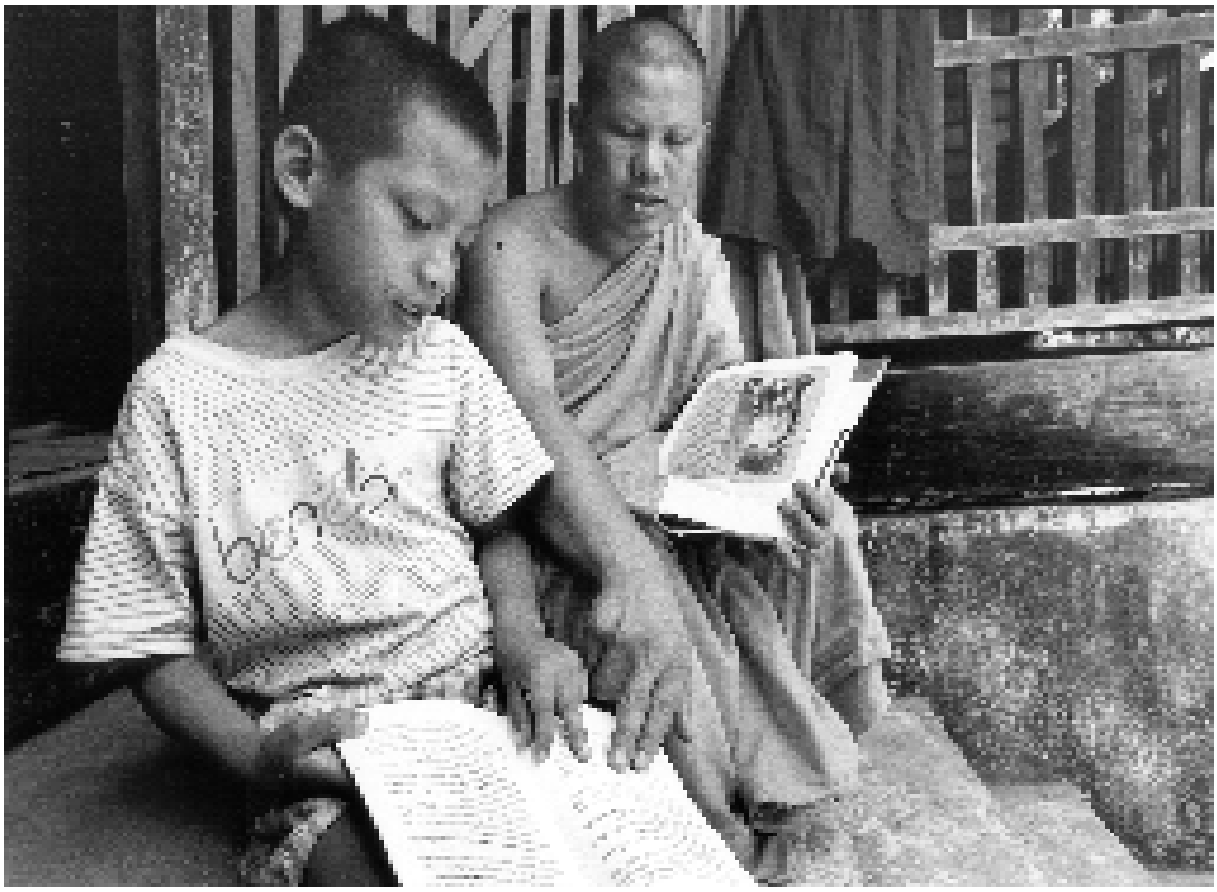
Securing a Future

Mekong Children and HIV/AIDS



SECURING A FUTURE UPDATE APRIL 2002

UNICEF EAST ASIA & PACIFIC REGIONAL OFFICE, BANGKOK

Securing a Future

Mekong Children and HIV/AIDS

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HIV/AIDS Program

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All the countries in the Mekong subregion have HIV/AIDS epidemics, most of them growing rapidly. Infections are concentrated in youth and young adults. But as the disease spreads, a growing number of children – the children of people with HIV/AIDS – urgently need our help.

Grief, poverty, discrimination, vulnerability – the ways HIV/AIDS affects children follow a tragically predictable pattern across the developing world. But a global consensus is emerging on how we can respond to minimize these impacts, through planning, analysis and learning from the experiences of those around us.

