

BUILDING STRENGTH ON STRENGTH

LESSONS FROM COMMUNITY RESPONSES
TO HIV IN NORTHERN THAILAND





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TO HIV IN NORTHERN THAILAND**



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FOREWORD

Thailand's response to HIV is a story of impressive past achievements and new prevention and treatment challenges. Since 1991, yearly new infections have fallen dramatically and millions of lives have been spared. Thailand has demonstrated that a well-funded, politically supported and wisely implemented response can change the course of the HIV epidemic, and that to be successful, this response needs to be sustained over time, particularly when such efforts begin to bear fruit. The purpose of this publication is to share some of Thailand's experiences and lessons learned in its response to HIV with other developing countries and development partners within the region and beyond.

Thailand is one of the very first countries to have achieved the Sixth Millennium Development Goal target to reverse the spread of HIV by 2015 well in advance of the target date. One of the success factors for Thailand in the fight against the HIV epidemic has been the active involvement of and support for community groups, HIV activists, people living with HIV and non-governmental organizations (NGOs). These groups have pioneered community-based efforts at the local level, and have often initiated activities to further support the public sector's services and/or to fill any gaps in required services. While this publication focuses on efforts in six northern provinces in Thailand, there are various projects and activities on HIV that have been initiated by community groups in all parts of Thailand, with financial support from different sources, including government, international donors/NGOs, and their own mobilized community resources.

This publication is the product of a joint partnership of the Faculty of Nursing of Chiang Mai University, the Thailand International Development Cooperation Agency (TICA) of the Ministry of Foreign Affairs and the United Nations Development Programme (UNDP) in Thailand. The preparation of this publication brought together key eminent experts, government officials, academics, NGOs and people living with or affected by HIV in a long process of consultations and dialogues. The organizing members for this publication wish to express sincere appreciation to the members of the Faculty of Nursing of Chiang Mai University, who guided much of the work for this publication. It is hoped that this publication will be a valuable contribution for Thailand to share lessons learned and best practices, along with analytical views on key elements and options for such successful cases, with policy makers and development partners within and outside Thailand.

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A NOTE ON TERMINOLOGY

AIDS (acquired immunodeficiency syndrome) is but once aspect of living with HIV. Many people have HIV yet do not have AIDS. HIV can lead to a fall in the number of a certain type of white blood cells and can cause a variety of opportunistic infections.

The presence of certain opportunistic infections combined with a low count for a specific type of white blood cells – all caused by the presence of HIV – may lead to a diagnosis of AIDS. The infections and social issues that people living with HIV deal with are all a result of having HIV, but only under specific circumstances can these be directly attributed to a diagnosis of AIDS. Because of this, and in the interest of better comprehending the many effects of HIV, this document rarely refers to AIDS. Instead, this document refers to HIV-related illnesses or infections. However, since some statistics were collected using the definition “AIDS”, those statistics are still referred to with that description. Names that have usually been translated from Thai using the word “AIDS” remain the same.

Person living with HIV refers to a person who has been diagnosed by a medical doctor as being infected by the HIV virus and being asymptomatic. If the person is symptomatic, he or she must have physical symptoms that are not severe, such as weight loss, diarrhoea, oral candidiasis and lymphadenopathy.

Person with an HIV-related illness refers to a person living with HIV who has the manifestation of the symptoms developed from opportunistic infections, such as persistent fever or respiratory tract infection that causes diseases like pneumonia or tuberculosis.

Caregiver refers to a person who provides care directly to a person with HIV or a person with an HIV-related illness without expecting wages or any kind of remuneration.

What is HIV and What is AIDS?

HIV is the abbreviation for the human immunodeficiency virus, which weakens the immune system. Contracting HIV can ultimately lead to acquired immunodeficiency syndrome, more commonly known as AIDS. An immune system weakened by the HIV virus can be vulnerable to certain opportunistic infections such as tuberculosis, toxoplasmosis or a rare cancer called Kaposi's Sarcoma. Many of these opportunistic infections can themselves be fatal.

The diagnosis of AIDS is made for a person living with HIV when he or she has one or more of these opportunistic infections, especially when found in combination with a low number of a certain type of white blood cell commonly referred to as "T-cells." T-cells are integral to the immune system and help defend the body against disease.

A person living with HIV does not by definition have AIDS and may live many years without experiencing HIV-related health problems. However, the weakening of an immune system by HIV commonly causes progression to AIDS.

People with HIV and low T-cell counts often take drugs referred to as antiretrovirals (ARVs) to decrease the amount of HIV in their blood and to help improve their immune system. This is known as antiretroviral therapy (often abbreviated as ART). If a person has an opportunistic infection, he or she may take other drugs to treat that specific disease.

HIV is most commonly spread through sexual intercourse without condoms, unsafe blood supply practices, not taking proper precautions in medical settings or by injecting drugs with contaminated injecting equipment such as a needle that has recently been used by another person and has not been sterilized. HIV cannot be contracted through sharing food or utensils with another person, kissing, shaking hands, breathing the same air as a person living with HIV, sharing sanitary facilities or undertaking other normal daily activities.

ACRONYMS

ABC	“abstain, be faithful, use condoms” (HIV prevention advocacy method)
AIDS	acquired immunodeficiency syndrome
ART	antiretroviral therapy
ARV	antiretroviral
AZT	Zidovudine (a widely used ARV)
BMT	Baan Metta Tham (Phayao)
CAM	Church of Christ in Thailand AIDS Ministry
CCCC	Centre of Comprehensive and Continuous Care
CCN	Community Care Network (Chiang Mai)
CCT	Church of Christ of Thailand
CNN	“condom, needle exchange and negotiation” (HIV prevention advocacy method)
ECI	Enhancing Care Initiative
GIPA	greater involvement of people living with HIV and AIDS
HCCP	Home and Community Care Project (Chiang Mai)
HIV	human immunodeficiency virus
IEC	information, education and communication
MTCT	mother-to-child transmission
NGO	non-governmental organization
PHO	Chiang Mai Provincial Public Health Office
STI	sexually transmitted infection
TICA	Thailand International Development Cooperation Agency of the Ministry of Foreign Affairs
TNP+	Thailand Network of People Living with HIV and AIDS
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV and AIDS
UNDP	United Nations Development Programme
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNICEF	United Nations Children’s Fund
VCT	voluntary counselling and testing
WHO	World Health Organization
YAPS	Youth and Adult Partnership with Schools
YFCD	Youth Family and Community Development project (Chiang Mai)

EXECUTIVE SUMMARY

Six provinces that are part of Thailand's Upper North region – Chiang Mai, Lamphun, Lampang, Mae Hong Song, Chiang Rai and Phayao – have borne the brunt of the HIV epidemic in Thailand, accounting for approximately 40 percent of the country's AIDS cases. Since the late 1980s, a multi-sectoral holistic response has developed in the Upper North which has provided examples of effective practices in HIV prevention, care and support work. Thailand's past success in reducing the number of new annual HIV infections has made it one of the first countries to meet Millennium Development Goal number 6 of reversing the spread of HIV and AIDS by 2015.

This document describes some of the good practices in HIV work that have been implemented. Many organizations have contributed to the development of an effective response to HIV in Thailand. Practicality dictates that only a few can be discussed here. Absence of mention in this document by no means indicates a lack of quality or effectiveness for any organization's activities or programme.

The document focuses on 1.) Providing support and care for children affected by HIV; 2.) HIV prevention efforts aimed at youth and youth leadership on HIV; 3.) Working with older people on HIV issues; 4.) Mobilizing the strengths of people affected by HIV; 5.) Faith-based responses to HIV; 6.) Developing community and home-based care and support; and 7.) Working on HIV issues with marginalized populations.

Key points for each section are listed below.

Support and care for children affected by HIV

- The stigmatization and discrimination that affects people living with HIV often similarly affects their children, making the lives of those children more difficult.
- Programmes which are effective for addressing the issues of children affected by HIV often target the entire family.
- As children who are living with HIV enter adolescence, programmes need to address their emotional maturation process and the social and emotional issues they will face as young adults
- Capacity on the issues of HIV-affected children should be built in school administrators, teachers and local education officials as schools offer some of the best environments for psychosocial support for HIV-affected children.

HIV prevention and youth

- Peer education is one of the most effective means to educate youth on sexual and reproductive health and HIV prevention.
- Full involvement of youth is crucial for the development of successful sexual and reproductive health and HIV prevention programmes.
- Parents, educators and youth must all be fully involved to create effective sexual and reproductive health and HIV prevention programmes for youth.
- Parents should be educated on sexual and reproductive health and HIV prevention.

Older people and HIV

- Older people are impacted by HIV when they care for or provide financial or material support to family members who have the HIV virus. They may also raise grandchildren who may have been orphaned by HIV-related illnesses, suffer emotional distress at losing children and lose the support that they expected in their old age.
- Older people are often still sexually active, have risk behaviours and are therefore also at risk of HIV infection.
- 70 percent of people living with HIV-related illnesses who were in need of care were cared for by older people.
- Policymakers and local authorities need to explicitly include HIV prevention and care efforts developed for and aimed at older people.
- Health care professionals should be trained on the issues of older people in relation to HIV.

Mobilizing the strengths of people affected by HIV

- Mobilization of the leadership strengths of people living with HIV is crucial to a successful HIV care, support and prevention effort.
- Leadership of people living with HIV within a community helps improve the situations of everyone in that community, not just those who are living with or affected by HIV.
- The leadership skills of people living with HIV can be supported through continuing capacity building on HIV prevention, care, support, rights and treatment issues and through building organizational, public speaking, advocacy, and economic empowerment skills.
- People living with HIV strengthen the effectiveness of their leadership through partnership efforts with government institutions such as health facilities and research centres, community groups, faith-based organizations, NGOs and other organizations.

Faith-based responses to HIV

- The key tenets of all faiths are based on love and compassion for other people and therefore can support work on HIV issues.
- Religious leaders of all faiths should learn about other faiths in order to minister to individuals of those faiths who may turn to them for support.
- Faith-based organizations are effective in dealing with issues concerning people living with or affected by HIV in a holistic way, including spiritual, psychological, community and economic issues.

Community and home-based care and support

- Projects can be very effective when they involve people living with HIV, their families, community organizations, NGOs, faith-based organizations and research teams in a participatory research and development process and in capacity-building learning forums held within and outside of the community.
- Capacity-building among people living with HIV on holistic health care, self-care and prevention of opportunistic infections empowers people living with HIV to be key persons in providing knowledge to their peers and people in the community.
- Activities carried out by using community resources and potential as well as local wisdom ensure sustainability.
- Empowering people living with HIV and the community is the key approach to the success of community-based care.
- A home-based care system must be flexible in ways that can be modified to meet the needs and contexts of each community, and should cover physical, mental, social and spiritual aspects.

Working on HIV issues with marginalized populations

- Marginalized groups need programmes which are developed with and specifically target their population.
- Materials and resources should be available in all languages.
- HIV should be addressed in a holistic fashion that includes marginalized populations, who often are faced with stigma and discrimination or legal issues that help create an environment in which they are more likely to be at greater risk.

OVERVIEW OF HIV IN NORTHERN THAILAND

In 2006 Thailand's population numbered over 64 million people, which included approximately 580,000 people living with HIV. The first instance of HIV infection had been documented in 1984, with the number of new infections in a year peaking at 143,000 in 1993. Thanks to political will and concerted government, NGO and community action that deftly implemented a well-funded national response over ten years ago, new HIV infections plummeted to about 19,000 in 2003. By 2006, HIV prevalence had declined to around 1.4 percent, and approximately 100,000 people who were HIV-positive had access to antiretroviral treatments (ARVs).

The National Economic and Social Development Board drew up the first five- year National AIDS Plan (1992-1996). The tasking of an economic and social planning, research and policy body with the development of the national plan dealing with the effects of HIV and the inclusion of that first National AIDS Plan into Thailand's overall five-year development plan was an early example of a multi-sectoral, holistic approach that characterized much of the Thai response to HIV.

The development of the National AIDS Plan outside of normal channels was also recognition of the need to mobilize all parts of Thai society in a collaborative effort. As part of the multi-sectoral approach, the Office of the Prime Minister, the Ministries of Defence, Education, Interior and the Ministry of Public Health – which was managing most of the interventions, including the successful “10 Percent Condom Programme”, and soon took over responsibility for the overall response – all instituted efforts in their sectors to halt the spread of the virus and to mitigate its impact.

From the beginning, six provinces that are part of the Upper North region of Thailand – Chiang Mai, Lamphun, Lampang, Mae Hong Song, Chiang Rai and Phayao – bore the brunt of the epidemic. By 1989, HIV prevalence as high as 43% had been found in one survey of brothel-based sex workers in Chiang Mai. In 1993, HIV prevalence among 21-year-old conscripts in the Thai Army had climbed to almost 4 percent nationally, but had soared to over 12 percent in the Upper North, where rural areas provided most of the fledgling soldiers. As a group, young women under 25 who were giving birth to their first child at Chiang Rai Hospital in that year had a 6.4 percent HIV prevalence.

Decentralization efforts such as the 1994 establishment of the Upper North HIV/AIDS Prevention Committee for work in these six provinces and direct grants for HIV and AIDS work to the Upper North region led to promotion of the roles of non-governmental organizations (NGOs) and community-based organizations in the response. Increased participation and partnership by civil society organizations, transparency, accountability with clearly defined roles and responsibilities for all parties and de-bureaucratization of funding processes were essential parts of good governance that supported an effective response to HIV in the Upper North.

These six Upper North provinces still continue to face economic development issues. Some provinces have large areas with mountainous terrain where transportation links are far weaker than in other areas. In some provinces, as much as 13 percent of the population belong to hill tribes who do not have Thai as a first language and who may lack full citizenship, both of which limit their access to services. The provinces are also hosts a large number of migrants from neighbouring Myanmar and Lao PDR, for whom Thai is not their first language and who are not eligible for many state-supported services. All but Phayao rank in the bottom quartile in the Health Index of Thailand's 2006 Human Achievement Index. They are all in the bottom half of the country's 2006 Income Index, which covers household income, households with debt, and poverty incidence. However, all these Upper North provinces rank high or very high in the Participation Index, which measures voter turnout, participation in social services, participation in community groups, and the number of community groups. This strong social fabric has proven important in the Upper North's response to HIV.



Thailand is already one of the few countries to have achieved its Millennium Development Goal of reversing the spread of HIV. In the course of the decade and a half since the first National AIDS Plan was implemented in Thailand, many elements, though not sustained, contributed to the past effectiveness of the Thai response to HIV. A massive public information and education campaign, the 100% condom programme, work to change male attitudes toward buying sex, development of responses to meet the specific needs of different segments of the population, development of prevention of mother-to-child transmission of HIV programmes, provision of ARVs on a wide scale and the commitment of communities and individuals affected by HIV to respond to the threats and impact of the virus in a way that was appropriate to their particular culture and situation were just some of the reasons new HIV infections declined. While the lack of sustained efforts on a number of these fronts are now posing new challenges for the Thai response to AIDS, the lessons that these actions have to offer are useful to understand the dynamics that have helped Thailand reach its situation today.

By 1999, over 220 groups of people living with or affected by HIV were active and providing support in the Upper North. Groups in the Upper North undertook some of the earliest community and home-based care pilot activities. The response of individuals and communities to HIV in the Upper North remains strong today, with new groups continuing to form to meet specific needs. Some organizations are adopting formal structures while others coordinate themselves more loosely, using the national bonds and structures of their community as the basis for their work.

The Upper North is still addressing the current and potential impact of HIV. Life expectancy in Chiang Mai is almost five years less than it would have been without HIV-related illnesses and deaths, and twice as many adults between the ages of 15 and 40 were dying than would have if HIV had not taken hold. Caregivers are still taking responsibility for children whose parents have died, and the number of elderly who have been affected by the death of a child is an issue. In 2005, parts of the Upper North still had higher HIV prevalence than many other parts of the country, and prevalence statistics for certain behaviours are still high, with the statistics for men who have sex with men in Chiang Mai showing a worrying increase. Infections among brothel-based sex workers also remain high. The Upper North is also home to a large population of various ethnic groups and migrants who may not have access to HIV prevention and care services due to lack of citizenship or cultural and linguistic factors.

Although HIV prevalence rates in the Upper North have declined since the height of the Thai HIV epidemic in the mid-1990s, and the following pages showcase some of the many effective activities from these provinces for both prevention and care work, complacency on HIV prevention in the Upper Northern provinces and in Thailand as a whole is still not an option if the successes and lessons of the past are to be sustained rather than reversed.

Support and Care for Children Affected by HIV

1

Despite Thailand's recent success in reducing new HIV infection, the number of children with at least one parent who lives with HIV has gradually increased. Studies suggest that approximately 3,000 Thai children contract HIV each year. Even with the success of anti-retroviral therapies (ARVs), some children still die of HIV-related illnesses, while other children who are not living with the virus lose one or both parents to HIV-related illnesses. By 2005, the number of children who had lost one or both parents to AIDS-related illnesses had risen to approximately 380,000.

Children affected by HIV are confronted with complex impacts of the disease and need the support and care of others. The stigmatization and discrimination that affects people living with HIV often similarly affects their children, making their lives more difficult. HIV-affected children may grow up while their parent or caregiver becomes ill with HIV-related illnesses and unable to work; as a result, the entire family feels the economic shock. Non-attendance of affected children at school, especially among children in the 14-18 age range who may be more likely to take on work responsibilities, rises.

Children affected by HIV also suffer from other physical and psychological impacts. Some children face malnutrition, illness, delayed development and lack of care. Children affected by HIV often suffer from losing one or both parents to HIV-related illnesses. These children often grow up with less support and care than they need and are often separated from their siblings. Without the protective environment of their homes, children affected by the disease may face an increased risk of violence, exploitation, and abuse. They are sometimes ill-treated by their guardians, who may dispose of their inheritance and property. Those living with foster families are more likely to be malnourished, underweight, and short for their age in comparison to non-orphans.

While children with HIV previously often died from HIV-related illnesses, many now are surviving with ARVs. As they grow older, children with HIV will face the normal development and questions of any adolescent, but they will have to address these questions in light of their HIV status.

"As [children with HIV] grow up, they know more about HIV and they may face discrimination from outside society. They know the basics of HIV and that they have to take medicines, that they are HIV-positive. Now we are facing the issues that HIV-positive children will face growing up as teenagers and as young adults." Says Ms. Pimjai Inthamoon, Project Administrator & Coordinator of the Community Health Project in Mae Rim.

Children present any combination of economic, health, and psychosocial needs. Support and care programmes therefore need to address these needs simultaneously. There are many support and care programmes for HIV-affected children provided by organizations in Thailand. Most of the organizations work to help HIV-affected people, including children, by implementing material, financial, educational, psychosocial, medical, referral support and protection of children's rights. However, each programme varies in their approach and each organization makes its own assessment of the needs of affected children and the ability of that programme to provide such services.



The Volunteers for Children Development Center developed a board game which entertains children while teaching them about HIV.

Guidelines for working with HIV-affected children

There are many organizations in the North of Thailand that address the impacts of HIV on children. Organizations may only deal with children or the affected children's issues may be addressed as part of a larger community or HIV support organization.

In July 2004, a wide variety of development practitioners including the United Nations Children's Fund (UNICEF), the Joint United Nations Programme on HIV and AIDS (UNAIDS), governmental agencies, faith-based and non-governmental organizations (NGOs), academic institutions, the private sector, and civil society drew up a framework for addressing the needs of children affected by HIV. The framework drew on lessons learned and saw families and the community as the foundation for a successful, scaled-up response. The framework recommended that interventions be aimed at all vulnerable children and the communities in which they lived, and that these interventions be integrated into other programmes to reduce poverty and to promote child welfare.

Key strategies in the framework were:

1. Strengthening the capacity of families to protect and care for orphans and vulnerable children by providing economic, psychosocial and other support and by prolonging the lives of parents;
2. Mobilizing and supporting community-based responses;
3. Ensuring access for orphans and vulnerable children to essential services, including education, health care, birth registration and others;
4. Ensuring that governments protect the most vulnerable children through improved policy and legislation and by channelling resources to families and communities;
5. Raising awareness at all levels through advocacy and social mobilization to create a supportive environment for children and families affected by HIV/AIDS.

Work for HIV-affected children by many groups in Northern Thailand utilises these internationally-agreed strategies. Also in 2004, the International HIV and AIDS Alliance, together with AIDSNet (Northern Thai branch), developed a set of guidelines for community workers who work with HIV-affected children (under the age of 18). The guidelines address problems or negative impacts on children arising from adult infection and suggest principles and ways to solve or minimize problems.

These guidelines, which can be summarized as follows, also encapsulate the various aims of many different organizations working on issues of children and HIV in the Upper North provinces of Thailand:

1. Promote life skills, self-esteem and educate children about their own rights;
2. Promote self-care among children with HIV;
3. Promote sex and HIV education among children and youth;
4. Promote children's rights and violence prevention;
5. Educate and increase awareness of families and the community regarding child development, child health, child nutrition, child care, children's education and children's rights;
6. Educate teachers, students and people in the community on the importance of HIV education;
7. Promote collaboration between government and NGOs;
8. Facilitate access to health care services for children by providing information and coordinating with health care service providers;
9. Facilitate access to social welfare for children by providing information and coordinating with social welfare service providers;
10. Encourage networking among persons living with HIV and among their families;
11. Provide consultant and counselling services for children and families by coordinating with religious services and community groups;
12. Provide funding sources for children's education and vocational training;
13. Encourage families and communities in providing tangible support for people living with HIV;
14. Encourage parents to plan for their children's future;
15. Promote community understanding regarding living with HIV and with HIV-related illnesses;
16. Increase awareness of policemen and law officers of violence prevention and protection of children's rights; and
17. Provide shelter/homes for abandoned children.

The impact of HIV on children in Thailand

UNAIDS and the World Health Organization (WHO) estimated that there were 2.3 million children living with HIV by the end of 2005. Since the 1980s, Thailand has been profoundly affected by HIV. Although Thailand has had substantial success in HIV prevention efforts, approximately one-seventh of new infections occurred in children. In 2005, the Ministry of Public Health and UNAIDS released figures that showed the number of children in Thailand living with HIV to be estimated at 23,000.

Around 1996-1997, the short-course ARV Zidovudine (known as AZT), began to be provided to prevent mother-to-child-transmission (MTCT) of HIV in Thailand in pilot projects. The research showed that AZT could reduce MTCT of HIV by 50 percent. These successful results brought about the support of the Thai government for the provision of short-course AZT to prevent MTCT of HIV. By 1999, AZT was being used in most hospitals in Thailand.

This programme is reducing the rate of HIV transmission from mother to child; however, the number of HIV-affected children is still increasing. Nevirapine, another ARV, has been adopted for short-course treatment to prevent MTCT in some hospitals under a research-based intervention programme (Phanuphak, 2005). The Thai government included in its 30-baht health scheme short course treatment to prevent MTCT and ARV treatment for patients living with HIV who had low T-cell counts and/or HIV-related infections, including children living with HIV.

HIV-affected children in Thailand face threats to normal child development beyond those of physical survival. In the case of children living with HIV, they are likely to have delay in developmental tasks. Some of the children experience less responsive care and interpersonal and environmental stimulation, and this can cause malnutrition, morbidity and mortality. Neglect is also found among children affected by HIV. All these factors inhibit their healthy psychosocial and cognitive development.

Physical impact

Children of HIV-positive mothers may or may not inherit the virus. Children living with HIV can have frequent infections, especially opportunistic infections. Physical problems occur because these children have a weakened immune system, making it easy for them to become ill and acquire opportunistic infections that can cause other serious symptoms related to HIV. Research on disease progression among Thai children living with HIV before the widespread advent of ARV provision suggests that about half the children who contracted HIV died by age 5, with an estimated 82 percent, 74 percent, 56 percent, 49 percent and 43 percent survival rate for 1-, 2-, 3-, 5-, and 6-year-olds, respectively. Infectious causes of death that were most often reported included pneumonia, diarrhoea, sepsis, and fungal oesophageal infections. Children living with HIV will continue to require intensive medical and emotional attention as a result of their HIV exposure.

If their parents have died of an HIV/AIDS-related illness, children who are affected by HIV but who are not actually living with the virus have been likely to live with relatives, foster families or in orphanages. These children are more likely to be malnourished, underweight, and short for their age in comparison to non-orphans. A study of children affected by HIV found that most of the children presented physical problems and malnutrition. Some of them lacked vaccination, had delayed development, poor hygiene, and psychological problems.

Psychosocial impact

Children are important resources for the development of every country. Securing the well-being of children, protecting them from all forms of harm and ensuring that their development needs are responded to appropriately are the primary aims of children's health care. To facilitate a child's development into a healthy, well-balanced adult, it is necessary to start at the beginning of their lives. If children lack the appropriate direction from early childhood, they may have developmental problems that become difficult to solve later on.

Children affected by HIV have often lost one or both parents to the disease. On top of the psychosocial impact of losing their parents, they often do not live with a biological parent. Infants from HIV-affected families are at an increased risk of abandonment. In Thailand, children abandoned after delivery occurred in the highest proportion in mothers who are living with HIV. HIV has also been used as a justification in some cases for removal of children from their parents, with cases of children of HIV-positive mothers being taken from their families at birth. Such children have often been placed in foster or residential institutions or with relatives in the hope that the children's material needs will be met.

Children orphaned by HIV-related illnesses who do not live with a parent or close relative often develop anxiety from the drastic change in lifestyle and exhibit frustration when neglected. They may think that they have no one to take care of them. For example, one affected 5-year-old girl said: "I have been living with my aunt since last year. My mom died and my dad left home a long time ago. I miss them very much."

HIV-affected children live with families or communities where adult illness and death as well as the stigma surrounding the disease have brought additional hardships. The HIV pandemic has posed unprecedented long-term dilemmas for those taking the responsibility of organizing out-of-home care for children. This further underlines the need for recognized international guidelines and standards.

The traditional response of kinship care has become increasingly overwhelmed. There are fewer adult family members available to look after an ever-increasing number of affected children. As a result, other relatives – often widowed grandmothers – are attempting to take care of these children. For elderly carers, the children's future is often a major concern. As an example, one 74-year-old grandmother of an affected child stated that:

I felt pity for [my granddaughter]. My daughter went to work in Bangkok and came back with AIDS. She passed away and left her daughter with me 3 years ago. I am so poor and too old, but I must take care of my granddaughter when she has nobody. I don't know what will happen next if I die. Who will take care of my granddaughter?

When one parent is living with HIV, there is a high probability that the other parent will be living with HIV as well. Before ARV treatment became widely available, children often lost both parents in quick succession. Furthermore, an orphan's caregivers would also sometimes succumb to HIV-related illnesses, with the result that children suffered multiple bereavements. In some cases, a child's suffering was compounded by being separated from his or her brothers and sisters as extended families and communities tried to cope with caring for newly orphaned siblings.

A study of HIV-affected children aged 6-14 years in northern Thailand indicated that these children experienced psychological distress before and after a parent died. They expressed feelings of depression, sadness, loneliness, discrimination, being teased by school friends, and tended to evaluate themselves negatively. These feelings can consequently lead to psychological problems such as post-traumatic stress syndrome, alcohol and drug abuse, aggression, and even suicide.

Social dislocation further compounded the children's emotional distress. Some of the children had difficulty building relationships with others. They were anxious about their home situation and had low self-esteem. For instance, the grandmother of a 15-year-old girl who lost both parents to HIV-related illnesses at age 7 expressed her feelings in an interview:

My granddaughter was shocked when she saw her father attempt suicide by hanging himself. She screamed continuously. Then, she suffered from depression. After her father died, I brought her here. Two years later, her mother was sick and presented some of the symptoms related to AIDS. Others teased my granddaughter, calling her "E AIDS". ("E" is a negative form of address for girls/women in the Thai language).

