treatment;
- 2) home visit and support group preparation meeting;
- 3) support during ART initiation day;
- 4) first follow up at home to check up on how treatment is progressing and if any problems have arisen; and
- 5) home-based support during long-term follow up.

While the programme model has proven to be a success within the Thai context, those involved in the effort believe more can be done to improve paediatric HIV treatment, care and support. After consultations with stakeholders, the following key recommendations were arrived at:

- Develop, implement, and scale up access to comprehensive paediatric HIV care and treatment;
- Remove restrictions to access to paediatric HIV care and treatment based upon national status;
- Promote greater participation and skills development for children/adolescents living with HIV; and
- Strengthen and support networks of PLHA towards ensuring improved service delivery and greater advocacy potential.

Greater detail on the recommendations listed above can be found in the body of the text.

1. Introduction

This paper examines a programme developed in Thailand's Chiangrai province to provide paediatric treatment and care to children infected and affected by HIV and AIDS. Through field visits and interviews with a range of stakeholders, the case study seeks to determine whether Thailand's public health officials, including its doctors and health care workers, have been able to establish the cooperation and working relationships with people living with HIV and AIDS and other groups needed to make the programme work, and whether children cared for under such partnerships are surviving – and thriving. Where such partnerships exist, it analyzes what has contributed to their success, while also looking at what obstacles remain for providing children with the treatment and care they need.

Thailand has been called the epicentre of the HIV and AIDS epidemic in Asia. In 1984, the Southeast Asian kingdom became the first country on the continent where HIV cases were detected. Fuelled by a large commercial sex industry, injecting drug use and unsafe migration, the virus rapidly spread, and by the early 1990s Thailand was among the countries with the highest prevalence levels in Asia. Around the same time, Thai governments began taking action, including implementing 100 per cent brothel-based condom use programmes and public education campaigns. The response was hailed as a model of how a developing country could address HIV and AIDS. But, despite Thailand's efforts, by 2000, nearly a million Thais had been infected with HIV since the beginning of the epidemic, and 289,000 had died of AIDS-related diseases. The epidemic was still growing and its patterns among the population were shifting. The pathways of the virus were expanding beyond members of most-at-risk groups to infect increasing numbers of women. Ultimately, HIV infections began appearing among the country's children. To date, UNAIDS estimates that more than 600,000 Thais are living with HIV, and approximately 14,000 of them are children.

Chiangrai was the logical place for such a programme to develop as it has had a high level of HIV prevalence since the epidemic began in Thailand. The location in northernmost of Thailand's 76 provinces made it particularly vulnerable as HIV swept across Southeast Asia. Bordered by Lao PDR and Myanmar, Chiangrai is part of the area known as the Golden Triangle, infamous as a nexus of armed conflict and criminal enterprise. Drugs are rife in the region. Ethnic rebels fighting the government in Myanmar, and criminal gangs in Lao PDR, funnel opium, heroin and methamphetamines to Thailand in exchange for money and weapons. The porous borders provide easy passage for those engaged in trafficking people, some of them destined for Thailand's sex industry. A relatively poor province, Chiangrai is also home to dozens of hill tribes, each with its own distinct language and culture, and most of whose members lack Thai citizenship, effectively barring them from health and education services.

Such conditions proved an effective incubator for an HIV epidemic. By the early 1990s, Chiangrai had some of the highest HIV prevalence in Thailand. The epidemic had coursed throughout the six provinces of the Upper North – Chiangrai, Chiang Mai, Mae Hong Son, Lamphun, Lampang, Payao – and beyond. Although home to just 8 per cent of Thailand's population, by 1992 the Upper North had more than 50 per cent of the country's HIV infections. A survey that same year found that as many as 18.7 per cent of all military conscripts stationed in Chiangrai were HIV positive. By 1994, the prevalence among pregnant women was 8.5 per cent, foreshadowing an epidemic among children.

Relatively early on, Thailand adopted a multisectoral response to this health emergency. Integrating HIV prevention, treatment and care into the existing public health system was a key feature. In 1995, after the International Conference on AIDS in Asia and the Pacific was hosted by the city of Chiang Mai, it became government policy, at least on paper, to involve PLHA groups in the response.

By that time, doctors at Chiangrai Prachanukroh Hospital had begun seeing a steady stream of HIV-infected children being admitted to the paediatric ward with opportunistic infections (OI). With no cure for HIV, there was little they could do.

Nonetheless, public health officials kept searching for any developments in prevention or treatment that might help. In 1997, they launched a pilot project for prevention of mother-to-child transmission (PMTCT) of HIV, and selected Dr. Rawiwan Hansudewechakul to oversee it. "The results were remarkable," she said. Using a combination of AZT and Nevirapine, transmission rates at the hospital dropped from 21 per cent in 1993 (n=100) to 0 per cent in 2008 (n=64) and 2009 (n=70). In 1998, the programme was scaled up throughout the province – but not without a degree of resistance. Some obstetricians were not interested. Counselling pregnant women and giving them HIV medications were difficult, sensitive and complex tasks. "We had to show them the number of children who were sick and dying before more of them wanted to help," Dr. Rawiwan said.

As the PMTCT programme gathered steam, the under-five ward saw a modest decline in the numbers of children turning up with HIV infections. But the numbers were still high. Often, more than half of the beds in the 30-bed ward were filled with children with HIV. And still, “there was no hope for them,” Dr. Rawiwan said.

In 2001, a breakthrough finally came. Paediatric services Director Dr. Siriraj Puapanwattana was given new drugs called antiretrovirals (ARVs) to treat children with HIV. They were provided by the “Programme for HIV Prevention and Treatment (PHPT),” a collaboration between the Institut de Recherche Pour le Développement, Chiang Mai University and the Ministry of Public Health. The three or four children who were treated markedly improved. Suddenly, there was hope for the children who previously had no hope. The new drugs were only available, however, on an experimental basis. They were prohibitively expensive, and when the experiment ended after a few months, their price put them well beyond the reach of a public hospital such as Chiangrai Prachanukroh.

With effective treatment so tantalizingly close, all now seemed lost – until February 2002, when Namphung Plangraun, Manager of AIDS ACCESS Foundation, Chiangrai approached Dr. Siriraj with some interesting news: her group had received funds from donors to provide ARV imported from India for ten children. She wanted Chiangrai Prachanukroh Hospital to administer the treatment. Dr. Siriraj sent her to see Dr. Rawiwan.

Dr. Rawiwan was at once intrigued and enthusiastic, but also hesitant. She was acutely aware of the plight of children living with HIV, but she had several reservations.

First, AIDS ACCESS was a nongovernmental organization (NGO), and NGOs, and PLHA NGOs in particular, had a reputation for being troublesome, especially among government officials and bureaucrats. Doctors and health care workers at public hospitals are government officials, and many shared a negative view of NGOs. Although Dr. Rawiwan had not personally worked with nor experienced any difficulties with NGOs, “at that time, those of us working in government did not trust NGOs. They were very demanding and often sought publicity for their causes by staging protests and demonstrations. From what I could see, they were not easy to work with,” she said.

Second, there was no guarantee that AIDS ACCESS could supply the ARVs indefinitely or for as long as the children might need them. And no one could say how long that would be. Having witnessed the end of Dr. Siriraj’s experiment, Dr. Rawiwan did not want to be part of giving children with HIV and their families hope only to have it snatched away yet again. Ultimately, “they would all just end up dying,” she said.

Lastly, although she was not yet expert on the subject, Dr. Rawiwan understood that adherence to the medication was extremely important for antiretroviral therapy (ART) to work. Adherence must be maintained at a minimum of 95 per cent. Medication must be taken on time and without fail. Making sure a child living at home took his or her medication was a daily responsibility beyond the capacity of her hospital’s doctors and nurses. “If you have a child in the hospital you can control their adherence to the treatment. But when they are at home, we can’t control anything that happens there,” she said.

Despite her reservations, Dr. Rawiwan agreed to meet with the activist and hear what she had to offer. As always, she put what was best for the children first.

Namphung wasn’t what Dr. Rawiwan expected. Far from a firebrand, she was polite and unassuming. She didn’t make demands. Instead she was cooperative and sought common ground. Namphung assured Dr. Rawiwan that AIDS ACCESS staff and other PLHA volunteers would take direction from the doctors and nurses, share the workload and assume responsibilities outside the hospital. They would work with Chiangrai Regional staff to explain to children and caregivers what was required. Most importantly, they would establish home care teams to visit the children and monitor their adherence, and would inform the doctors of any difficulties the children and their families were experiencing at home that might affect whether or not treatment would be successful.

They just wanted the chance to prove that they could help children living with HIV.

Dr. Rawiwan was still sceptical. ARVs were effective, but she didn’t believe that people, much less children, would maintain the required level of adherence, and so she was doubtful patients would actually live long lives even if treated. But, just as with Namphung, she desperately wanted to help children living with HIV. Other doctors might have succumbed to the institutional ambivalence about working with NGOs that was so prevalent at the time. Not Dr. Rawiwan. For the sake of the children, she decided it was worth a try. “But,” she said, “I was certain we were going to fail.”

2. HIV and AIDS in Thailand and among its children

2.1 Children and HIV and AIDS in Thailand

Compared to many of its immediate neighbours, Thailand has a well-developed public health infrastructure, including an established sentinel surveillance system. Nonetheless, data and information on children infected and affected by HIV and AIDS are still lacking. UNAIDS estimates there are 14,000 children infected with HIV in Thailand. In 2007, according to the government's status report on the epidemic, 6,687 children were receiving ART. Dr. Peeramon Ningsanong of the Ministry of Public Health (MOPH), said that in 2005 the number of orphans resulting from AIDS had reached 380,000, or 34.8 per cent of all orphans.

The changing character of the epidemic has impacted Thailand's young. By the start of the current decade, the profile of those newly infected shifted from overwhelmingly male to increasingly female, presaging infections among children through vertical transmission. The Thai government's 2008 situation report on the epidemic noted that "the increasing trend of HIV prevalence among women attending antenatal care (ANC) at second and third pregnancies indicates that the infection is spreading more deeply into families in general, and probably will remain at relatively high levels going forward."

Children of ethnic minorities and migrants were especially vulnerable to HIV infection, as they and their parents often lack Thai identity cards and could not access health care and education services. HIV has increasingly become an epidemic that chiefly affects the poor, and so poor children are also at greater risk.

Young people are now one of the chief at-risk groups. Both HIV and STD infections are rising among young people. Despite expanding life skills education programmes, accurate knowledge about HIV and AIDS among young people remains limited, and myths and misconceptions endure. Young people can also be found among many of the most-at-risk populations, such as injecting drug users (IDU), men who have sex with men (MSM), sex workers and migrants.

As children who are infected have survived into their teen years, new sets of problems have emerged as far as behaviours and treatment adherence are concerned. These new difficulties and challenges are just beginning to be studied, understood and addressed.

2.2 Origins of the paediatric response

By the late 1990s, Chiangrai Prachanukroh Hospital was admitting 30 to 35 HIV-infected children a month to its under-five ward. Aside from treating their opportunistic infections as best as possible, with no cure or effective treatment for HIV there wasn't much that doctors could do for those children. A PMTCT programme launched in Chiangrai in 1997-98 produced a modest decrease in the numbers of newly infected children.

Around the same time, a local NGO named AIDS ACCESS Foundation had begun providing care and support for children with HIV in Chiangrai. AIDS ACCESS, founded in Bangkok in 1991 by activist and later senator Jon Ungpakorn, was one of the first NGOs working on HIV and AIDS issues in Thailand. In 1993, it opened its second office in Chiangrai. The group provides care and support for PLHA and advocates for their rights and better treatment. It is part of the Thai Network of People Living with HIV (TNP+) and has received funding from the MOPH and a variety of international donors including UNICEF, the Global Fund, the Rockefeller Foundation, OXFAM Great Britain, Medecins sans Frontiers, ICCO of the Netherlands and Plan International.

UNICEF has supported AIDS ACCESS for over four years in building capacity of TNP+ and other PLHA groups to be actively involved in the Comprehensive Continuum of Care (CCC) Centre and HIV paediatric care. CCC volunteers come from trained PLHA groups, thus, they are referred to in this report as PLHA volunteers.

Chiangrai was the logical place for AIDS ACCESS to expand its work because of the high prevalence and concentration of cases in the Upper North, and also because the area had a strong tradition of community help groups. That would provide a strong point to be relied upon in the response to the epidemic. In 1994, there were 13 PLHA groups in the Upper North, with two in Chiangrai. One year later there were 35. By 2005, there were 309 PLHA groups active in the region. Many PLHA join not just for support and to advocate for their rights, but also to ensure they have access to treatment.

In Chiangrai, before treatment was available, AIDS ACCESS began by counselling PLHA, and afterwards it started a radio programme to encourage understanding of HIV issues. AIDS ACCESS Chiangrai, which has five full-time staff, one part timer and one volunteer, has attempted to increase understanding and support for PLHA among the community and provide support to families of HIV-positive children.

This was the general setting in Chiangrai before ART could be provided and treating children with HIV became possible.

2.3 Public health workers and PLHA unite to help children infected with HIV

Treating and caring for children infected with HIV can often be more challenging than treating and caring for HIV-positive adults. Just as in general paediatric care, specialised sets of skills are needed by doctors, health care workers and others who care for children – and never more so than in dealing with HIV, a complex health condition that touches many aspects of a person's life, and the lives of those around them.