Other factors such as loss of household incomes, costs of treating HIV-related illnesses and funeral expenses may leave orphaned children destitute. Poverty, inadequate food and a lower standard of housing are other problems faced by children affected by HIV. HIV-affected children are not only at risk of violence, exploitation, and abuse; they may also be ill-treated by their caregivers. These HIV-affected children are at a higher risk of becoming "street children" due to low self-esteem, poor socialization skills, dysfunctional family or caregiver situations or lack of vocational skills. These factors increase the likelihood of risk behaviours as well as abuse.

Affected children also have an additional burden from the residual stigma left over from the time when the disease was seen as unacceptable in society. This stigma can increase the sense of isolation that children of an HIV-positive parent often feel. Having a parent with HIV is different from having a parent sick from other illnesses because the stigma of HIV is greater. This puts a greater burden on HIV-affected children. These children not only need to be cared for, but also need to adjust their lives to live with the stigma that may result if a parent dies. Children affected by HIV are sometimes treated with suspicion or rejected, while children whose parents had less-stigmatized diseases than those associated with HIV and AIDS are pitied.

Key lessons from organizations that specialize in care and support for children affected by HIV

The majority of HIV-affected children in Thailand continue to live with surviving parents or their extended families. When HIV or AIDS affects a household, children must be at the core of the response strategy. Most of these organizations that work specifically on children's HIV and AIDS issues can be categorized into government organizations, NGOs and faith-based groups.

Target groups

The main target groups for support and care programmes by organizations working specifically on children's HIV issues were HIV-affected children, HIV-affected families, students in school, and people in the community. The majority of the HIV-affected children are those children who are affected by the disease but do not have the virus. However, some children living with HIV are included as participants in some projects. Many of the programmes offering support and care for HIV-affected children involve family members and other adults in the community as the target groups.

In general, these programmes encourage children to be active participants in the organization and implementation of programme activities. This ensures that the children are able to provide feedback on the operation of the activities that have been designed to assist them. Child participation at almost every level is part and parcel of project design. Children are invited to attend the planning meetings and other project activities. Experience has shown that contrary to the popular belief that children are timid and unable to be assertive among adults, they have participated actively and have made intelligent contributions to discussions.

A programme that targets a family unit is more likely to be successful in terms of benefiting the intended beneficiaries. The parents or primary caregivers of HIV-affected children should be involved in the programme for promoting care for the children as well as themselves. Female family members of HIV-affected families have been an integral part of programmes where they were involved in planning as well as implementation.

School administrators, teachers and local education officials are a target population in the support and care programme as schools offer some of the best environments for psychosocial support for HIV-affected children. Schools expose the children to peer interaction and provide opportunities to develop their mental faculties. They therefore have the potential to provide an environment in which a foundation for positive attitudes and knowledge on HIV can be built. Schools are an important aspect of support and care, especially since HIV-affected children often discontinue schooling for a variety of reasons.

The community-based support and care programmes for HIV-affected children are obviously dependant on the degree of community mobilization. Community mobilization involves facilitating awareness, internalization and active involvement of both community members and local leaders in an effort to alleviate the problem. Involvement of local leaders is a crucial aspect of community mobilization. Local leaders have the legitimate authority to take action and mobilize resources and they usually command respect from their community members.

Planning, advocacy and networking

The majority of the support and care programmes offer consultation and coordination at all levels and in various ways between HIV-affected children, HIV-affected families, schools, communities, health centres/clinics, hospitals, social welfare sections, etc.

Given that HIV-affected children have varied needs, and given the limited resource availability, consultation and coordination are essential for the effective operation of support and care programmes. When care and support programmes started, many did not assess the needs of children beforehand. Consultation and coordination helps support such assessment in a holistic fashion. Coordination ensures that available resources are used optimally by the children and their families and consultation helps assure a holistic approach to the problem of HIV-affected children, which is essential for ensuring that the varied needs of the children are met effectively.

For instance, a national consultation was held by one organization on the situation of children in Thailand, especially in areas of high prevalence of HIV, such as the northern region. This consultation produced policy guidelines that have been instrumental in guiding and coordinating the direction of orphan care programmes. Gaining endorsement and support from government ministries, national and international NGOs, United Nations (UN) organizations and religious organizations was a major landmark in the development of the support and care programmes.

Coordination and consultation involves advocacy in all sectors and society. Community advocacy is a crucial aspect of support and care programmes because it directly supports community mobilization. Effective community advocacy often involves various media channels such as community radio, print media and film. Effective community advocacy explains clearly the rationale and importance of the programme.

Networking between organizations involved in the support and care for HIV-affected children facilitates not only information sharing but also dissemination of materials and messages and advocacy through meetings and conferences. It enhances possibilities for fundraising and capacity-building on HIV issues and allows organizations to become aware of the work others are doing. Networking also leads to improvements in programme execution through the sharing of best practices and lessons learned, as well as facilitating the coordination of activities.

Interventions, activities and implementation

Material and financial support

Assessment has shown that material assistance, such as the issuance of clothes, nutrition, shelter, and food as well as medication, is necessary both for children living with and affected by HIV. Financial support by care and support programmes may also be necessary as HIV-affected children may have a low economic status and need support in meeting living costs. Many projects provided income-generating activities to help meet the economic needs of the children as well as their family. Some projects set up work skills training for family members and older children as well.

Educational support

Many support and care projects for HIV-affected children also provided educational support, covering tuition fees for one academic year or more, depending on the project's funds. Some projects have sent HIV-affected children to schools as well as promoted positive attitudes among teachers and other students. The placement of HIV-affected children in day-care centres, pre-schools, primary schools and secondary schools has been included in support and care programming.

Health education in small groups of people, including students, village youth and community leaders, has been conducted on issues that are related to knowledge and awareness on HIV, prevention of the disease, care for people affected by or living with HIV, life skills for counselling and problem solving. The strategies used were varied. Many projects set up a stage for discussions by target groups. Others provided study visits, lectures, participatory action, learning and training.

Psychological support

Concerns about the psychological needs of HIV-affected children are often addressed by projects providing holistic interventions for the support and care of children. These included shelter, food, health care, education, love, affection and early stimulation. These activities are especially important in orphanages supported by government organizations and NGOs such as Baan Vieng Ping and AGAPE in Chiang Mai province in northern Thailand.

Social support

Social support is provided by programmes through the provision of moral and emotional guidance including life skills training, counselling and recreation among HIV-affected children's groups as well as unaffected children in schools and the community. Some support and care programmes initiated networking for school-age and teenage children affected by HIV in the community.

ARV support

There are a few projects that provided free-of-charge ARV medication for children living with HIV and for family members who also live with the virus. These projects had monitored participants who are living with HIV by evaluating the results of treatment in both the hospital and home settings. They then instituted regular home visits and monitored participants closely with the aim of ensuring that children adhere to ARV treatment.

Coordination and referral support

The provision of referral services is one of the distinguishing activities in support and care for HIV-affected children. The projects' workers coordinate with other organizations for referring HIV-affected children to institutions that can best meet each individual's specific needs.

Protection of child rights

There are a few support and care projects concerned with the protection of children's rights. Child rights activities have been conducted by some project workers, such as promoting the issue of children's rights to the community, to the family, and to the children themselves. Some organizations work for the protection of HIV-affected children who participated in their projects. Moreover, the organizations attempt to raise the children's problems as an issue for policy makers.

Long-term outcomes

Not all long-term outcomes seen in HIV-affected children can be measured by all projects because they require time to see changes occur in those children. For example, the effectiveness of sex education programming on children could not be evaluated after completion of the programme as any results would have to be monitored as the children mature. Organizations that support HIV-affected children to study do not know what educational level they will eventually attain. However, some of the affected children have already completed university and are role models for later generations of HIV-affected children. The support and care programmes also encouraged participation of people in communities, with the aim of increasing acceptance of affected children. This helps the children live in communities normally and decreases social discrimination; however, these results will also take time to become clear in the long term.

Examples of organizations working on support and care for children affected by HIV

Community Care Network

Founded in 1995 by a Christian priest, the Community Care Network (CCN) Project is one of the most far-reaching projects for support and care for HIV-affected children in the northern region of Thailand. It targets people living with HIV, HIV-affected elders and HIV-affected children in five communities in Chiang Mai.

The project has implemented support and care for elders to be able to care for their affected grandchildren. Currently, the CCN is assisting close to 150 aging men and women who care for grandchildren who have lost one or both parents to HIV-related illnesses. Working with about 400 children ranging from newborns to those in their late teens, the CCN project provides support and care for HIV-affected children directly by training them in many life skills and in seeking out resources. It also enables older people affected by HIV and their families to better cope with their situation by improving care and support systems and raising awareness in the community about the impact of HIV and AIDS on older people and children so that they are included in HIV services, programmes and strategies. The project works to improve the problem-solving potential of people in the community through participatory actions. It endeavours to develop strong working group networks and improve collaborative systems for members of working groups and people in the community.

The project's main objectives are to change the attitudes of people in the community and of HIV-affected elders and children in the northern part of Thailand regarding support and care for HIV-affected children, as well as to improve the quality of care for affected children. The project believes that providing more education, awareness, resources, group support and empowerment for elders are the main concerns facing elders in caring for their grandchildren. In the past, older people were dependant on their children's income during old age. That money is no longer available due to their children being affected by HIV-related illnesses, and often they have taken on the role of caregivers for orphaned or affected grandchildren. This project also provides activities to raise concern, recognition, interaction, and improve the relationship between elders and children, as well as among people in the community.

The project uses community leaders, child leaders, people living with HIV and elders trained as community care workers. The project leader has gained cooperation from people in the community as well as government and NGO workers in the area. He acts as leader, coordinator, negotiator, provider, educator, counsellor and supporter for all people in the groups. He supports the development of leaders from the community by offering suggestions, supervision and guidance. This encourages acceptance from people in the community, and the project thus gains more members in all target groups.

Since the project began in 1995, there have been many improvements in community response to HIV-affected elders and children. The elders are able to provide more quality care for their grandchildren as they have gained knowledge and learned best practices. Some children have been sheltered from the impact of HIV and AIDS by receiving education, gaining an appropriate career and having an income. Some children were trained to be community workers on HIV prevention and care. Community networks were set up and these community networks continue to run all activities by themselves.

Many working groups on community care for people affected by HIV were set up and run independently by learning skills from the Community Care Network. The Community Care Network operates under the Christian church's financial support, but many members of the project are Buddhist. The project runs with limited funding but the project provides time, a place, some meals, and transportation costs for members to set up activities such as meetings, teaching and learning activities, and discussion. The majority of activities carried out by the project provide information about resources and cooperating with organizations to support community groups so that they are able to function themselves.

For example, to ensure that an HIV-affected child is able to pursue higher education, the project would assist by giving information on applying for a grant. The family could then proceed by themselves. As another example, an HIV-affected child who is approaching adolescence would receive guidance and support from older children in the group. Additionally, community networks would play an important role in monitoring and providing help to the families affected by HIV since they perceive the issue as a community issue. People in the community would support the family in solving problems.

All activities are evaluated at monthly meetings with the project leader, community leaders, child leaders, and elder leaders. Suggestions for improvements would be analysed and adjusted for further activities. Activities that have been undertaken include:

- Community surveys carried out to identify those in need;
- Community volunteers and community leaders, including older people, recruited to raise awareness of older people and children affected by HIV;
- A support group of older people affected by HIV that meets weekly to share their feelings and ideas, and also to receive information on HIV;
- Awareness-raising activities that include promoting the participation of HIV-affected children and older people in key events, such as community school activities, village activities and networking with other groups working on HIV programming;
- Collaboration with government, NGOs and academics in order to promote HIV prevention in the community;
- Establishing a camp for HIV-affected children and setting up children's activities such as peer-led academic tutoring by older children to younger children every weekend and instituting learning centres in five subdistricts;
- Group visits by elders and children in the community to different places such as the zoo, forests, mountains, tourist areas, and shopping centres;
- Programming to improve children's life skills;
- Training of child leaders to work in the community to lead programmes on HIV prevention and care measures; and
- Careful evaluation of all activities set up and run by community leaders, child leaders, and elder leaders for effectiveness.

The project has achieved many of its goals. Members of the support group are more comfortable talking about issues relating to HIV and have become more involved in social activities. Family and community members are recognizing the contributions of older people and children. Quality relationships between elders and children in families have been developed and capacity-building of child leaders in the community has been achieved.

Baan Metta Tham

Baan Metta Tham was founded when the Daughters of Charity came to Thailand's northern Phayao province in 1996. The objectives of the project's HIV work with children's issues included:

- Providing integrated and holistic community-based care to persons living with HIV and their families;
- Empowering patients to actively participate in psycho-spiritual, social and economic activities geared towards a better quality of life;
- Promoting networking and support within and outside the communities to strengthen their ability to care for sick family members as well promoting their basic human rights;
- Providing education on the prevention and spread of HIV; and
- Promoting the development of children and youth through the provision of education assistance, opportunities for social integration and acquisition of skills for daily living.

The Sisters provide pastoral care, visiting not only those who are living with HIV but also those who are affected, including the elders who take care of orphans and abandoned children. Volunteers in the project collaborate with the Phayao Provincial Hospital in the monitoring of patients who are undergoing ARV therapy and also with the Primary Care Unit of each subdistrict. In this way, the patients and families are encouraged and learn how to cope with their situations. Most of the participating children are suffering and experiencing hardships due to unstable family situations caused by parental illness, family disintegration due to separation of parents and children, and/or being abandoned to grandparents and relatives. The project creates a dynamic working relationship with the family and carers, which provides an environment that is conducive to the holistic development of the child.

The Sisters and staff work closely with support groups for people affected by HIV in Phayao province. The project provides group counselling, life-skills building, information exchange and experience sharing, and organizes income-generating activities. The project also works with the support groups to monitor growth and development of children who are in the child and youth development programme.

Baan Metta Tham started helping 50 affected children with education concerns in 1997. By the year 2005, the programme had served 1,028 children, aged 18 months to university level, of which 578 were still enrolled in school. The main service is the provision of educational assistance from kindergarten to university level. There are three levels of educational assistance, ranging from nursery school assistance to scholarships for higher education, which are provided for senior high school and vocational colleges and universities.

There have been isolated cases in which a child with parents living with HIV was not admitted to the village nursery for fear that the child could somehow cause other children to catch the virus. In cases like this, Baan Metta Tham, together with leaders of the community, health officers and leaders of HIV support groups, exerted effort to provide adequate information on health and the child's rights to parents. Children and their families are then encouraged to actively participate in community affairs so that integration can be achieved.

The Sisters also undertake regular home and school visits to see the living conditions of the child and learn how he/she copes with the school environment. Information is exchanged with government agencies and school authorities to avoid duplication of services. The project monitors and makes yearly evaluations on the progress and development of each child, counsels them regarding studies in higher education, provides opportunities to participate in a youth camp or other activities to gain knowledge of life skills as prevention against HIV, and celebrates Christmas/New Year, Family Day and Children's Day in each subdistrict with the purpose of reducing stigma and discrimination against children who are affected by HIV. The project also advocates with local government officials on issues concerning children living with or affected by HIV and their families.

Personal contact with caretakers is maintained through regular home visits, family conferences and counselling as well as participation in annual evaluation on the progress of the child. Baan Metta Tham also establishes rapport with the schools the children attend by monitoring the children's development. This monitoring is done through school visits, consultation with teachers and participation in school activities.

Chiang Rai Aids Access Foundation

Chiang Rai AIDS Access Foundation was established in 1993 to provide counselling services via mail and telephone, health clinics, home visits, health education via radio programmes, and networking coordination among HIV support groups. In 1999, Chiang Rai AIDS Access expanded their work to HIV-affected children and families by implementing the principles and guidelines of the International HIV and AIDS Alliance in working with HIV-affected children.

The project operates through the work of volunteers and HIV support groups in the villages. Their activities include workshops on capacity-building for community leaders who work with HIV-affected children. Topics have included child development, children's needs and communication with children. They have also collaborated with Chiang Rai's Prachanukroh Regional Hospital in providing health services and ARVs for children living with HIV and preparing and supporting families and children throughout ARV therapy.

The project has undertaken home visits aimed at assessing the needs and problems of children and families, and providing support and counselling. Group activities aimed at providing support and learning how to live together were developed, and the project held art camps aimed at building self-esteem and hope for children and held workshops on sex education for teenagers.

Home and Community Care Project

The Training Centre for AIDS Awareness at the Rajabhat Institute (Rajabhat University) in Chiang Mai runs the Home and Community Care Project (HCCP). The HCCP works with 60 children, aged 5 to 15, from four districts of Chiang Mai province. They live with their remaining parents or grandparents or close relatives. Most of them have never been tested for HIV. The main objective of the project is to strengthen the position of HIV-affected children physically, emotionally and psychosocially through life skills training to help them cope with their emotions and problems due to loss of parents, siblings, isolation by peer groups and loss of self-confidence and self-esteem.

The project also provides training for caretakers on child development and child psychology and provides a venue for caretakers to become more self-aware and to deal with their own biases about HIV. They also provide training for school teachers on issues surrounding HIV and orphaned children and for fieldworkers to develop the necessary skills, knowledge and attitudes to support both children and caretakers. Each project fieldworker is responsible for 10 children and caretakers who visit children and families twice a month.

The project aims to ensure that children with HIV are well-nourished, tries to establish support groups that will ensure project continuity, and works to identify persons who are willing to take responsibility in emergency cases and to provide a listening ear or to discuss problems with the children. It also provides a venue and mechanism for AIDS orphans to share experiences among themselves.

Project activities have included life-skills training for children (self awareness, youth reporters, painting, English language, sex education, etc.) and activities with caretakers such as sharing experiences and feelings, setting up a support group and counselling. Activities on counselling techniques, field visits to other projects, and workshops to learn how to work with affected children were undertaken with field workers. Schoolteachers were offered a workshop on "Ways to Work with Children Affected By or Living with HIV."

The project understood that activities involving children need an element of entertainment and enjoyment. Sports days involving children, caretakers, fieldworkers and committee members helped build stronger relationships between all members of the projects. Other activities to promote family relationships initiated by the children and caretakers included fish and hen raising, vegetable growing, and gardening. The community became involved in the project, too, with one company in Hang Dong district organizing a Mini-Marathon fundraising event, in which more than 500 marathon participants wore T-shirts carrying the project's name.

Baan Mitratorn

Baan Mitratorn is an NGO established in Chiang Dao district, Chiang Mai province, by the congregation of the Sisters of Saint Paul de Chartres in Thailand. In the Thai language, Baan Mitratorn translates as the "Home of Caring Friends". It receives support under The Princess Ubolratana Foundation, under the Royal patronage of Her Majesty the Queen of Thailand, to support children orphaned by HIV-related illnesses. Baan Mitratorn provides housing, child care and other child development services for both affected children and those with the HIV virus and takes in children from all over the country. Many of the children for which Baan Mitratorn cares are on ARV treatment.

Baan Mitratorn aims to provide appropriate treatment and care for children with HIV by health professionals and caregivers and to promote the rights of affected children and children living with the virus. It provides educational opportunities for affected children and those living with HIV both via home school taught by professional elementary teachers and in community schools and puts an emphasis on emotional support for children affected. The project also provides HIV education, meditation practice and spiritual training for teachers, nurses and foundation officers in preparation for caring for HIV-affected children.

Baan Mitratorn emphasises children's participation in local social activities such as Children's Day festivities and the Songkran water festival. During the weekends, the children participate in hobbies and some earn money from handicrafts they make, which engenders pride in themselves. An herb garden provides herbal medicines for children living with HIV. If needed, Baan Mitratorn provides dignified hospice care for terminally ill children.

Key points

- The stigmatization and discrimination that affects people living with HIV often similarly affects their children, making the lives of those children more difficult.
- Programmes that are effective for addressing the issues of children affected by HIV often target the entire family.
- As children who are living with HIV enter adolescence, programmes need to address their emotional maturation process and the social and emotional issues they will face as young adults
- Capacity on the issues of HIV-affected children should be built in school administrators, teachers and local education officials as schools offer some of the best environments for psychosocial support for HIV-affected children.

HIV Prevention and Youth: Promoting and Protecting the Promise of the Future

2

More than half the people living with HIV today are between the ages of 18 and 35. In 2004, studies found that a growing pattern of casual sex among Thai teenagers led to an increase of up to 30 percent in sexually transmitted infections (STIs). The median age of initial intercourse had decreased from 17-18 to 15. Some studies suggested that sexual activity with multiple short-term partners had increased among male and female students.

Only a small proportion of Thai young people consistently use condoms with casual partners, and even fewer do so with steady partners. Most said that though they know that unprotected sex carries a high risk of infection, they feel confident that they are not at risk. Even if they feel at risk or if they have already been exposed to HIV, "ARVs are changing teen behaviour," said Associate Professor Dr. Warunee Fongkaew of the Faculty of Nursing at the University of Chiang Mai. "Some believe that the doctors and the pharmaceutical companies will keep finding new drugs to treat all the strains of HIV. They think that if they can have drugs, they don't have to change their behaviour. We're trying to raise their awareness that they should have some responsibility for society."

"Young people are the future and have to have information on HIV so they can make informed decisions," said Mr. Lawrence Maund, of the Sangha Metta Project. Projects aimed at both in-school and out-of-school youth and young people are crucial to successfully address changing sexual behaviour and its impact on young people in relation to HIV. Thailand has taken many concrete actions to place young people at the centre of the response and emphasize HIV prevention for young people. Government and non-government sectors have worked both independently and together to implement HIV prevention strategies that include in-school programmes, out-of-school programmes, and community outreach services.

In northern Thailand, work continues to foster collaboration and consistency between schools, religious leaders and communities to overcome contradictory messages. Innovative, participatory strategies link sexual and reproductive health and rights to HIV education among young people. Such programming addresses the biological, socio-cultural, psychological, and moral and spiritual dimensions of sexuality and HIV. Key efforts included creating a supportive environment, working to engage individuals of all ages and walks of life who influence young people in HIV prevention, mobilizing the educational system, mainstreaming HIV prevention and care for young people with HIV-related illnesses and infections into other sectors, addressing gender inequalities and opening dialogue with stakeholders – youth, teachers, parents, local authorities and others – on sensitive issues.

Accepting generational differences is a factor in success

One of the barriers to reducing transmission of HIV infection is the ambivalent attitude of adults to adolescent sexuality. Another barrier is the resistance by adults to sex education programmes from the fear that sex education promotes earlier or increased sexual activity. Discussion on sexual issues between parents and children in Thai families is rare, and Thai families cannot yet be seen as a primary resource of sexual information for adolescents.

Parents, who often feel uncomfortable with this subject, may perceive sex education as promoting sex. They may believe that it is the responsibility of the teachers and health care providers to give such information to their children. This cultural ambivalence toward sexuality produces confusing messages for adolescents and often leads them to sexual exploration with friends and peer groups, whose views are often inaccurate, based on rumours and riddled with misconceptions. Information provided by the media - which is easily accessible - often gives sensationalized and mixed messages. These mixed messages can lead to anxiety, confusion and a strengthened notion that being sexually active is normal for teens.

Peer education is a mainstay of many programmes, both in-school and out-of-school. Youth leaders are used to conduct campaigns for HIV prevention in schools and raise awareness of risk behaviour through discussion about HIV prevention, condom use and the receipt of accurate information from peers. The Volunteers for Children Development Center, the Sangha Metta Project, the Community Health Project and numerous other organizations focus on peer education for youth as a way to increase knowledge on HIV.

HIV-positive volunteers from local support groups and peer educators have provided volunteer services such as home visits, risk-reduction counselling, and voluntary counselling and testing (VCT) in order to meet the actual needs of specific groups of youth. The commitment of young people living with HIV has been integral to the success of educating other youth on HIV issues.

Migrant or hill tribe youth who may need counselling in languages which are not Thai, street children, young women and men in sex work, youth who inject drugs or young men who participate in male to male sex have specific issues which need to be addressed. Projects such as those of the Volunteers for Children Development Center, Radio Thailand Chiang Mai and other organizations cater to some of those young people who have special situations. Some programmes such as the "Increased Access to Gender-Sensitive Reproductive Health and HIV Prevention Education and Services by Youth" project, conducted by the Planned Parenthood Association of Thailand, have claimed success in improving access to reproductive health education and services for youth (in- and out-of-school) through appropriate, gender-sensitive, age-specific, and community- and institution-based activities, including HIV prevention.

Participatory learning is key

Participatory learning and 'edutainment' approaches have been found to be effective in providing information about sexual and reproductive health and HIV prevention, because they are culturally appropriate in the context of each particular group and meet target population demands. Participatory learning helps create an exchange of knowledge and experiences, transference of knowledge, development of skills, a rise in awareness, reflection on personal actions, and teamwork among peer groups.

The 'edutainment' approach, involving such activities as games, role play, movies and rally activities, offers a favourable learning environment and promotes learning accomplishment on issues related to sexual and reproductive health among early adolescents. The "snakes and ladders" board game of the Volunteers for Children Development Center, in which players must negotiate through risk situations in order to avoid catching HIV, or the "STD game" of Empower, in which players take team roles of germs, viruses and antibodies to learn how the body is affected by HIV, are two of the many examples of successful "edutainment" efforts. For younger children, the Volunteers for Children Development Center communicates through cartoons or play. Afterwards a trainer integrates knowledge on what kind of risk they might have. "In the games we concentrate on the future," says the manager of the Center, "Then we ask them, 'If you have AIDS, what kind of future will you have?'"

Some organizations have trained youth leaders to produce information, education and communication (IEC) about HIV prevention, such as magazines, radio broadcasts, drama and role plays that draw from real life experiences. These IEC materials have been able to successfully disseminate the HIV prevention messages to young people in the communities, relating to issues directly affecting those communities.

Radio Thailand Chiang Mai worked with Akha, Lahu and Shan groups, collaborating with youth to develop HIV prevention soap operas that dealt with the daily reality of life for hill tribe youth. "The younger hill tribes know how to put things in their common and interesting ways, so it is better to have the story be written by younger people in case we want to draw attention from younger listeners – this may make the story somehow vivid and up-to-date," said Khun Somjai Sasomsarp of Radio Chiang Mai. The station also used hill tribe youth to select the bands that performed at the Hill Tribe Pop Concert Against AIDS, Trafficking and Drugs, which was broadcasted nationally and in which groups of youth performed traditional dances from various tribes.

Youth are also taking leadership initiative by maximizing their creative abilities to use the Internet and modern IEC techniques to share information. Said teenager Natthavut Manachai, who participated in the Youth and Adult Partnership with Schools project discussed below, "With four other friends, I have formed a new team, and together we have joined a training course for creating a website to teach young people about sexual and reproductive health...I am very excited and believe that my website, www.prc.ac.th/hukmao, will be able to give correct and accurate information to friends all around the country."

Youth community efforts

Community-based efforts to work with youth often involve developing a sense of leadership and a commitment to the community in young people. At the Community Health Project in Mae Rim, near the city of Chiang Mai, teenagers in the youth group have been given the specific responsibility to take care of the condom vending machines in ten villages. "This makes them feel actively involved in HIV issues and gains them more respect," says Khun Pimjai Inthamoon, the project's administrator and founder.

Temple-based HIV projects also address the needs of the community in relation to youth. Temples such as Wat Doi Saket and Wat Hua Rin work with youth groups and offer camps and other opportunities for HIV training, often examining good HIV prevention and attitudes in relation to Buddhist practice. One innovative effort by the Sangha Metta project works with novice monks to educate them as peer educators for their eventual return to their villages and communities. Back in their communities, the novices serve as the lynchpin in peer education networks.

One of Sangha Metta's more recent efforts has been to encourage young people in communities to set up living blood banks. They take a vow in front of Buddha not to do anything that might make their blood unsuitable for medical use. The young people give their name, blood type and phone number to the hospital so they can be called on by the community at any time. Novices are in charge of the blood bank and then promote it among other youth.

Mr. Lawrence Maund of Sangha Metta explained, "The vow helps young people avoid risk behaviours that can lead to HIV infection. The hospital then has a group of donors it can call any time to donate. This is a good example of where HIV has strengthened the social fabric."

Reaching out-of-school youth and children

Programmes to reach out to the out-of-school youth in different parts of Thailand have been focused on various groups, such as youth in non-formal education, youth working in general and, specifically, in night clubs or night-time entertainment venues, factory workers, street youth, hill tribe youth and youth in child protection centres. These young people may not always be able to participate in traditional community group efforts for a wide variety of reasons. However, there is a need to acknowledge the influence of local sociocultural beliefs and taboos on young people's sexual and reproductive health and thus consider the needs of the young people based on their own perspectives.

One good example of a successful programme that reaches out-of-school youth and children is the programme of the Volunteers for Children Development Center, which for ten years has been working with street children in Chiang Mai who range in age from six or seven to 20. The Center has found, like many other projects, that peers are the best educators. "Peer leadership works best," says Mr. Anuchon Holsong, the manager of the Center who is known locally as "Kru Ek" (Teacher Ek). "By developing peer leaders, a bridge between the foundation and family and friends can be created. The street children are a partner in protecting themselves from HIV. Although street children are perceived as troublemakers, if you try to understand and reach out to them, you understand that they want to help other people, too."

It took two years for the Center to build the street children's network, and now the peer educators conduct information education with their friends once or twice a week. "We have to teach the children the difference between having HIV and having an HIV-related illness. They have a hard time believing that people who look normal can have HIV," says Kru Ek. He noted, "The peer educators are part of the social fabric. When they find new street children, they bring them to the foundation. If they have a sick friend, they refer that friend to a hospital that works with us."

The street children also serve as a conduit to get HIV information to their parents. Training on HIV makes the street children more confident, and a trainer goes with them to find their parents, who might be in the slum or selling flowers or handicrafts to tourists around Chiang Mai's famous Night Bazaar. "We get three families together," says Kru Ek. "The children talk to their parents and they teach their parents what they have learned. The trainers just support the kids, and parents are very proud of the children when they do this. Most of the parents are street sellers. The children educate their parents."

Mobilizing in-school youth, teachers and administrators

HIV prevention programmes among in-school adolescents in different parts of Thailand have taken place at a variety of school levels, from primary, secondary, high school, vocational school and university.

Youth and adult partnership is one of the strategies that contribute to successful and sustainable programmes for HIV prevention among Thai youth. The use of partnership and the participatory process mobilized both parents and teachers to play an active role in the prevention of sexual risk behaviour and promotion of good sexual and reproductive health practices for early adolescents.

The "power dynamic" between young people and adults has been a crucial partnership element in programme development. The success of the resulting model suggested that early adolescents can be highly competent and able to play an active role as "change agents" when adults provide social, cultural and political environments that are supportive of them and recognize younger peoples' place as stakeholders in society.

While some programmes only involve adults and experts in HIV prevention to develop the programmes and activities for this target population, a programme entitled "Because the World Needs You" encouraged youth and adult partnership in the programme development phase. All of the programme stakeholders – teachers, parents and youth (took equally important roles in sexual and reproductive health and HIV prevention programme development.

Teachers who work on life skill issues were trained to analyse why youngsters engage in high-risk behaviours. Youth worked side-by-side as an equal partner with adults in programme development and implementation, which gave them a voice in shaping the programme and information that affects them. Youth-adult partnerships create an exchange of knowledge and experiences, skills development, rise in awareness, reflection on personal actions, and team work between youth and adults. Being an equal partner with adults increases youth's interests, commitments, dedication and awareness of the programme.

For in-school youth, sexuality, HIV and STI education programmes were implemented as formal and non-formal education. HIV support groups participated and shared real life experiences to raise awareness. These programmes successfully improved HIV-related knowledge, attitudes about people living with HIV, attitudes about condom use and increased actual use.

Strategies used were peer education, participatory learning, 'edutainment', youth-adult partnerships and advocacy to promote and enable sociopolitical environments. Youth who became competent peer educators developed communication skills to advise friends and family members about sexual and reproductive health. They also have played an important role in setting up youth clubs or friend clubs, such as "Youth Leaders – Power of the New Generation", "Love Friends and Care for Friends," and "Friends Warn Friends" to conduct peer-led activities and provide peer counselling in schools.

A successful school intervention

One successful intervention in Thailand was the Youth and Adult Partnership with Schools (YAPS) model that developed curricula on leadership, rights, duties and responsibilities, and a sexual and reproductive health programme. The model included strategies for capacity-building of both youth who acted as leader trainers for younger people ("Youth Leader Trainers") and the younger people they trained ("Younger Youth Leaders") to promote sexual and reproductive health and prevent HIV in young Thai students. It involved full participation of all key stakeholders and integrated sexual and reproductive health and rights into education.

The YAPS model was based on four key beliefs:

- the ability of young people to participate and contribute can be enhanced significantly through partnerships with adults;
- young people's participation can lead to the improvement of the overall social, cultural, economic and political environment;
- young people's participation is important to and inseparable from their individual development; and
- communities need to support youth in their development for the potential future contributions to the communities.

The YAPS model was implemented by the Youth Family and Community Development Project in collaboration with ten schools in Chiang Mai, using a participatory approach that emphasized emancipation, collaboration and empowerment. Key project aims were to develop a capacity-building curriculum, a sexual and reproductive health programme and strategies for capacity-building in youth. The project's goal was to develop the capacity of youth leaders to play a major role in educating their peers to improve their ability to share knowledge and promote positive attitudes. To achieve this, the project emphasized parental and school involvement in order to empower parents, teachers and school administrators to take on new roles and accept greater responsibility for sexuality education.

Above all, however, the model emphasized the participation of early adolescents in order to develop their capacity and enhance their power. It found that enhancement of youth leaders' capacities through peer-led activities, reflective discussion, consciousness-raising and exchange of experiences in groups promoted awareness and led to self-reflection by youth. Brainstorming, planning and learning how to work together to share information on sexual and reproductive health rights with their friends empowered them. They could then more readily apply the knowledge for their own benefit and disseminate it to their friends, families and communities.

Promoting school administration involvement was a key part of developing resources for sexual and reproductive health rights and HIV knowledge for students. In order to achieve an enabling environment where students could access this knowledge, it was necessary to create an environment where not just students but also teachers, school administrators and local policy makers felt empowered, were educated on these issues and developed supportive attitudes to ensure policy and administrative planning would support implementation of YAPS in schools. Encouraging parental participation in programme development also helped reduce conflicts and obstacles in teaching sex education to early adolescents and empowered and built capacity in parents to promote good sexual reproductive health and HIV prevention among early adolescents.

The core working group developing the curricula consisted of 28 teachers from the ten schools and the project research team. Workshops were held to clarify the work process with partner organizations. In these workshops, participants developed, debated and discussed youth risk behaviours and sexual reproductive health issues. Some Youth Leader Trainers were recruited from youth who were studying in higher education and had previously participated in research activities. Other Youth Leader Trainers were in grades 11-12 or were studying in vocational schools. All ranged in age from 16-20 years.

The Younger Youth Leaders, who would be trained by the Youth Leader Trainers, were studying in grades 5 through 7. They were selected according to their ability to think critically, take action and express themselves; their emotional quotient and connection to friends; their ability to give time; and the permission of their parents. There were 64 females and 47 males, ranging in age from 10-14, with an average age of 13.03 years. Written consent was obtained from both the Younger Youth Leaders and their parents. Parents of this younger group were recruited on a voluntary basis to participate in skill-building sessions, in developing the sexual reproductive health programme, and in conducting parent-youth activities and parent network activities.

The YAPS curricula

Three curricula for sexual and reproductive health rights education and HIV prevention were developed by the Youth Leader Trainers. These curricula included curriculum on leadership; rights, duties and responsibilities; and sexual and reproductive health rights.

Curriculum on leadership was composed of:

- exploring and analysing one's self;
- group process and the importance of the group;
- roles of a leader – how to be a good leader and a good follower;
- the decision-making process and problem-solving;
- working as a team, sacrifice, and unity;
- the definition, duties and qualifications of a leader; and
- steps towards leadership.

Curriculum on rights, duties and responsibilities comprised:

- definitions of rights, duties and responsibilities;
- right to survive or live one's life;
- right to receive protection;
- right of children to participate;
- right to be involved in all development processes concerning them; and
- rights, duties and responsibilities of children and youth.

Curriculum for education on sexual and reproductive health, entitled "Because the World Needs You", was developed through involvement of all significant stakeholders, including 108 early adolescents aged 10-14, 10 fully trained youth leaders, 30 teachers and 25 parents. Participatory learning methods and 'edutainment' approaches were used in developing teaching/learning activities. Through needs assessment and reflection sessions, the core content desired by key stakeholders was identified. These activities helped define the four core concepts to be addressed: human and sexual development; relationships; sexual health and rights; and gender. All were relevant to the "Comprehensive Sexuality Education" and "Abstinence-Plus Sexuality Education" Programmes.

Sexual and reproductive health curriculum content included:

- know-how to protect personal rights, including SRHR;
- sexual development;
- "Who am I?";
- friendship;
- love, desire and responsibility;
- sexual feelings and control; and
- sexual values, responsibilities, STI and AIDS prevention, and contraception.

Enhancing the capacity of Younger Youth Leaders and their parents

Before becoming Youth Leader Trainers, potential candidates were assessed to ascertain whether they possessed appropriate knowledge levels and the ability to transfer knowledge to fulfil their roles. Youth Leader Trainers were provided with the knowledge and skills to undertake their role by attending skills-training camps, rehearsing and practising, serving as trainers and mentors for Younger Youth Leaders, and participating in the presentation of research results at national and international conferences.

Youth Leader Trainers served as trainers and mentors for the Younger Youth Leaders at capacity-building camps, transferring knowledge and skills. This capitalized on traditional older-to-younger youth relationships, using both the respect which younger adolescents have for older ones and the caring and supportive role that older adolescents often take on for their younger peers. Capacity-building for Younger Youth Leaders focused on empowering them to take a lead in disseminating knowledge on leadership, rights, duties, responsibilities, and sexual and reproductive health to their peers in school. Said Ms. Premkamol Settheekul, a Youth Leader Trainer, "Being a trainer of Younger Youth Leaders makes me feel that I have prepared younger generations for passing along the necessary knowledge and skills to their fellow youth. This is important, because when I was their age, I did not have the same opportunity to receive such training."

In the YAPS model, Younger Youth Leaders and their parents were supported by partner organizations to develop their capacity to disseminate knowledge on issues of sexual reproductive health rights, duties and responsibilities. Younger Youth Leaders from each of the ten schools brainstormed and worked together to initiate and develop two projects to provide knowledge to their fellow students and to plan the implementation and evaluation of the projects. Teachers on the working committee also provided knowledge, explanation of techniques and methods for implementation and helped supply an enabling environment by providing time, a budget, and the setting required for conducting and summarizing peer-led activities.

As the Younger Youth Leaders implemented the peer-led activities in their own schools, they had an opportunity to exercise their own creative and constructive ideas for such activities on their own or in consultation with teachers. "We brainstormed to come up with new, interesting and attractive activities," said Natthavut Manochai, a Younger Youth Leader. "These included broadcasting the 'Small DJ' radio programme in school, initiating an essay-writing contest, organizing sex education sessions to be taught after paying homage to the national flag in the morning, and implementing summer day-camps in school."

Parents were key partners in the YAPS effort. Because discussion of sexual issues between parents and children in Thai families is rare and because adults often have an ambivalent attitude to adolescent sexuality, skill-building sessions were conducted to raise awareness and strengthen parent capacity in promoting adolescent sexual and reproductive health. In addition, a parent network was formed to support youth leader activities and conduct workshops to disseminate knowledge on adolescent sexual and reproductive health and child rights to other parents in other schools and communities.

The YAPS curriculum for parent skill-building included:

- problems that need to be considered;
- understanding the nature and needs of teenagers;
- parents' recognition of child rights;
- developing skills for winning teenagers' hearts;
- parents' expectations of their children; and
- the role of parents in dealing with the behaviours of their children.

The community also had a role to play in the YAPS experience. Cooperative networks were established with families by building the capacity of family leaders to support the abilities of Youth Leader Trainers and Younger Youth Leaders. Parent leaders provided support by taking part in creating community environments that were favourable for building the capacity of leaders and promoting sexual reproductive health among adolescents. Community awareness was raised about the importance of ensuring that young people were prepared and had appropriate skills regarding sexual reproductive health. Awareness was also built around the fact that increased knowledge about rights, duties and responsibilities was a way to prevent and lessen problems of risky sexual behaviours. This was done by disseminating knowledge, experiences, lessons learned and recommendations obtained from the YAPS research through a column named "Only Understanding" in local newspapers, through radio broadcasting programmes and by organizing sexual health forums.

YAPS evaluation and lessons learned

The processes and outcome of YAPS were assessed through process evaluation, self-reflection of participants, questionnaires on sexual reproductive health knowledge and attitudes for Younger Youth Leaders, and assessment of peer-led activities.

A final workshop with 50 participants, including Younger Youth Leaders, parents, the working committee, school administrators, health department experts, NGO workers and the press, reviewed and commented on the final YAPS study with the goal of extending the implementation of results and converting them into practice in a tangible manner. The aim of the workshop was to increase awareness, understanding and commitment to the integration of the sexual and reproductive health programme in educational institutions and in the community. The workshop emphasized that new curriculum needed to include more life skills practice on dealing with offers and persuasion and avoiding risks that may lead to danger. It also highlighted that the YAPS curricula contained topics missing in other sex education programmes, such as sexual and reproductive health rights and related laws.

At the workshop, participatory learning was highlighted as the most correct and appropriate method for giving sex education. Separating males and females in learning about topics such as physical changes in adolescence, where emphases are different, was considered suitable. Younger Youth Leaders who participated in the forum indicated that learning sex education was exciting and important for children reaching early adolescence, who often had no opportunity to learn about it. From the knowledge acquired, children learn how to protect themselves from everything around them and from incorrect values. As one of them said "Sex education is needed by early adolescents; it does not open a hole for the squirrel but in fact, it closes the hole to the squirrel."

From the workshop and the YAPS study, it was concluded that the core contents of sexual reproductive health education should be based on and supported by:

- needs, concerns and involvement of all significant stakeholders - youth, parents, teachers and administrators – to ensure that it is effective and up to date;
- effective teaching-learning processes for promoting adolescent sexual reproductive health needed to use participatory techniques;
- practical ways to integrate adolescent sexual reproductive education in school settings;
- equality between young people and adults when working as partners; and
- a sex education movement created at the provincial policy level in Chiang Mai.

Key lessons from YAPS

To summarize, key lessons that came out of the YAPS experience were:

- The ability of young people to participate and contribute to communities can be enhanced significantly through peer education.
- To create positive values regarding sexual reproductive health education for HIV prevention, teachers have to understand the reasons why children must learn this subject, be able to inform them correctly and be able to clarify misunderstandings. They should be qualified to convey the content, adjust teaching methods and organize activities appropriately. They must also keep abreast of current events, search for good learning resources for youth and make students feel confident that teachers really know what they are teaching.
- Learning methods must be participatory. The integration of the programme into the school system can be conducted in the form of extracurricular activities and learner development activities. Using youth who are trained as Younger Youth Leaders to convey and transfer knowledge will help students feel more comfortable to ask questions and absorb more knowledge than if adults are the teachers. However, adults still need to serve as consultants and mentors, giving advice to Younger Youth Leaders and helping them to discuss some topics that are beyond their capacity. Teachers should provide support, additional knowledge, media and learning resources that allow children to search for knowledge themselves. Parents who feel uncomfortable talking with children about sexual and reproductive health subjects should be offered activities they can attend as a way for them to learn.

- Capacity-building of Younger Youth Leaders is an efficient strategy for leadership role preparation. Youth Leader Trainers serve as positive role models in supportive capacity-building activities for Younger Youth Leaders.
- Adults are key stakeholders for effective programme implementation and must take the critical role of providing opportunities, assistance and guidance so that Young Leader Trainers and Younger Youth Leaders can develop their capacity in an atmosphere of trust and respect.
- Positive roles of parents, educators and adults are needed. Adults can encourage and foster positive, holistic and constructive thought in young people; empower youth to take responsibility for their actions, future and environment; and re-invent traditional human values suitable to Thai culture for the benefit of themselves, their families, communities and country.
- Understanding and promoting awareness of the participation and partnership working method for all parties is a priority that needs to be undertaken in the initial stages.
- All parties must share a common belief that they all have the capacity and ability to work together, no matter whether they are adults or children. Because this may challenge traditional assumptions, the participatory working tactic applied in YAPS can be time-consuming, especially in the initial stages. All parties must agree to commit to work throughout the entire process.

Sustainability of the YAPS model

The sustainability of the YAP school model has become assured through:

- Integration of sexual and reproductive health curriculum and capacity-building strategies into school curricula and teaching-learning activities in the form of extracurricular activities and learner development. The school administrators continue supporting Younger Youth Leaders activities in sexual and reproductive health rights education and HIV prevention.
- Teachers from partner organizations applied the programme and teaching-learning activities in their own schools. One of the schools adopted capacity-building strategies to promote sexual and reproductive health education and HIV and AIDS prevention and won the first national award for organizing peer-led activity on sex education in school.
- Younger Youth Leaders whose capacity had been enhanced played an important role in producing a new generation of Younger Youth Leaders in their own schools.
- Parent network activity was integrated into the school policy and action plan to strengthen school and family collaborative work for preventing and reducing risk behaviours.

Policy recommendations

Several policy related recommendations were proposed based on the YAPS conclusions and the lessons learned. These included the following:

- It is crucial for policy makers to be aware of the need for the actual participation of adolescents and all partner parties and to develop strategies to concert recommendations into action.
- Schools must understand the important role they play in integrating sexuality education and HIV prevention into school curricula to ensure continuity and sustainability.
- In developing a programme for sexual reproductive health education, focus should be put on the adolescent gaining awareness and understanding about themselves and others; learning how to think; being mindful and discrete in thinking, talking and doing; and knowing how to live amidst the global and changing trends of information without borders.
- Persons who work with adolescents need to change the approach from 'leading the thoughts' and 'domination' to 'working together' with adolescents and to allow adolescents to be 'partners in thinking and taking action.'

YAPS impact extended beyond the schools and communities in which it was implemented. Exchange of experiences and lessons learned took place amongst academics, activists, researchers and youth leaders from inside and outside the country who paid study visits to the project. Results of the participatory research have also been disseminated at national and international conferences, and the YAPS model of capacity-building was to be used for a project to develop youth leaders in Sri Lanka.

Sustainability

Youth grow and become adults, children turn into teenagers. Work on sexual and reproductive health and HIV prevention with youth cannot be one-off efforts, but must become part of the paradigm through which society educates its young.

In a review of the health sector response to HIV in Thailand by the Ministry of Public Health and the World Health Organization in 2005, one of the suggestions was that the Ministry of Education should ensure the implementation of sex and HIV education in the core curriculum in schools. Moreover, the experience of a project called Teenpath suggested that the sexual education curriculum only serves as a framework.

“Teenpath adopts a child-centred learning approach, in which teachers start by asking what the students would like to know – the myths and misinformation they’ve heard – and then explain these issues as the students raise them,” Waranuch Chinvarasopak, a programme officer at the Programme for Appropriate Technology in Health, told the Bangkok Post newspaper. Users of sexual and reproductive health and HIV prevention curriculum, including school administrative members and teachers, need to adapt a curriculum to better fit the needs of the students in various formats and settings. Programming for HIV prevention among college students in Thailand indicates that intensive teacher training requires teachers to be prepared for teaching all aspects of the programme and to follow-up evaluation findings to ensure the success and sustainability of school-based HIV programmes.

Another sustainability concern involves maintaining an environment in which students can be engaged in programme development and in which the learning process is enabled so that the needs of specific groups and subgroups of youth will be served. Additionally, clear policies of support by the school administrators as well as budget allocation are major challenges for the sustainability of the HIV prevention programme for youth.

However, youth themselves are ensuring that sexual and reproductive health and HIV prevention education efforts will continue in some areas. “Right now, I train new leaders in younger classes and serve as a consultant for them,” said Mr. Weerachat Kaewpradit, a Younger Youth Leader in the YAPS project. “This group of younger friends ensures me that whenever I am away from school, the club and all activities will continue, and the knowledge and skills will be passed on from generation to generation. This is what I call ‘sustainable development.’”

Key points

- Peer education is one of the most effective means to educate youth on sexual and reproductive health and HIV prevention.
- Full involvement of youth is crucial for the development of successful sexual and reproductive health and HIV prevention programmes.
- Parents and educators must all be fully involved to create effective sexual and reproductive health and HIV prevention programmes for youth.
- Parents should be educated on sexual and reproductive health and HIV prevention.

A great number of older people in Thailand are affected by HIV either directly or indirectly. HIV infection in younger people leads to a number of macrolevel effects on older people. Older people are impacted when they take on the burden of caregiving or when they provide financial or material support to family members who have HIV. They may also raise grandchildren who have been orphaned, suffer emotional distress at losing children and lose the support that they expected in their old age. In addition, some practice self-discrimination and isolate themselves, especially if they feel there is any discrimination toward them in the community.

“Every person living with HIV has parents. That means there are a lot of affected older people, even if they’re not recognized,” says Prof. Dr. Linchong Pothiban of the Faculty of Nursing of Chiang Mai University.

While the problems of older people or the elderly associated with HIV have often been overlooked, several formal and informal organizations in northern Thailand have made specific efforts to address these issues. The focus of this work has been on social support, HIV education, income generation or retention, capture and sharing of local wisdom, capacity-building for communities and individuals, community planning, advocacy on the issues of older people and improvement in intergenerational understanding.

Situation of older people and HIV in Thailand

Like many other countries, Thailand has an aging population. While 5.5 percent of the population was classified as ‘elderly’ in 1980, that figure changed to 9.4 percent in 2000 and is projected to be 15.2 percent by 2020. In the North, 11.1 percent of the population in 2000 was classified as ‘elderly’, and that percentage is expected to be 21.2 percent by 2020. In Thailand, the elderly have been defined as people 60 years of age and older. However, for HIV statistics, the elderly are defined as 50 and older. By 2020, there are expected to be 30 elderly people for every 100 working people in the North.

In 2003, 4.5 percent of the total reported number of people living with HIV in Chiang Mai was over 50 years of age. Most HIV awareness and prevention programmes are aimed at younger people, and older persons very often have limited knowledge of the nature, cause and transmission of HIV, leaving them at risk of infection. Television has been cited by studies as the most important source of information on HIV for all age groups, but older people often think such efforts are not germane to their situation and cite friends and acquaintances as other important sources of information.

Despite societal assumptions that older people are not sexually active, many are and may engage in risky sexual practices through lack of knowledge about those risks. “When we did a survey, we found that 20 percent of older people engaged in risk behaviours such as not using condoms and being sexually active when drunk,” said Dr. Linjong. The elderly may be reluctant to disclose their HIV status and get assistance because of these social assumptions and lack of knowledge. If they are looking after sick children, they may be at greater risk of infection because of a lack of understanding of basic transmission issues.

The indirect impact of HIV on older people

The percentage of older people living with HIV is not large in comparison to other groups, but the indirect impacts are substantial. Research studies on the affects of HIV on the elderly in Thailand are limited, but they show that the elderly have their own distinct problems and burdens in dealing with the affects of HIV. Studies have found that older people are often the caregivers for their children who have HIV. Seventy percent of people who died from HIV-related illnesses were in the care of their parents before their death, with older mothers more likely to be carers.

The 2002 survey of the elderly by the National Statistics Office found that about 55 percent of older people in Thailand were classified as being in the “poverty” group, with an income of less than 20,000 baht a year (around US\$600). HIV can exacerbate the economic problems of older people just at the time in their life when they are expecting economic support from their working children, as is the custom in Thai society. Instead, affected elderly people bear the cost of caring for children and grandchildren.

While older carers can get 500 baht a month in government support, studies have found that the costs of care add greatly to psychological stress. The care responsibilities of older people who are taking care of children with HIV-related illnesses or who care for grandchildren limit the amount of time to find employment. Age and gender discrimination may also make finding work difficult, and physical challenges may prevent elderly people from finding work they can undertake, especially in rural areas.

Older people are also very concerned that funerary rites be carried out properly should their child with an HIV-related illness die, representing another large financial burden. For those in the poverty group, the cost of a funeral (between 20,000-40,000 baht) can equal more than a year's cash income.

Older people affected by HIV have also faced stigma and social exclusion from their neighbours. Because they may have increased responsibilities caring for children or grandchildren, they may not have the time to participate in community activities at just the time when they are most in need of social support networks. They also suffer serious psychological impacts if a child dies from HIV-related illnesses. Isolation from the community may be self-imposed or community-led, and this adds to loneliness and stress. With the death of a child, their future may feel bleak and unsure.

Whether or not an elderly person is living with HIV, there are few well-trained health care staff who understand the specific needs of the elderly, especially in relation to HIV. Lastly, because of financial problems or health issues, some elderly cannot find transportation to medical facilities. There may also be no one who can go with them to assist them.

Initiatives addressing the HIV issues of older people

Some initiatives directly confront the problems which the elderly face when they are affected by or living with HIV. However, most initiatives may address the issues of HIV and older people as part of a holistic community approach to HIV. These initiatives involve different parts of the community and try to address as many of the specific needs and concerns as possible.

One community-led initiative was started informally by Mr. Suay Chantima of Chiang Rai. It is an example of putting to use the natural networking skills of people who share a community and have knowledge of that community because of their long association to it. The father of a woman who leads her local HIV support group, Mr. Suay and his wife sell food in the local market. Older people they knew would ask when their daughter would be coming to visit them, so that they could ask her questions about how to deal with HIV. “I had some knowledge and first-hand experience to share with them.”

In 1997, Mr. Suay founded a group which includes both older people affected by HIV and those who aren't, because “After their retirement, the elderly feel lonely and useless. We aim to bring back a sense of community and integrity. We are aware that older people face loneliness and need someone to talk to. So, on the 15th of every month we meet at our local health station where we grow herbs, and every Friday we pick our herbs and use them for our local spa. By organizing them and letting them do things together, the group promotes their self-worthiness and local culture.”

The mixed group also helps with community acceptance for those affected by HIV, said Mr Suay, and it also helped the elderly who were afraid to disclose their health status. "Many of them who have children with HIV are afraid of being discriminated, so they are afraid to share their problem with anyone. As the president of the group, I share my experiences with them and support them." Activities of the group include bicycle-riding days, to which they invite other groups. "This activity is very good, because it provides us opportunity to meet with other elderly people, discuss concerns and share and learn from each other's experiences. It helps us to stay fit and healthy. Sometime we bike to see the old temple with the children, too."

Mr. Suay found that affected parents in the group were most concerned about their children not dying before them and about not having sufficient information on HIV to know how to care for their children properly and how it would affect their health and that of their grandchildren. They were also very concerned about having a secure income.

Getting correct information to the elderly about HIV is one of the goals of this group, and Mr. Suay felt that leading by example was important. "There are parents who are afraid that they may get HIV from their children. I showed them by example that HIV can't be transmitted by living with positive people; I invited the positive people and those parents to have a meal at my house," he said. The group also created mini networks to make sure that the elderly were updated on their HIV information. "At our monthly meeting it is part of our key agenda to update on HIV. If someone misses a meeting, we'll send someone to update them. We also promote a chain-of-knowledge system by asking one elderly person to serve as a volunteer to help take care of or provide information to 3-7 other people in their network."

The group also tries to help the elderly by giving them income generation skills such as bicycle repair, flower making, and rattan and basket weaving. But to Mr. Suay the core value of the group is that, "We promote a sense of community, because that is very important for those facing stigma or discrimination. They need someone to talk to. Then we play the role of HIV information provider, because we believe there are still many people facing discrimination because they don't understand the issue."