Just as with adults, counselling and psychosocial support are important components of treatment and care. With children, however, matters can be complicated by the child's age, level of comprehension and development, emotional maturity, family and community circumstances. As far as treatment regimens are concerned, without specific paediatric formulations, determining proper dosages can be difficult and imprecise; efficacy can be compromised and side effects can be more severe.

In Thailand, the government's health care programme now provides first-line ARV medications free of charge to HIV-infected people who need them. As important as the availability of medications is, the drugs are of little benefit unless patients strictly adhere to the treatment regimen. Failure to do so results in the virus rapidly developing resistance to the drugs. Second-line medications are far more expensive, and the government has been forced to ration access to them. For those on first-line treatment, adherence is crucial.

This is especially true for children, as the virus can progress more rapidly in young children if left untreated or adherence is not maintained. Children, however, can be more temperamental about taking medicine or not yet fully comprehend the consequences of not doing so. It is not uncommon that the parents of an HIV-positive child are ill themselves and unable to fully tend to their offspring. Perhaps they have already died. Grandparents or elderly relatives may have assumed the role of caregivers, and they may have little understanding about HIV, or lack the capacity to keep the child on the regimen or give medications correctly.

This presents a dilemma for doctors and health care workers, who cannot tend to the child on a daily basis at their homes to ensure adherence is maintained. Partnerships with PLHA and community groups are, therefore, essential.

In Thailand, however, despite 25 years of responding to HIV and AIDS, stigma and discrimination persist – even among some health care workers. As this study was being written, local newspapers reported education officials in some provinces were discouraging children living with HIV from attending public schools, underscoring the stubborn discrimination that still exists among some government officials.

And although NGOs have played an important role in Thailand's development, by nature they tend to question or challenge authority, which goes against Thai social mores. Consequently, attitudes toward NGOs and community-based organizations (CBOs) among the public, and especially among government officials, are ambivalent, and sometimes hostile.

Effective HIV treatment and care requires partnerships between medical professionals and PLHA groups or NGOs. In fact, it can be posited that effective public health in general requires and relies on such partnerships with civil society. Public health programmes need to involve the public as partners, not just as patients. The attitudes prevalent in Thailand at the time, which could also be observed in many countries in the region, presented a significant challenge to successfully providing paediatric HIV treatment and care.

That challenge was evident from the start. Despite their experience and dedication in providing care and support, when AIDS ACCESS approached Chiangrai Prachanukroh Hospital with its offer of providing ARV for ten children, they were met with reservations by the staff. “I did not want to talk to an NGO,” Dr. Rawiwan said, recalling her initial reaction. AIDS ACCESS Manager Namphung Plangraun was not surprised. Having worked with public health officials in the past, she knew it could take time to win them over so they could see the positive side of NGOs.

Namphung said that NGOs work chiefly in two ways: 1) educating and empowering people to solve problems within communities, and 2) organizing people’s groups – which sometimes requires protests or demonstrations. She admits that many people are more familiar with the organizing approach but that it goes against Thailand’s cultural norm of avoidance of conflict; although over time such methods have become more “normal”. Furthermore, because many NGOs receive funding from foreign donors, more conservative elements in society portray them as agents or dupes of foreign powers determined to undermine Thailand’s independence.

The doctors at the paediatric ward had never worked with an NGO before. That did not surprise Namphung. What did surprise her was that they had never used a combination of three ARVs to treat children, which was the World Health Organization standard at the time. The experimental treatment tried earlier was either mono- or dual-drug therapy. In attempting to persuade Dr. Rawiwan and others at the hospital to allow AIDS ACCESS to assist in providing care and support, Namphung made sure that the focus would be more on how AIDS ACCESS could actually help doctors achieve their goals rather than on use of the more confrontational organizing approach.

AIDS ACCESS’ offer would have been difficult for any conscientious doctor to refuse. The time and the circumstances were ripe for a dedicated and visionary public health official to step forward, go beyond institutional attitudes and put the welfare of the children first. Dr. Rawiwan did exactly that.

3. The Chiangrai approach

3.1 Launching the pilot project

AIDS ACCESS brought more to the table than just funding for ART. Group members had acquired knowledge and training from international sources and networks of PLHA, along with experience working with Thai PLHA. Dr. Rawiwan also had some training from PHPT, and some time after the project began would make a study trip to San Francisco to learn more about comprehensive HIV care, treatment and support. These foundations of knowledge and experience were essential to making the pilot a success.

At the start of the pilot project it was discovered that the funds were actually only sufficient to supply nine children with ARVs. Early on, one of the children dropped out. That left eight children in the pilot.

Shortly after the eight children were chosen, with advice from AIDS ACCESS, the first ARV Care Team was established. Based on a model from PHPT, the team consisted of a doctor, two nurses, two staff from AIDS ACCESS and three PLHA. The ARV Care Team assisted doctors and nurses in the hospital and began conducting home visits to the eight families.

The involvement of PLHA was crucial from the start. "At first it was just a doctor and myself," said Noodchane Maneerat, a nurse who works on paediatric HIV care and treatment with Dr. Rawiwan. "We quickly learned how important team work is."

PLHA were instrumental in winning the trust of the eight children and their families. "Children aren't as immediately trusting as adults and it's harder to communicate with them. You learn how to do it. Working with adults is easier," said Rungprapa Kahwin, a PLHA volunteer.

Most children and their families seeking treatment at public hospitals are poor, and the poor and marginalised can often be uncomfortable with doctors and nurses, whom they view as government officials. And, official reaction to those living with HIV and AIDS could still be tinged with stigma and discrimination. "At first they don't trust us. It's as if they feel they did something wrong and don't want to admit it to us. We have a gap, and the PLHA volunteers help us to close that gap," said Suporn Wattanaporn, the Program Coordinator.

Having contributed to bridging the gap between PLHA and health workers in the hospital setting, the PLHA volunteers were also instrumental in ensuring treatment adherence through home visits to the children and their families. With a small staff, the public hospital's paediatric ward did not have the resources to conduct such visits. For some children and their families, having PLHA volunteers visit their home was less intimidating than having a public health worker/official arrive, and also less conspicuous for those whose status was unknown in their community.

The pilot lasted for five months from February to July, and the results astounded Dr. Rawiwan. "It was incredible. All eight continued on the treatment for the full five months with 100 per cent adherence," she said. "We believed if we could do this with eight children, then we could do it with more than that. This could actually work."

To reinforce the results of the first pilot, Dr. Rawiwan and her team launched a second pilot project, this time with 22 children. The results were equally impressive. They were also extremely important because government policy makers were watching. The success or failure of the pilot would factor into their decision on whether or not to make ARVs widely available to those who need them under a government-run universal health care programme.

That decision would soon be needed, because when other parents of HIV-infected children in Chiangrai learned about the pilot and the promising results, they began demanding the hospital also treat their children. "How would we be able to choose among them?" Dr. Rawiwan said, still exasperated over the dilemma.

In late 2002, the MOPH began adopting a continuum of care approach to HIV and AIDS response, and expanding access to ARVs. It began inviting hospitals to set up Continuum of Care teams composed of doctors, nurses, pharmacists and lab technicians. The Thai Network of People Living with HIV and AIDS (TNP+), an umbrella organization of PLHA groups of which AIDS ACCESS is a member, resolved to join this effort by providing treatment support.

In 2003, the Thai government included ARV in its low-cost universal health care coverage programme, making the medications available to those in need. AIDS ACCESS, the TNP+ and other local NGOs played a key role in lobbying with the government to include ARVs in the programme. Once the second pilot was completed, Chiangrai Prachanukroh Hospital launched its full programme, accepting 80 paediatric HIV cases for ART. An average of ten to 15 new children started ART each month, and over the next few years, the hospital took in between 80 and 102 ART initiations each year.

It is important to note that while Chiangrai Prachanukroh Hospital established a team specializing in paediatric HIV treatment and care, no separate clinic was set up for HIV-positive children. Existing facilities, staff and resources were used. The programme was integrated into the paediatric unit of the hospital and the health care system as a whole.

3.2 How the programme works

3.2.1 Working with caregivers to ensure adherence

“When will my child be able to stop taking the medicine?” asked the old woman. She was one of four women and one man who had come to Chiangrai Prachanukroh Hospital to attend a refresher session after their children had begun ART. They sat in a cramped cubicle on plastic chairs arranged around a desk. The meeting was led by a nurse. The woman was 84 years old, wizened and cloudy eyed. She had journeyed to the hospital from Mae Sai, a town nestled against the border with Burma, and, unlike the other participants, this session was her first. Although her granddaughter had begun treatment, she still seemed unclear about some aspects of HIV or AIDS. Nonetheless, she was attending because she loves the 15-year-old child whom she has been caring for since her parents died of AIDS.

Before the nurse explained about the treatment regimen, she playfully told the old woman that she looked just like a famous television soap opera actress. It brought a broad smile to the woman’s face. Everyone chuckled at the soap star reference, and all seemed more at ease after a bit of laughter. The grandmother from Mae Sai was not alone in her situation. The other caregivers were aged 78, 73, 59, with the youngest being a woman of 43.

The nurse explained that the granddaughter will always have to take her medication. “I’m worried she will stop,” said the old woman. The nurse told her that as long as she takes her medication regularly she will be healthy and just like other children. She will grow strong. But if she stops, the HIV will grow again.

Do you know how someone gets the virus, she asked the caregivers. “Through injecting drugs or having sex,” answered an old man. Through unsafe sex, countered the nurse. “Can our children have a boyfriend or girlfriend?” asked the old woman. Yes, they can even have a family, answered the nurse, when the time is right. But they must practice safe sex, not do drugs or gamble or drink alcohol if they want to stay as healthy as possible. The caregivers all nodded in agreement. Their children and grandchildren had been on treatment for several months now. All appeared to be doing well. Slowly but surely, their initial sense of despair and nervousness was giving way to a glimmer of hope.

3.2.2 The programme model

Working with caregivers is just one cornerstone of the model used to effectively treat and support children with HIV. The holistic, community-based model adopted by the team at Chiangrai Prachanukroh Hospital was developed through discussions with PHPT and AIDS ACCESS, both of which had studied similar approaches with adults in other countries, or had employed similar models in treating adults in Thailand.

The model consists of five steps:

1. Clinical screening for ART initiation and family preparation for treatment: A CD4 count, blood chemistry and other tests are conducted to determine whether the child is in need of ART. Other tests include lipid profiles, a chest x-ray and tests for hepatitis B and C infections. Today, national treatment guidelines exist and would be followed to decide whether the child should begin ART.

If the child is eligible for treatment, two to three family hospital visits are required for preparation. These visits are handled variously by doctors, nurses and members of NGOs, many of whom are PLHA. They involve assessing the level of knowledge about HIV among the caregivers, educating the family about the condition and finding out as much about the home situation of the family as possible to aid in treatment adherence.

2. Group preparation meeting and home visit: AIDS ACCESS staff and PLHA volunteers lead group preparation meetings and conduct home visits so they can learn as much about the family's situation as possible and devise solutions to any difficulties that might affect treatment adherence. As part of this, group meetings consisting of families preparing to have their children start ART are held, often at a community health facility. Topics discussed and reviewed include disclosure, the nature of HIV and AIDS, side effects of ARVs and adherence. The group meeting also serves to assure the families that they are not living in isolation – there are others in similar circumstances facing similar problems and attempting similar solutions. This can also help to strengthen the support network and build a sense of community. Lastly, the home visit team will meet with family members within the home and try and discover the two people who would best be responsible for ensuring that the child takes his or her medication daily and on time. This information is reported back to the hospital and ARV care team.
3. ART initiation day: After seeing a paediatrician, the child and his or her caregivers meet with PLHA volunteers or AIDS ACCESS staff to once again review what is necessary for treatment, and to practice preparing the medications and recording methods to help monitor adherence. Treatment then begins.
4. First follow ups: Three days after start of treatment, a PLHA volunteer or AIDS ACCESS staff visits the child's home to check up on how treatment is progressing and if any problems have arisen. On the 14th day after treatment is initiated, the child and caregivers visit the hospital so doctors and nurses can monitor progress on treatment and adherence.
5. Long-term follow up: During the first six months, the child and caregivers return to the hospital once a month so doctors can assess the child's condition and check treatment adherence. After that, if the child has been adhering to treatment, hospital visits take place once every two months. At the same time, home visits by PLHA volunteers or AIDS ACCESS staff take place on average once a month, but may be more or less frequent depending upon the needs and desires of the children and their families.

3.3 Expanding the programme throughout the province

Chiangrai is a fairly large province. Reaching the provincial capital from one of the outlying districts can be expensive for poor people, time-consuming and at times physically difficult because of monsoon rains and poor infrastructure. In 2005, the hospital addressed this issue by expanding the programme to 16 community hospitals throughout the province. The expansion took place over a two-year period. Each community hospital, working with a CCC centre in the area, now provides comprehensive paediatric HIV care services.

The expansion to community hospitals was necessary to relieve the original team of an increasingly large caseload, and to satisfy the demands of children and those caring for them. "We had problems with caregivers asking us why adults can get ART at community hospitals, but not children," Dr. Rawiwan said. "The nurses and doctors could not deal with it, and so we started the programme in 16 community hospitals."