Sharing traditional wisdom to bridge the generation gap

At the Community Health Project in Mae Rim near Chiang Mai town, as in most projects, work with the elderly began with a discussion of what their concerns were. "There were many older people affected by HIV. We had a public discussion among 10 villages about their needs in relation to HIV. We had an older group of people who were living with the virus or affected by it, and we had a youth group who were affected and were taken care of by the older people," said Ms. Pimjai Inthamoon, the project administrator and coordinator.

"One cultural challenge with the older group is that once they reach a certain age, the family still respects them but may think of them as a little useless because they don't bring in any money," continued Ms. Inthamoon. "The group tries to share the capacity to give them economic power. The older group will discuss anything. Sometimes they discuss herbal medicine because they had more knowledge. The older group shared their knowledge with the rest of the community, and it resulted in a book on herbal medicine and more people learning how to use herbal medicine to treat opportunistic infections."

The Community Health Project worked to try to bridge the generation gap between affected older people and younger people in the community, including the children for which they cared. "We created a 'local wisdom' network to promote collaboration between older and younger people in order to bridge the gap. They discuss anything about beliefs and cultures. It's building community capacity. For instance, they wanted a rice farming demonstration at school from the older people, because nowadays the children don't know where the rice comes from. We are also part of the wisdom national network, so that we can learn from others in other parts of the country," said Ms. Pimjai.

In addition, the Community Health Project worked with both the elderly and the children for which they cared to try to help each understand the other better. They worked to make each understand the needs of the other and their perceptions of the world based on the experiences they have had, which differ not only because of age but also because of the times through which they have lived.¹

Developing a model package for enhancing the quality of life of HIV affected older persons

Little attention had been given to the issues of older people in relation to HIV when The Faculty of Nursing at Chiang Mai University, HelpAge, The Northern Region Economic and Social Development Office, The Planned Parenthood Association of Thailand and the Foundation for Older Person's Development began to develop a model package for work on HIV with older people in October, 2004. There was a lack of information and little awareness about the impact of HIV on older people. Policy makers, planners and programmers had inadequate information to develop support mechanisms, and health service providers had insufficient knowledge, skills and sensitivity to deal with the issues of older people in relation to HIV. Communities were equally unskilled in meeting these challenges. Older persons were not a target for development issues, with the exception of the National Plan for Older Persons.

The project aimed to share its results in order to develop a proper plan to enhance the lives of older people. "The Northern Region Economic and Social Development Office did the policy analysis looking for policy gaps. They found the policy was there but nothing had been implemented," said Dr Linchong Pothiban, who was part of the Chiang Mai University team.

The project worked in 43 subdistricts in four provinces in Chiang Mai, chosen based on the prevalence in the district, the level of networking among involved groups and their willingness to participate. Three were rural and one was urban, which allowed comparison between the two types of environment. The project then did an in-depth situational analysis of each area using focus groups, in-depth interviews and field surveys. "In the situational analysis we knew the problems, but we needed to know each area specifically," said Dr Linchong. "Networking in the community is very important when you work on HIV, because other older people know where the affected are and where the people living with the virus are. In the field investigation they helped bring us to the target group. In the village the older people set up their own networks during the project, but not formal networks. The simply used who they knew and linked up to find out who had problems."

A model package was developed by a group made up of the project team and two people from each community. The two key components of the model package were impact mitigation and policy advocacy, with the former sometimes providing knowledge in order to undertake the latter.

Impact mitigation

The process focused on alleviating the economic, health and social impacts of HIV. One of the major concerns for older people affected by HIV was economic security, and the project needed to address resource, time and physical limitations of older people. Said Dr. Linchong, "We set up income generation based around their general needs and capabilities. We tried to look for projects where there is already a market outlet but which are not too physically challenging for them. They did frog farming, fish farming, bamboo weaving, herbal shampoo making and massage. It didn't bring income into the village, but what it did do was lessen their expenses and help sustain them; so in essence, they had more income."

The income generation activities also helped to strengthen the project participants' position in the community and to strengthen the social fabric. "They would give vegetables to other people in the community so that they could give something to share and show their worth. Income generation is not only about raising cash, but it is also about contributing something to the community. Each month they collected one baht (US 3 cents) from each household, and then the money was used to make cotton bags to try to generate income for older people. That way everyone was helping each other," explained Dr. Linchong. As another example, in a district in the city of Chiang Mai, people made biofertilizer, which helped provide older people with a daily wage.

¹ For more information on the Community Health Project, see Chapter Four.

The project also worked with affected teenagers to help them understand their grandparents and with the grandparents to help them understand their grandchildren. Some grandparents were overprotective of their grandchildren and didn't want them to work, but the grandchildren became bored. The project stressed that income generation could be intergenerational and that providing opportunities for the affected children was important.

Intergenerational activities were developed to help create better understanding between the affected elders, the children they were caring for, and other children in the village. In one village, older people worked with HIV affected children to create handicrafts, which the children then gave to affected older people. Essay and poster contests on HIV issues were held, and both young and old were trained on Thai massage. In the city district, staff worked with youth to repair an affected older person's home and trained orphaned children to help in the community on mosquito eradication. Older people taught affected children in Chiang Mai city traditional instruments. The children then played traditional music in the street market for tourists, while affected older people sold the instruments they had made during the shows, taking advantage of the crowds.

Increasing the knowledge of the elderly on HIV and health issues was an important component of the project. "Some of them were not sure about getting the disease from the children, so we had to train them on the basics of HIV," said Dr. Linchong. "They had many questions. They didn't know what they needed to know. There were many questions like 'Can you get HIV from drinking water in a person's home?' We used very small groups in training to make sure they understood."

The project also trained village health workers and monks. Older persons had often worked with traditional practitioners and they, too, were included. HIV support networks were trained on issues of impact of HIV on older persons and how the support networks could help. Mobile clinics provided health promotions on HIV prevention to older people and HIV screening. They also dealt with other problems involving older people. Health volunteers did home visits to screen for health problems and would refer the older people on if they found any cause for concern. There were monthly visits for elderly people who were affected who might be too busy, too infirm or whose homes were too far away to come to the mobile clinic. The home visitors could see if there were problems such as lack of food, and on the next visit the visitor might arrive with provisions. If older people needed help, the visits became more frequent. In the city the visits could be more frequent than once a month.

Advocacy

Advocacy at all levels was an important element in the success of the project. At the community level, community radio was a channel to reach people. Five volunteers for each village were trained and acted as DJs. They held call-in quiz shows with gifts and were pleased that many people called them. In communities where there was no community radio, the project used the village megaphone system to share information about HIV.

IEC materials were also developed for training, raising awareness and advocacy. Materials were developed with both the audience and subject in mind, with materials developed specifically for health care professionals, the community and for older affected persons themselves. Handbooks, posters, movies and VCDs were all forms which were used to disseminate messages and knowledge.

Local authority and policy level impact

Policy dialogues on the problems of the elderly and HIV were held in the community and at the provincial level. Advocacy with local tambon (subdistrict) officials was an integral part of the project from the beginning, and the project helped officials create an HIV plan for the community. Before the project, tambon planning in general had focused more on infrastructure. Tambon plans which included work on HIV and old people were distributed to all the other tambons in the province. The project's findings also were shared during the consultations and planning meetings for the Fourth National AIDS Plan, which became the first National AIDS Plan to explicitly recognize the need to increase older people's access to HIV information, and to offer prevention services for older people and services for those affected.

Key points

- Older people are impacted by HIV when they care for or provide financial or material support to family members who have HIV. They may also raise grandchildren who may have been orphaned by HIV-related illnesses, suffer emotional distress at losing children and lose the support that they expected in their old age.
- Older people are often still sexually active, engage in risk behaviours and are at risk of HIV infection.
- Seventy percent of people living with HIV-related illnesses who were in need of care were cared for by older people.
- Policy makers and local authorities need to explicitly include HIV prevention and care efforts developed for and aimed at older people.
- Health care professionals should be trained on the issues of older people in relation to HIV.

Mobilizing the Strength of People Affected by HIV and AIDS

4

“Leadership doesn’t mean you have to be part of an organization. It means you’re trying to do good for society in some way. People living with HIV want their leadership to promote well-being to both HIV-positive people and to the community. They helped educate the community and try to give them the right message. They try to give a good example of someone living with HIV. That’s leadership.” Rev. Sanan Wutti, Coordinator of Church of Christ in Thailand AIDS Ministry (CAM).

Northern Thailand has benefited from a vigorous response to the HIV epidemic from the community of people living with HIV. After the development of the Wednesday Friends group in Bangkok, the second HIV self-help group in Thailand quickly formed in the North. When the first conference for people living with HIV in Thailand was held in Chiang Mai in 1995, the 100 HIV support groups which joined together to found the Thai Network of People Living with HIV/AIDS were primarily based in the North of Thailand. The development of leadership within the community of people living with HIV or affected by HIV has been one of the great strengths and supports of the Thai response.

While some HIV support groups and networks were formed in cooperation with hospitals and other institutions, other groups were formed at the community level with no resources except those that people living with HIV in the community mustered. A holistic approach in which social, medical, economic, psychological, spiritual and other issues are all addressed in relation to HIV has, over time, become the basis for much of the work of these organizations.

Continued capacity-building, the development of self-confidence, the reinforcement of strengths through alliances with various organizations to address key issues and the realization that work on HIV issues must include the entire community have all been part of the leadership development of people living with HIV. Emerging issues, such as the needs of adolescents living with HIV in addressing the social challenges that all teenagers face, are often identified through the work of the community of people living with HIV.

Since the very beginning of the HIV epidemic, NGOs and support groups of people living with HIV in Thailand have played a key role in response, especially in protecting rights in relation to HIV. Through continuous networking, they put pressure on the government to reduce stigma and discrimination. They proposed to abandon legislation that would have required compulsory HIV testing. People living with HIV also fought high prices and the monopoly of provision of ARVs in Thailand. The work of a movement of networks of HIV-positive people and NGOs led to legal and political support for generic drug production. In 2002, people living with HIV won a court case in Thailand against a multinational pharmaceutical company, overturning a patent on a key ARV drug. They have continued to lobby for universal access to antiretroviral therapy (ART) for all people living with HIV who need it and to lobby to ensure that new drugs are offered at an affordable price as they become available.

Many local administrative leaders have begun to recognize the leadership role of people living with HIV and the contribution they make to their communities. In many subdistricts, people living with HIV are accepted by the subdistrict administrative organization as resources in the community. HIV-related activities organized by people living with HIV are included in the master plans of more than one subdistrict administrative organization. This results in reallocation of budget into the HIV response in the community.



The income-generation projects such as teddy bear making of the HIV-focused Community Health Project in Mae Rim, coordinated for the last decade by Khun Pimjai Inthamoon, include everyone in the community.

The GIPA principle

Although HIV support groups at the community level have often been driven by people living with HIV, since launching an ART programme in 2001, the government of Thailand has been establishing appropriate health care systems to meet the principle of establishing a greater involvement of people living with HIV and AIDS (GIPA). The GIPA principle was formally acknowledged in the 1994 Paris AIDS Summit Declaration when 42 countries (including Thailand) agreed to support an initiative to “strengthen the capacity and coordination of networks of people living with HIV and AIDS and community-based organizations”. This acknowledged the commitment to involve and integrate people living with HIV in work on programmes providing HIV care, support, prevention, and education. The Declaration aims to facilitate more successful local, national and global responses. It also acknowledged that for people living with HIV to have the level of involvement in the response that was needed, there was often a need for help and support from many sectors.

One step Thailand has taken to make progress in this realm is that government health institutions providing an ART regimen have established Centres of Comprehensive and Continuous Care (CCCCs). A CCCC is a multidisciplinary partnership between hospitals and people living with HIV that offers medical care and peer-provided home and community care, support, counselling and home visits. The CCCCs are practical implementations of Thailand’s commitment to the international call for GIPA.²

Involvement of people living with or affected by HIV contains two key components: 1) recognizing the important contribution people living with or affected by HIV can make in the response to the epidemic and 2) creating space within society for their involvement and active participation in all aspects of that response. The involvement of people living with HIV means that opportunities are available for them to use their experiences. The contributions can be made by individuals, groups or organizations, and from social, cultural, economic and political sectors.

² See more details under “GIPA in Thailand in the Age of Retroviral Therapy”.

There is a broad consensus that the GIPA principle is important for numerous reasons. Public acknowledgement of the involvement of people living with HIV can be a powerful tool in breaking down barriers of fear and prejudice. This results in increased social acceptance as well as reduced stigma and discrimination. Despite these endorsements of the GIPA principle and its importance, the active involvement of people living with HIV in real decision-making is often still limited, and the degree of involvement of people living with HIV occurs in different levels across different countries and regions.

Peer support is an integral part of leadership

Meeting other people living with HIV is an effective strategy of empowering people who are themselves living with the virus. Many community-based HIV support groups start simply when people who are living with or affected by HIV come together informally to share their experiences and information and to figure out ways to best support each other within their communities. Meeting peers can help people who have recently learned they are living with HIV to accept their status and realize that they are not alone. In focus groups of people living with HIV, most participants agreed that joining group activities helped them to learn more about living with HIV. Meeting other group members also motivated them to learn about taking care of their own health.

By being open about their situation with others, people living with HIV in these groups gave themselves space to receive and share information about how best to take care of their health. At the same time, their openness served as a model of confident disclosure to other people who were living with the virus but felt stigmatized and unable to take advantage of the knowledge or support that was available.

Group meetings provided an opportunity for people with HIV to share their feelings openly. They exchanged ideas about ways to make themselves stronger and healthier, including what to eat, lifestyle changes and ways to care for various AIDS-related conditions. They also provided each other with encouragement. As they analysed their situations, many groups developed income generation activities and capacity-building activities, which helped individuals support themselves and also helped individuals and the group represent themselves to the community and advocate issues related to them, attempting to gain the attention of local authorities.

Once HIV support groups began, people living with HIV were able to make new friends with people who could clearly understand their situation. This was of tremendous value to the group members, as indicated by some of the quotes below from people living with HIV:

- *"Joining the group meant I made friends with other people with HIV. We supported each other, which gave me hope to keep living."*
- *"Joining the group was good. It gave me encouragement."*
- *"Having the group made me talk more; we could share our feelings."*
- *"I feel glad that I joined a group because we can talk about things. I feel that I can rely on the group."*
- *"I'm glad I made friends with others like me, with the same problems, so I was able to reveal I had HIV."*
- *"I joined the group with all my heart. I wanted to come because I wanted friends to talk to, to share my feelings, and I also didn't know how to care for my health then."*

Over time, helpers who were "outsiders" increased the incentive for people living with HIV to reveal their status by providing social welfare, money or goods to those who joined group meetings. This altered the value and aim of group participation. Some persons joined the group just because it was an easy channel to receive tangible support from various organizations. This change led to an increased number of groups in upper northern Thailand. However, for most people living with HIV, joining the group meant more than receiving tangible support; it meant having opportunities to meet friends, to be trained in income generation and other skills and to focus on positive living, as illustrated by some of the quotes below:

- *"I joined the group and learned a lot of useful information about taking care of my health."*
- *"I learned a lot and did many activities, such as carving jasmine flowers out of soap, making leather products and making clothes. If someone buys my products, it means the community accepts people with HIV."*
- *"Meeting the group let me have a chance to learn and train about living with AIDS in positive ways."*
- *"Before I became a trainer, I had never spoken in front of a large group of people before. Now I'm very good at it because I have done it often, and I can get up and speak anywhere."*

From perceived community burden to community resource

The work of HIV support groups consists not only of looking after the health of each member, but also of offering opportunities to learn and develop leadership skills and personal commitment. In the words of one person living with HIV, "I'm glad I have HIV. If I didn't have HIV, I probably wouldn't have the opportunity to develop myself and work for my community like this."

In the early days of the HIV epidemic, communities sometimes felt that people with HIV could only be a burden on society. As the section below on the Community Health Project of Mae Rim details, some groups which began solely as a support group for people with HIV realized that their issues were often issues affecting the whole community, not just members of it who were affected by HIV. They developed activities on income generation, education and other issues which helped address stigma and discrimination by including members of the group who were not affected by the virus. This work also helped show the positive contributions that people living with HIV could make to the community in many different ways.

However, the main focus of HIV support groups has always remained supporting people living with and affected by HIV. After joining support groups, people with HIV have the chance to learn and develop skills in dealing with matters related to HIV and AIDS. Through their leadership, people living with HIV support and empower other people in their community on HIV issues. This boosts confidence and can reassure people with HIV, who may be self-stigmatizing, that they can make valuable contributions to society.

Members of groups often are trained to be counsellors and helpers of people in their own villages who have only recently learned they have HIV and their families. This helps ensure that people who have only recently learned of their HIV-positive status are more prepared to accept their situation and take care of their health. Many people who live with HIV reveal their condition so they can use their time to help other HIV-positive people and their families, often training others on care and support issues.

Public HIV education should help reduce stigma and discrimination, promoting how to live together in society as well as promoting HIV prevention. People living with HIV have been effective leaders in HIV prevention efforts. When trained people living with HIV speak out openly, they put a human face to HIV and break the silence surrounding the epidemic. Meeting people who live with HIV can change people's attitudes about living with the virus. People with HIV can promote effective prevention campaigns by using their own experiences and can also make a major impact on health care workers. Many people have limited knowledge and experience about living with people who have HIV and are often impressed by meeting HIV-positive people who are empowered and knowledgeable about the virus.

By undertaking these activities, people with HIV feel valued for what they can offer to their communities, as shown by the following interview excerpts:

- *"People in the village came to ask me for help because they had a family member with AIDS. Then, when they saw that I was in good health, they asked me what I did to stay healthy and not get sick. They would ask me to please go and see their family member with AIDS, so I went. I thought that if I go and help their child, this meritorious deed would mean someone, in turn, would help my child so that nothing would happen to my child."*
- *"I'm like other people because I helped care for someone with AIDS in my village so that, now, sick people trust me. If they have any problems, they can call me, telephone me."*
- *"Before this, I never helped anyone, never did anything good for anyone. But now I have helped many people and have done many things for the community."*
- *"People in my village praised me, saying that I am clever and strong enough to take care of my own health. I feel glad and very proud of this."*
- *"When I teach about AIDS, I can talk about my real feelings because it's how I really am. I can take care of myself, so people listen to me. It's my actual experience. No matter how many times a doctor can speak, it's not the same as someone with HIV talking."*
- *"I was very proud when I took care of a person in the village. He even called me 'doctor'. I told him I'm not a doctor, I'm just someone with HIV, and he said that I take good care of others."*

- *“At that time, there were no ARV drugs yet and local methods of health care were used. People from the village would come and ask me to go and visit a family member who had AIDS. As their condition worsened, I would go to help them. I would tell the family to show compassion for the person with HIV and not show disgust. I would also help feed and give water to the person and bathe them because their own families would not dare. Sometimes I taught them how to be caregivers.”*
- *“When I teach about AIDS, I can talk about my real feelings because it’s how I really am. I can take care of myself, so people listen to me. It’s my actual experience. No matter how many times a doctor can speak, it’s not the same as someone with HIV talking.”*
- *“When raising awareness on AIDS, having a person living with HIV speak is different from having a doctor speak, because we can say that we don’t want others to end up like us and because we can tell others what difficulties we have faced. But a doctor doesn’t have this experience and can only speak in theory.”*

Lifestyle education and holistic health care

For people living with HIV, questions concerning how to deal with personal relationships, how to choose treatment regimens, how to maintain health and how to better live with the virus frequently arise. Group activities promote learning about how to live positively with HIV. While medical facilities are continually trying to develop more appropriate care, many people living with HIV in Thailand feel that health care strategies do not depend solely on Western treatment methods and include alternative therapies such as herbs, Thai traditional medicines, massage, and spiritual or religious ceremonies. In addition, they are aware that a healthy lifestyle, in terms of physical, mental, spiritual and social relationships and economic conditions, is crucial. All this combined is known as holistic health care.

Support groups led by people living with HIV have often been leaders in examining health care opportunities which could be carried out within the community. Emphasis is often put on the use of herbs, massage and living a simple life. As such, lifestyle choices have become more important. For example, even though Western medicine says that people living with HIV can eat whatever they want, some people observed that eating certain foods gave them allergies or that some foods seemed to be healthier than others. Some performed rituals according to their own religious or spiritual beliefs. Villagers and communities do this on their own initiative within their community, and it gives community members more of a role in HIV work.

GIPA in Thailand in the age of antiretroviral therapy

As a result of the “Call to Action” at the UN General Assembly Special Session on HIV and AIDS (UNGASS) in June 2001, a new global consensus on the need for ART was reached. The World Health Organization (WHO) released guidelines for antiretroviral use in resource-constrained settings in April 2002. Later, in September 2003, WHO declared the lack of access to ART for HIV a “global health emergency” and announced that it would release an emergency plan to scale up access to ART for at least three million people by the end of 2005. This joint WHO/UNAIDS announcement came to be known as the “3 by 5 initiative”. The WHO guidelines for ARV use in resource-constrained settings were revised in December, 2003. These guiding principles stated that, “The initiative clearly places the needs and involvement of people living with HIV and AIDS in the centre of all of its programming”.

Serving as partners in Thailand’s health care system

In April 2002, Thailand’s Ministry of Public Health expanded access to ART and invited government hospitals to apply for treatment slots. Not all hospitals joined this project, often because of a lack of staff and laboratory equipment. To address these concerns, CCCCs were established in each participating hospital. Through a CCCC, ART and the necessary medical follow-up would be provided by a multidisciplinary team, including doctors, nurses, pharmacists and laboratory technicians.

The CCCC enabled people living with HIV and AIDS who needed antiretrovirals to receive them, but it also provided space for them to take part in care and support. In conjunction with the CCCCs, people living with HIV provide group counselling, case counselling and home visits. Many of the activities focused on promoting ART accessibility and adherence. Through this, numerous support groups for people living with HIV have become more official and now have a structure and a budget for expenses from both the state and from non-profit organizations.

In participating in care and support initiatives, especially for people living with HIV who receive ART, the group leaders or volunteers have to have knowledge and skills in ART adherence support. They have to be trained on counselling skills as well as comprehensive care for related symptoms and problems. Most of them apply knowledge and skills they have used with opportunistic infection prophylaxis and treatment. They also have to learn about how to deal with ART-related situations. In this service system, people living with HIV have to work in collaboration with a hospital. Under this programme, people living with HIV who provide care have to attend three training workshops on opportunistic infections and ART, counselling and the continuation of care. A budget is available for these activities. Thus, transparent financial management and reports are necessary for the support groups.

One other positive outcome from the development of the CCCCs was that both people living with HIV and health care facilities can more effectively mobilize work on prevention and health care. Social acceptance and public attitudes towards people living with HIV improve as communities see the contribution that people living with HIV are making.

Examples of leadership strengthening activities

Malisorn

The Malisorn group was founded in Phrao district, Chiang Mai province, in 1995, supported by the nursing staff of Phrao Hospital. In 2006, it had 180 members and 14 leaders.

One of the group's objectives is to create a space for people living with HIV to meet and support each other. Another objective is to participate in all aspects of the response to the HIV epidemic. Other objectives include providing care and support for people living with and affected by HIV and AIDS, promoting positive living with HIV by all members of the group, promoting social acceptance for people living with HIV, and raising awareness and promoting better understanding about HIV prevention, care and support among people living in the community.

Malisorn's activities

Phrao Hospital provides a room in its building for the Malisorn office, where meetings take place at least once a month. The meeting agenda is determined by the group and special trainings are sometimes conducted at the meeting. Normally, members receive no financial support for joining, although some members might bring food from home to eat together at the meeting. Regular activities of the group are aimed at educating, training and capacity-building for new members. Well-trained members of the group or persons who have shown good habits for a long time are encouraged to become trainers. Group representatives are also sometimes selected to join the trainings provided by other organizations. In order to promote leadership in future generations, new members work with the group leaders in their various activities, such as conducting home visits and HIV education sessions in the community and school.

One of the regular activities of the Malisorn group is providing AIDS education to the community. In 2001, the leaders of Malisorn completed training from the Enhancing Care Initiative Project conducted by the Faculty of Nursing of Chiang Mai University and CAM. The training covered HIV education and symptom management for opportunistic infection by using pharmacological and non-pharmacological remedies and counselling skills. After the initial training, the group began to create their own media to use in their teaching. The media is very simple and can be easily understood. The content explains what HIV is, the function and living process of HIV in the human body, how HIV is transmitted, how to live with HIV and how to care for people living with HIV.

These community-based HIV education sessions always take place at the home of a person living with HIV. The group representative asks permission of the person and their family to invite their neighbours, usually approximately two to four families, to join the session. The participants always include adults, elderly people, teenagers and children so that everyone can gain knowledge about and better understanding of HIV. The group leaders may demonstrate how to care for the sick and how to manage symptoms in order to develop the skills of the family caregivers. The representative of the group is generally accepted as the resource person of the community.

Malisorn works with teachers to provide HIV education. By using their direct experience of living with HIV, Malisorn's representatives answer students' questions. The aim of this activity is to enhance the students' awareness and understanding of HIV prevention and HIV-related issues. Malisorn also provides HIV education to the monks through sessions conducted at temples. Senior monks and the temple committee support the use of temple facilities to conduct the HIV education sessions. This activity aims to promote better understanding about HIV among monks so they can share their knowledge and understanding with laypeople in the community.

Group leaders and representatives collect data about the elderly and children who are affected by HIV and monitor the care and support they receive from various resources. This data has been used by community leaders, especially the local organizing committee, to develop policy and allocate budget to fill the gaps in their community practices.

Promoting ART Adherence

Like other groups operating in Chiang Mai province, Malisorn collaborates with hospital staff to promote ART adherence for their members receiving ARVs. The group works very closely with the nurses and hospital staff to counsel individuals before they begin receiving ART. New cases are followed up by conducting home visits in order to monitor progress and make suggestions on how to adhere to ART protocol and manage side effects. The group continues to monitor their self-care and ART adherence over the long term. They also provide trainings to their members regarding new knowledge, best practices for ART adherence and integration of ART into their daily lives.

The Community Health Project

The Community Health Project in Mae Rim, Chiang Mai province, is in a peri-urban community that was only farmland not too long ago. The project started 14 years ago, when several people found that they had HIV and wanted to support each other. Since then, over 5,000 people living with and affected by HIV have been involved in the project. One of the main principles of the project is that the work must be holistic and integrated.

"Initially, I was the key person to facilitate, but eventually I realized it shouldn't just be HIV-positive people; it should be the whole community who was involved," said Ms. Pimjai Inthamoon, the project administrator and coordinator. "All the issues work together to support those affected. The project works with everyone in the community and deals with the economic problems in the community. The income generation includes both people who are affected and those who are not."

The stigma and discrimination against people with HIV has decreased in the community since the group was started. "HIV-positive people now feel that it is okay for them to disclose, and they participate in almost all the community activities," explained Ms. Pimjai.

In the beginning, people with HIV were looked on as a burden on the community, but the success of the support group began to dissolve the discrimination in the area. "An HIV-positive person bringing in funds to start a community project made people more accepting in the beginning," said Ms. Pimjai. The project started a savings group from the funds of the HIV support group. The savings group now includes 1,000 people in the community, both those who are affected and those who are not. Since many people living with or affected by HIV had economic problems, the project also developed a strong focus on income generation and capacity-building.

"We facilitate learning and self-sufficiency and sustainability," said Ms. Pimjai, sitting in the workroom of the project, surrounded by sewing machines, teddy bears, slippers and reams of cloth for other sewing projects. "The members of this group come and learn and become entrepreneurs. We have one affected woman selling stuffed elephants. Sometimes when she gets a big order she asks the centre to help her. One older HIV-positive woman produces bags for the Japanese market. Some of the hill tribe women we have worked with have moved back to their villages and now produce handicrafts for sale in the night bazaar. We also train them to market as well. Both those affected by and those living with HIV have good skills and have hired others to work in the community."

The project helps support itself through these activities, which often focus on income generation skills for women. "For our own products, we basically spent two years training on sales and marketing. We participated and won the government's nationwide One Tambon One Product award in the doll and bag category for two years running. We manufacture for other businesses and get bag orders from universities and conferences. We also do silkscreen."

The holistic integration of issues across the whole community has broken down many barriers that people living with HIV felt. "Working together has really helped discussions," said Ms. Pimjai. "Working together, the community learns how people with HIV live and work. By having this experience, the other people understand more and change their attitudes. Working together has solved the negative attitudes in the community 100 percent. It also is important for prevention. We have not seen new infections for the last five years in the village."

The centre, which also helps migrant women in need,³ tries to address issues around HIV which affects anyone in the village, from elementary school children to older people, looking at each group's specific needs. For teenagers, the project tries to come up with activities that educate them on life skills, and it also takes into account their stage in life, as they begin to change from carefree children to adults. The adolescents in the youth group (aged 13-20) have specific responsibilities for the care of condom vending machines in ten villages. These responsibilities make them feel actively involved in HIV issues and gain them respect.

For elders in the village affected by HIV, the project tries to bring some economic empowerment. A significant number of older people are taking care of children affected by HIV, and the project also tries to address the generation gap between the young and the old through dialogue and by sharing the resource that elders possess most: wisdom and traditional knowledge.

Part of the leadership strategy of the group is to address new issues concerning HIV as they arise. One of the concerns that the group is starting to work on are the emotional issues facing youth living with HIV and those who are affected by it as they mature into adults. The group wants to hold discussions between families that are affected and those that aren't and learn about their issues and attitudes.

Said Ms. Pimjai, "For the kids who are 12 or 13 years old, we have been providing knowledge on opportunistic infections and how to control that. They have informal counselling also. The guardians are worried about the next few years. We promote family involvement and talk with the guardians so that parents and guardians understand what the children will go through. It's through the guardian's network of older people that we share problems and questions. There are some cases in which children aren't HIV-positive and aren't sure whether they should get married, because the parents of their potential spouse would wonder where their parents are, why there are only guardians or aunts. They wonder how their spouse would feel if they are from an 'infected' family."

Although it took time at the beginning, the project now works closely with local officials. Explained Ms. Pimjai, "We have to educate and include the tambon officials. They are an important partner, but sometimes new officials aren't aware of the different ways HIV affects society. We have to advocate to them and try to include them in the activities. I personally might not be seen as someone who should have influence because I am female, HIV-positive and only have a low education, but sometimes they feel intimidated because I can draw funds and know how to reach out to people in the community. I spent two years trying to involve the local tambon head in our activities and ended up serving on the board to produce the tambon master plan. By working together, we learned that alcohol is a big problem in the community and now the centre works together with the tambon on health, water and other matters, in addition to HIV."

AIDSNet "Real Life" project

The AIDS Network Development Foundation (AIDSNet) and its forerunner, the Northern AIDS Prevention and Control (NAPAC) project, helped pioneer community-based HIV prevention efforts within northern Thailand. Its interventions focus on developing understanding, skills and self-competence in diverse communities. AIDSNet currently focuses on assisting people living with HIV, young people, minorities and migrant labourers to develop positive approaches to living with HIV and protecting oneself and others from transmission of HIV.

³ See the section entitled "Accepting our Differences: Working with Marginalized Populations."

AIDSNet's "Real Life" project helps support the leadership of people living with HIV by providing the opportunity for HIV positive persons to share their experiences and concerns with others in similar situations, to visualize new ways of seeing themselves and their communities, and to develop skills and strategies to implement a new vision of the HIV-positive person as a constructive contributor to community and society.

AIDSNet, working with the International HIV/AIDS Alliance, has developed a set of training modules which update HIV-positive persons who are taking ARVs about opportunistic infections, sexually transmitted diseases, self-acceptance, community acceptance and reproductive choices. Working with HIV groups that belong to the Thailand Network of People Living with HIV and AIDS (TNP+), peer facilitators were trained to conduct small group trainings on the modules. Members of these groups also serve as informal trainers for their peers, helping to pass on information and knowledge to other individuals who are also on ARVs.

Key points

- Mobilization of the leadership strengths of people living with HIV is crucial to a successful HIV care, support and prevention effort.
- The leadership of people living with HIV in a community helps improve the situations of everyone in that community, not just those living with or affected by HIV.
- The leadership skills of people living with HIV can be supported by continuing capacity-building on HIV prevention, care, support, rights and treatment issues and through building organizational, public speaking, advocacy and economic empowerment skills.
- People living with HIV strengthen the effectiveness of their leadership through partnership efforts with government institutions such as health facilities and research centres, community groups, faith-based organizations, NGOs and other organizations.

The psychosocial implications of HIV can be as problematic as the physical implications. People living with or affected by HIV need emotional and spiritual support, and religion plays a very important role in providing this support. Every religion offers important ethical guidelines for living, for interpreting natural events and for coping with life's challenges.

Religions help provide important ethical guidelines for living based on each religious philosophy. Each religion teaches its followers to live according to their religious beliefs and to maintain a balance in life. Faith brings with it a powerful support system for people affected by HIV. "The temple's role is to support the community," said the Ven. Tanawat Wannalee of the Buddhist Wat Hua Rin in San Patong, near Chiang Mai city.

"Religion is part of life. Religion represents life in a spiritual way and impacts the physical, mental, social and economic parts of life. People of every religion promote love and affection to each other; if you have that, it helps in terms of prevention and education. Religion teaches us to live our life mindfully, to protect ourselves and others," said Rev. Sanun Wutti of CAM. While around 95 percent of Thais are Buddhist, there is no state religion in Thailand, and religious leaders and organizations from Buddhist, Islamic, Protestant Christian, Catholic and Hindu faiths, as well as others, have all played an important role in HIV work in the country.

All religions contain principles that promote love of fellow human beings and support for the greater well-being of others. Faith-based activities in all religions provide opportunities for education and awareness-building on HIV issues. "We have to promote the knowledge about this, because people still think that HIV is not related to their lives. What I have done is that I have integrated information into related lessons, such as those concerning religious study. In addition, Muslim youth have come to religion class on weekends. This is a good opportunity for both HIV activists and Imam to integrate the issue into the lesson or to take an hour talking exclusively about it," said Aj. Winai Saengsiriphon, Imam at Sarapee Masjid in Chiang Mai.

Faith and the application of religious philosophies also help people living with or affected by HIV to interpret their situation as a natural part of life, combating feelings of stigma, discrimination, guilt, sorrow, shame, doubt, hopelessness and fatality. An understanding of such conditions enables people living with and affected by the disease to enhance their spiritual well-being. It gives them hope and brings meaning to their life, even if they are confronted with clinical symptoms or stigmatization. Religious beliefs, such as the law of karma in Buddhism, give people hope and encouragement and enable them to cope more easily with HIV infection. In the teachings of Islam, faith teaches people not to harm themselves, either directly or indirectly. In Christianity, said one religious believer, "Trust in God, hope and compassion make a great difference with HIV."

Networking within and among faiths

Interfaith networking plays a crucial role in developing faith-based prevention, care and support services. The Northern provinces play host to Thailand's Interfaith Network on HIV/AIDS, a network of Buddhist monks and novices working on HIV issues and the Asian Interfaith Network on HIV/AIDS. Religious leaders of every creed have found it important to learn about the creeds of other religions, since individuals looking for support and guidance on HIV issues may not always be from the religion they practice. They try to provide appropriate counselling for people of other religions and to connect them with faith-based organizations of their own religion if they want.



Buddhist monks like the Venerable Insorn Khunwutto linked wats with other community structures, building on each organization's strengths to create a more efficient and effective response to the epidemic.

The monks of Wat Doi Saket are part of this interfaith network, developing guidelines on each religion to be shared with all faiths. Rev. Sanam of CAM says the learning is continuous. "The first thing we try to work on with people of the three main religions is to try to update knowledge, particularly for monks, preachers and imams. Each religion has stories, canons and teachings which can be used to create positive teachings on HIV. We combine these teachings in the education programme. There are many religious leaders who have negative attitudes. By having negative attitudes, they don't give space for HIV-positive people to have a normal life and don't support them in working on prevention issues. Some religious leaders pick out small parts of their religious texts as proof that there is not support for HIV work, but when you think of the core values of each religion, they are all about providing care, love and kindness."

Challenges to faith-based work on HIV

The belief that HIV was related only to sex, prostitution, intravenous drug use and homosexuality often fostered misunderstanding in communities, which resulted in resistance from some communities to implementing prevention and care programming. In Thailand during the beginning of the HIV epidemic, HIV was often considered a secular matter not related to the life of monks, so Buddhist faith-based groups were not interested in supporting activities.

Some people did not clearly understand the role of monks in HIV prevention and care since they believed that a monk should not be involved in issues related to sex. Religious leaders in all faiths faced similar resistance. However, today's generation of monks have analysed their roles and attempt to modernize and make their actions more relevant to the modern community. Like the new generation of monks, faith-based organizations of many creeds now carry out activities to help people living with HIV, their families and the community in Thailand.

Because of stigmatization and discrimination, faith-based organizations may have trouble identifying people living with or affected by HIV who may be in need of assistance. Despite successes in helping to overcome stigma and discrimination, some people living with HIV feel shame and others are rejected by their families and not included in family affairs. Both people living with HIV and their families are sometimes reluctant to disclose themselves to others. Thus, prevention and care activities of faith-based organizations do not always reach those who are in need.

Activities of faith-based organizations regarding HIV

CAM has been recognized as a pioneer in setting up a model and designing methods for home visits and the process of home-based care for people living with HIV and their families. The Ministry has also become a resource centre, sharing its knowledge and experience. Another example of a faith-based organization working with HIV issues is Baan Mitratorn (Home of Caring Friends), which was established by the congregation of the Sisters of Saint Paul de Chartres in Chiang Mai. Baan Mitratorn aims to provide education, treatment, medication, love and care to orphaned children who are living with or affected by HIV. Christian and Buddhist groups both have introduced home-based care services and have greatly contributed to the destigmatization of HIV.

Examples of Buddhist work on HIV

Even though there are other religious groups in Thailand, around 95 percent of Thais are Buddhist, and that which follows will focus on the Buddhist response to HIV. In Thailand, Buddhist monks have always had a traditional role in providing spiritual support to communities and particularly to people who are very ill, including people living with HIV and their families. Some temples provide hospice care for people with an HIV-related illness.

The monks in the temple (*wat*) have the crucial roles of not only teaching Buddhist philosophy and morality to the public, but also of helping people feel more content and helping them maintain psychological well-being. The *wat* serves as the centre of the community, particularly in regard to spiritual matters and times of trouble. It also serves as a centre of learning and a refuge in times of emotional need. Buddhist monks play crucial roles in teaching Buddhist philosophy and morality to the public and in contributing to rural development work. Other duties include serving as general consultants to lay members of the temples and conducting religious rites for people on different occasions.

Buddhist organizations have focused their work on various aspects of HIV, including education, youth activities, home and community visits, networking and integrating HIV issues holistically into community work.

The Buddhist temple as a centre of the community

The temple is the centre of the Buddhist community and community life revolves around it. Monks serve community members during the different rites of passage in life, from birth to death. Moreover, monks have had a traditional role in providing emotional and spiritual support to communities. The temple is a centre for education, both secular and non-secular. Through the temple, people learn the law of *karma* and its application to life. At the temple, the elderly assist monks in passing on traditional teachings to the young.

Traditionally, Thais live in an extended family arrangement. Prior to being ordained, monks were members of the community and part of an extended family. This relationship still exists after ordination, but greater respect is given due to the monks' status. People pay attention to them, listen to what they say and turn to them in times of trouble. Faith-based responses to HIV in Thailand have been successful because they employ respected community leaders. They use traditional values and beliefs and indigenize contemporary methods. Temple-based projects encourage community participation. They focus on HIV as a socio-economic crisis rather than an illness, are cost-effective and benefit all community members.

Education

Various wats and Buddhist institutions have provided education on HIV through seminars, training programmes and workshops for monks, nuns, novices and Buddhist laity. Monks have gone on to assist people affected by HIV through providing education and training programmes in the community. Some monks have joined the local hospital HIV support group and attend monthly meetings where they conduct counselling and give training in Buddhist meditation. Others have established their own projects to educate and raise awareness in the provincial prison and among people whose situations are of high risk. Monks conduct education and awareness-raising programmes for school children and youths, individuals in high-risk settings like prisons and detention centres, people living with and affected by HIV and other community members.

Youth activities/summer training camps for the young

Youth camps in temple settings are popular as a way of educating young people on HIV issues and life skills. Many camps like the ones held at Wat Doi Saket are “dharma camps”, which focus primarily on Buddhist teachings in relation to HIV and other issues. Other camps organized by *wats* may focus more on skill-building and “edutainment” as a medium through which to send HIV messages and information, such as the music camp at Wat Hua Rin. “If you just talk about HIV, sometimes people think it’s an old subject,” said the Ven. Tanawat Wannalee. “We integrate it with other activities so young people don’t think it is boring.” The camps focus on general HIV education and on life skills in relation to issues like injecting drug use. Youth attending the camps also learn how to live with HIV affected people or those who have HIV-related illnesses.

Home and community visits

Monks have been sensitized to the needs of people living with HIV, their families and their children. They understand how to collaborate with community groups and resources. Many monks have developed counselling skills and can now put the emotional needs of people affected by HIV into the framework of Buddhist practices. People visited by monks also have the opportunity to take part in traditional religious ceremonies, which brings great satisfaction and helps to raise morale. Visits by monks demonstrate to the community that there is nothing to fear from people who are living with HIV.

Other temple activities

Monks encourage villagers and people living with or affected by HIV to come to the temples for such activities as dharma teaching, meditating, making merit, donation and prayer. As part of efforts to widen understanding in communities, several *wats* run income generation activities for the community that combine people affected by HIV and those who are not. As community temples play a significant role in the community, an important part of addressing stigma and discrimination is to ensure that people affected by HIV join in on such activities and that the community continues to welcome them. Some temples also support HIV support groups in a variety of ways. For example, Wat Hua Rin built a facility within the temple compound where the local support group can meet together. Wat San Kang Pla also provides a room for such gatherings.

Cooperation among Buddhist religious organizations and other networks

The HIV epidemic impacts the individual, the family, the community and society. Religious organizations such as Buddhist monk groups in Thailand generally help people by providing emotional and spiritual support. The temple is the centre of the community for spiritual matters and during times of suffering. Many people affected by HIV go to the temple to help reduce emotional distress. Buddhist monks are aware of the role they have in mitigating the suffering of the people and have established a network of religious organizations to support people with HIV.

During an in-depth interview with the director of the Sangha Metta Project, a Buddhist faith-based organization, Mr. Lawrence Maund said “Educated monks attending the Lanna Campus of Mahamakut Buddhist University in Chiang Mai gain knowledge from their university about HIV and AIDS and come to realize that people affected by HIV and AIDS and their families face many different types of suffering, including the clinical manifestations and social stigmatization. As part of their teaching roles, monks can apply the core teachings of Buddhism in helping and teaching both people with HIV or AIDS and the general public about the ways of coping and managing their lives.”

Informal networks among district temples have been developed so that monks and temples can share ideas and resources relating to HIV prevention and care. The Sangha Metta Project has also assisted in the establishment of the Northern Monks’ Community Development Network. The abbot from Wat San Kang Pla said, “This illness causes discrimination, and the *wat* is one place that is available for them”. The abbot from Wat Hua Rin said, “Monks come together to help the people who are suffering. Monks have established the Northern Monks’ Community Development Network, and one mission is to help HIV-affected people, including their families and communities.”

Integration of religious philosophy into HIV prevention and care measures

A good HIV training programme in the Buddhist faith systematically integrates the core philosophy of Buddhism (the Four Noble Truths) in HIV prevention and care measures. A central teaching of Buddhism, the Four Noble Truths are, namely, suffering (*Dukkha*), the cause of suffering (*Samudaya*), the cessation of suffering (*Nirodha*) and the path leading to the cessation of suffering (*Magga*). These teachings and principles can be used as a guide for living for Buddhists in Thai society. They help participants identify the suffering brought about by HIV, its causes and its cessation, as defined by Buddhist principles.

The integration of the Four Noble Truths in HIV education helps monks develop strategies for HIV prevention activities and the care of people with HIV-related illnesses. The Buddha defined suffering as birth, old age, sickness and death. Monks work together to identify the different types of suffering related to HIV. They then work to identify the cause, the cessation and the path leading to the cessation of HIV-related suffering, all as defined in the Buddhist context. In this way, they see that everyone – the individual, the family and the community – is affected in one way or another by HIV.

Buddhism is based on the desire to be free of suffering. It teaches people to live in the spirit of *Metta* and *Karuna*, that is, kindness and compassion. Monks apply these values when working with those living with or affected by HIV. Buddhists believe that their lives are in a cycle of rebirth, through which they are continuously reborn in human or animal form, in either gender, depending on deeds or *karma* of the previous life. Thai Buddhists believe in the law of *karma* as the law of cause and effect. Buddhism teaches people that performing good deeds affects their *karma* and that they may make merit, or accumulate good karma, by practicing morality (*sila*), mental discipline (*samadhi*) and wisdom (*panya*).

Each person is responsible for his or her own actions and the resultant *karma*. Belief in *karma* also enables people to cope more easily with the painful reality of life, for instance, the suffering that can be associated in various ways with HIV. In this way, people see HIV as a result of actions performed in the past or present lives and not a form of punishment or divine retribution. Strategies developed include teaching, guiding and discussions with people living with or affected by HIV about 1) the various situations which can be defined as suffering in Buddhism brought about by HIV; 2) the cause of HIV-related suffering; 3) the cessation of HIV-related suffering as defined in Buddhism; and 4) the way to the cessation of suffering related to HIV issues. These strategies can help people living with or affected by HIV realize that living with HIV is a natural part of their lives.

Wat Hua Rin

Wat Hua Rin was one of the earliest community temples to work on HIV issues. Community temples serve as places for meetings of HIV support groups, where people can gather, share experiences and develop useful activities. Wat Hua Rin, located in San Patong district of Chiang Mai province, provides space for all of these activities in a community of about 1,800 people.

The abbot of Wat Hua Rin trains the monks so that they understand and accept people living with HIV. He explained, "It took almost two years to gain acceptance of people living with HIV in this community". In addition to training, the abbot provides vocational training for people living with HIV, such as sewing, handicraft production and making souvenirs. They are also trained in small business management, increasing their capacity. "Community and HIV support groups always join in the same activities. "The community and people living with HIV are more united," said the abbot. "People living with HIV are not discriminated against, and their self-esteem has increased along with their general quality of life."

The Buddhist monks schedule gatherings for the HIV support group on all Buddhist holy days. The rationale of these gatherings is to enhance psychological well-being by integrating Buddhist philosophy into the teachings during these Buddhist rituals. The Buddhist monks help to encourage participants to think optimistically and never lose hope. "I encouraged them to never lose hope... I taught them to observe the sun and the moon, which always rise," said the abbot.

The monks also work with HIV support groups to enhance their fund-raising skills in order secure scholarships for higher education for children affected by HIV. Scholarships are raised for between 50 and 60 children annually. Children and youth are at the centre of the *wat's* work, and the *wat* works with them to train them to develop life skills on dealing with HIV related issues such as injecting drug use. They facilitate sharing of experiences among children who are affected by HIV, and through the *wat*, children volunteer to take informal surveys in the community and share the results with other communities on needs and issues relating to children and HIV. There are also camps for children based on the "edutainment" concept, in which the children learn about HIV and other life issues in relation to Buddhism and also enjoy activities such as music.

Wat Hua Rin also helps facilitate a tambon committee on HIV issues. Members of the committee include youth from six villages and representatives of a housewives club, an HIV support group and the temple. Every year they choose a theme on which to work, such as HIV and alcohol, or anything else that affects the quality of life.

"You have to work with what interests the community and the activities have to reflect what the community is interested in," explained Wat Hua Rin's Ven. Tanawat Wannalee. For instance, because of the presence of the Royal Botanical Fair in Chiang Mai one year, the community chose to use gardening as the means of expressing their thoughts on and experiences with HIV. As part of the activities each year, the monks work to train villagers on avoiding high-risk behaviours, including those associated with excess alcohol consumption.

As part of the *wat's* holistic approach to HIV issues, the *wat* also works with the elderly. Part of the vocational skills training programme teaches affected elderly people to make funeral materials for sale. The *wat* also worked with local tambon authorities to provide support so that older people could start raising chickens and pigs. The *wat* also has a fund to support HIV-affected elderly and monks perform home visits. Monks enquire what kind of support the older people are getting from other older people, what kind of help they feel they need and what the goals are for their grandchildren. The monks also work to try to create understanding between grandparents and their grandchildren to bridge the generation gap.

The *wat* also networks with other entities to increase the scope of their services. For instance, a room in the local hospital was set aside as a dharma treatment centre for individuals who inject drugs. The *wat* also works with the local tambon authority on a number of issues related to HIV. In addition, the abbot networks with NGOs. It also works with a group of Japanese monks that was interested in the work provided at the temple. The Japanese monks support the vocational activities of Wat Hua Rin by distributing their handmade products in Japan. They also supported a field trip of the sewing groups to experience the similar work of others.

In conducting temple-supported community-based activities, monks at Wat Hua Rin, include community members in all stages of planning and conducting activities. They recruited from and cooperated with other community resources. These activities resulted in a permanent commitment of local resources. Capacity-building of individuals has been enhanced and their skills have been developed. This has created a feeling of ownership among villagers in Wat Hua Rin.

Wat San Kang Pla

Wat San Kang Pla's activities are an example of applying Buddhist philosophy and knowledge regarding HIV to life. Wat San Kang Pla is the district *wat* in San Kampaeng district, Chiang Mai. It focuses on helping people living with HIV and their families. Within five years of the start of the *wat's* HIV activities, the people in the community became more capable of accepting people living with HIV, reducing stigmatization in the community and empowering people living with HIV and their families to live their lives with dignity. The abbot of Wat San Kang Pla demonstrates the integration of Buddhist philosophies, in particular the Four Noble Truths, to help people living with HIV, their families and their friends in the community. The objectives of the *wat's* activities include:

- Supporting the role of Buddhist monks in HIV prevention and care;
- Establishing a network of people living with HIV capable of functioning within the community;
- Serving as a resource centre, providing information and materials on HIV;
- Cooperating and coordinating with other organizations working on HIV; and
- Educating laypeople on the core philosophy of Buddhism through Buddhist rituals.

The abbot helps educate people and train Buddhist monks to understand the role they can play in HIV prevention and care. Buddhist monks also help educate laypeople on the core philosophy of Buddhism, the four Noble Truths, during Buddhist rituals. Education also involved health training and Dharma teaching in working with HIV, provided not only by Wat San Kang Pla's monks, but also by available health care professionals from the district or public health sector within the community.

In addition, Wat San Kang Pla works with school groups to provide knowledge of HIV prevention and care for boys and girls aged 13 to 16. In these groups, participants learn how to avoid high-risk behaviours. Work done by monks has assisted greatly in returning children of parents who are living with HIV, once denied admission to school, back into the classroom. Monks and nuns also assist in caring for children orphaned by HIV-related illnesses through providing temple-based care and support, and consumer goods. They also assist the elderly who have lost grown children – quite often the family's main breadwinners – to HIV-related illnesses by setting up income-generating activities.

The monks of the *wat* worked to establish a network of people affected by HIV capable of living productively within the community and serving as a resource centre for providing information, materials and other activities regarding HIV for people with HIV, their families and people in the community. They also worked to cooperate and coordinate with other organizations working on HIV. The abbot of Wat San Kang Pla encouraged villagers and people with HIV to come to the temple for activities such as Dharma teaching, meditation, making merit, donation and prayer, allowing everyone to feel part of a whole community. Wat San Kang Pla also provides a room at the temple for HIV support groups to organize and carry out activities.

Buddhist monks help to teach people how to integrate Buddhist philosophy into providing care for people with HIV, their families and the community during home visits. With suggestions from the abbot, people living with HIV formed a home-visit group to provide psychological and financial support and health education to people in the community who had recently learned they had HIV. Trained people from the community provide moral support for the people living with HIV and their families via Buddhist-based counselling, advice on self/home-based care and occasional material support from donations taken from temple offerings.

The *wat's* work demonstrates a clear chain of cause and effect regarding HIV prevention, advocacy and care, which has been able to increase awareness, reduce situational risk and decrease the stigmatization and discrimination of people who are living with HIV in the community. After participating in HIV and narcotics education and awareness-raising programmes conducted by community-level monasteries and monks, some youth groups have formed peer support groups and "Friends Tell Friends" programmes. The *wat* is part of informal networks among district temples that have been developed so that monks and temples can share ideas and resources related to HIV prevention and care.

The Sangha Metta Project

The Sangha Metta Project is an NGO that was developed and operated by instructors and Buddhist monks at the Lanna Campus of Mahamakut Buddhist University in Chiang Mai in November of 1996. The project was started in response to the call for Buddhist monks to have a more active role in HIV prevention and care.

The main objectives of the project are to educate and train Buddhist monks, nuns and novices in HIV prevention and care and to support their role in the response. Sangha Metta also has targeted fourth year students in religious universities, who go on to do a year of community work. Establishing training at this level allows younger monks to continue to educate the communities within which they will then work, where they can train more monks. In the eleven years the Sangha Metta project has been in existence, it has helped train over 4,000 monks across Southeast Asia on HIV issues, refining the lessons learned in Thailand and helping monks in other cultures to adapt the wisdom gained from Thailand's experiences to their own settings.

The project conducts seminars, training programmes and workshops for monks, nuns, novices and Buddhist laity. A significant aspect of the training programmes is raising participants' awareness of HIV as a socio-economic problem that affects the lives of everyone and can have potentially devastating impacts on both personal and community development. Training also aims to promote positive attitudes among monks and nuns towards people living with HIV and those affected by the virus. It emphasizes the importance of compassion and awareness in responding to those people.

Seminars focus on the roles of Buddhist monks in solving problems caused by HIV. During the seminars, all aspects of HIV, including misunderstandings and superstitions, are discussed with the experts from local hospitals and health offices. At the community level, seminars and trainings are conducted for different sectors of the community with the objective of raising awareness of HIV and its potential impact on the community. Education is also given on caring for people with HIV-related conditions, as well as how to understand the different resources in the community and the ways people can work together with those resources to strengthen the community and develop its potential to resist or mitigate the impact of the virus on the community as a whole.

The project works to provide technical, informational, financial and material support in order to assist in the production and dissemination of information and learning materials, such as Sangha Metta's newsletter, documentary, video, magazines and newspaper articles. The project also emphasizes that documents and other materials need to be produced in hill tribe languages and languages used by migrant groups, who may not be comfortable in Thai. "There are documents in Shan now. There are documents on self-care and community-based care. But there are many other groups which still need information in their own languages," says Mr. Lawrence Maund, Sangha Metta's coordinator. Sangha Metta has worked with monks from various ethnic communities in Asia on efforts to help those communities get HIV information from the *wats* which serve them.

Sangha Metta's focus in recent years has shifted to working with novice monks, an effort which is based on the structure of Thai and Buddhist cultures. "Faith orders the cultural basis on which you work, especially since you have to understand the hierarchy of the culture you work in," says Mr. Lawrence Maund. "Everyone has their own responsibilities. Older monks can't train younger people the way young monks can in the hierarchy. You have to find a way to educate the young using young religious leaders. Novice monks have bonds of friendship within the communities. When they return to their communities, they are peer educators as well as youth spiritual leaders. Kids may be a bit reluctant to talk to monks, but they are friends of novices. This gives the novices a change to prove their worth to the community. They have authority and they use it. It doesn't have to be a formal training to get the messages across."