Once again, there was initial resistance from the health care sector. "At first, most did not want to, because sometimes taking care of children on ART is hard," Dr. Rawiwan said. Chiangrai Prachanukroh set up a programme for the staff at the community hospitals that were reluctant, providing technical training courses to increase their capacity. They learned quickly and efficiently enough that during the first two years, when patients who could be treated at community hospitals would still show up at Chiangrai Prachanukroh, those patients would be sent back to their community hospitals. "Some of these hospitals can do an even better job than Chiangrai Prachanukroh in some aspects of the programme, such as home visits or dealing with children and families at the patient centre," Dr. Rawiwan said. Parents now bring their children to Chiangrai Prachanukroh only once every six months for a more complete evaluation, including assessing for development of resistance or more serious, but less common side effects from the treatment, such as lypodystrophy or lactic acidosis. As capacity in the community hospitals continues to expand, Dr. Rawiwan hopes that children receiving treatment will only need to come to her hospital once a year, and will be able to receive all other HIV-related services at the community hospital close to where they live.

Nurse Chulaporn Singpae of Phan Community Hospital in Mae Chan district credits Chiangrai Prachanukroh for "giving us a good model and support." But, she said that most patients who can access her hospital "don't want to send their children to Chiangrai Prachanukroh, because the caregivers are often old and it is difficult, dangerous and costly for them to go. We would prefer a doctor from Chiangrai Prachanukroh come visit them here. When families can get treatment and care here, they are happier. It leads to a better quality of life for the children and the caregivers. If they have a problem we can get someone out there to see them because they are not far away. Every child can be reached."

Chiangrai Prachanukroh Hospital remains the hub for the programme in the province. Health care staffers from community hospitals are trained there. Children and their caregivers receiving treatment at community hospitals also go to Chiangrai Prachanukroh every six months to have their adherence and progress monitored. In this way, the regional hospital monitors the performance of the community hospitals and the programme throughout the province, and disseminates new guidance and protocols throughout the hospital network.

3.4 Results of the programme in Chiangrai

By 2005, Dr. Rawiwan reported that 209 paediatric HIV cases had started ART, of which 17 had died. The rest were still on treatment. She said, “30 episodes of poor adherence were observed in 25 individuals. Most of them could be corrected and so far there is no one who dropped out.” Fifteen children were switched to second-line ART using Efavirenz. Three changed to Efavirenz because of side effects from first-line medications, while 12 were switched because of concurrent treatment for tuberculosis.

By mid-2009, Chiangrai Prachanukroh reported that it had treated a total of 488 children with ARV under its programme, and that 48 had died. HIV had gone from a virus that left children with no hope of survival to one where 90 per cent of children were surviving. The key was treatment adherence – achieved through the assistance and involvement of PLHA volunteers and AIDS ACCESS staff in providing care and support through home visits.

3.5 Constraints and hurdles discovered and encountered

A number of factors emerged or were discovered during the pilot projects that presented potential difficulties for successful treatment adherence. They included:

Elderly caregivers – More than 50 per cent of the caregivers were elderly because many parents had already died of AIDS. Elderly caregivers often have less knowledge or understanding of HIV and AIDS, may have medical conditions of their own, be less able to deal with children as they get older and approach or enter adolescence, or have less capacity to care for children for a variety of reasons.

Mistrust – In addition, some caregivers may be illiterate or have little formal education. Some may come from hill tribes where the language and culture are different. The more poor or marginalized people are, the less they tend to trust public health officials including doctors and nurses at public hospitals.

Lack of generic paediatric formulations – The Thai government recognises the need for such formulations, but at the time of the pilot until now they have not been available. This means that ART requires taking several pills, some of which must be cut in sections depending upon the child’s age and weight. As the child grows, however, determining how to change the dosage can be a challenge. If the pill is cut too small and the dosage is too weak, treatment will be less efficacious. If the pill is cut too large and the dosage too strong, side effects could be more severe.

Accessing the hospital and its treatment – Some children and their caregivers may live far away, and transportation costs can be high for the poor. Paediatricians at most community hospitals already have a heavy caseload and are unwilling to work on weekends, meaning children will have to give up school, and caregivers may have to give up work, to visit the hospital to receive their check-up, medication, counselling or other services. It is not always possible for the caregiver to take time off from work.

Psychosocial problems – Most of the problems encountered, according to Dr. Rawiwan, were psychosocial in nature. Although the hospital has a psychiatrist, there is great reluctance among many Thais to consult a psychiatrist, for fear of being labelled as “crazy”. Most psychosocial problems occur in the home, school or community, and the hospital staff is not able to be that deeply involved in the children’s lives.

Disclosure – At some point, the child needs to be told about his or her condition. Deciding when to tell a child he or she has HIV is a sensitive issue, and many factors need to be weighed. Caregivers may feel they are not able to disclose to the child his or her condition and need assistance in doing so.

Stigma and discrimination – These remain problems and can lead to the isolation of those living with HIV and AIDS, which in turn can cause depression and other psychosocial problems. While there has been a reduction in stigma and discrimination since the early days of the epidemic, it still persists at significant levels, and perhaps at more significant levels than either the hospital staff or PLHA would admit.

Adolescence – As children live longer and reach adolescence, new and more complicated sets of problems emerge. These include the beginning of sexual relations, illegal drug use and selling drugs, problems with the law, the challenge of keeping HIV status private, unwillingness to continue taking medication and a range of other problems common to adolescents and complicated by HIV.

3.6 Additional activities developed to strengthen the approach

Issues such as psychosocial problems, the limitations of elderly caregivers and other difficulties, as well as additional activities in which children and caregivers are encouraged to participate have been designed and integrated into the programme to make it stronger, more effective and comprehensive.



Children play with volunteers at the Day Care Centre, AIDS ACCESS Foundation, Thailand, 2004

AIDS ACCESS Foundation has long been involved in strategies and activities designed to respond to psychosocial problems and strengthen psychosocial capabilities. Dealing with psychosocial issues is a crucial component of responding to HIV and AIDS. A person living with HIV, whether child or adult, is unlikely to maintain adherence to medication, or their health in general, if they are depressed or experiencing other psychosocial problems brought on by, or related to their condition. Without a psychosocial component to care, their chances of survival will diminish.

AIDS ACCESS Foundation's psychosocial activities go beyond counselling. It engages in efforts to develop coping and prevention skills among youth (life skills), promoting loving bonds within families and communication and understanding between children and caregivers, and raising awareness and understanding among community members about living with

PLHA and also children's issues and child development issues. The Foundation's experiences in these areas contributed to developing the following additional activities used to strengthen the paediatric programme's approach.

Continual counselling for outpatient children and caregivers – As illustrated in the opening anecdote, even after treatment has begun children and caregivers can remain unclear about aspects of HIV and the treatment for it. Continual counselling provides a means to reinforce or strengthen knowledge, and an opportunity for concerns and questions to be raised and addressed. Lives are fluid. Situations change. New problems arise when old ones have been dealt with. The counselling sessions provide a forum both for health care staff to gauge how children and caregivers are doing, and also for children and caregivers to reach out to health care staff for knowledge and assistance.

Regular case conferences – Held at the beginning of every clinic day by the care team, they provide a means for reviewing how each child is doing and the opportunity to raise any issues that may be affecting their adherence. The meetings are attended by a paediatrician, nurses and members of NGO or PLHA volunteers. The team also meets every one to two months to review results and seek ways to improve its own performance.



Nurse assisting a child with colouring activity at the Day Care Centre, AIDS ACCESS Foundation, Thailand, 2006

Bridging the gap – uniting to treat children with HIV in Thailand

Day Care Activities – Held at day care centres, these allow HIV-positive children in similar health circumstances to play together, relax and have fun outside the hospital. Fear, stigma and discrimination are absent in this setting. Activities have been designed to also bolster HIV knowledge and education. Books and pictures on HIV and medication are included, but not forced upon the children. They can read about them if they want to. Older children demonstrating good adherence are encouraged to teach younger children what they know and have experienced. There may be organised talks at times. The agenda and activities are flexible. Nurses and NGO staff are present to guide and help when needed.



Home visit by AIDS ACCESS Foundation, Chiangrai Prachanukroh Hospital, Thailand, 2005

ART camps – Sponsored by UNICEF, Plan International, TUC, and the We Understand group, these camps are held on occasion. They can be trips to the beach, a national park or other places children and their families rarely have a chance to see or visit. The camps not only provide enjoyment and a sense of community but also include health educational activities.

Home visits – Home visits are the most important activity. Handled by PLHA volunteers and AIDS ACCESS staff, they are conducted before and after ART begins. There are two compulsory home visits before ART starts, and one three days after, to assess the home situation. After that, most children and caregivers will receive a home visit once a month or once every two months. PLHA are assigned specific children and a caseload. But children experiencing problems may receive more home visits, and AIDS ACCESS staff and PLHA volunteers are committed to being available to the children and caregivers as often as they are needed and where possible.

Leadership programmes – These were developed by AIDS ACCESS as a means of increasing the confidence, skills and participation of PLHA group leaders and PLHA volunteers in peer care and support, and to enable HIV positive children and their families to cope with the impact of the virus.

Arts therapy – Non-verbal expression and communication through the arts can be a useful and therapeutic tool to reach children experiencing psychosocial difficulties, which are not uncommon among HIV-infected children. AIDS ACCESS initiated art programmes for the children.

These additional activities made the programme broader than just dispensing drugs and providing treatment. ART was embedded within comprehensive care and support. “The programme sometimes goes beyond the scope of a hospital’s role,” said Dr. Rawiwan, but those involved were convinced it was the only way to ensure treatment adherence and higher quality of life for affected children and families.

3.7 Scaling up to other provinces

In 2006, the US Government’s Centers for Disease Control and Prevention, through its collaboration with the Thai Ministry of Public Health, had helped expand the programme throughout Chiangrai province, and to several sites in Udon Thani and Ubon Ratchathani provinces in Thailand’s northeast, generally regarded as the country’s poorest region. Following the Chiangrai model, each province’s main public hospital was used as the hub for the programme, and teams were set up in community hospitals. In 2007 and 2008, with support from TUC and the Global Fund, the programme was scaled up to an additional 12 provinces. Teams from each of the provincial hospitals visited Chiangrai Prachanukroh Hospital to observe the programme as part of their training.

To coordinate and integrate paediatric HIV treatment and care across the 15 provinces and 16 regional/provincial hospitals, the Children ART Network (CAN Thailand) was formed. The network is supported by three major hospitals in Bangkok, Bamrasnaradura Institute of the MOPH, Queen Sirikit National Institute of Child Health, and Siriraj Hospitals. The top-level paediatric and other staffers from those hospitals attend CAN meetings. As Bangkok is the capital and has the strongest links with the international medical community, the latest knowledge and developments often enter the Thai medical community through this gateway.

3.8 Innovations to support adherence

While the additional programme activities tend to support accessing treatment and psychosocial difficulties, the issue of treatment adherence required further thought and innovations. Even with strong psychosocial support, home visits and counselling, other factors mentioned previously, such as illiterate caregivers or a child's limited comprehension, may undermine treatment adherence.

A number of innovations were adopted to address these difficulties. These innovations often emerged from care team meetings and credit for them should be shared among hospital staff and PLHA volunteers. Some were simple, already well known or borrowed from other programmes and experiences, while others were original.



Pill counting by hospital staff and PLHA volunteers, Chiangrai Prachanukroh Hospital, Thailand

Direct Observation Technique – Primary and secondary caregivers (as a back up) are assigned to take responsibility for physically observing the child intake of his or her medications at the proper time and in the proper dosage. This eliminates the possibility that a child who does not want to take his or her medication will not tell the truth and say he or she took it when in fact did not. During hospital or home visits, children may be asked “how many times during the last ten times have you taken your medicine without anybody seeing you?” Caregivers may be asked, “the last ten times, how many times have you actually seen the child swallow the pills?” These open questions are intended to reinforce the direct observation technique and to encourage its practice.

Pill counting and direct questioning – Hospital staff and PLHA volunteers monitor if the child is taking the medication properly by counting how many pills were given on a certain date and how many remain at the time of the count. Patients are also asked a series of questions including: what time did you take your medicine this morning, which one, how did you take it, how many pills each, and what about yesterday? Those overseeing the programme stress that neither the pill count nor the questioning should be done in a judgmental manner, or have the feel of an interrogation. Rather, they “should be an opportunity to discuss and remind the importance of adherence.”

Pill boxes – Seven-day Pill boxes are a common tool used to help patients keep track of which medications and what dosages they should be taking each day. In this instance, the idea was borrowed from the hospital's tuberculosis programme. Caregivers practice filling the pill boxes during their pre-ART initiation sessions.

Adherence diaries, record books – Notebooks are set up so that children and their caregivers can keep a written record of what medications they are taking, when they are taking them and in what doses. Pages are columned and ruled and have dates. The heading will be the name of the drug that is to be taken and in what dose. For illiterate or elderly caregivers with poor eyesight or limited memory or capacity, small photos of each medication are placed in the heading atop each column so they can recognise and match the pills to the pictures. The photo may be of a pill cut in half to indicate the dosage that should be given. These record books are then reviewed during home visits by PLHA and also when children and their caregivers come to hospital.



Pillbox and booklet check help children and caregivers keep track of medications, Chiangrai Prachanukroh Hospital, Thailand

Alarm clocks and watches – It can be easy for anyone to lose track of time and miss the appointed hour at which they are supposed to take their medication. A simple alarm watch or clock can be an effective aid to remembering it is time. However, most patients at public hospitals are poor, and their children do not own watches. Some homes may not even have an alarm clock. The programme, therefore, has made a small investment in buying alarm watches for children and alarm clocks for some homes so that children and their caregivers won't miss the proper time to take the medication. The watches are colourful, and made of sturdy plastic to appeal to and be appropriate for children.