With its work with novices, Sangha Metta focuses on the impact of HIV on personal, cultural and community life and how Buddhist teachings can be used to mitigate that impact. It has helped novices set up the Novices AIDS Interaction Rehabilitation Network (NAIRN), through which the novices go into temple schools and give education on HIV. Novices are encouraged to go back to their communities and initiate youth groups in temples in collaboration with community groups and health centres. Sangha Metta also recently encouraged novices to start living blood banks and then to promote them among young people, as discussed in Chapter Two.

Wat Doi Saket

Wat Doi Saket is located in Doi Saket district, 15 kilometres from the city of Chiang Mai, and has served the community since 1805. The *wat* is located on a hill, surrounded by forest and a botanical garden, creating a feeling of peacefulness for everyone. The community surrounds the temple, with approximately 100 households. Some villagers rent areas of the *wat* to use as temporary housing with very low rental fees. The abbot of Wat Doi Saket developed a training programme on HIV in the early years of the epidemic, focusing on promoting community awareness and improving the quality of life of people living with or affected by HIV in the community. The monks at Wat Doi Saket work with monks from other temples and share knowledge and lessons learned. These groups of monks have established a network for people living with or and affected by HIV. The objectives of the Wat Doi Saket programme on HIV have been:

- To educate Buddhist monks, people living with HIV, their families and the community on all aspects of HIV;
- To raise the awareness of HIV as a socio-economic crisis and the potential impact of the disease on the community;
- To set up networks for monks working with HIV;
- To motivate and support people living with HIV and encourage community acceptance of them so that they may coexist peacefully in religious practice and community activities; and
- To advise in planning and strategies and to empower monks to set up network activities.

The *wat* set up training on HIV for monks, adults, the elderly, working people and youths in the form of a dharma camp, in which large numbers of people participate. The dharma camps help reduce risk behaviours and also help to reduce stigma. Monks learn counselling techniques which, "...combine the principles of Buddhism with the counselling techniques of the public health sector," said the Ven. Insorn Khunwutto.

In addition, a workshop was organized on Buddhist responses to HIV prevention and care that involved not only people in the community but also overseas participants. For example, nine Kempo (heads of Bhutan's main Mahayana Buddhism sect) from different regions of Bhutan participated. The workshop was participatory in nature and was conducted within the framework of the Four Noble Truths of Buddhism. In addition, trainings on vocations, life skills and stress management were introduced to people by the educated monks.

Wat Doi Saket, led by the abbot and a set of monks who were interested in community development, also started a monks' network. The network aimed to enhance Buddhist roles in working with HIV groups by setting up focus groups and discussions with 97 monks in Thailand. Following the discussions, activities were set up with the cooperation of the district abbot. The financial and material support for the network was received from donations from the government and NGOs. The network would meet frequently, using Wat Doi Saket as their centre, in order to empower the monks' network in working with people living with HIV in their own communities. In addition, a network of people living with HIV was set up. The main objectives for these projects were working together, empowering people living with HIV to live with others and to gain acceptance.

"When we started out, we thought the *wat* was the answer to everything, but we soon realized that we needed community participation," said Ven. Insorn Khunwutto. Coordination in the district is crucial to that participation and the empowerment of people with HIV. A tambon committee was set up for HIV work, and the *wat* specifically asked that older people who were respected in the community be members of that group. The *wat*, community health offices, support groups and NGOs work together to create a district strategy for the direction which HIV and AIDS work will take in a given time period. They do this in order to pool and maximize resources and ensure that everyone is working in the same direction while not duplicating efforts. Said Ven. Insorn Khunwutto, "By having a strategy, we build strength on strength, each effort being stronger because we are supporting each other and sharing our resources".

Key points

- The key tenets of all faiths are based on love and compassion for other people, thus ideally supporting work on HIV and AIDS issues.
- Religious leaders of all faiths should learn about other faiths so that they can minister to individuals of other faiths who may turn to them for support.
- Faith-based organizations are effective in dealing with the spiritual, psychological, community and economic issues of people living with or affected by HIV or AIDS in a holistic way.

Over the past 10 to 15 years, it became apparent in northern Thailand that HIV was having a strong impact on the social and economic well-being of the population, which, in turn, affected the quality of life of people living with or affected by HIV. For the purposes of this document, 'community-based care' is defined as care and support provided to people living with HIV in collaboration with a variety of different organizations in the community. These include government, NGOs, faith-based organizations, and people living with HIV and their networks, including their families. Community-care can include a wide variety of activities that aim to enable people living with HIV and affected persons to access quality care, to undertake self-care and to be self-reliant.

'Home-based care' refers to all kinds of care provided routinely every day to people living with HIV inside the home by family members or caregivers, with support from friends, relatives, neighbours, volunteers, public health personnel or NGO staff. A holistic approach to HIV issues undertaken in a supportive community environment enables each actor to undertake their care role with sufficient resources and support in order to ensure effective care.

Because of the wide-ranging impact of the virus and the number of factors that impact an individual's ability to address issues relating to HIV, community-based care is considered important in order to foster social and community acceptance of people affected by the virus in any way. Community-based care concepts focus on pooling all the resources available in the community, including government organizations, NGOs, faith-based organizations, HIV support networks, families and people with HIV themselves to provide care and support for people living with or affected by the virus. This care includes hospital care, ARV, treatment for opportunistic infections, home care, complementary care, vocational training, and social welfare through capacity-building and empowerment.

Community responses to HIV that were supported by the public sector initially focused on attitudes and behaviours of people living with HIV, analyzing risk factors and working on prevention. The non-governmental sector focused more on marginalized populations and hard-to-reach groups. Self-care and home-based care by people living with HIV, their families, peer support groups and communities have contributed greatly to an improved quality of life for people living with the virus.

Significant factors in successful community-based care for HIV-related illnesses in Thailand include:

- a national policy on HIV;
- community acceptance;
- commitment of community members and health-care providers;
- efficient programme budget management;
- good coordination between stakeholders;
- full participation from people living with HIV and those affected by the virus; and
- learning forums.

Community-based care is comprehensive and requires collaboration and involvement from all sectors and disciplines to maximize use of resources. Empowerment of both the community and people living with HIV is the key approach to success. A holistic approach which looks at HIV in light of other issues in the community is equally important.

Every phase of community participation is done in cooperation with volunteers, using the leader of the community as a model. Community members are invited to analyse, synthesize and solve certain problems according to their needs. Participants identify ways to improve the community through the provision of basic knowledge, study tours, project development and advice, and through working in real-life situations. This helps community members learn from working together and encourages them to continue cooperation.

Management teams for community efforts are often identified by using a learning forum format where input is generated from all stakeholders. However, success depends on the capability and suitability of the area where work is being conducted. Learning experiences may be needed to change the thinking paradigm of people in the community. A stage for open discussion is provided, information is exchanged and updated, and people learn from best practices in the community. Community members share experiences to identify and familiarize themselves with the problem as well as the community's potential to solve it.

Among the approaches used in implementing community- and home-based care in Thailand are:

- comprehensive and continuous care;
- prevention campaigns, including the "abstinence, be faithful, use condoms" (ABC) campaign and the condoms and needle exchange and negotiation (CNN) campaign;
- research and development;
- foster families for children orphaned by HIV-related illnesses;
- learning forums to share learning experiences;
- capacity-building; and
- empowerment.

Being able to successfully work on HIV issues in a community using the above approaches depends on many factors, especially the dynamics of the community. Communities are constantly changing. As each community has its own unique characteristics, many factors have to be considered when working with HIV. Some of these concerns include:

- national policy on working with people living with or affected by HIV;
- attitudes of the community to which people living with HIV belong, as well as coordination mechanisms available in that community for coordination of activities
- efficient budget management;
- whether there are an adequate number of personnel who are responsible for managing the HIV problem and whether that number is sufficient to sustain the project;
- coordination between the public and private sector;
- whether the health system is in a state of readiness in terms of its personnel and services, especially with regard to ARV provision;
- ensuring that people living with or affected by HIV participate in providing community-based care and efficient treatment;
- developing learning processes between people living with HIV, those who do not have the virus, the private sectors and parents or family members of individuals who are living with HIV; and
- community needs and participation of the community in addition to organizational participation.

Home-based care works best in an enabling community setting

For individuals living with HIV or who have an HIV-related illness, the disclosure of HIV status plays an important role in accessing home-based care services. Often, family members agree to be caregivers. Many of these caregivers are older, and mothers, in particular, serve as principal caregivers.

The most common problems and obstacles in providing home-based care to people with HIV or an HIV-related illness are financial-related. Other problems include stress, lack of emotional support, limited access to ARVs or to medicines to treat opportunistic infections and other conditions, lack of knowledge by caregivers and the person in need of care about HIV and related illnesses and conditions, lack of budget from the public sector, an inadequate number of public health care workers, a lack of knowledge and understanding about how to provide care, especially in spiritual dimensions, stigmatization in the community, inability to ensure continuous care after being discharged from the hospital and a lack of coordination among institutions.

The most urgent need of caregivers and people living with HIV is often money. Other needs include employment for generating income, access to ART, education on self-care, acceptance and encouragement by community and society, and attention and care from the public sector. A community-based approach to HIV issues which involves accessing, including and developing various resources in the community in a holistic manner creates a space for successful home-based care.

In Thailand, home-based care services are often provided for people living with HIV-related illnesses by public and private sources as well as religious organizations and networks of people living with HIV. Services provided include capacity-building for people living with HIV and their families, education and skills training on self-care, counselling and psychosocial care. Psychosocial care should be adjusted to fit the situation of each community with respect to its specific sociocultural, religious and socio-economic contexts.

The Enhancing Care Initiative in northern Thailand

The Enhancing Care Initiative (ECI) is an example of good practice in both home- and community-based care. The Thai ECI team was formed in 1998 as a collaboration among six organizations: the Faculty of Nursing at Chiang Mai University, the Office of Disease Prevention and Control 10 (CDC10), the Chiang Mai Provincial Public Health Office, AIDSNet, the Upper Northern Network of People Living with HIV, and CAM. Thus, the team comprised four sectors: government, NGOs, academic institutions and networks of people living with HIV.

ECI was the first and largest multidisciplinary and multisectoral HIV care project in Thailand at the regional level. Over five years of activity, the ECI team included 22 to 26 members. These included nurses, doctors, public health personnel, social workers, religious leaders, community leaders, academics and people living with HIV. Team members devoted a great deal of attention to learning how they could collaborate most effectively in order to achieve results that none of the partner organizations could have achieved on their own.

Representatives from the six organizations worked together to prepare the team's original proposal. All team members were encouraged to participate in establishing the objectives, work plan and indicators. The team used workshops, community forums, written reports and monthly meetings to gather and share information. The monthly meetings were a particularly important means of keeping the team unified, because working groups were expected to summarize their progress at these sessions. The monthly meetings also provided an opportunity for participants to have a dialogue about what decisions the team should make regarding major issues.

Phase I – Situation analysis

The team was fortunate to be able to draw on relevant data concerning the capacity and availability of HIV services in northern Thailand previously gathered by team members. For the situation analysis, the team collected qualitative data through focus group discussions with individuals living with HIV and their families, as well as with community health volunteers, community leaders, Buddhist monks, health personnel and members of NGOs in the region. Data from interviews with health workers, caregivers and HIV-positive people revealed a perceived neglect of holistic care for individuals with very serious HIV-related illnesses. Care and support issues which the team examined included end-of-life issues of pain management, physical management, mental and spiritual care, ethical aspects of care, and the legal and socio-economic aspects of care.

Based on examination of this data, the team targeted two districts of the Chiang Mai province and four areas for improving care: treatment, care, counselling and social support.

Phase II – Developing programme activities

The ECI Thai project aimed to find appropriate solutions to enhance good quality care for people living with or affected by HIV in upper northern Thailand. A multidisciplinary and multisectoral care team was established to conduct action research. The steps in this action research were:

1. Identify the situation and problems;
2. Identify the goals and outcomes;
3. Determine areas of HIV-related illness care and sub-projects;
4. Identify settings of the study;
5. Establish work plan and responsible working groups;
6. Implement the work plan; and
7. Evaluate the results of the project.

Phase III – Implementing programme activities

In the third phase of the project programme, activities were implemented. Programme activities were undertaken in seven major areas:

- Improving quality of service in health care institutions;
- End-of-life care;
- Home-based care;
- Empowerment of people living with HIV;
- Community empowerment;
- Human rights; and
- Quality of life of people living with HIV and people affected by the virus.

Improving quality of service in health care institutions

The ECI team partner leading this working group was the Chiang Mai Provincial Public Health Office (PHO). The quality of service in health care institutions was already a responsibility of PHO, so much of the ECI working group's attention focused on enhancing PHO's ability to help institutions and personnel meet some of the HIV-related needs of their clients. The two major institutions located in ECI's target area were Phrao Hospital and Doi Saket Hospital. Three health centres in the Phrao district and another three in Doi Saket district served as additional institutional settings for ECI.

The major components in improving the quality of service in health care institutions were:

- Improving standards of treatment and care for opportunistic infections;
- Improving standard precautions practice; and
- Implementing institutional care programmes addressing the unique needs of people living with HIV.

Improving standards of treatment and care for opportunistic infections

During its first phase of operation, the ECI Thai team found evidence of insufficient care and treatment for people with opportunistic infections and that the existing protocol was impractical for most health care settings. After further assessment of the situation, the working group decided to address this problem by promoting standards of treatment and care for these infections. The ECI Thai project supported the PHO in developing practice guidelines for treatment.

At the end of the first phase of this project, the PHO and ECI team organized a workshop on opportunistic infection treatment and care. Twenty-five physicians joined and discussed issues relating to effective standards of treatment and care. This workshop helped the working group determine the content of the new guidelines. The working group held a second workshop to introduce the newly completed treatment protocol within the following three months. The 165 participants included doctors, nurses and health care personnel.

As a component of its routine work, PHO followed up with monitoring and evaluation to determine whether the guidelines were being properly implemented and worked with institutions that needed assistance overcoming barriers in implementation.

Improving standard precautions practice

The need for standard precautions practice in health care settings, like the need for standards of treatment and care for opportunistic infections, came to the attention of the ECI team during the first phase, situation analysis. Although national guidelines prepared by the Ministry of Public Health existed, these guidelines were not applicable to all situations. Again, PHO shared ECI's interest in revising the guidelines for standard precautions. A workshop was held and health personnel from different hospitals in the Upper North were invited to participate in order to discuss and revise the existing standard precaution guidelines. The newly agreed guidelines were tested by those hospitals and were then modified as recommended. The ECI team then provided financial support for PHO to publish and distribute the finished document.

Implementing an institutional care programme addressing the unique needs of people living with HIV

Part of the working group's agenda was to address issues that people living with HIV encountered when they went to seek care and treatment from hospitals. The working group realized that a hospital care programme addressing the unique needs of HIV-positive people would benefit both people living with HIV and health care personnel. Patients who were not HIV-positive also stood to benefit from a programme of this nature if it increased the hospital's overall efficiency. With the support of the ECI working group, Doi Saket Hospital and Phrao Hospital both held seminars in order to review their existing HIV care programmes in terms of quality, strengths and weaknesses, and opportunities to improve. Each hospital identified improvement opportunities in the care programmes and prioritized activities. At both hospitals, the working group's strategy was to bring together people living with HIV and hospital personnel so that the two groups could cooperate in addressing various objectives and activities.

End-of-life care

CDC10 was the leader of the working group, in collaboration with the Faculty of Nursing at Chiang Mai University, CAM, and the Upper North Network of People Living with HIV. The major activities in addressing end-of-life care issues were training in counselling for the dying and production of booklets on end-of-life care.

Training in counselling for the dying

The ECI working group organized a course that provided training in end-of-life counselling to health care providers. Expert counsellors were invited to teach throughout the course over a period of eight months, with the participants convening for a two-day period every two months. Twenty health care personnel attended the first session and sixteen persons completed all four sessions.

The curriculum, which was developed by the ECI working group in collaboration with outside experts, combined basic counselling instruction with a discussion of principles related specifically to HIV. Participants in the training were encouraged to think about the people they counselled in the full context of their lives rather than only focusing on the clients' health-related needs. They also learned that since many people living with HIV, including those with stable health, have concerns about dying, "end-of-life" counselling is not intended to benefit only people whose deaths appear to be imminent. As it is conceptualized by ECI, this service is for all people living with HIV who seek support in the process of reflecting on the meaning and value of their lives.

Another characteristic of the training course is that it utilized the “case-conference” technique. Participants were instructed to look for ways to relate what they learned at each session to their ongoing interactions with people living with HIV during the intervals between sessions. Every participant chose a situation with one particular person in his or her life and presented that as a case for the group to discuss. The trainers helped the participants articulate what they were learning from the cases and how they could apply these insights to their future efforts.

Production of booklets on end-of-life care

In response to the need for concrete information about end-of-life care, the working group decided to publish booklets on six topics. The contents of all of the booklets were developed through consultation with the appropriate experts, including both ECI team members and outsiders. The working group wanted the target audience for all of the booklets to be the entire range of people dealing with HIV, including people living with HIV, their families and other caregivers, health care personnel and community volunteers. These booklets were introduced and tested within four months with the target audiences to determine their efficiency and applicability. Group discussions were used to evaluate the results, and then the booklets were revised as recommended. While the working group took the lead in writing the booklets, the full ECI team was responsible for distributing them in the various settings where the team worked. The ECI team printed 1,000 copies of each booklet, which were distributed to hospitals, health centres, groups of people living with HIV and other health care settings as requested. The topics of the booklets were as follows:

- Pain management
 - Causes of pain
 - Pain assessment
 - Pharmacological and non-pharmacological management
 - Roles of family caregivers in pain management
- Physical care
 - Respiratory care, mouth care
 - Fluid and food intake
 - Bowel movements
 - Prevention and control of infection: hand washing, injury prevention, personal protection barrier and waste management
- Death counselling
 - Objective of death and dying counselling
 - Counselling skills: process and evaluation
 - Case studies and lessons learned
- Legal issues
 - Tips for will preparation
 - Debt management
 - Rights of people living with HIV
 - Case studies of legal issues
 - Questions and answers
- Empowering spirituality (power in crisis)
 - Power of life
 - Fears
 - Perfect love eradicates fear
 - Loss
 - Problems
 - Rejoicing and happiness
 - Power of religious practice

- After-death care
 - Care of the corpse
 - Funeral preparation and procedures
 - Social support and social resources for family

Home-based care

The ECI team partner leading this working group was CAM. The co-partners of the home-based care sub-project were the Faculty of Nursing at Chiang Mai University and the Upper North Network of People Living with HIV. One of the main priorities for this sub-project was to find ways to improve the quality of home-based care for people living with HIV. The ECI working group contributed to this effort in multiple ways.

Activities consisted of three major components: a training programme for community members who had volunteered to work on HIV care issues, development of home-based care guidelines and development of home-based care networks.

Training programme for community volunteers on HIV issues

The purpose of this activity was to enhance the skills of community volunteers in terms of home visits and comprehensive home-based care for people living with HIV. CAM and their co-partners designed a one-year training programme to develop people from the community as volunteers to deal with HIV care and support issues. The trainees included church members and people living with HIV. Among these trainees, seven community volunteers were from the ECI project. The training programme comprised two parts, namely, theory and field practice. In the first three months, the trainees were provided with relevant knowledge regarding HIV, opportunistic infections and treatment, ARVs and ART, home-based counselling, AIDS organizations and resources, home visiting and the concepts of home-based care. Several workshops were conducted as appropriate within a three-month period. In the last nine months of the programme, the volunteers were given training in field practice. They ran home visits with their mentors from CAM as well as by themselves. Case conference was used as a way of learning.

Development of home-based care guidelines

With more than 10 years experience, CAM is generally accepted as a pioneer organization providing home-based care for people living with HIV in the north of Thailand. Before the ECI Thai project, CAM already had a well-established home-based care programme. In order to expand the model of effective home-based care, the ECI project supported CAM to develop guidelines based on their experiences. Seminars and workshops were held in order to document and disseminate knowledge and experiences of the 15 CAM personnel. Experts were invited to help them synthesize the lessons they had learned and to develop practice guidelines that could be used by community volunteers and others doing work related to HIV care. The guidelines were tested by CAM's personnel and volunteers, and then were revised as recommended. Once developed, 1,000 copies were published in Thai and another 1,000 in English. These were distributed and used throughout the project.

Development of home-based care networks

Throughout the home-based care sub-project, community volunteers were trained on how to coordinate their efforts with those of the health care system, families, community leaders, as well as with other resources. The community volunteers were supported to join and learn with others, particularly in the sub-projects of empowerment of people living with HIV and community empowerment. The ECI working group introduced them to others in the care network in order to enhance their value as co-partners of the care team.

Empowerment of people living with HIV

The ECI Thai project aimed to create a learning process for self-reliance and to encourage participation of people living with HIV in the care system. The ECI team partner leading this working group was the Upper Northern People Living with HIV Network. Throughout the three-year project implementation, people living with HIV were encouraged to reflect on themselves, to identify their own strengths and weaknesses, to learn from best practices regarding self-reliance, and to find the ways to participate in the care system in order to improve the quality of life.

The work to empower people living with HIV consisted of five components:

- Promoting self-care ability;
- Promoting involvement in the health care system;
- Promoting involvement in home-based care;
- Promoting involvement in community empowerment activities; and
- Participating in project evaluation regarding human rights and quality of life.

Promoting self-care ability

A major accomplishment of the working group was the development of a training module that provided people living with HIV information on how to care for themselves in multiple ways. The three-day training course was held in August of 2001 for 40 participants in Doi Saket district and 50 participants in Phrao district. A large section of the training curriculum dealt with opportunistic infections. People living with HIV learned about what they could do to prevent different opportunistic infections and how they should deal with care and treatment measures that they developed.

The training curriculum also included information about how HIV works, how ARVs work, how they should deal with ART and about other topics of interest, such as how to provide support and education to other people living with HIV and to the community. The most important key to success in training was the emphasis on interactive participation, enjoyable activities, a learner-focused approach and the use of layman's language.

Promoting involvement in the health care system

As collaborators of all sub-projects in the ECI Thai project, people living with HIV were invited and encouraged to become involved in the health care system. In collaboration with the sub-project of improving health care institutions, they were provided opportunities to share information about their problems, needs and potential with health personnel, both in hospitals and health centres. Sharing and learning with the key partners was an important part of the strategy for changing their way of thinking and doing. At the ECI monthly meetings and community forums, people living with HIV were encouraged to summarize and report their lessons learned. Through these activities, people living with HIV could learn how to gather and analyse data that would help them develop more systematic thinking.

Promoting involvement in home-based care

The working group for home-based care was led by CAM. The most important co-partner of this sub-project was the Upper Northern People Living with HIV Network. The working group established the goal of getting HIV-positive people more involved in home-based care activities. As community volunteers, people living with HIV were invited to attend a training course for home-based care conducted by the CAM. They also were trained in conducting home visits by trainers or mentors from the CAM. This training complemented the knowledge and skills that people living with HIV gained from other ECI sub-projects, such as improving empowerment of people living with HIV, quality of health care institutions, end-of-life care and community empowerment. They were encouraged to use and practice home-based care and provide it to their friends. The working group held meetings and group discussions in order to draw from lessons they had learned together.

Promoting involvement in community empowerment activities

The working group on the empowerment of people living with HIV was closely affiliated with the community empowerment working group, whose activities are described below. HIV-positive members of the working group were encouraged to join and learn throughout the process of people research and development (PR&D). The goal of the PR&D process is to help people change their paradigm of development and productive living. Consequently, people living with HIV learned how to change their role from care recipients to care collaborators and care providers. Learning how to gather and analyse data was a way to help them think and work more systematically. People living with HIV had the opportunity to learn and practice income generation activities with the community, such as organic farming. They were provided opportunities to learn how to promote healthy habits, healthy food and a healthy environment for their community. They also participated in trainings in self-care practices such as Thai massage.

Participating in project evaluation regarding human rights and quality of life

Since the goals of the whole ECI Thai project were to improve human rights and quality of life among people living with HIV, they and their families were considered key informants. As such, they were requested to report their perceptions and opinions regarding those two key outcome indicators of the project. Focus group discussions as well as individual interviews were used for data collection before and after the project implementation.

Community empowerment

The ECI team partner leading this working group was the Faculty of Nursing of Chiang Mai University. The co-partners of this sub-project were AIDSNet, the Upper Northern People Living with HIV Network, CAM and CDC10.

The activities consisted of three components:

- Introduction to a new paradigm of community development;
- People research and development (PR&D); and
- Implementation of the people's projects.

Introduction to a new paradigm of community development

Community forums were conducted in all target subdistricts of the ECI project. The participants comprised community leaders, different community organizations, health personnel and people living with HIV. At these forums, special lectures about new paradigms – ways of thinking, ways of valuing and ways of doing – were presented by team experts in community empowerment. These activities aimed to enhance understanding of the new paradigm of community development and to understand how to participate in the ECI project. The contents of community empowerment focused on significance and relationships of local wisdom, human and natural resources, management, learning and self-reliance.

People research and development (PR&D)

The ultimate goal of community empowerment was to enhance community self-reliance and then to care for people living with or affected by HIV. The main purpose of this activity was to introduce PR&D as a process of community empowerment and to reach a consensus for each subdistrict on participation in the ECI project. The five steps of PR&D were as follows:

Step 1 – Community assessment

The first step aimed to help people in communities to know themselves and their community. In this step, participants identified and collected their baseline data, their resources, their assets, their property, and their economic and social capital and potential – e.g., human resources, natural resources, cultural/traditional care and local wisdom. Three to five representatives from each village were selected by community members to be their data collectors. The ECI team trained these data collectors. The data was analysed by the community members themselves, assisted by external resource persons with a deep understanding of the reality of the community. Their representatives presented the results of the community assessment to all members at the community forum.

Step 2 – Analysis of problems and related factors

The second step of PR&D aimed to examine community problems and their causes as well as factors related to them. In this step, the ECI team helped the people identify their problems, the causes of these problems and any current or past solutions. The problems discussed and analysed in the groups comprised financial problems, occupational problems, health and illness, environmental problems and so forth. Quality of life and human rights issues were included in the context of analysis.

Step 3 – Learning from best practice

The third step of PR&D aimed to help people in the target community gain more knowledge, experience, motivation and confidence regarding the possibility of sustainable community development. One hundred and thirty five representatives from target communities were provided with opportunities to visit a well-developed and successful community, familiarizing them with the learning processes and self-management used by that community.

Step 4 – Identifying potential

The fourth step focused on the process of self-reflection to summarize the community's potential. Based on the knowledge and experiences gathered throughout the first three steps of the PR&D process, the community participants were expected to gain more self-understanding in terms of their social capital and potential for development. This part of the process aimed at promoting self-recognition, self-realization, motivation and self-confidence among community members and leaders. It was the preparatory step to strategic plan development.

Step 5 – Community strategic plan/programme development

This final step aimed at developing the strategic plan of each subdistrict. These strategic plans focused on what the villagers would like to accomplish or had to accomplish, not what they would like to have or to receive. Community members realized that they could start projects or interventions with their existing capital, as it was much more than they thought, and external assistance could complement what they had within their community.

Implementation of the people's projects

While the aim of introducing PR&D was to help local people become less dependent on outside support, the ECI Thai team helped in the early stages of three projects developed by the community: organic farming, education on health promotion and Thai massage training. Other projects, such as traditional medicines, the rice mill project and the golden garbage project evolved without direct ECI support. This expansion of the people's project demonstrated the ongoing learning process and potential for the community development that people gained through the process of PR&D. Details of the people's projects are as follows:

■ Organic farming project

ECI provided financial support for 12 community members to participate in a "training-of-trainers" programme, which enabled them to spend 10 days learning about organic farming from outside experts. They then served as trainers for other members of the community who wanted to learn organic farming techniques.

■ Health promotion education

ECI organized a number of community forums where people could learn about health issues such as those relating to food and the environment.