Disclosure sheet – One of the most difficult tasks hospital staff can have is disclosing to the child his or her status. Dr. Rawiwan and her staff have developed a sheet from content provided by Siriraj Hospital in Bangkok to guide nurses and doctors through this process. The sheet contains ten steps and questions, along with options depending upon the child's answers, to use and follow in order to disclose to them their status. It asks doctors and nurses to gauge the child's level of comprehension and emotional state as they proceed. "Children should know about their status as soon as they have the ability to understand it," said Dr. Rawiwan. "Younger children with more limited comprehension should be told of their health condition and the need for medication." She said, on average, children are able to understand the diagnoses at age seven or eight, but it depends upon each individual. AIDS ACCESS agrees that disclosure is a complex and difficult issue, and adds that in most cases children end up learning their status from family members, neighbours and classmates.

Hospital staff and PLHA volunteers said they believe these various innovations or ideas have contributed to the high percentage of children maintaining treatment adherence. Most are relatively simple solutions to a complex health situation. Aside from their effectiveness in helping children adhere to their treatment, they are also evidence that the disparate group of health care workers and PLHA volunteers have achieved the creative thinking, teamwork and the rapport necessary to work together to find solutions to the challenges of paediatric HIV care and treatment.

4. Conclusions and recommendations

4.1 Lessons learned

The two lessons learned cited most often by those involved in the programme, both at Chiangrai Prachanukroh Hospital and community hospitals, were the need for teamwork and employing a holistic approach to providing paediatric HIV treatment, care and support.

Because of the complex nature of HIV and its impact upon various aspects of a patient's life and the lives of those around them, a successful response must go beyond simply dispensing medication. A holistic approach that involves providing care and support on psychosocial and even financial issues is necessary to ensure that patients actually receive and take the drugs and maintain treatment adherence.

The care and support required to make treatment a success raises demands that go beyond what hospital workers can provide. Teamwork with PLHA or NGO staff is, therefore, essential. In Thailand, as in most settings, only PLHA or NGO workers can assume the responsibility of making home visits and serving as the eyes and ears of the hospital staff in the patient's environment. "PLHA can go into people's lives in a way we doctors cannot," Dr. Rawiwan said. Furthermore, the experience opened the eyes of the public health officials involved to the positive side of NGOs and the value of partnering with NGOs and civil society to achieve public health goals. "They did everything we asked them to do and more," Dr. Rawiwan said. "The NGOs really inspired us."



Four days training for provincial hospital team, Chiangrai Prachanukroh Hospital, Thailand

From AIDS ACCESS' point of view, Namphung said it was advantageous to work with diverse groups of people. "We have to respect other people's opinion so that every party can take part in analyzing and solving problems," she said. By working together on setting goals, planning the work process, wrapping up work reports, and working on adherence, she believed management systems had improved among all groups that participated. "Actually everything we have done together can be counted as learning. Because treating children with anti-HIV drugs was very new, it was never mentioned in any classroom nor textbooks, especially for a country with limited resources like Thailand," Namphung said.

The teamwork also helped provide care and support to the PLHA who were providing care and support to the children and their families. "I've gotten a lot out of this. I can see a different world. I can see how big the problems are that others are facing and my problems seem small in comparison. It encourages me. I can help people and that makes me feel good and useful," PLHA volunteer Rungprapa Kahwin said. "If you didn't pay me I would still come to do this," said Yokfah Prachoomkong, another PLHA volunteer who receives a small stipend from the hospital. "This is what I want to do. I get something back by doing this. I get more knowledge on how to take care of myself." Namphung said that when giving support to PLHA groups working with children/adolescents, support should be provided to the whole team.

In caring for children, according to Namphung, it is most important to wholly care for them, physically, mentally, and within families and communities. Age also needs to be taken into account when dealing with adherence issues, as needs differ among children in different age ranges. "It's not only about illness, treatment and drugs," she said. Even a positive test will not motivate some HIV-infected children and their families to go on and maintain treatment. "More approaches are needed to increase their sense of self-worth and hope," Namphung said.

Treating the child holistically means doing what can be done to keep them in school, Dr. Rawiwan said, and also treating and supporting the whole family. "Try not to let the father die. Treat them as a family. Try not to let them drop out of school. Let them grow as other children, not as sick children. After treatment, they are healthy. They just have their own disease to cope with," she said.

Bridging the gap – uniting to treat children with HIV in Thailand

The final lesson was the most obvious: “Adherence is the most important thing. There are a lot of ways to help with adherence. While it is easy for non-adherence to happen, it’s better to respond, even if we are one step behind them, than to do nothing,” Dr. Rawiwan said.

Key to ensuring adherence, she said, was the presence of a concerned and committed caregiver. Despite the best efforts of hospital workers and NGO or PLHA volunteers, if such a person does not exist the chances of the child adhering to treatment and surviving diminish. “If there is no one responsible for them who loves them enough to give them the drugs, then there is no hope for them. The key is to find that one person who loves them and will take responsibility,” Dr. Rawiwan said.



Grandmother and grandson at the Family Camp, AIDS ACCESS Foundation, Thailand, 2009

4.2 Conclusions

The model developed in Chiangrai for paediatric treatment, care and support has proven to be a strong model for success for such a programme. The evidence, first and foremost, is in the numbers: In the nearly seven years since Chiangrai Prachanukroh Hospital initiated the programme, it has treated 488 children who were living with HIV and the survival rate to this point in time has been 90 per cent. The children who had no hope, now have more than hope – they have the odds in their favour that they will live at least until adulthood.

Many of the cases first treated at Chiangrai Prachanukroh Hospital have been referred to the province’s community hospitals, where survival rates are similar. At Phan Hospital in Mae Chan, the paediatric team has had 31 children on ART since scale up began in 2005, and all the patients have survived to this point in time. This, and the fact that approach piloted at Chiangrai Prachanukroh Hospital has been expanded to currently cover 14 additional provinces supports the contention that the model is replicable and applicable, at least to many other settings in Thailand. Dr. Rawiwan said that bureaucrats once questioned whether the programme’s success in Chiangrai was attributable solely to that team. She disagreed. The scale up shows it is not dependent upon any one group of people. “Leadership is needed, however. In other provinces, other people took leadership roles and made it happen. It is not only here that it can happen,” she said.

The programme also demonstrated that the model of hospital-PLHA partnerships is able to work in a setting such as Thailand. The mix of creative ideas, solutions and sharing of responsibilities is the bedrock on which a programme of holistic treatment, care and support must be built. That can only be achieved when the chasm of mistrust and antagonisms is bridged through compromise and cooperation for the sake of the higher goal of treating children. It requires effort and a new mindset on the part of all involved. “It works because of the good relationships, both formal and informal, between hospital staff and PLHA volunteers,” said nurse Chulaporn Singpae of Phan Hospital.

Integrating the programme into paediatric health care not only made efficient use of existing human, equipment and budgetary resources, but also allowed the programme to get up and running and as quickly as possible, without delays or roadblocks in the form of bureaucratic approvals and procedures.

4.3 Key Recommendations

“Children are the valuable assets of the country. We must protect them. We are the present and the past. They are the future, and so we must do everything we can to help them.” – Dr. Rawiwan Hansudewechakul.

Even within a relatively resource-limited setting such as Thailand, a number of additional measures could be taken up to sustain and improve paediatric HIV treatment, care and support. From discussions with various stakeholders, the following set of key recommendations was formulated.

1. *Develop, implement, and scale up access to comprehensive paediatric HIV care and treatment.*
 - With doctors and health care workers, emphasize the importance of a holistic approach and adherence when treating and caring for HIV-infected children.
 - Wherever possible, expand hours for paediatricians to include weekends and off hours so that children or caregivers won't need to miss school or work to come for treatment. If necessary, increase staffing to achieve this.
 - Train all new paediatricians in paediatric HIV treatment, care and support, and expand training for current health care workers, particularly at community hospitals, in paediatric HIV care and treatment.
 - Continue and increase funding for PLHA workers conducting home visits, and fund and support further training for them.
2. *Remove restrictions to access to paediatric HIV care and treatment based upon national status.*
 - Treat and provide ARV and OI medications under the government universal health care scheme to all children who need them, whether or not they possess a Thai identification card.
3. *Promote greater participation and skills development for children/adolescents living with HIV.*
 - Help HIV infected/affected children/adolescents to develop their self-reliance and skills necessary to lead productive, healthy and fulfilling lives.
 - Develop, encourage, and promote children/adolescent's participation in providing services/attending activities for people with the same problems such as home visit, group activities, and work camps.
 - Provide life skills education and training in the school system for adolescents so that they have the knowledge they will need and will be better equipped to handle the situations they will be facing.
 - Foster exchanges of experiences among those caring for adolescents and children in order to improve communication, behaviour, and manage conflicts.
4. *Strengthen and support networks of PLHA towards ensuring improved service delivery and greater advocacy potential*
 - Develop among NGO workers, civil-society organization workers research skills and access to information tools and networks to gain and apply knowledge on caring for children. This will also increase their capabilities for communicating, connecting and strategically working with other related international, national and regional organizations.
 - Emphasize the development of leaders among PLHA and community groups so they can play important roles in working with hospitals and other parties in community.
 - Collaborate and form networks to work against discrimination and barriers to rights to treatments and medications.

“Nothing is impossible if you try hard enough.” – Dr. Rawiwan Hansudewechakul

Building from scratch

HIV funds rebuild paediatric health care in Cambodia

Executive summary

This paper examines the situation of HIV and AIDS and children in Cambodia, and how the country has initiated and sustained, against great odds, a programme of paediatric HIV care, treatment and support that is functioning and reaching thousands of children and their families. Based on field visits to four Cambodian provinces during June 2009, it details how funds intended for paediatric HIV treatment and care in a low-prevalence nation that is also extremely poor, have helped to build a paediatric health care system and provide services that could benefit all children.

During the past 40 years, Cambodia has suffered through wars, genocide, invasions and civil war. Although the country has been at peace during the last decade, its infrastructure, including its health care, was shattered or had fallen into decay. Cambodia is also one of the hardest hit by HIV and AIDS in East Asia and Pacific. Nonetheless, it has implemented one of the most effective national responses to the epidemic. The national programme has succeeded in reducing prevalence from a peak of 3.2 per cent of the population in 1999 to 0.9 per cent in 2007. This was achieved through political commitment, a multisectoral response, adoption of an evidence-based Continuum of Care approach and the support of donors and development partners. The lion's share of the government's national budget is supplied by donors and development partners.

Cambodia has been scaling up PMTCT services, and has reached a relatively small percentage of pregnant women – 29.1 per cent of pregnant women were tested for HIV and received their results (Ministry of health, December 2008). Furthermore, only 69 per cent of pregnant women received antenatal care at least once from a trained health professional (CDHS, 2005); although this is an increase from 38 per cent in 2000 (CDHS, 2000). Public hospitals and health centres are also generally underutilised. Experience also has shown that when paediatric wards at public hospitals are dilapidated and ill-equipped, parents do not bring their children there.

Faced with this serious barrier to providing treatment and care to children infected with HIV, public health officials decided to use HIV funds to restart, rebuild and revitalise paediatric health care and services for all children. HIV and AIDS treatment and care was integrated into the public health system and services so that costs could be kept low and the response would be sustainable. A similar approach would make sense for paediatric HIV treatment and care. Cambodia, however, did not have a well functioning paediatric health care system. There was, essentially, very little into which to integrate.

With support from UNICEF and other development partners, public health officials began using HIV funds to renovate and resupply paediatric wards. New beds with mattresses were donated, as were lights, fans, furniture, and office supplies. Each facility was also given medical supplies for general paediatric care.

The results were significant. At the paediatric ward in Battambang Provincial Hospital, occupancy rose from 30 per cent before renovations to 80 per cent to 100 per cent afterwards. At Chhey Chumneas Hospital in Kandal province, where the paediatric ward was reopened and refurbished, is now running at 80 per cent to 100 per cent occupancy, with about 1,000 children who come in for outpatient services each month. About 10 per cent of the children who use these services at Chhey Chumneas are receiving treatment for HIV. Also, at Kampong Chhnang Provincial Hospital, where renovations were completed at the start of 2009, occupancy increased from 39 per cent to 54 per cent and the average stay is longer. "When patients have a comfortable bed, a fan and good light, it is more likely they will stay and finish the treatment," said Dr. Rintaravuthy, of Kampong Chhnang Provincial Hospital.

Overall, about 35 per cent of Cambodian children are malnourished. In response to this critical problem affecting children, HIV funds have also been used to fund the severe malnutrition ward at the National Paediatric Hospital in Phnom Penh. Doctors there say that about 20 per cent of the children they treat for malnutrition are HIV positive, and this is an important way of finding infected children. Furthermore, treating malnutrition is essential if ART is to be effective.

Equally important to the response has been the part played by NGOs, community-based organizations (CBOs) and PLHA groups. Follow up of pregnant women who tested positive during ANC and PMTCT is crucial for locating infected infants. Treatment adherence, especially with children, is a challenge, and home visits and follow ups are necessary to maintain adherence and monitor other problems. NGOs, CBOs and PLHA groups are providing these services, or are doing so as part of home and community based care teams from the public health system. Battambang Provincial Hospital, which has a strong NGO dedicated solely to these tasks, loses few patients to follow up. In Kampong Chhnang, where this role is just part of what local NGOs do, about 20 per cent of patients are lost in follow up.

These civil society groups are essential to the Continuum of Care. They perform outreach, provide psychosocial support, help reduce stigma and discrimination, and give valuable feedback to public health officials about various aspects of their programmes and services. Without their partnership and participation, the response would not be as effective.