■ Thai massage training

ECI organized courses in Thai massage and issued certification to 24 people who completed the course. Many of these people subsequently use their new skills to treat the muscular aches and joint pains of family members, with the result that those family members were able to decrease their use of pain medication. Some people also used their new skills to earn money by providing Thai massage to other community members. Some members of the original group of people trained have gone on to train others, making this a self-sustaining resource in their communities.

■ Traditional medicine project

This came from identifying the potential of people during the PR&D process in the target areas. They identified ways to use herbal medicines based on local wisdom and past traditions to treat specific diseases and symptoms as well as to care for people's health. The use of herbal medicines relates to the daily life of communities, such as pain relief from manual labour and common illness among villagers. As a result of these activities, health expenses have been reduced and self-care knowledge and skills have been passed to the next generation.

■ Rice mill project

From the analysis of problems in Phatum subdistrict, the poorest village in Phrao district, one common problem among people is that they do not have enough rice for family consumption. In discussions to identify ways out of this crisis, they agreed to establish a small rice mill through co-investment from the villagers. This resulted in people having enough good quality rice at a reasonable price. Now, Phatum subdistrict has established another mid-sized rice mill to serve its population. This helps in supporting the economic status of the community.

Human rights

The ECI team partner leading this working group was the Faculty of Nursing of Chiang Mai University. Human rights were considered a cross-cutting area of the whole project. This sub-project was conducted to evaluate the situation before and after ECI implementation.

The activities consisted of situational analyses regarding human rights before, during and after ECI implementation.

Situational analysis regarding human rights before ECI implementation

The objective of the analysis was to assess the human rights aspects of HIV care in the target areas before implementation of the ECI project. Data was collected in July and August 2000. There were 136 participants in the study, comprising 34 people living with HIV, 16 family members of people living with HIV, 35 community leaders and neighbours, and 51 health care personnel. Data collection came from individual interviews and group discussions. Content analysis was used to summarize the results in terms of human rights in HIV care.

Situational analysis regarding the human rights aspects of ECI implementation

This analysis was conducted by the human rights working group throughout the implementation phase in order to assess and synthesize the strategies that were used by all sub-projects in terms of promoting human rights. Data was gathered in multiple ways: 1) participatory observation in ECI activities; 2) individual participant interviews; 3) group discussions; and 4) reviews of the ECI monthly reports. Data was analysed and categorized by the working group.

Situational analysis regarding human rights after ECI implementation

The same methods as those that were used to study the human rights situation before ECI implementation were used to assess the situation after implementation. Data was collected from November to December 2002. There were 107 participants, comprising 31 people living with HIV, 18 family members of people living with HIV, 42 community leaders and neighbours and 16 health personnel. The data was analysed for its content and then compared with the data gathered before implementation. Confounding factors during the study were discussed.

Quality of life of people living with HIV and people affected by HIV

The ECI team partners leading this working group were the Faculty of Nursing at Chiang Mai University and AIDSNet. The central activity was quantitative and qualitative research on quality of life. As with the sub-project of human rights, the sub-project of quality of life aimed at evaluation of the whole ECI project.

The working group conducted a study that had two objectives: 1) to develop an indicator for measuring the effectiveness of the Thai ECI team's work; and 2) to investigate how people living with HIV and HIV-affected people in northern Thailand perceive the quality of their lives. In the first stage of the study, researchers used multiple methods to better understand the elements of quality of life. These approaches included consultation with key informants and focus group discussions, as well as a review of other quality-of-life research in the HIV field. The researchers drew on their findings to develop a questionnaire for use in the study's second and third stages. The content of the questionnaire encompassed physical, mental, social and spiritual well-being.

During the second stage, 64 people living with HIV and 55 family members of people living with HIV responded to the questionnaire. This data helped the full ECI team decide on its priorities and also provided the baseline for a quantitative assessment of the team's effectiveness. During the third stage, after the Thai ECI team had concluded its work in the field, the same questionnaire was given to 55 people living with HIV and 37 family members of people living with HIV, and the results were then compared to the baseline data.

One limitation of the study is that not all of the subjects providing the baseline data were the same subjects who provided the later data. Another limitation is that not all subjects were from the geographical areas that ECI targeted. Nonetheless, the results still helped the Thai ECI team gain insight into the effectiveness of its activities. An overall conclusion was that physical health is only one component of how people assess the quality of their lives, which means that it is important to address other issues such as employment and social acceptance.

Phase IV – Evaluation

In order to evaluate the project outcomes, multiple methods were used. The target population that participated in the project evaluation process included people living with HIV and their families, community leaders, health care personnel and community volunteers. The evaluation process included both process evaluation and outcome evaluation.

The methods included the following:

- Individual interviews;
- Group discussions;
- Community forums;
- Questionnaires; and
- Reviews of project reports.

The objectives of the ECI project were attained through interrelated sub-projects, including improving service quality in health care institutions, empowerment of people living with HIV, end-of-life care and home-based care. All those sub-projects had the same ultimate goals of improving the quality of health care for people living with HIV, improving the quality of life among people living with HIV, promoting human rights for people living with HIV and affected families, and establishing a care network for people living with HIV.

Improved quality of health care for people living with HIV

Improved care system in health care institutions

The ECI team worked in partnership with the hospital personnel by supporting and facilitating the opportunity for health care personnel to discover themselves, their strengths, weaknesses and their potential to plan for intervention to improve quality care service. The ECI project facilitated opportunities that brought together all stakeholders in HIV care, including hospital personnel, health centre personnel, representatives of people living with HIV, community volunteers and a home-based care team to share experiences, needs and options. After implementing the work plan for more than two years, the results revealed significant changes in the health care system as follows:

A new system of care service in hospitals

People living with HIV were accepted to be part of the care service and were involved in providing care in health care institutions to other people living with HIV, including counselling for ART, for opportunistic infection treatment and for how to deal with HIV-related situations.

Better support and welfare for the HIV support group

Hospital administrators provided space in the hospital to the HIV support group to use as an office. This assisted them in their work and in conducting group activities such as group support and counselling.

Fast-track health services for people living with HIV

Hospital personnel established a fast-track service for people living with HIV at the hospital. This reduced waiting time, stress and the anxiety of both people living with HIV and health care providers. These particular development processes facilitated the readiness of ART service for people living with HIV at the hospital.

Better standard of ART and opportunistic infection treatment and care

This quality of health care was attained by introducing a well-developed standard of treatment and a standard of universal practice among health care providers. These protocols were distributed to health care settings and their effectiveness was addressed among health care personnel at several meetings.

Improved quality of counselling and end-of-life care

Health personnel who participated in training on death and dying counselling reported good practice in providing care to dying patients. Most of the participants reported that the booklets on end-of-life care could be used effectively in real practice. In addition, as the policy maker, CDC10 proposed that this aspect of care be added into the national policy on AIDS care. This agenda was approved in the nation's Ninth Health Development Plan.

Improved quality of home and community care

Better quality of home and community care for people living with HIV and affected people could be attained through sub-projects involving empowerment of people living with HIV, end-of-life care, home-based care and community empowerment. Project participants reported the following results:

Improved ability in self-care and self-reliance among people living with HIV

People living with HIV who participated in the ECI project reported that they gained more knowledge and skills in self-care as well as in providing care for others in terms of ART and opportunistic infection treatment. Participants who were living with HIV also gained experience and learned from other sub-projects, especially home-based care, end-of-life care and community empowerment.

Improved quality of home-based care

Health personnel at health centres in the six subdistricts who participated in the end-of life care training programme reported that they could provide better care for their clients. HIV community volunteers who were trained by the ECI working group were able to provide quality care to people with an HIV-related illness at home. They could also work together with other care providers in the community and could refer patients more effectively to hospitals. People living with HIV who participated in the care system at the hospitals reported that their confidence and abilities to provide care for their friends at home have improved.

Improved understanding and social acceptance for people living with HIV

After participation in the process of PR&D of the community empowerment sub-project, most people living in target communities reported that they had changed their attitudes towards people living with HIV. Many community leaders began to provide opportunities to people living with HIV to join in community activities and to be members of village committees. Participants of the community empowerment sub-project who had received training in organic farming took up farming in their villages. Some people living with HIV have learned from them and have started their own organic farms. This has resulted in an increase in their income, which has helped them gain more social acceptance.

Improved quality of life of people living with HIV and their families

Quality of health and performance

This includes health conditions, health care, longevity, management of family responsibilities, control of life, self-reliance, not being a burden on the family and society, and sexual life. Most family members were more aware of their health care and have engaged in health-related activities, such as exercise, education on health care, herbal medicine, and Thai massage.

Quality of social and economic conditions

People living with HIV had opportunities to join group activities so that they could share experiences and learn from each other. They became more involved in their care networks and were able to join in community activities such as organic farming and other income-generating activities. Quantitative data showed that the mean score of the quality of social and economic conditions was much higher in all aspects after the project. This included acceptance from friends and neighbours, assistance from people outside the family, spiritual support, friendship and engaging in social activities. From the group meeting, most family members reported that participation in Thai massage training and herbal medicines helped them gain knowledge and skills. Some of them could use these skills to earn their family an income.

Quality of psychological and spiritual conditions

From the group discussions, it was revealed that most people living with HIV became more self-accepting, have developed self-empowerment and goal-setting, and are becoming more stable and less worried. Consequently, they can live a normal life with HIV in productive ways. Being trained as care providers and counsellors has made them gain more self-confidence and increased their self-esteem. The mean score on the quality of psychological and spiritual conditions was much higher in all aspects after the project. This included less worries, more self-confidence, higher quality of life, hope, success and security in life.

Quality of family life

From the group discussions, most people living with HIV emphasized the importance of family in their quality of life. The mean score of the quality of family life was much higher in all aspects after the project, such as family health, partners/spouses, family happiness, assistance from people outside the family and support from the family members.

Improved human rights

In addition to quality of life, the results of the study revealed better situations regarding human rights aspects of HIV in the target areas. Data gathered before and after ECI implementation through group discussions and individual interviews among people living with HIV, their families and their neighbours, community leaders and health personnel indicated that most of them are satisfied with their participation in the ECI project in terms of human rights promotion. The human rights that have improved through the process of the ECI project can be categorized as follows:

Stigma and discrimination

Comparisons of data collected before and after ECI implementation revealed that most people living with HIV and their families reported better situations regarding stigma, discrimination and inequality in the areas of health care, employment, education, living and social acceptance.

Rights to health

People living with HIV reported that throughout the ECI project implementation they were ensured equal and adequate access to health care in terms of ART, prevention and treatment of opportunistic infections, and nursing care provided by health care institutions. Most participants reported that ECI helped people in the community to be more concerned about health for all members of their community, no matter what their HIV status. In the process of PR&D, each subdistrict established a master plan for community development. Healthy food and healthy environment were among the plan's goals. As a result, people began to learn about organic farming.

Rights to human dignity

People living with HIV and other participants indicated that through the ECI process, especially PR&D, they had opportunities to increase self-development and self-reliance, resulting in an increase in self-confidence. Most of them reported that they could improve their ability to promote productive living. They could take better care of themselves as well as provide care and counselling for their friends. They turned out to be an important part of care in the health care setting, which made them feel that doctors and nurses trusted them. Many people living with HIV reported increased self-value and dignity.

Strengthened networks of care and support for people living with HIV

One objective of the ECI project was to strengthen networks of care and support for people living with HIV and affected persons. ECI Thai is comprised of local experts and people who formed care teams in communities and health-care settings in the two districts of Chiang Mai province. The multisectoral care network set up by the ECI includes resources from government agencies, academic institutions, NGOs and people living with HIV.

Throughout the five-year project, good relationships across sectors developed. According to the ECI work plan, every sector had opportunities to engage in all activities of the project through their representatives. All members were able to get to know each other and work together. They learned how to pool diverse capabilities, which helped them achieve their mutual goals through coordinating HIV care activities across the various sectors.

In the last two years of the ECI project, collaboration across the sectors could be seen increasingly in terms of sharing resources and information. Expertise of each sector came to be recognized by others. Collaboration in HIV activities beyond the ECI work plan have been conducted more often among ECI organizations. In addition, the word 'ECI' has become well-known among other HIV-related organizations and groups as a major multidisciplinary HIV care network. This phenomenon enhanced a more effective referral system so that comprehensive care for people living with HIV could be met.

Lessons learned and implications

This five-year project was completed with the commitment, dedication, cooperation and mutual trust of ECI team members and involved persons. After two years, the project expanded to eight subdistricts from three. The communities in Phrao today identify their future through involvement in all sectors. They are able to develop their own community lifestyle, education, process of sharing and self-confidence.

Many lessons have been shared and learned among the team, including lessons on multisectoral and multi-disciplinary collaboration, empowering people and communities, enhancing sustainable development and promoting human rights. For the ECI Thai team, multisectoral collaboration meant cooperation between different organizations in setting mutual goals, sharing information and resources, and then working together in order to meet those common goals. This was based on the assumption that HIV work does not start from zero. All sectors, including government, non-government, groups or networks for people living with HIV and the community have their own unique experiences in HIV work. They also have their own strengths and weaknesses in achieving their goals. Closer collaboration with other partners could help a particular organization find new ways of thinking and working and in improving their capacities to achieve the maximum impact.

Multi-disciplinary collaboration means working together across disciplines. This means cooperation between people from a wide range of disciplines or areas of study, such as medical doctors, nurses, health-associated personnel, social workers, academics, psychiatrists, religious leaders and so forth. Working together among disciplines can help people living with HIV deal with their complicated problems.

From the beginning of the project, the ECI Thai team recognized the trend towards and potential of multisectoral and multi-disciplinary work on HIV-related problems. The agreement among the team was a commitment to establish a comprehensive care system for people living with HIV in the north of Thailand. To compose a multi-sectoral team, government, non-government, community and HIV support groups were considered and included. A wide range of people from several disciplines such as academics, doctors, nurses, health personnel, social workers, psychological counsellors, religious leaders, traditional healers and people living with HIV were involved in the running of the project.

Lessons learned throughout the project regarding multisectoral and multi-disciplinary collaboration can be summarized as below:

1. Multisectoral and multi-disciplinary approaches and integration of knowledge and experiences are important for working together.
2. Empowering people by raising their self-esteem through participation and restoring relationships results in bringing people together and establishing harmony.
3. New ideas, new ways of thinking and positive attitudes towards each other help to improve self-management. This is supported by the application of local wisdom, collaboration with community resources, a pleasant work atmosphere and mutual understanding. This helps all activities to be self-reliant and sustainable.
4. The community preparation process needs time to shift the thinking paradigm of the people.
5. Partnerships and continuous sharing of knowledge are also key factors contributing to the success.
6. The indicators for success are attitudes, care systems and sustainability.
7. Farming alternatives (e.g. bio-fertilizer) and self-reliance can be used as common approaches in an agricultural community.
8. Three qualities are necessary to establish a strong community: a) a learning community that wishes to know how to empower itself and be self-reliant; b) independence in decision-making; and c) efficient budget management.

Key points

- Projects can be very effective when they involve people living with HIV, their families, community organizations, NGOs, faith-based organizations and research teams in a participatory research and development process and in capacity-building learning forums held within and outside of the community.
- Capacity-building among people living with HIV on holistic health care, self-care and prevention of opportunistic infections empowers people living with HIV to be key persons in providing knowledge to their peers and people in the community.
- Activities carried out by using community resources and potential as well as local wisdom ensure sustainability.
- Empowering people living with HIV and their communities is the key approach to the success of community-based care.
- A home-based care system must be flexible in ways that can be modified to meet the needs and contexts of each community and should cover physical, mental, social and spiritual aspects.

Accepting our Differences: Working with Marginalized Populations

7

If there is any truism in HIV work, it is that not every effort is effective with every target population. This is especially true for people who may be or feel marginalized from what is considered the majority of society in some way.

When dealing with HIV issues in Thailand, people may be considered marginalized for a wide variety of reasons. They may be at risk from HIV because they put themselves in risky situations, such as injecting drug use. Mainstream efforts on HIV may not reach other people because they are from a different culture and may not speak Thai well enough to feel comfortable receiving information on HIV and reproductive health issues in Thai. In other situations, such as those for men who have sex with men (MSM), there may be stigma widely associated with their situations, and they may not feel comfortable receiving information on or disclosing their situation in most circumstances.

Marginalized populations are often stigmatized in some way by parts of society, and in some cases their economic circumstances may be more difficult because of that marginalization. In some cases, there may be legal issues that complicate their ability to fully access HIV prevention and care services. Each population, however, has its own specific set of issues and its own culture that needs to be addressed. Projects working with marginalized populations usually include members of the target population in the development team. This team conceptualizes and implements activities and often uses peer outreach techniques to ensure that messages are accepted.

Below are examples of projects that work with members of three different marginalized populations in the upper north of Thailand: hill tribe people, MSM and female sex workers.

Addressing differences in languages and cultures

The six upper north provinces of Thailand are home to a large number of hill tribe groups: Akha, Karen, Shan, Lahu, Lisu and other hill tribes live in the mountainous areas that characterize the borders between Thailand, Lao PDR and Myanmar. The hill tribes make up a considerable percentage of the population: over 13 percent of people in Chiang Rai province are classified as members of hill tribes.

These groups do not use Thai as their first language, and their cultural constructs are often different than those of many Thai people. Each group has its own historical, religious culture and way of conceiving a person's role within society. A hill tribe may have a different way of conceptualizing how disease develops and spreads. Each society may have a different understanding of who is the best person to deliver health messages to a particular individual in that society.

The hill tribes are faced with many unique challenges. Many of the hill tribes have members not only in Thailand but also in Myanmar, Lao PDR or China. Many hill tribe people from Thailand live in remote areas with relatively limited transportation routes, making outreach and access to services difficult. As many as 400,000 hill tribe people who are originally from Thailand are without full citizenship. While moves are underway to ensure that all who should have Thai citizenship are granted full rights, their current status limits access to some services. In addition, some members of these hill tribes who originally came from Myanmar, Lao PDR or China have migrated to Thailand recently and are not eligible for citizenship, thus complicating the picture.



MPlus has worked with local pharmacies to offer medicines and other services to transgender and MSM populations in a non-discriminatory environment. Participating pharmacies display the MPlus sign in their windows.

If they lack full citizenship, Thai hill tribe people may face many difficult situations that limit their life choices. Without citizenship, travel is restricted to certain areas, hill tribe children can go to school but cannot receive a high school diploma, and access to good jobs and further education is difficult. Finally, this lack of citizenship means that hill tribe people may not always have access to all necessary medical facilities unless they pay for them. "The impact of HIV on hill tribes is worse than on others because they don't have the same access or security," said Mr. Prasaeng Na Kiri, Secretary of the Thai-Lahu Foundation. "People in the cities have facilities that aren't provided up in the hills, particularly the access to health care treatment."

While hill tribe peoples lived in relative isolation before, their cultures are changing quickly. Modern life has meant that many young hill tribe people travel to larger towns in search of work, where they may be at risk from exploitation because of their lack of proper documentation. The culture their parents grew up in will not be the culture of their future.

"Many aspects of the current situation affect HIV, such as drug issues. Migration, economics and cultural change are all weaved into HIV and AIDS. The old culture is fading so younger people don't understand the strengths of the old culture and don't understand what is good and bad in the current culture for them," said Mr. Prasaeng Na Kiri.

Information is key

For many hill tribe people, receiving information on HIV in their own languages is critical. However, there is still limited information in many of the hill tribe tongues. "The response has to address all the cultures in the region in which you are working," said Mr. Lawrence Maund of the Sangha Metta project. "The cultures are very different." He noted that he had held a training which 17 people attended, but they represented five different ethnic groups.

Mr. Maund noted that each hill tribe faces a different situation in relation to the provision of information. "You can't just do publications in one language. Documents have to be translated and adapted appropriately for each language and, equally important, distributed. There are a lot of documents in Shan now. There are documents on self-care and community-based care. But there are many other groups which still need information in their own languages."

While a strategy is always needed to disseminate printed documents and other materials like DVDs, tape cassettes and VCDs, one relatively low cost but effective way to get information to hill tribe people is via radio soap operas in their own languages. Radio Thailand Chiang Mai started broadcasting in 1968 to hill tribes such as Akha, Lahu, Lisu, Hmong, Yao, Shan and Karen in their own languages. They have developed soap operas that focus on HIV, human trafficking, unsafe migration and drug issues in Akha, Lahu and Shan. As part of a holistic approach to community problems, the radio station also does outreach in all the eight hill tribe languages in which it broadcasts on birth registration and citizenship. If hill tribe people possess appropriate identification and citizenship, they can access HIV services much more easily and are much less at risk of potential exploitation.

"There is a need to broadcast programmes in hill tribe languages since most hill tribe people still have some difficulties in understanding Thai or other languages. Information on HIV/AIDS, trafficking, citizenship, drugs, etc. can be easily passed on air in minority languages. Radio Thailand Chiang Mai plays a key role in helping the hill tribes to be updated. It's important for the hill tribes to have rights and access to necessary information, so Radio Thailand Chiang Mai sees the need for broadcasting our programmes in the hill tribe languages," said Khun Somjai Sasomsarp of Radio Chiang Mai.

Each script is unique. The soap operas had a different plot and set of characters in each hill tribe language. All the soap operas were developed for each group by writers from that group. They developed scripts in their own language that were appropriate to that group's culture and needs and created characters and situations with which members of the tribe could identify. The scripts also had to address what traditional aspects of each culture supported work on HIV and what traditional aspects might be seen as risk behaviours. "Some of the old culture has aspects which would increase HIV risk, such as multiple partners in young people. Now that's a risky behaviour," said Mr. Prasaeng of the Thai-Lahu Foundation. "However, a positive input from the culture is that each helps support the other. If that can be promoted more, it would help in all health issues, not just HIV."

A group of professional Shan writer put together the initial Shan script, while Lahu members from the New Life Center developed the Lahu story and the Akha Creative Group penned the Akha script. Each script went through testing and revisions before it was produced. Younger hill tribe people were key in developing the stories, since young men and women are whom health workers like Mr. Prasaeng are most concerned about: "There are many cases of young girls moving to the city and getting jobs in 'entertainment'. They become HIV-positive and move home and marry without telling people that they are HIV-positive. If both partners die, there are orphans and there are many cases like this."

As with every culture, younger hill tribe people also know how to address their peers best. "It is better to have the story to be written by younger people in case we want to draw attention from younger listeners – this may make the story somehow vivid and up-to-date," said Khun Somjai Sasomsarp of Radio Chiang Mai. "Also it is good to have the story reviewed by people from the hill tribes themselves since they know their culture and they can tell about their lives better."

Radio Chiang Mai used the UNESCO methodology for minority language HIV prevention radio drama to develop the scripts. The methodology has nine key steps:

1. All programmes are research-based.
2. Focus groups are held with villagers to collect life stories, issues and concerns. These form the basis for the radio dramas, allowing increased audience identification.
3. All programmes use drama as the format. Drama has been found to be the most effective vehicle for reaching young people among these groups, who are frequently unresponsive to participatory social assessments or didactic programmes.
4. Programmes are written in the local languages by native speakers rather than simply translated from English or the national language. This is essential if they are to be culturally as well as linguistically acceptable to the audience.
5. Local musicians compose traditional and contemporary local music and songs that underline themes of the shows. A theme song is composed for each series, which is tested for popularity with local audiences. Locally recorded folk music is also used.
6. The programmes are translated into English and the national language to check for scientific accuracy.
7. A pilot programme is tested with villagers; revisions are made as necessary.

8. The programmes are broadcast on radio stations with an existing capacity for minority language programming and that are already listened to and trusted by highland people.
9. Follow-up audience research is conducted in villages, and the radio stations collect audience feedback. Various creative formats can be used to promote engagement with the radio audience, including quiz shows and call-in programmes.

Taped cassettes of the programmes were distributed by NGOs after the programmes were broadcasted. Radio Chiang Mai is continuing to develop radio soap operas in other hill tribe languages that integrate HIV issues into the story. The successes of the programmes were attributed in part to the following reasons:

- The content of the programme is based on real stories.
- The local language is used throughout the process.
- Professionals are selected at each level: research is undertaken by professional researchers with high levels of linguistic and cultural competence, and radio programmes are produced by radio professionals.
- Follow-up and audience research help to improve the next phases of the ongoing radio project.

Organizations dedicated to hill tribe issues also work in the villages on peer outreach for HIV information, taking advantage of the social structures and culture of each hill tribe. For instance, in 30 Lahu villages, the Thai-Lahu Foundation has a network of volunteers on HIV and other issues. At funerals they create informal group discussions on HIV issues.

“Funerals involve the whole community and last a couple nights before the burial. It’s a time everyone in the village comes together. They just start an information discussion of HIV issues. People tend to be more open to discussing death and HIV, discussing this in relation to the life of the person who has passed away,” said Mr. Prasaeng. “They’ll open up more like this at any funeral, but it’s especially effective when the person has died due to an HIV-related illness. We also have these information discussions at New Years and at the Lahu celebration for the end of the harvest season. For children, we may talk on Sunday afternoon.”

Part of many hill tribe cultures has been traditional opium use. In the years since the eradication of opium in Thailand, heroin use has become more of an issue in hill tribe villages. Hill tribe organizations also address HIV issues in relation to injecting drug use. Said Mr. Prasaeng, “We have ex-injecting drug users as volunteers, and there is another network of former Lahu drug users that work with the Lahu Foundation. They set up rehabilitation centres in Doi Saket, Chiang Rai and Mae Ai. Some former addicts serve on the village committee, especially on drugs and HIV. It’s important to integrate into the community. Everyone is involved in the issue and no one should just be seen as a ‘target’, but rather as part of the solution.”

Distance affects care and support issues

Because of the amount of internal migration by young members of hill tribes and the distance and difficulty which many hill tribe people face in accessing services, hill tribe people may face care and support difficulties. Lack of knowledge and lack of easy transportation are often problems. Organizations which specialize in hill tribe issues try to pass knowledge onto villagers and local health care workers in order to facilitate care and support. “Staff at the foundation must take a course in taking care of HIV-positive people,” said Mr. Prasaeng. “Staff members learn skills to teach families for home care and they collaborate with community health centres. Together they work with the health centre to train the Lahu health volunteers. They usually start from a low level of knowledge. One real issue is travelling, since it’s difficult to travel to some sites, especially in rainy season.”

For hill tribe people who migrate to other areas, language problems impact care and support. “Communication is a major problem. Hill tribe people do not understand Thai perfectly and the medical personnel don’t understand their Thai,” said Mr. Prasaeng.

Hill tribe people who have migrated often do not have relatives or strong support systems in the places to which they have migrated. Thai organizations that work on HIV issues may help by providing care and support services for hill tribe people who do not have a support structure in place.



Members of Friends for a New Life and Violet Home who are members of ethnic communities perform traditional dances at festivals and other gatherings to promote HIV prevention and acceptance messages.

“We have a homestay boarding area for HIV-positive and displaced women who don’t have anyone to take care of them. Most of them are hill tribe women or migrants,” said Ms. Pimjai Inthamoon, Project Administrator & Coordinator

of the Community Health Project in Mae Rim. “It also serves as rehabilitation in that they have a chance to learn vocational skills. Besides training on HIV, we also talk about rights, logging and nationality issues. The women are sometimes referred by hospitals or partner organizations. They include Burmese, Lahu, Akha, Kachin, Pakakyaw and Shan.”

The Community Health Project uses the women’s stay as an opportunity to train them on HIV issues. “Eventually many will serve as volunteers for their communities on HIV issues. One even trained enough to go back into a displaced camp on the Burmese side and volunteer as an assistant nurse,” said Ms. Pimjai.

The care and support activities of the Community Health Project, however, are not limited to work in Mae Rim. They also address the needs of the women in their home villages and the needs of their families. “The minimum stay for women is three months, but most stay longer. We also go and talk with their families. They come from everywhere – east, west, north, south. The most memorable case was from Mae Sariang. We had to walk 38 kilometres on foot to get to the village. She had been gone for five years before she went back to be a volunteer there. We went back three times, walking in each time. It took a whole day, from dawn, to walk 38 kilometres,” said Ms. Pimjai.