As of June 2009, 3,366 children were receiving ART and 1,583 children were receiving treatment for opportunistic infections at 29 sites around the country (NCHADS, Ministry of Health). Additionally, voluntary testing and counselling for adults and children are available at 217 sites. As the programme moves forward, public health officials say the focus will shift from expansion of sites to improvement of quality of services. Through monitoring and evaluation, protocols for several aspects of treatment are already being revised.

Most children infected by HIV can only be identified and provided with treatment and care through paediatric health care systems and services. If those systems and services do not exist, children infected by HIV cannot be found, treated and cared for in significant numbers. Cambodia has used its HIV funds to rebuild paediatric health care and services so that children infected with HIV can be reached, treated and cared for. In another context, such broad use of HIV funds might be questioned or criticized by donors, but in the Cambodian context it has brought the results donors and development partners had been seeking – and so much more. Cambodia's children as a whole have benefited. It is money well spent.

Against great odds, Cambodia, a resource-poor nation, has achieved impressive results in adopting and implementing paediatric HIV treatment and care. HIV is an epidemic, however, that morphs over time in terms of transmission patterns and a range of other characteristics and impacts. Achievements in responding to the epidemic can prove ephemeral unless efforts are sustained and adapted to changing circumstances. Therefore, the following recommendations are being put forward for consideration by those involved in the response to paediatric HIV:

- Maintain funding for physical renovation, refurbishment, resupply and maintenance of paediatric health wards in public hospitals. Also, maintain funding for health programmes that are related to HIV or have a bearing on treatment, such as nutrition programmes;
- Strengthen linkages between Maternal and Child Health (MCH), Reproductive Health (RH), Sexually Transmitted Infection (STI) and HIV programmes, including paediatric care and HIV programmes;
- Develop capacity and expand health care staff training on paediatric HIV treatment and care, including training on counselling techniques;
- Increase utilization of PMTCT and ANC services, as they are a key to reducing the future number of paediatric HIV cases;
- Strengthen and support NGOs and PLHA networks to train and/or recruit similar groups towards ensuring follow up, home visits, home care and outreach of those who need it; and
- Advocate with government and donors for the eventuality that at some point they may need to shoulder more of the funding responsibility for broader paediatric health care.

Greater detail on the recommendations listed above can be found in the body of the text.

1. Introduction

The first HIV infection in Cambodia was reported in 1991, and the first case of AIDS diagnosed in 1993. By 1997, the National Committee on HIV and AIDS, Dermatology and Sexually Transmitted Infections (NCHADS) estimated there were 210,000 adults living with HIV and AIDS in Cambodia. Prevalence peaked in 1999 at 3.2 per cent of the adult population. The main route of transmission was heterosexual sex, accelerated by a large commercial sex industry. Since then, numerous efforts have been made to address the epidemic. By 2006, HIV prevalence had declined to 0.9 per cent, and is expected to fall to 0.6 per cent by 2010.

As the HIV and AIDS epidemic advanced across Asia during the early 1990s, Cambodia was ill prepared to respond. Ravaged and rendered destitute by more than three decades of invasions, genocide and civil war, Cambodia was a country where the health care system, along with most other infrastructure, had been shattered. Doctors and trained professionals were few. Hospitals were crumbling or had been closed. Basic equipment, medicines and supplies were often beyond the country's means. In light of these constraints, Cambodia did not seem capable of mounting an effective response to this complex epidemic – much less provide treatment and care for its children infected and affected by the virus.

The epidemic is still present and its patterns have been changing. A UNAIDS Country Situation report dated July 2008 said that 96 per cent of brothel-based sexual transactions are protected. However, men “increasingly turn to non-brothel-based sex workers, sweethearts and concurrent non-regular partners for sex with whom they are less likely to use a condom. Almost half of new infections are among married women. One third of new infections occur from mothers to their new-born infants.”

With funding and collaboration from donors, and commitment from the country's political leadership and health care workers, Cambodia started turning the tide in its campaign to stem the spread of the virus. It began with a brothel-based 100 per cent condom use programme, and then expanded to education and awareness campaigns, training for health care workers, partnerships with donors, NGOs, community-based organizations (CBO) and groups of people living with HIV and AIDS (PLHA). Cambodia has employed a comprehensive national response, including providing antiretroviral therapy (ART) with international assistance since 2001, and a Continuum-of-Care approach since 2003.

As the country still struggles to recover and rebuild, nearly the entire government budget comes from international donors. Each year, Cambodia receives a large amount of money from a variety of international donors to respond to the HIV epidemic. A total of \$294 million has been pledged to the national programme for 2006-2010. However, given the difficult economic times when hard choices have to be made about the allocation of significantly scarcer resources, every dollar spent must have sound justification. Considering the range of health problems facing Cambodians and Cambodian children, is the response to the HIV epidemic commanding too great a share of financial, human and other resources? Is the money being spent wisely and with maximum effectiveness? Are there other benefits to Cambodia and its children brought about by the funding devoted to HIV and AIDS that justify the costs?

Beyond the grand question of whether or not donors are spending their money to best effect, more specific questions can be raised about Cambodia's approach to responding to the epidemic, and the effectiveness of specific programmes. Are sufficient numbers of children being reached? To what degree has the response achieved success, and what are the factors that are essential to that success? What constraints exist and how can they be overcome? Is the response sustainable? What more needs to be done?

Children were still missing from the response. However, presenting an accurate picture of the situation in Cambodia regarding children infected and affected by HIV and AIDS is extremely difficult because of a lack of official national data and an applicable modelling method. UNAIDS estimated that there were 4,400 (ranging from 4,000 to 5,000) children living with HIV and 51,000 children orphaned by AIDS in 2007.

There are essentially four ways of locating children infected by HIV: through PMTCT programmes and follow up where infants and children are tested; through testing the children of parents who are infected; through testing of children who turn up at hospitals with illnesses that are not responding to treatment; and through various NGOs making home visits who spot children whose symptoms and situations may suggest they are infected, although this last method finds the fewest numbers of infected children.

Cambodia's PMTCT programme, which has been in place since 2002, has had some success in reducing transmission rates, but was still only reaching about 12 per cent of pregnant women by 2008. And until recently, the state of paediatric health care across most of the country was dismal, if it existed at all. Cambodian mothers, as with mothers everywhere, desperately want good health care for their children, but there are few places for them to find it. Even if children came to hospitals with illnesses, health care workers were not necessarily trained to spot them as possibly symptomatic of HIV infection, nor did they have the capacity to perform counselling and a rapid test.

Meanwhile, if paediatric care and treatment for HIV and AIDS are meant to be integrated into paediatric health care in general, that wouldn't be possible if paediatric health care in general isn't functioning. And because of the complexity of treating and caring for those infected with HIV, a functioning paediatric health care system is essential, as are partnerships with civil society groups, PLHA organizations, and the community at large. As with adults, to be successful it requires a Continuum of Care (CoC) – a comprehensive service package that is systematic, coordinated, integrated, inclusive and covers both the hospital and the home.

"An HIV programme alone cannot improve HIV and AIDS care because treatment has to be provided for a range of diseases and illnesses that show up as opportunistic infections. Nutritional support is necessary as well. This is why we need a strong paediatric health care system. We need to revitalise paediatric services, because we don't have and can't have separate staff just for HIV; we need to use regular paediatric health staff. This is generally not recognised," said Dr. Mean Chhi Vun, NCHADS Director. Similar to the response to the adult epidemic, a Continuum of Care approach would have to be integrated into the health care system, and in this case paediatric services.

If the public health officials running the National HIV and AIDS programme wanted to provide care and treatment for children infected and affected by HIV, they would have to begin by helping to build the paediatric health care system as a whole. That meant that funds from the HIV programme would go towards reopening the paediatric ward, supplying furniture, medical equipment and supplies, paying staff and providing services to all children, not just those infected by HIV.

In Kandal province, just outside the capital of Phnom Penh, the problems of providing paediatric care were illustrated at Chey Chumneas Referral Hospital. Dr. Kong Chhumly, the Hospital Director, wanted to help children, but he simply did not have the means. At one time, he had overseen the care and treatment of thousands of children each year at Chey Chumneas. Its two-floor, 60-bed paediatric ward was nearly always full. But not anymore. Times and circumstances had changed.

In 1975, when the Khmer Rouge swept to power, Chey Chumneas, and the country's other hospitals, were shuttered as the radical regime forced all those living in cities to leave for labour camps in the countryside. After the Khmer Rouge was overthrown in 1979, people started drifting back to the cities. Chey Chumneas reopened with the help and support of a Western charity. However, Chey Chumneas was not yet ready to stand on its own. Without support, its services, supplies and staff all started to dwindle and decline. The lovely, tree-lined grounds and the modest complex of one- and two-storey buildings became increasingly run down and dilapidated. Beds were old and had no mattresses. Medicines were in short supply. Equipment was essentially nonexistent. As the years went by, fewer and fewer parents brought their children to Chey Chumneas. The children that did turn up were afraid to stay in the empty, bare and spooky ward. So, in 2002, Dr. Chhumly gave up. Reluctantly, he closed the doors, locked the ward and walked away. "It was a painful thing to do," he said, because he knew how desperately Cambodia's children needed health care.

After a decade, the charity decided its work was done, and so it pulled up stakes and moved on. Although it is a public hospital, Chey Chumneas is dependent upon funds from international donors and nongovernmental organizations to operate. That's not unusual in Cambodia.

One day in mid-2005, Dr. Chhumly received a visitor. Dr. Mean Chhi Vun, Director of NCHADS, had come to talk with him about improving services for adults in Kandal living with the virus. While touring the hospital, he asked Dr. Chhumly if it had a paediatric ward. The hospital director led him up a flight of stairs and showed him the locked doors and dark rooms. Dr. Vun's reaction was swift and firm. "We have to get this open and running again," he said.

Had Dr. Vun visited just a few years earlier, he would never have asked to see the paediatric ward. Care and treatment for children infected and affected by HIV and AIDS had not been a component of Cambodia's response to the epidemic. Before 2003, Dr. Vun had never even seen a child infected by HIV. He was certain they were out there, but almost no data existed on them, and so the subject of providing treatment, care and support to children had never been seriously raised. And when it had been Dr. Vun was not enthusiastic. There were no antiretroviral (ARV) paediatric formulations, no protocols for treatment and no staff skilled or trained in the area. "It was just too difficult," he said. As much as he wanted to help, he simply did not have the means.

Then, in 2003, Dr. Vun was approached by Brown University in the United States about conducting some small-scale research on paediatric formulations for ARV. Dr. Vun cited all the aforementioned reasons why it did not seem feasible, but the university responded that it would provide the recommended protocol for the paediatric formulations and the training. UNICEF also agreed to lend financial and technical support to the effort. Subsequently, in September of that year, UNICEF provided paediatric ART supplies to kick-start the programme at the National Paediatric Hospital in Phnom Penh. In 2004, Cambodia drew up its own protocols with technical support from the team at Brown, the University of New South Wales, UNICEF and others. In an effort to further build clinical skills and knowledge, in 2005, a working group of 13 Cambodian doctors was formed, and a mission sent to Thailand to study Prevention of Mother to Child Transmission (PMTCT) of HIV and to observe the protocols for paediatric care and treatment the Thais had developed in their own successful response. These doctors returned to serve as trainers of physicians countrywide delivering OI and ART services to children.

With a regimen in hand, NCHADS and its partners set out on a pilot project to start up paediatric care and treatment at ten provincial hospitals. One of the places they arrived at was Chey Chumneas. The situation there was typical. In virtually every public hospital, including the National Paediatric Hospital in Phnom Penh, conditions were poor and equipment was lacking. But the provincial hospitals were in far worse shape than the National Paediatric Hospital.

Dr. Chhumly felt a mix of joy and cautiousness when Dr. Vun expressed a determination to restart paediatric care. Dr. Chhumly was concerned because no children with HIV had ever turned up at the hospital. As with Dr. Vun, he was certain they were out there, but with so few children coming to his hospital in the first place, he hadn't actually encountered any. And even if he could locate a few children, would that be enough to justify the funding needed to reopen the ward?

Dr. Vun assured him that it would be, because providing care and treatment for children with HIV and AIDS is not a stand-alone programme. To be effective it must, by necessity, be integrated into total paediatric health care for all children. If paediatric health care for all children did not exist, it would have to be created.

That was all fine with Dr. Chhumly. "I have more children here in Kandal suffering from malnutrition, dengue and diseases other than HIV. If HIV money can allow me to reopen the ward and help those children too, then let's use the HIV money," he said. "It doesn't matter where the money comes from, as long as they are getting care." He estimates that about 10 per cent of the children he treats are infected with HIV.

At Chhey Chumneas, UNICEF funded the complete refurbishment of the ward, including the provision of medical equipment and furniture. The hospital began providing paediatric HIV care and treatment in mid-2006, and then general paediatric care about six months later. UNICEF's involvement was limited and time bound. Six months after the ward was up and running, the agency moved on to other hospitals in need. Nonetheless, it was a successful kick start to a programme of providing paediatric health care that had come to a halt. UNICEF did not leave, however, before other partners had committed to sustain the efforts at Chhey Chumneas. Chief among them are Magna, an international NGO providing paediatric ART, care and support. No one wanted a repeat of what happened after the first charity left in 1989.

Today, the paediatric ward is among the cleanest and well-stocked at Chey Chumneas. Occupancy of the 30 beds is usually 90 per cent, but exceeds 100 per cent during dengue season. Dr. Chhumly says that he and his staff are providing out-patient paediatric health care to more than 1,000 children every month. Among them are 315 children receiving ART.

"In truth, I wish donors would give more money as a total package to provide care for malnutrition, dengue and other diseases. HIV is important, but all kids want to be able to survive," Dr. Chhumly said. "But for now, those kids are being helped with HIV money, so please don't change it. Finally, after so long, we are helping children again."

2. Building a response to children infected and affected by HIV and AIDS

2.1 Determining the scope of the problem and the approach

Globally, the growing problem of children infected and affected by HIV and AIDS began gaining widespread attention around the dawn of the new millennium. As epidemics evolved and matured, moving beyond most-at-risk groups to bridge populations, increasing numbers of women were being infected. That eventually led to growing numbers of infected children, mainly through vertical transmission at birth.

Although Cambodia is a country that is far from the cutting edge of medical and public health care, in the early part of this decade it began a serious effort to scale up its response to the epidemic. A combination of international donor support and domestic political commitment made this possible. As Cambodia scaled up, the issue of children infected and affected by HIV and AIDS was injected into the scope of the response. UNAIDS estimated there were 4,400 (or a range of 4,000-5,000) children living with HIV and about 51,000 children orphaned by AIDS in the country in 2007.

Cambodian public health officials decided the best approach to paediatric HIV treatment and care would be the same approach as for treatment and care for adults – the Continuum of Care. It proved to be a foundation for the success of the response. The CoC involved integrating the response into a decentralised public health care system with strong referral networks, and involvement of community-based organizations and PLHA groups. “We clearly understood that we should move the service close to the patients, so we wanted to scale up the service, making it available at the local level,” Dr. Vun said.

Although integration is essential, health officials recognise that paediatric HIV and AIDS treatment and care, and paediatric care in general, are complex and require their own specialised protocols, training, medicines and formulations, equipment and staff. But they must exist within the health care system as a whole, rather than as stand-alone programmes in order to be sustainable and to maximise benefits.

The CoC requires certain components, such as protocols for treatment, training of health care staff, counselling and testing, and laboratory support for testing. Furthermore, treatment for opportunistic infections and ART must be available, along with nutritional support and support for costs that present barriers to access for the poor, such as for transportation and food. Home and Community Based Care (HCBC) is also a must to maintain treatment adherence, necessitating the involvement of PLHA and community groups. Also, strong levels of ANC, VCCT and PMTCT coverage are essential, both in preventing infections and locating infants and children who may be infected.

The long list of components of the CoC would naturally generate a high price tag, something not possible to meet in the Cambodian context. “We have limited resources, and so we have to use existing resources at the local level. So integration is very important,” Dr. Vun said. “Integration is the key.”

There must, however, be an existing paediatric health care system into which to integrate. The state of the health care system, and paediatric health care, would prove to be the first major hurdle to the response.

2.2 Integration into what? Cambodia’s public health care system

The simple two-storey building housing Kampong Chhnang’s Provincial Health Department is surrounded by gardens and a statue of a mother breastfeeding her infant. The manicured grounds, however, are a stark contrast to what lies inside. This is the nerve centre for public health in a province of 480,000 people about an hour’s drive northwest of Phnom Penh, but it is dank, dusty and dingy. Paint is peeling, holes in walls are patched over with spare bits of plywood and a gray film of crud seems to cover just about everything.

Just across the street, behind two billboards promoting PMTCT and condom use is Kampong Chhnang Provincial Hospital. The hospital is a complex of simple one-story buildings. The Maternal Health Ward is like most of them: dark, cramped and stuffy in the tropical heat. Everything seems decades old. Beds few of which have mattresses, are lined up in the hallways, affording patients little to no privacy. Blankets seem to be little more than rags. Women resting or breastfeeding their newborns recline on cheap straw mats as their families of farmers or fishermen arrive with their day’s food. “Maternal and Child Health services get only a tiny fraction of the money HIV does,” said Sedtha Chin, HIV Officer of UNICEF Cambodia. The condition of the ward at Kampong Chhnang is evidence of that. It’s not only MCH, however, that suffers from a lack of resources.

Cambodia's public health care facilities are rudimentary at best. Most are lacking in equipment and supplies, and their dilapidated physical condition can make them unpleasant places to stay. Barriers to access exist for the poor. Consequently they are underutilised. Doctors say that those who do come to public health centres often don't want to stay until treatment is complete. "We have had to build our system from scratch, from zero," said Dr. Vun, explaining the state of public health care. A June 2004 article in the Asian Development Bank Review said "Cambodia's poor, when they get sick, can be more likely to flee public health care workers than to seek advice or treatment. Many will self-treat or call in traditional healers before showing up at government-run clinics."

According to the 2005 CDHS, only 22 per cent of people who are ill or injured seek treatment at a public health centre. But demand for health care is high, as 48 per cent seek medical care in the private sector, and 21 per cent go to the non-medical sector (a shop or market, magicians, monks or religious figures, and traditional birth attendants). Seeking treatment in the private sector can be risky. "There is a wide diversity in private health care and the quality is questionable. Some big towns have private clinics, but there is no licensing system yet, so the quality is suspect. There are drug sellers who are untrained. There are people working in the public sector, but providing private services after office hours," Chin said.

Education is also a factor in whether or when someone might use public health care. "Being able to recognise the danger signs, and being able to take the right decisions in the interest of the child and bring them to the hospital," is dependent on a mother's knowledge or education, Chin said.

The World Bank repeatedly cites the mother's education level as a factor in child health and survival. Cambodia has made important strides in girls' education, with primary school enrolment rates at 89 per cent in 2007. However, a generation of women had reached child-bearing age before those efforts to expand education were made.

When Dr. Vun and his team began appraising the paediatric health care system into which they planned to integrate the response, they were disappointed in what they discovered. "We found a lack of infrastructure at provincial and district hospitals, and limited capacity among staff," Dr. Vun said. "In this country, for the most part, (specialist) paediatric wards simply do not exist," Chin said. "Children are housed in the adult ward. They call it children's services, but it isn't really. Some don't have any child-specific services at all." Dr. Vun said there was no choice: "we would have to revitalise paediatric services and restart them in some hospitals."

2.3 Appearances are important: making hospitals a place where patients want to come

In hospitals such as Kampong Chhnang Provincial, the paediatric wards were in sad shape – old, run down and filthy. Even in Battambang Provincial Hospital, in the second largest city in Cambodia, the ward was crumbling; plumbing was leaking, beds were without mattresses, floors and walls had holes in them, mould was growing on surfaces from the dampness of the monsoons.

Today, it's a different story. With funding from the HIV budget of UNICEF, the paediatric ward at Kampong Chhnang was renovated, with the job being completed in early 2009. It is now a bright, clean and comfortable place to stay. All the beds have mattresses, the sheets are laundered and changed often, and the rooms are cooled by fans. A new coat of paint, along with new bed frames and other furniture, has made the rooms brighter and more welcoming. "Everything here is so clean and comfortable, and the staff is helpful. I'm happy, and I couldn't ask for anything more," said Leng Sokby, whose 12-year-old son Torn was being treated for dengue. "I don't want to have to go to Phnom Penh, when things here are clean and the care is good," said Mak Mayome, a 27-year-old rice farmer, cradling her four-month-old daughter, Plalla, who was recovering from pneumonia. She had travelled 40 kilometres to reach the hospital.



In-door play ground, Paediatric Ward, Prey Veng Provincial Referral Hospital, Sedtha CHIN/ UNICEF Cambodia/2010

In a room at the far end of the bungalow-style building, three HIV-positive young boys and their mother are being counselled by a nurse who is checking their pill boxes and asking them questions in a friendly tone to see if they are adhering to their medication regimen. Everyone's mood seems bright and positive. Health officials said there are between 60 and 70 HIV-positive children in the province, but that they expect to find more as PMTCT and other services improve. So far, 39 are on ART, and 26 have been treated for opportunistic infections.

The paediatric ward is the most pleasant ward in the hospital, and its utilization has increased. "After refurbishment the occupancy rates have gone up and the average stay is longer," said hospital Director Dr. So Rintaravuthy. Hospital records show that average occupancy rose from 39 per cent to 54 per cent after renovations, and the average stay increased from 3.9 days to 4.3 days. "When patients have a comfortable bed, a fan and good light, it is more likely they will stay and finish the treatment," Dr. Rintaravuthy said. The doctors believe these numbers will continue to rise as more parents become aware of the improvements. "We would actually like to refer some cases to the National Paediatric Hospital in Phnom Penh, but some parents don't want to take their children there because they feel more comfortable here and they don't have to spend the money to travel and stay in Phnom Penh," Dr. Rintaravuthy said.



Battambang paediatric care unit, Battambang Hospital, Sedtha CHIN/UNICEF Cambodia/2009

It's a similar story in Battambang, a province of about one million that was the first site for implementing the CoC. Since paediatric HIV care and treatment was launched, the hospital has 237 children on ART, another 414 have been treated for opportunistic infections, and another 121 who have tested positive are being monitored. "Before the integration of paediatric HIV care the paediatric service was not functioning well," said Dr. Nek Bun Chhup, the provincial health director. "Only a small number of children came here. But since integration, the ward has been renovated and refurbished with medical equipment and furniture. That has helped all children, not just HIV children, and now we see a lot of improvement in the numbers of children coming to use the paediatric ward whether they are HIV positive or not."

Before renovation, in 2006, the average occupancy in the 30-bed ward was about 30 per cent. Today it is usually 80 per cent, and exceeds 100 per cent during dengue season. But the biggest increases are in outpatients. Dr. Chea Peuv, Chief of the paediatric ward, insists demand for paediatric care is strong. "Parents only bring their children to a public hospital when the case is serious, otherwise they go to a private health service. If we have enough beds and equipment, and it is a comfortable environment, the mother will bring them to the public hospital. Too often, they wait until it is too late," he said.

The paediatric wards at Battambang and Kampong Chhnang are similar in appearance because they follow a model UNICEF used at the start of the scale up and was adopted as the standard by the MOH. Even paediatric wards renovated by other agencies or NGOs have used the model. Recently included in the design is a small indoor playground with books and toys. At Battambang Hospital, children hug stuffed animals while one child pushes a plastic bird on a wheel, laughing in glee. The simple addition of a few toys and books can make the hospital stay more bearable.

Dr. Vun says "More than 17 buildings have been renovated by UNICEF and the Clinton Foundation." Along with the furniture and renovations came comprehensive paediatric care equipment and supplies. "Not just for AIDS care, but for all paediatric care," he said. UNICEF conducted a needs assessment at each hospital before determining what to send. Other agencies, such as Family Health International, have also used funds to purchase office supplies for health staff. Simple items such as folders or binders allow health staff to better organise case histories and other information to more efficiently care for patients.

Care cannot be provided without equipment, supplies and medicines. But, while it may appear odd at first that UNICEF or other agencies allow HIV money to be used to buy mattresses and fans, if a hospital is not clean and comfortable, the experience in Cambodia has shown, parents will be reluctant to bring their children there. Clean and comfortable conditions inspire confidence in the competence of hospital staff and the quality of care they will give.

To effectively deliver treatment and care for children infected with HIV, it is imperative to improve the general physical condition of paediatric wards at public hospitals as one of the first steps. This will allow the public health system to reach more of the country's children with a wide range of treatment and care, and among them will be children living with HIV.

2.4 Funding other hospital services in order to reach HIV-infected children

The National Paediatric Hospital in Phnom Penh is the gold standard in paediatric care in Cambodia. It is larger and better equipped than any other health care facility for children in the country. Funds for the paediatric HIV response are spread throughout several components of the 150-bed facility, such as the intensive care unit, surgical unit, emergency ward and malnutrition ward. "Some of the children in these wards have HIV and are also poor, so the HIV money is helping everyone," said Dr. Un Vuthy, head of the department of diarrhoea and severe malnutrition.

Because the hospital has a reputation for providing the best quality paediatric care, families from far and wide bring their children there for treatment if they can afford the transportation. To date, the 22-bed severe malnutrition ward is fully occupied, and more than half the children are from provinces outside of Phnom Penh. As Dr. Vuthy strolls from room to room, he examines an 8-year-old boy eating a meal of fish, rice and vegetables from a tray as his mother sits on the bed beside him. The boy looks up and smiles at the doctor, happy with his meal. He is rail thin, small for his age, and there are blotches on his exposed arms. "I suspect he may have HIV," Dr. Vuthy whispers in English, adding that they will have to counsel the family and recommend the boy be tested. "About 20 per cent of the children who come here for malnutrition turn out to be HIV positive," he said.



Kratie paediatric care and nutrition support, Sedtha CHIN/UNICEF Cambodia/2009

Public debate and appeals about caring and treating children for HIV often centre around ART and the high cost of drugs. National Paediatric Hospital Director, Dr. Chhour Y Meng, says ART alone is not a solution to paediatric HIV and AIDS. "There are a number of illnesses associated with HIV and we have to treat them all. Severe malnutrition is related. HIV has to be treated as a package. The Continuum of Care is a package. If a child is malnourished, the side effects of ART may be more severe, and so his malnourishment must be treated for ART to be successful," he said. So, HIV funds have also been used to build the ward's kitchen, which provides special meals to children specific to their condition.

If the boy tests positive, he will not be separated, but remain in the malnutrition ward with the other children, although there is a separate ward for HIV-positive children who have come for treatment of opportunistic infections. A mark on his chart will alert health care workers as to his status, but it will not be revealed to other children or families for fear of stigma and discrimination. These remain a problem in Cambodia, although slowly improving. In fact, when the hospital first started treating children for HIV, "some of the staff fled. At that time knowledge about HIV was not very high, and staff were afraid of these cases. It was solved through education and training – and through the courageousness of the PLHA groups, who were not afraid to share their experiences," Dr. Meng said.