Ms. Pimjai continued, “Usually I go for at least three visits. If you only go once, the person living with HIV feels uncomfortable going back home immediately. If you go three times it provides room to adjust. That doesn’t mean it’s always successful.”

“If it’s not too far I ask my mother to come. It makes the other family more comfortable. I want to promote the concept of family to family, helping each other.

The families do not know the women are HIV-positive. Often they don’t know what HIV is and how to take care of HIV-positive people. They also may have discrimination within themselves.”

Men who have sex with men

The term “men who have sex with men” covers a variety of individuals: men who define themselves as gay, transgendered individuals, male sex workers and men who have sex with other men but yet define themselves as heterosexual. In 2005, the HIV prevalence rate in men who have sex with men who were not transgendered or sex workers was found to be 15.4 percent, while transgenders registered a 17.6 percent prevalence and male sex workers, 11.4 percent. HIV prevalence was especially high for MSM who were between the ages of 15 and 22.

MSM often face a number of barriers to adequate HIV information and services. In Thai society, MSM often feel they cannot disclose themselves for fear of stigma and discrimination. Some MSM do not actually think of what they do with men as sex. Medical personnel may have stigmatizing attitudes of which they are not aware, and most general HIV prevention materials do not discuss issues that are specific to MSM. Because of discrimination, many MSM can be difficult to reach with interventions.

Two efforts to address the issues of MSM in Chiang Mai

Mplus+

The NGO MPlus+ was started in 2004 to address the needs of MSM in Chiang Mai. An organization composed primarily of volunteers, one of their first activities was to survey both gay and straight men and their attitudes and needs on sexual health issues. The NGO soon found that the survey was more challenging than had been predicted.

“The whole subject is very sensitive and it was difficult to find out where gay men congregated,” said Mr. Phongthorn Chanlearn, a project manager with Mplus+. “It’s easy to find male sex workers, but not general MSM. We tried areas where they would cruise. We tried to find the gatekeepers. In some areas there is a godmother or godfather for the sex workers. In one area, one side is for transgenders and the other is for male sex workers, but they have a good relationship. They support each other. In that area there are “godmothers,” transgenders who have a lot of experience. There is also a good relationship with the female sex workers in the area.”

The project found that male sex workers were easier to access, especially if MPlus+ could make good relationships with the bar owners. However, many MSM did not frequent bars and, instead, met each other in different venues. “We tried to map meeting areas. Usually they are public places like parks. Our volunteers are part of the community already. We recruit from our target group. Several nights a week we have activities; we try to create games which deliver basic information and entertainment at the same time. We try to promote safer sex. It’s easy in the bar; most are concerned about their health and they already have some awareness of the issues.”

The project also found that creating interventions was more difficult than anticipated, because the target audience defined themselves differently than had been thought. “In the beginning of our work, our staff had very little experience in the gay community,” said Mr. Phongthorn. “We created our own activities and practiced with the targets, but we didn’t work in gay bars because most of our targets said, ‘I’m not gay; I’m a straight man. We need sex education in general. It’s not just a gay issue.’”

MPlus+ learned from the feedback and started again. In their next effort they especially invited ‘money boys’ – freelance sex workers more likely to be found in parks than bars – in order to help create a curriculum appropriate to them. Together they created curricula with specific information on HIV and STIs. They also invited representatives of the transgender community and community of MSM who were not sex workers to help create curricula.

Transgenders – individuals who were born biological males but who identify themselves as females – had their own special set of issues. “In the beginning we didn’t include transgenders,” said Mr. Phongthorn. “It’s a rather sensitive issue. When we talk about HIV and STIs among transgenders, they say it’s a male and female issue; they’re not concerned. They say it’s not an issue for transgenders, yet they have the highest prevalence. But many are interested in issues such as taking hormones to change their body, so we integrate information on HIV and sexually transmitted infections into training on body building and hormones. Now most understand they need condoms, but we still find that they don’t use them. For many it’s an economic issue. Many of the transgenders are very poor and have little education.”

In Chiang Mai, the project found that about half of the male sex workers are members of minority groups. Economic and legal issues may have been reason to lead them into a profession with more HIV risk associated with it. Said Mr. Phongthorn, "Many are hill tribe or migrant and have no identity card or no nationality. Half are Thai. The hill tribes and migrants are considered 'dark, tall and handsome'. Many cannot speak Thai. Economics are the main reason many jump into the career. We've found that 80 percent of male sex workers consider themselves straight."

"We have hill tribe and Burmese volunteers in the bars but not among the money boys, the freelancers in the parks. It takes time to gain trust. In the gay bars, most are over 18. In the public parks, you'll find money boys 13 years or younger. Many of the money boys use glue, too, those who work outside. When they have sex they are not concerned about safe sex; they are only concerned about the money," explained Mr. Phongthorn. The project cannot provide services to those who are under 18, so it refers them to the Thai Volunteer Network for Child Development.

The project initially tried to work on male sexual health with all audiences. They made a special effort to talk to students about male sexual health but found that talking about sex between men was very sensitive in schools and universities. Some teachers didn't want the project on campus if Mplus+ talked about issues that involved men having sex with men. The project solved this issue by going to the administrative level and explaining the need.

"I learned that to create a curriculum we had to include stakeholders and decision makers. We invited teachers from the schools and universities and had them help us make the curricula," explained Mr. Phongthorn.

Mplus+ also tried to address stigma and discrimination issues in the medical community. "Many doctors and nurses have negative attitudes toward gays. When an MSM would go to the clinic or hospital sometimes the personnel would ask, 'Why are you gay? Why are you having anal sex?' In truth, most are just interested, but they don't know they are being insensitive," said Mr. Phongthorn. Mplus+ then worked with the CDC10 and the Chiang Mai Ministry of Public Health to talk with doctors and nurses about the male-to-male sex issues and sensitivities. The local head of the CDC also agreed to work as a doctor in the Mplus+ clinic. "His presence is advocacy to the rest of the community," said Mr. Phongthorn.

The Mplus+ clinic has one doctor and four technicians to provide clinical support. Having learned the lessons from their first efforts to address the community they served, they first asked the target audience if they would prefer a gay or non-gay doctor. Explained Mr. Phongthorn, "Most said it didn't matter whether they were gay or not gay, we shouldn't have to disclose ourselves. So most of our doctors are straight. Both gay and straight are comfortable."

Violet Home

Violet Home was founded three years ago as an offshoot of the New Life Friends Association, one of the oldest self-help groups in Chiang Mai for people living with HIV. The mission of Violet Home is to improve the quality of life of MSM and transgenders who are living with HIV by helping them access prevention and treatment services and helping to reduce stigma and discrimination against them.

Founder Samran Tagun had noticed that he was seeing more and more MSM and transgenders in Chiang Mai and wondered about the HIV knowledge. Realizing that these groups needed to know more about HIV and STIs, the Violet Home staff instigated a project to develop peer educators among MSM.

"We started with the objective of training 270 hotel workers from five-star hotels," said Mr. Samran. "We thought by concentrating on male hotel workers we could reach MSM, but not explicitly. We figured 60 percent of the male hotel workers we targeted were MSM, both those who identified themselves as gay and those who didn't. By including all the male workers, we didn't stigmatize. We contacted the HR departments and told them our objectives. We asked to train 50 percent of the staff, and HR would choose the individuals. In the end we trained over 900 male workers and ended up with over 1,000 volunteers. That's because they would tell their friends about the training. The volunteers came from all sorts of industries."

The success of this project made the staff of Violet Home wonder if they could successfully meet all the needs of their constituency. Each group and age had different issues about which they were concerned. One thing they found was that HIV-positive MSM felt uncomfortable with health activities that were for a mixed group that included both positive and negative members, so Violet Home's focus shifted to those who were HIV-positive. "We will never leave you," became the Home's motto.

"Most men who have sex with men in Chiang Mai are from other provinces," said Mr. Samran. "When they get sick and are admitted to the hospital, often they feel they can't tell their family that they are HIV-positive. They don't have anyone to help take care of them when they go back to their apartment. We try to help with that."

Violet Home provides counselling on the telephone and in outreach: they have home visits and home care and a referral service. Often HIV-positive MSM who are wealthy or in good positions don't want to reveal themselves, but they want counselling over the phone, and Violet Home provides that.

"For those who are on ARVs, there is a system to train them about adherence, because most people are forgetful," said Mr. Samran. Economic issues and a need for vocational training are also a concern for Violet Home's target population. Violet Home helps connect their clientele with state support systems and with shops who are willing to hire HIV-positive MSM who want to work. As another way to help generate income, Violet Home is planning to open a shop featuring flowers, clothes, handicrafts and other works made by MSM.

Stigma and discrimination work is central to Violet Home's goals. They work with families of MSM, trying to open communication. Violet Home works with the parents to help reduce stress and tension. "Families have expectations that an only son will keep the family name going. Fathers in particular have a hard time when their son has sex with men and is HIV-positive," said Mr. Samran.

Violet Home works to help improve society's attitude toward MSM and transgenders. They have a radio show in prime time, 'The Violet Variety'. "We talk about terms and language and how to address the group. There is also a radio show in Mae Rim run by a group of men who have sex with men," said Mr. Samran.

While MSM in Chiang Mai have more chance to be part of a community, Violet Home is working to develop support networks outside the central city. The organization has volunteers in 15 districts in Chiang Mai and Lamphun provinces, who have often found that the local caf' is the best place to meet men who can benefit from Violet Home's activities. "Men who have sex with men in districts outside Chiang Mai don't have access to services where they feel comfortable. Often they won't go to counselling services in hospitals because they feel they will be stigmatized or made to feel that they deserve it somehow because they have sex with men. There are many men who have sex with men who feel really uncomfortable and stigmatized. They may find out from private testing that they are positive but they don't try to get medicine. They would rather go without medicine and put their lives at risk than deal with the stigma," explained Mr. Samran.

Violet Home has a system to facilitate treatment that helps men who need treatment go directly to a hospital in Chiang Mai. They also try to teach men outside Chiang Mai how the social security system works and how to get the drugs they need without feeling stigmatized. Said Mr. Samran, "Part of our work is to educate them about their rights."

Empowering female sex workers

EMPOWER is an NGO which has a large focus on sex worker rights and HIV issues. Former and current sex workers staff and work on EMPOWER activities, however, EMPOWER offers services to all women. The organization works in Chiang Mai, Phuket, Chiang Rai and Bangkok and approaches the different situations for sex workers in each location differently.

"In Chiang Mai it's probably one-half Thais and one-half immigrants working in the entertainment industry. In Bangkok it's 90-95 percent Thai. In Phuket, 80 percent Thai, in Mae Sai, on the border with Myanmar, it's 90 percent immigrant. It's very different in each place. In Mae Sai we teach them rights as they come across and we also teach them Thai law," said Ms. Thanta Laovilawanyakul, Coordinator of the Live to Dream Project at EMPOWER Chiang Mai.



EMPOWER created a series of amusing posters teaching sex workers how to negotiate condom use with clients.

"It's a very diverse situation in Chiang Mai," continued Ms. Thanta. "We have sex workers from many different cultures, and we have many different types of bars: bars, karaoke, caf's, brothels, a-gogo, massage palaces, beer bars. There's been a big change in the last few years from brothel-based sex work to independent sex work. Now if you want a job in a bar you literally have to fill in an application. The role of the brothel has changed. The girls have their own cell phones. They get an assignment and go."

HIV education and support for those women who are HIV-positive is a central part of EMPOWER's work. "Those outside have a perception that sex workers are a risk group. What we would like to communicate to society is that anyone can get HIV, not just sex workers," said Ms. Thanta. "People like to think that sex workers are at more risk because sex workers have more sex than anyone else. But how about those people who have less sex but don't use protection?"

EMPOWER provides basic HIV prevention information to women who use their services. Much of the prevention information is explained via games. Said Ms. Thanta, "We have an STI game that divides the field into three parts. Five people represent antibodies. At the other end of the field are three teams of two people who represent diseases. The objective is for the people who are diseases to run down the field and not get caught by the antibodies. The diseases are in teams: diarrhoea, flu and HIV."

"The HIV team's goal is not to go to the other end; its goal is to catch the antibodies and that's how they score. Once the HIV team catches someone from the antibody team, it is more likely that the diarrhoea or flu team will score. This makes it easy to understand how HIV works, especially for dealing with groups that have many different languages. If you do it in a technical or academic way it will be very hard for them to understand," said Ms. Thanta.

EMPOWER's work is rights-based and they provide translations of laws and rights in simple language. By addressing the needs of sex workers from a rights perspective, they are also addressing HIV issues. "We operate the "Can Do" bar in Chiang Mai, founded by a group of sex workers," said Ms. Thanta. "The principal is that the bar should use work standards that follow the labour law. Minimum wage, social security, leave, overtime, occupational health and safety standards should be observed. One of the regulations is that all the staff must have sex safe and HIV prevention training. They have a three-day course on prevention, safe sex and counselling. The staff of Can Do bar, after the course, can then serve as peer counsellors. Even volunteers at the EMPOWER centre have to attend the course."

The EMPOWER centre provides counselling on HIV for three groups of sex workers: those who suspect they may be HIV-positive, those who know they are and those wanting to have a blood test. Although the centre provides gynaecological services provided by a doctor from the Ministry of Public Health several times a month, women who want an HIV test are referred to another clinic.

EMPOWER also stresses the importance of sex workers providing support to each other. "It's like we're in the same family from the beginning. It's easy to communicate among ourselves," said Ms. Thanta. This support includes providing space for an informal support group for sex workers who are HIV-positive. EMPOWER did refer women to general support groups, but many women felt that somehow they were looked down upon because they were sex workers, as if they were the cause of the disease. Many of the women in the support group have not disclosed, but they learn how to protect themselves and others through the group.

The "Live to Dream" project at EMPOWER takes care of women who have an HIV-related illness. "We recruit volunteers from among ourselves to make sure that there's someone to help take care of anyone who doesn't have someone to look after them when they're ill," said Ms. Thanta. It also provides counselling services for any problem. After women leave hospital, they can stay at EMPOWER, and EMPOWER also has an emergency fund run from member donations which can help women get ARVs.

EMPOWER feels it improves the social fabric of the whole community by improving the social fabric of the sex worker community. The organization focuses on teaching all kinds of skills to women, be they life skills, computers, handicrafts or hairdressing. The activities are developed from requests from the women. The language courses help them learn to negotiate safe sex in English, Japanese, Chinese, French and Dutch, all languages important in an international tourist centre. EMPOWER is also an official External Learning Center certified from the Ministry of Education, so women can finish studying for their high school diploma through the organization.

Key points

- Marginalized populations need programmes that are developed together with the target population.
- Materials and resources should be available in all languages.
- HIV should be addressed in a holistic fashion with marginalized populations, who are often faced with stigma and discrimination or legal issues that create an environment in which they are more likely to be in situations of greater risk.

APPENDIX: STATEMENTS FROM YOUTH LEADERS

Below are statements from Youth Leader Trainers and Younger Youth Leaders from the YAPS project who served as role models, initiated creative ideas and showed their abilities to transfer knowledge and skills to their peers. (All names used with permission.)

Ms. Athariya Phuangyod

A 15-year-old Younger Youth Leader, Ms. Athariya Phuangyod describes her achievements.

When I was first selected to be a Younger Youth Leader, I thought that learning about sexual and reproductive health would be useless. But I changed my mind after attending two capacity-building camps. The first camp discussed leadership, rights, duties and responsibilities. The second camp was about sexual and reproductive health, reproductive health rights and HIV prevention. A group of Youth Leader Trainers taught me about sex in an informative and beautiful way. I gained a lot of knowledge from the group sessions, games and activities. I felt that it was much better than a lecture in a classroom.

With all of this knowledge and skills, I was able to prepare myself for upcoming changes in my body and not panic when they occurred. I had a much better understanding and no longer thought that sex education was obscene or forbidden. In contrast, I think sex education is a good thing and very useful to students my age. I learned how to associate and interact with friends of the opposite sex properly. I learned the difference between love, lust and sexual desire, how to protect my rights, and that I should not take advantage of other people. I also learned how to use my leisure time in a useful way.

Also, the other Younger Youth Leaders and I used the knowledge we had acquired to give correct information to our family members. For example, some of my friends told their mothers how to do breast self-examinations and taught their younger sisters about what to do when menstruation starts or when any other changes of puberty begin. They also told people outside of their family about rights, duties and responsibilities.

At school, I was admired and well accepted by friends for serving as a Younger Youth Leader. I was elected to be the leader of female students in the school, and could give advice about sexual and reproductive health to my friends. Our team of Younger Youth Leaders has implemented many activities both inside and outside of the classroom. We have adopted and created a new method of teaching that is suitable for each target group by learning from mistakes we have made in the past and improving more and more each time.

I am very proud of all of these achievements. I hope that the next generation will also have the opportunity to receive accurate information about sexual and reproductive health. In doing so, they will be able to take good care of their own health and can become an effective human resource for society in the future.

Mr. Natthavut Manochai

Fifteen-year-old Younger Youth Leader Mr. Natthavut Manochai has shown his creative ability to transfer knowledge and skills through integrative strategies to the public sphere. He discusses his experience below.

After another 11 friends and I attended capacity-building camps and had the opportunity to serve as Younger Youth Leaders in my school, I have learned how to work with other people. This was my first time to be selected as leader of a team, so I tried to develop teamwork by thinking, making decisions, being a reasonable person, being generous to others, and learning to forgive and forget. At the same time, I had to be a good follower by listening to other's opinions and accepting any arguments or objections.

The teachers encouraged our team to organize activities for teaching the knowledge we gained at capacity-building camps to our friends in school. Organizing such activities on our own gave us a great opportunity to demonstrate our ability to serve as trainers and to exercise our creative and constructive ideas.

While preparing peer-led activities, I had to think of teaching methods and media that would create an effective learning environment for my friends. We brainstormed to come up with new, interesting and attractive activities. These included broadcasting the "Small DJ" radio programme in school, initiating an essay-writing contest, organizing sex education sessions to be taught after paying homage to the national flag in the morning, and implementing summer day-camps in school.

Throughout the experience, we faced some obstacles that made us feel so discouraged that we almost gave up. We were able to overcome these obstacles due to our good teamwork and supportive teachers. I was proud of our team and myself for achieving success when serving as a Younger Youth Leader for the first time.

Now I have moved to a new school, but I still continue to explore more effective strategies of educating young people about sex education because I want to maintain my capability. With four other friends, I have formed a new team, and together, we have joined a training course for creating a website to teach young people about sexual and reproductive health. Currently, we are working on this website and we hope that it will be accessible by the end of this month. I am very excited and believe that my website, www.prc.ac.th/hukmao, will be able to give correct and accurate information to friends all around the country.

When I am down, I always keep in mind that even if we feel hopeless and failing, we should just take a small break, but not give up. We have to believe in ourselves and hold on to our spirit in what we are doing. Our dream will come true someday.

Ms. Premkamol Settheekul

Youth leaders who served as Youth Leader Trainers have expressed their positive personal development and are learning how to be competent, as the following statement by Ms. Premkamol Settheekul shows.

Before becoming a Youth Leader Trainer, my two older sisters, who had previously worked on this project, served as good role models for me to learn from. Their fully developed capacity and devotion to society that came from serving as Youth Leader Trainers inspired me tremendously to be like them in the future.

My dream finally came true when my sisters introduced me to the project and I was invited to be a new face in the Youth Leader Trainer group. I was given the opportunity to attend capacity-building camps and many training activities with the other 34 volunteer youth leaders. During these sessions, I learned about the essential knowledge and skills necessary for serving as Youth Leader Trainer. I learned skills regarding issues of rights, duties, responsibilities, teamwork, leadership, knowledge about sexual and reproductive health, and HIV prevention for young people.

Through the training courses, I learned that I need to have the necessary knowledge and a true understanding in order to be Youth Leader Trainer. I have learned how to use teaching methods that attract the attention of learners, create a lively learning atmosphere and avoid implication of obscene meaning. I also learned how to produce teaching media from an expert, Mr. Supod Sukklad, who is an instructor that specializes in communication art. He has taught me appropriate ways of teaching younger learners.

Being a trainer of Younger Youth Leaders makes me feel that I have prepared younger generations for passing along the necessary knowledge and skills to their fellow youth. This is important because, when I was their age, I did not have the same opportunity to receive such training.

Taking on the role of a trainer and facilitator for Younger Youth Leaders has helped me demonstrate my strengths. As a result of this working experience, I have acquired several self-development skills, gained a better understanding of myself and have a clearer insight. I have also had the opportunity to share and exchange my views with colleagues so I was able to learn how to accept opinions of others and develop self-confidence in expressing my ideas to other people.

The knowledge, skills and experiences gained from serving as Youth Leader Trainer are valuable to both society and me. I learned a lot and developed myself in many aspects. I have used the acquired knowledge and abilities in taking good care of my health and learning how to adjust well in society. Most importantly, serving as Youth Leader Trainer has changed my personality. I was a shy person with low self-esteem, who rarely spoke and did not recognize my own self-worth. Now I am a new person who has confidence in thinking and doing, as well as speaking in public. So now I can say to all of you that serving as Youth Leader Trainer has made my life better.

Mr. Arnut Wanna

Mr. Arnut Wanna, a Youth Leader Trainer who reached his achievements from continuous commitment and through the sacrifices of being a Youth Leader Trainer, discusses his experience below.

I began serving as a youth leader of the YFCD project when I was in 7th grade, which was in 1996. During this wonderful time, I developed my capacity and gained necessary skills regarding sexual and reproductive health, reproductive health rights and HIV prevention among young people. When I was invited to be a Youth Leader Trainer in 2000, I had no hesitation in accepting this great opportunity.

During the preparation to becoming Youth Leader Trainers, I and 34 other Youth Leader Trainers took part in developing the contents and learning activities of the capacity-building curriculum. We also developed a sexual and reproductive health programme for Younger Youth Leaders called 'Because the World Needs You'. This work was extremely hard for me. It caused a lot of stress and required a high level of patience. Writing activity plans was a very difficult job. The most stressful task was the modification of the action plan. I had to continuously adjust it in order to keep it as relevant as possible. I felt that this task could never be completely finished, because it required constant modification and I had to ensure that it was as perfect as possible. Looking back now, I realize I learned a lot from doing this, especially how to manage work effectively and to think systematically.

Sometimes I felt burnt-out and discouraged. I would ask myself, why do I have to work so hard instead of hanging out and having fun with friends, like most of the people my age get to do? However, our Youth Leader Trainer groups always reminded each other during a hard time that serving as Youth Leader Trainers and honouring our duties and responsibilities is our first priority. We must sacrifice our personal happiness because we have committed ourselves to make a contribution to society.

It was worth the sacrifice for me. I was very happy when I noticed that Younger Youth Leaders showed an interest and actively participated in the topics that I taught. Once my work was done, I was very proud of myself and any feelings of frustration disappeared. This especially happened when I saw the changes and positive developments among the Younger Youth Leaders. They began to utilize the knowledge and skills they had acquired to benefit themselves and their friends, families and communities. I was very excited when the group of Younger Youth Leaders under my advisory called the 'Sex Must Say Group' organized peer-led activities in my old school. In doing this, they beat 60 other schools throughout the country and won the first national award for organizing peer-led activities on sex education in school.

I now realize that serving as a Youth Leader Trainer is the way to reach further advancement in my life.

I am very proud of the other Youth Leader Trainers and myself for being able to do something useful for society and for serving as good role models for Younger Youth Leaders. Currently, my team and I have been invited by many organizations to be trainers and guest speakers on sexual and reproductive health issues and HIV prevention among young people. Being a Youth Leader Trainer has inspired me to continue my studies in nursing. I am now in the last year of my studies, and I cannot wait to become a nurse and further help society.

Another important thing I achieved as a Youth Leader Trainer was receiving the national award for being a youth volunteer in 2004, which was presented to me by the Crown Prince. This great honour convinced me to continue to commit and sacrifice myself in order to mobilize positive changes in society as long as I can.

I believe that everybody can reach their goals if they commit to doing what they love and work together with the opportunities and warm support given to them by the adults surrounding them.

Ms. Supaluck Boonlert

Fourteen-year-old Younger Youth Leader Ms. Supaluck Boonlert demonstrated her Younger Youth Leader capacity through programme implementation in school with a strong supportive environment from family and school.

As a student from a rural area, being a Younger Youth Leader was a great experience for me. The other nine students and I were glad that we were selected to be a part of this project and attend the capacity-building camps with 101 youth leaders from nine schools. It made us realize that we had equal potential compared to others with higher economic status or from bigger schools in the city.

All of us have changed a lot since attending the capacity-building camps. We have gained the courage to teach our friends. The administrators and teachers encouraged us to use the programme 'Because the World Needs You' to give knowledge and skills to our friends in school. They gave us the opportunity to organize a youth leader club and use two hours per week to teach our friends. Now, about 200 children in my school have some knowledge and skills on sexual and reproductive health. We also encouraged the younger classes to become members of the youth leader club. From this, they were able to develop their capacity to lead like us so they could be a new generation of Younger Youth Leaders to implement activities in the future.

Moreover, I have been given great opportunities to be a Youth Leader Trainer in capacity-building camps for school youth in Bangkok and youth affected with HIV, as well as to attend national and international conferences.

Along with these, we are very proud to have been chosen by CNN to broadcast our work around the world.

I would like to express my appreciation to everyone who has been involved in my advancement in the YFCD project. You all have given me the opportunity to be a Younger Youth Leader. Thank you to all 35 Youth Leader Trainers for being great and devoted role models, to the school administrators and teachers for their warm support, and to all of the Younger Youth Leaders and my friends for their teamwork.

Most of all, thank you to my parents for their understanding, love and willingness to stand beside me always. All of you are the wind beneath my wings; thank you very much.

Mr. Weerachat Kaewpradit

Fifteen-year-old Younger Youth Leader Mr. Weerachat Kaewpradit has shown his ability to build leadership skills from generation to generation for sustainable development.

During my participation in the capacity-building camps three years ago, the group of Youth Leader Trainers taught me that sex education was not about encouraging young people to be involved in sexual activities. In contrast, it gave me important knowledge and skills that would prevent me from doing so. As a result, I knew how to protect myself effectively from any inappropriate thoughts around me and from any incorrect beliefs among adolescents.

The leadership capabilities of the Youth Leader Trainers at the capacity-building camps inspired me and my Younger Youth Leader friends to commit ourselves to other people by taking what we gained from the camps to organize peer-led activities in our school. We used many methods in order to assist our friends and teachers in realizing that sex education was not a matter to be ashamed about and was something that everyone should learn.

At school, the Younger Youth Leader group members and I had to behave ourselves well so that our friends could rely on and trust us. While conducting each peer-led activity, we required a high level of leadership, teamwork and effective teaching strategies. Without these criteria, we would not have been able to organize the more than 500 school children who participated in each activity.

As a result of organizing activities in school, new younger friends showed interest in being Youth Leaders for teaching sex education. So our teacher encouraged us to set up a club called "Youth Leaders - Power of the New Generation." We built the capacity of new Younger Youth Leaders and increased the number of group members to 30. Our club has become well-known in school and has been invited to conduct activities in the "learner development session" for our school.

My school has become a recognized location where organizations working on youth development and sexual and reproductive health education come to visit and share lessons learned from Younger Youth Leader activities. Three years ago, I was just a normal student who only engaged in studying in the classroom. After my capacity was built by the Youth Leader Trainers of the Youth Family and Community Development Project, I became a Younger Youth Leader. Right now, I train new leaders in younger classes and serve as a consultant for them. This group of younger friends ensures me that whenever I am away from school, the club and all activities will continue, and the knowledge and skills will be passed on from generation to generation. This is what I call 'sustainable development'. Lastly, I would like to say that if I believe that I know everything, I will never have further advancement.

I need new experiences and to learn new things in order to grow – this is what being a Younger Youth Leader and the project activities have taught me.

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