It was a surprising reaction, considering the fact that doctors at the hospital knew they were dealing with infected children during the 1990s because of the patterns of their recurring illnesses, but had no means to test them at the time, said Dr. Ung Vibol, Head of the HIV and TB section. When tests became available, some staff reacted. Overcoming fears among health care staff was essential, said Dr. Meng, because whether it is HIV or malnutrition, children require follow up. "If there is a good relationship between the families and the health care staff, then the families are more willing to return," he said. In the malnutrition ward, 90 per cent of the children return for follow up.

2.5 Ancillary costs

There are a number of costs being met with HIV funds that would not appear at first to relate directly to treatment, but most of which help break down barriers to services and increase access, or help improve efficiency of services. Failure to fund them, through whatever means, will have a negative impact on the efficacy of the overall response.



Mothers and their children enjoy new supplies at Paediatric Ward, Kampong Chhnang Hospital, Sedtha CHIN/ UNICEF Cambodia/ 2009

At first glance, one of the more questionable costs is the incentives paid by the Ministry of Health to doctors and hospital staff working on paediatric HIV care and treatment. At Battambang Provincial Hospital, the two doctors and two nurses officially designated as working on paediatric HIV care and treatment are each paid a \$60 monthly incentive. Salaries are low among public health staff, but is it necessary, or even ethical, to motivate hospital staff with money to treat HIV cases? Dr. Chhup laughs at the question. There are actually 13 staff members working with these children, he says, and so the money is divided among all of them. "Of course we would be working on this if the cash incentive wasn't there. It's not that much, especially after it is shared. More than anything, it gives the staff a sense they are appreciated and so raises their morale," he said.

Morale is important, especially among health care staff working to provide treatment with limited resources. A sense of appreciation, along with improvements in training and equipment, has had an observable effect upon staff, according to Chau Sary, a project coordinator for Community Development For Children (CDFC), an NGO working on HIV-related issues in partnership with the Battambang hospital. "They have more commitment now. They have been willing to stay open and work longer hours to provide more service to patients," he said. When asked if the incentives might have a negative effect upon the morale of health care workers in other sections who are also working hard but not receiving them, the doctors overseeing paediatric HIV care and treatment declined to speculate.

The NPH also uses HIV funds provided by UNICEF to provide poor patients with money for transportation and other costs so they will return for follow up. Costs for transportation, food, and lodging if a child has to be hospitalised and the parents need some place to stay, can be significant barriers to poor patients accessing health care or returning for follow up. Failure to return for follow up can often mean conditions will worsen or recur. In Battambang, the CDFC, which operates with funds from UNICEF, also helps patients with transportation and other costs that overcome barriers to access. The CDFC also helps with costs of uniforms and books so children living with HIV can attend school. These are also funded with money from the HIV response.

The NPH not only serves as the training centre for paediatric HIV care and treatment, but also for the treatment of severe malnourishment among children for 24 provinces for health staff from around the country, and to date about 25 provincial doctors are receiving a lecture on ART regimens. Training is essential to the response because paediatric HIV care and treatment is a relatively new field and health care practitioners need to stay abreast of new developments in treatment regimens and other aspects of the response. "Special training is needed for those working in this field. Not just in clinical management, but in counselling and care also," said Dr. Meng, chief of the NPH.

Every six months, the hospital invites patients and members of PLHA groups to speak at the training sessions so they can share experiences and give important feedback on how the health care system and health care workers are responding to the epidemic. "The involvement of PLHA is very important," Dr. Meng said. "We couldn't do this as well without them."

2.6 Partnerships: The need for help outside the hospital

After he watched his wife die from AIDS, Bun Leap, a textile worker in northwestern Cambodia, thought all was lost. At the time, there was no treatment available to save her. And that meant there was no treatment available to save him and his son, Baney, when they would fall ill, as eventually they surely would. The future looked grim.

Things were also looking as bad as could be for Dy Theanita. The son of a farming family in the Sangke district of Battambang, he was born with HIV. By the time he was eight, both his parents had died from AIDS. With no relatives to speak of, he seemed destined for an orphanage, or perhaps he might be taken in by the monks at a local Buddhist temple.

But fortune smiled upon young Dy. He happened to live in the same village as Bun Leap. After Bun Leap's wife died, ART became available in Battambang, and both he and his son were now receiving care and treatment at the provincial hospital.

At the textile factory where Leap works, the pay is low, and the hours are long and hard. But Leap knew it can be harder living with HIV. Leap and his son, however, had each other for support. Now, Dy had no one. "My heart went out to him," Leap said. "I couldn't see him go off with strangers who may not care about him or his condition." And so, in an act of extraordinary kindness and compassion, Leap adopted Dy.

With the introduction, first of ART, the CoC and then paediatric care and treatment for HIV, Leap's attitude has changed. Both he and his boys, including 12-year-old Dy, are receiving ART free of charge. They are healthy. Although they live far from the provincial hospital, CDFC supports them with a transportation allowance so they can come for treatment and receive their medication. Leap says that without such help he could not afford the fares for the 28-kilometer journey. On occasion, they are checked on at home by CDFC, which is a degree of psychosocial support in itself; they know they are not forgotten or uncared for.

At the hospital, Leap and his sons participate in MMM ("Mondul Mith Chouy Mith" or Friends Helping Friends) meetings where they have made friends with other families in a similar situation. With these new friends they can either share thoughts and feelings or simply relax and enjoy each other's company, play games, and receive a nourishing meal. "I like coming here," Dy said with a smile. "They take good care of us, it is friendly and I'm happy."

Being cared for on several levels, as opposed to just receiving medicine, has changed their outlook. Baney says some day he wants to be a teacher. Dy says that when he grows up he would like to be a radio technician. And Leap, who once felt nothing but despair as he awaited certain death for his son and himself, now views the world in different terms. "My sons," he says, "have a life ahead of them. As a family, we have hope for the future."

As Dr. Meng of the National Paediatric Hospital said, drugs alone cannot solve HIV. Because of the complexity of providing treatment and care, and especially to children, more help is needed than hospital staff can provide, and especially in a resource-poor setting such as Cambodia. Children can be reluctant to take medication when at home. Parents living with HIV and AIDS may be ill and not have the wherewithal to keep their children on their regimens. When parents have already died, caregivers may be elderly relatives who are forgetful, illiterate or have little understanding of HIV. Keeping children on their medications is a challenge for them.

The CoC response to HIV and AIDS, therefore, has two broad strands: hospital and health system treatment and care, and home and community based care (HCBC). Home and community based care are crucial for making treatment and care at hospitals and health centres effective.



Mondul Mith Chouy Mith meeting in Takeo, Sedtha CHIN/UNICEF Cambodia/2010

HCBC is important for ensuring follow up for treatment, maintaining treatment adherence among those living with HIV, providing psychosocial and other forms of support, and helping to break down stigma and discrimination. Those involved in home and community base care can also alert health workers to the presence of children who may be infected with HIV in homes they visit. They can give important information to health care workers about situations in the homes of children living with HIV that may affect their treatment. They have given feedback on how various aspects of the programme are working or not, or can be improved. “We are the eyes and ears of the hospital in the community,” says Chau Sary of CDFC.

2.7 Groups involved in home and community based care

Home and community based care requires partnerships with village health volunteers, PLHA groups, community-based organizations, religious groups and nongovernmental organizations. People living with HIV and AIDS are an integral part of the response, and especially in home and community based care and support. Cambodia has scores of PLHA groups, mostly operating under the umbrella of the Cambodian Positive People’s Network (CPN+).

PLHA assist in hospitals, such as Battambang Provincial Hospital, with clerical work, and their presence can be reassuring to HIV-positive patients that the health care institution will not discriminate against them. PLHA are also involved in explaining and counselling people living with HIV and AIDS and their caregivers on what treatment entails and how treatment will proceed. These sessions, and there are usually three of them to prepare the family for treatment, take place in a hospital or health care setting.

PLHA groups are also involved in home visits to ensure treatment adherence and observe if there are other problems in the family that may affect treatment, and treatment adherence.

While the value of peer-to-peer networks, communication and outreach is undeniable, it is also important to note that, with the right training, attitude and commitment, non-PLHA community organizations can also do an effective job of home and community based care. Even then, however, they acknowledge the usefulness of help from PLHA in reaching and understanding the patients and their families.

3. A tale of two provinces: Lessons learned in Cambodia's response to paediatric HIV and AIDS

3.1 Limitations of the hospital-based response

In implementing the CoC approach to paediatric HIV treatment and care, Kampong Chhnang Provincial Hospital has 12 home and community based care teams operating around the province of about half a million people. Each has a village health volunteer, health centre staff member along with members of a local NGO named New Hope of Cambodian Children. The village health volunteer is a key person in providing feedback to the hospital on the state of the family. It is an unpaid position, but regarded by the Ministry of Health as an official part of the government health care mechanism. They receive some training, but it is minimal.

The NGO is dedicated, but works on a range of children's issues aside from health and paediatric HIV. They are not specific to the task, and neither is the health centre staff member. Consequently, Dr. Rintaravuthy says, "we are losing 20 per cent of our cases during follow up." Although the system used in Kampong Chhnang is the same used around the nation, he says it is not as effective in this province as in some others. What's needed, he says, is an NGO that is dedicated to working solely on paediatric HIV treatment and care in the community context. "Like what they have in Battambang," he says.

3.2 The key component: strong NGO support

In Battambang, Chau Sary is the project coordinator of Community Development for Children. It is a small NGO. He works with Ms. Doul Samphan, another project coordinator, and one administrative assistant, Ouch Limanat. That is the extent of their staff. And yet they cover 78 villages in the province of more than a million people. They also deal with more than paediatric HIV, working on the broadly-related issues of PMTCT and ANC follow up. Their efforts assist in several aspects of the CoC.

No one at CDFC is a person living with HIV. They came to their calling mainly through chance and opportunity. Chau Sary took up health work while living in a refugee camp in Thailand where he received some training from the Red Cross as a medical assistant. After returning to Cambodia, he joined other NGOs that worked on health-related issues, and from 1996, on HIV-related issues. The main reasons he and Doul chose to work on HIV were that they knew it was becoming a major problem, and both training and funding to work on it were available. "We both got training and money for training because the majority of training available to NGOs was for HIV," Samphan says.

They may have gone where the money was, but watching Sary and Doul work it would be difficult to doubt their commitment and their effectiveness in helping others. They are essential to the success of the CoC, and contribute to it on various levels.

CDFC works in three areas:

- Supporting PMTCT by assisting in follow up of HIV-positive mothers during pregnancy, providing referrals, performing home visits after delivery and referring their exposed babies to paediatric care.
- Supporting HIV paediatric care services by helping in the paediatric ward where they organise MMM (friends helping friends) meetings and gatherings, providing transportation money for hospital visits, and performing follow up visits to infected children and their families to check on treatment adherence and offer other kinds of help.
- Providing support to children living with HIV, providing them with money for uniforms, books and other essentials so they can attend school. CDFC is providing this coverage to 53 orphans in its coverage area, and eight from outside its boundaries.

Battambang was the first province to implement the Ministry of Health (MOH)'s national plan for PMTCT coverage (2002) and to scale up paediatric ART care (2005). There are 75 health centres and 1,400 health care workers in the province, but the doctors at Battambang Provincial Hospital have calculated that only about 33 per cent pregnant women are covered by the service. "During implementation, the big challenge was follow up of positive mothers and babies who may have been exposed," said Dr. Peuv. Then there are the babies and children who have tested positive. They also need follow up.

Since the beginning of its collaboration with the hospital at the start of 2008, the CDFC says it has maintained contact with 119 positive mothers and 155 exposed children. So far, 118 children were tested and six were positive. The rest were either under six weeks old, or their mother had not stopped breastfeeding yet, and so they were not ready for testing. So far, no one has been lost during follow up.

Losing patients during follow up can happen for several reasons. People and families move, and in a poor farming society hospital workers can't trace them. On the other hand, CDFC is able to. "We know the communities well because we live and work in them, and so we can almost always find someone," Sary says. Sometimes, parents will not accept the test results, refusing to believe they or their children are HIV positive. CDFC says it does its best to maintain contact with them, and slowly tries to work on them and convinces them to accept the results and get treatment.

Patients were also falling through the cracks because PMTCT, ANC, the Birth Departments and the Paediatric Departments all used different numbering systems to identify patients. CDFC developed a master form for women and their families to track them through ANC, PMTCT, the birth process and paediatric care. They coordinated with each department to develop a numbering system so that patients would have the same code number no matter which department they were dealing with, or which health centre in the province they had received services from. There were several instances of patients moving around and going to different health centres. Continuity in treatment did not exist because the records were disjointed. With the new system, health officials in any district can access the patient's treatment history and communicate with those who previously treated them.

The presence, actions, innovations and involvement of CDFC in the area served by Battambang Provincial Hospital has had a significant impact maintaining treatment and care continuity for people living with HIV. Unlike in Kampong Chhnang, the doctors in Battambang said they lose few patients during follow up, and they credit the work of the NGO for making that difference.

3.3 Lessons learned from collaboration

Clearly, the experiences in Battambang and Kampong Chhnang are instructive in demonstrating that improving the physical facilities of paediatric wards will draw patients to use them, thus reaching more children living with HIV and AIDS with treatment, care and support. However, strong NGO/PLHA involvement is crucial to advancing and amplifying these gains and preventing loss of patients to follow up. Experiences from the collaboration between public health care providers and community groups in the treatment and care of children living with HIV also highlight the importance of community, coordination and commitment.

A sense of community cannot be over-valued. Communities can be defined and bound by more than geography, and in this case the collaboration between public health workers and an NGO strengthened the sense of community between all involved with HIV and AIDS, whether members of that community are living with the virus or working to provide treatment, care and support.

CDFC's work in coordinating the patient records and identifications between ANC, PMTCT, birthing and paediatric HIV care and treatment helped draw all those involved into one larger community. CDFC also strengthened the bonds between the hospital and the PLHA community by convincing the hospital to expand its service hours. The issue was raised at the regular CoC meeting, which all partners attended. They explained to hospital staff how difficult it could be to encourage people to access treatment, and how some of those people had to travel long distances and take time off from work to come to the hospital, only to be turned away because they arrived at the wrong time. The hospital took the criticism seriously and expanded its service hours. Service is now available at any hour and on weekends. In doing so, public health officials demonstrated increased commitment.

That increased commitment has brought additional benefits, not just to patients, but also to health workers. Dr. Peuv of Battambang Hospital said that renovations to the ward and the increased operating hours have drawn many more children to the hospital. Consequently, his staff is gaining more experience, learning more and improving their skills. "The training and experience they are receiving from treating opportunistic infections help all children, because not only HIV children suffer from those illnesses," he said. He believes his staff are delivering better treatment and care for children, and will continue to improve with the more children they see.

Sary claims that the work of the CDFC has also helped reduce stigma and discrimination in its coverage area. “There isn’t much of that now. Mostly they discriminate against themselves at first, because they fear the reaction of the others,” he says. The essential ingredient in overcoming stigma was, once again, community. They appealed to community leaders, such as village headmen, to help them in their efforts. When respected figures in the community show acceptance, the community in general follows.

But Samphan readily admits that CDFC could not have achieved its results on its own. What has made its efforts successful, Samphan says, has been “good collaboration and cooperation from hospital and health centre staff and district and provincial health officials. And also gaining the trust and cooperation of the PLHA.”

More could be done, she says. For instance, there is not enough time to build up trust with the pregnant women in order to counsel them effectively and convince them to be tested. Too often, they are first called in close to or during birth. Thus, she suggests that counselling and testing for pregnant women be done earlier than this. The other relates to funding. To sustain their efforts, she would like to see longer-term agreements with donors so that they can do more medium-term planning to reach more people with more and better quality services.

4. Conclusions and recommendations

4.1 Conclusions

This paper began by noting that during difficult economic times, when every expenditure will receive even closer scrutiny than usual, donors may have questions about whether or not the response to HIV and AIDS is commanding too large a share of money given to Cambodia. Is this money being used to best effect, and are there other benefits that help justify the level of funding?

Considering the results of Cambodia's overall response to the HIV epidemic – having reduced prevalence from 3.2 per cent to 0.9 per cent – it would be hard to argue that Cambodia has not made effective use of the funding. There is always room for improvement, and several components of the response, such as ANC and PMTCT, are still not reaching enough women and families. Furthermore, greater linkages with RH and MCH services should be forged, and that is on the agenda of NCHADS.

In paediatric HIV and AIDS treatment and care, the funds devoted by donors are being used for a much broader set of services other than those specifically targeted to children infected and affected by HIV and AIDS. Considering the actual situation of paediatric health care in Cambodia, however, it is imperative to allow HIV funds to be spent in this manner. The expenditures are not wasteful. They are bringing additional benefits and results.

Children infected by HIV can only be identified and provided with treatment and care through paediatric health care systems and services. If those systems and services do not exist, children infected by HIV cannot be found, treated and cared for in significant numbers. Experience in Cambodia has shown that most parents are unwilling to bring their children to public health care facilities where paediatric health care services do not exist or are minimal at best. Experience in Cambodia has shown that when paediatric wards are run down and dilapidated, parents don't trust the care provided there and don't use the services. Meanwhile, the fact that 48 per cent of those who are ill or injured are using private health care, and 21 per cent are using non-medical practitioners, indicates that parents do want effective care for their children.

Since starting up paediatric HIV treatment and care in 2003 at the National Paediatric Hospital, there are now 29 sites around the country dispensing ARV, and as of March 2008 there were 3,207 children receiving ART from 29 sites around the country. HIV testing and counselling for children is available at 217 facilities through Voluntary Confidential Counselling and Testing (VCCT) sites. Also, NGOs are operating in many, but still not enough, communities to assist with home and community based care and support.

Along the way, many more times that number of children have received treatment and care for a wide range of illnesses as paediatric wards were reopened, restocked and revitalised with funds from the HIV response. Consequently, Cambodia has made greater progress towards Universal Access than most other countries in Asia and the Pacific, with 76 per cent of those in need of ART receiving it at the end of 2007. It is one of few countries that have achieved several of its MDG goals concerning child health.

Public health officials have learned that a narrow approach to treating HIV and AIDS does not work. It requires a broad response called the Continuum of Care. Similarly, a narrow approach to funding paediatric HIV treatment and care will not work in a context such as Cambodia's, where the health system is rudimentary and paediatric services were minimal or nonexistent. A broad approach to funding is the only viable avenue to take.

Donors and development partners should be advocating that the Government of Cambodia devote more of its resources to public health, and to rebuilding and improving general paediatric health services. Those who are funding the paediatric HIV response should appeal to other donors funding more sector-wide approaches to devote more money to developing a paediatric health care system. Achieving results from those courses of action are possible, but in all likelihood they will take time. Meanwhile, the problem of delivering treatment and care to children infected by HIV is immediate. The children cannot wait. While debates among donors and policy makers rage, a response is already being mounted and showing positive results.

That response is also exactly what the World Bank draft report on health care in Cambodia suggests donors should do. “In spite of good intentions, limited progress has been made by NGOs and development partners in reducing the extreme fragmentation of their support to the health system,” the report said, adding that there is a consensus that the MOH needs to consolidate and scale up health system innovations undertaken in recent years. Among the measures recommended were increasing integration of vertical national programmes into horizontal performance and resource management at provincial, district and facility levels.

If integration is the key, as Dr. Vun of NCHADS has said, then donors and development partners are now building and integrating at the same time. The dollars they are donating and the efforts they are contributing are achieving the results they intended – and far more. They are helping children and improving their lives in ways and to degrees they did not anticipate. In a different setting, the diffusion of HIV funds might be open to criticism. In Cambodia’s setting, it is the appropriate response. Scaling down funding would undermine the response to children infected and affected by HIV and AIDS. Scaling up broad paediatric health care has made the response to children infected by HIV a success.

Those working on, and depending upon the response to HIV and AIDS are fortunate in that it attracts and receives a relatively high degree of funding from donors in comparison to other illnesses or areas within the health sector that also require urgent action and are in need of support. In Cambodia, one of those areas was paediatric health care. The HIV response has succeeded in helping to build and deliver paediatric health care to far more children than those who are infected with HIV. There are cost implications in allowing HIV funds to be used to build health systems; but, judging from the results in Cambodia, it is money well spent.

4.2 Essential ingredients of Cambodia’s successful response

Many components contributed to a successful response to paediatric HIV in Cambodia. Some mirror those needed for a strong response to the epidemic among adults. At the most basic level, however, the following have been shown to be essential in Cambodia’s response:

- Political commitment/ownership – Political power is highly centralized in Cambodia, and the support of the country’s leadership to address the epidemic has been one of the foundations for success. A sense of ownership through helping to develop the programme has motivated those involved and deepened their commitment.
- International support – is crucial in the case of Cambodia, which is a resource-poor country that relies on donors for much of its budget. This support also encompasses knowledge and technical assistance.
- Effective management – clear, comprehensive and transparent management across the sector by NCHADS has delivered positive results.
- Continuum of Care approach – recognition that responding to HIV goes beyond hospital care.
- Integration – integrating the response into the health care system to maximise use of scarce resources and to help strengthen the overall system.
- A broad approach to funding – allowing the use of HIV funds to rebuild and resupply paediatric wards and support other health programmes, such as treating malnutrition, has helped build up the paediatric health care system, which in turn has provided the means to find and treat more children with HIV.
- Community participation – involvement of PLHA, NGOs, community and religious groups is necessary for providing the essential care required outside the hospital setting.

4.3 Does Cambodia provide a model for other developing countries?

Cambodia is not the only country with a paediatric health care system that either did not exist or was barely functioning. Can other countries in similar situations adopt Cambodia’s approach as a model? Each country has its own unique set of circumstances and conditions, so the answer is unclear. Dr. Vun of NCHADS cautions against assuming the Cambodian experience provides a blueprint for other nations, such as Papua New Guinea, because despite some similarities, important differences exist between countries.

Dr. Vun believes the Continuum of Care and policy of integration are what other countries should learn from Cambodia. However, each one must be adapted to the circumstances on the ground. Other countries in the region have attempted 100 per cent condom use programmes, for example, without the success achieved by Cambodia and Thailand. Elements of Cambodia’s response may be applicable in another country’s context, while others may not be. Certainly, though, integration and the CoC have proved effective in reversing the trend of the epidemic, and not just in Cambodia.

Should other countries without well-functioning paediatric services build them as Cambodia did? That would depend on many factors, not least of which is financial or donor support. But it has been shown to work in Cambodia, as far as effectively responding to paediatric HIV, while also expanding health care for larger numbers of children, so it is a model that is worth considering for adaptation by other countries facing similar constraints.

4.4 Is this approach sustainable?

Dr. Vun says that several years ago NCHADS was approached by a donor who offered to donate \$20 million to build 20 hospitals solely for providing treatment and care for people with HIV and AIDS. Cambodia turned the donor down. It was a high-cost intervention, and so its sustainability was questionable. “We have a low-cost, high-impact approach that is integrated into the health care system and uses our existing health care workers, and that is more sustainable,” Dr. Vun says. It makes sense. If hospitals are devoted solely to HIV and AIDS, then when the epidemic recedes past a certain point in a certain area, the funding may no longer be justified, and it will be closed. Those still living with the virus in that area will now have access to treatment difficulties. If HIV and AIDS treatment and care is integrated into existing full-service hospitals, those institutions are unlikely to close, and so HIV and AIDS programmes can be scaled back but still kept, and access maintained for those who need the services.

In Cambodia, however, sustainability is dependent on donors and development partners, and will be for many years to come. Cambodia does not have the economic and financial strength at this point in time to keep the programmes going without international assistance.

4.5 Moving forward

With the conclusion of the second National Strategic Plan to respond to the HIV and AIDS epidemic just a year and a half away, Cambodia’s public health officials are already working on adjusting and revising their policies and programmes based on evidence being gathered in the field. Greater linkages between RH, STI and HIV services at the provincial and district levels are on the drawing board. National standards and protocols for alternative care are being drawn up. Treatment protocols for TB are being revised and updated, and new ART protocols that allow for earlier treatment of children younger than one year of age were recently approved by the MOH.

Dr. Vun says that further expansion of the paediatric HIV programme is not what is needed in the future, because the response is already reaching most of the target population. Strengthening the programme and improving quality of services should be the focus in going forward. More training for health centre staff, and improved health centre management are needed.

4.6 Recommendations

Against great odds, Cambodia, a resource-poor nation, has achieved impressive results in adopting and implementing paediatric HIV treatment and care. HIV is an epidemic, however, that morphs over time in terms of transmission patterns and a range of other characteristics and impacts. Achievements in responding to the epidemic can prove ephemeral unless efforts are sustained and adapted to changing circumstances. Therefore, the following recommendations are being put forward for consideration by those involved in the response to paediatric HIV:

- *Funding support:* Maintain funding for physical renovation, refurbishment, maintenance and resupply of paediatric health wards in public hospitals. Also, consider funding one or two more laboratories outside of Phnom Penh capable of providing CD4 tests and results for patient convenience and access. Extend funding/contract periods for NGOs and PLHA groups with proven track records of effectively assisting in the CoC so that they can work on issues with more than just a short-term perspective. Maintain cash allowances and support where needed for poor patients who must travel long distances, and perhaps stay overnight, to access care for themselves or their children. Begin advocacy efforts with government and donors for stronger funding support for broad paediatric health care.
- *Strengthen systems, linkages and capacities:* Strengthen linkages between MCH, RH, STI and HIV programmes, including paediatric HIV programmes. Maintain and expand health care staff training in all aspects of paediatric HIV treatment and care, including training on disclosure and counselling techniques, and neonatal care and services. Train home based care teams to deliver basic services when they cannot bring children or patients back to the hospital for follow up. Support counselling and involvement by NGOs concerned with paediatric care at early entry points, such as ANC.

- *Ensure greater access to and utilization of services:* Greater efforts must be put into ANC and PMTCT to increase utilization of these services, as they are a key to reducing the future number of paediatric HIV cases. Ensure that all paediatric wards have services every day and around the clock to increase access for patients, and particularly poor patients.
- *Review salary and incentive schemes:* Review the policy of providing salary incentives for health care staff working on paediatric HIV and AIDS treatment and care. To continue strengthening the health care system as a whole, similar incentive schemes for all staff should be developed and standardised. The non-standardised delivery of incentives from various external partners is a problem (although understandable bearing in mind the low rates of pay). Consequently, the government has begun to address the issue. For example, the Merit Based Performance Incentive scheme is being introduced which is managed by government rather than external partners. While this is mainly for managers, similar incentive schemes for all staff also need to be developed and standardised.

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