Securing a Future is a call to action for the Mekong subregion and beyond. It presents the basic facts about how HIV/AIDS affects children, the priorities, the strategies. It addresses on some key issues – community-based care, education, emotional support – and looks at some successful projects within the subregion. Most of these examples come from Thailand, because it is the Mekong country with the most advanced epidemic and where most of the action for affected children has been taking place.

The Approaching Crisis

The impact HIV/AIDS epidemics will have on children in the Mekong countries adds up to a massive humanitarian disaster. In Thailand, where new infection rates have been falling since 1996, the number of children who will lose their mothers – and probably their fathers and their homes – because of AIDS, is set to keep rising, from around 30,000 now to an estimated 430,000 over the next five years. Many of these children will come from the poorest and most disadvantaged families.

By all the indications, the rest of the Mekong subregion faces similar or greater crises during the next decade or more. If we are not prepared, health sectors will have to deal with the consequences of greatly increased child malnutrition, neglect and missed immunizations. Social services will have to deal with massive increases in poverty. Numbers of children needing urgent care and support will far outstrip family and community substitute care options as well as the capacity of orphanages and other institutions. Families and whole communities will be impoverished. The achievements of years of progress in children's health, rights and well-being, not to mention social and economic development, will be erased.

The Challenges

Having a parent with HIV/AIDS will affect many aspects of a child's life. Some are unavoidable – sadness and loss, disruption, having to adjust to a new home, for example – but many are simply the result of ignorance, prejudice and our own failure to act sooner.

The impact of HIV/AIDS on affected children and families includes discrimination, physical and emotional care and support needs, loss of access to education and increased poverty. Families become poorer because breadwinners are unable to earn, while family medical bills rise. Widows and orphans lose their inheritances and are left with nothing. Because of poverty and parental illness, children have to leave school to cut costs, and provide care or earn an income. Family meals become less nutritious.

– and How We Can Help

Sickness is left untreated, immunizations skipped to save money. Families taking in children orphaned by AIDS – almost always part of the extended family in the Mekong subregion – may lack the resources to provide proper care.

Many people still assume that affected children must also be HIV infected and infectious. The fact is, even without medical intervention, on average less than a third of babies born to HIV-positive mothers become infected. Even those children who have HIV/AIDS can safely play with other children. However, as a result of this misinformation, affected children are excluded from schools, child care centres, medical treatment. Affected children are branded as "AIDS kids", and parents tell their children not to go near them. Sometimes, communities are so fearful that they drive out affected families. The prolonged distress this causes, coupled with grief at the loss of loved ones and uncertainty about the future, can leave the affected child with deep emotional and psychological scars.

Many affected children become vulnerable and easily exploited, falling into crime, street life, sexual exploitation, illegal drug use and situations that put them, in turn, at high risk of contracting HIV.

What We Can Do

Although we cannot avoid a vast increase in the number of orphans and affected, grieving children across the region, we are lucky in that we have some time to prepare before the worst of the crisis arrives. In the time we have, we should strive to ensure families and communities are prepared, ready and willing to help. We should put in place mechanisms for monitoring, counselling, support and arranging community-based care, and make sure they are running smoothly. We should see that the rights of affected children and families are protected. All concerned agencies should be working together efficiently, sharing information and not duplicating work. We can build on partnerships already established in the region.

The focus of activity should be at the local level. Most of the effective interventions for families and children affected by HIV/AIDS today have their origins in community-level initiatives – responses by local people to the problems around them. Each child, family and community affected has different needs, and these will change over time. Local people, supported by organizations which have reach at local level, are in the best position to monitor and assess the problems and plan tailored responses. Communities are and will remain our richest source of new ideas.

What national governments and organizations like UNICEF can do best is ensure that legislation, policy and services support children affected and local-level responses; help to build local capacity; facilitate the exchange of new information and ideas; and stimulate and support the forging of powerful new partnerships.

Spiralling numbers of orphans and vulnerable children due to AIDS across the Mekong subregion are not a probability but a certainty. If we face up to the nature and scale of this approaching crisis we have a chance to mitigate the worst impacts. If we continue to ignore it, our children, and our societies, will pay a heavy price.

The Impacts of HIV/AIDS

... ON COMMUNITIES

- The labour pool is reduced, particularly for agricultural labour and for skilled labour ...
- Poverty increases
- Infrastructure deteriorates
- Access to health care and education is reduced
- Mortality is elevated
- The community has fewer resources to marshal for mutual aid
- Communities suffer a general loss of resilience

from *Children on the Brink*

"My only wish is that I live long enough to see my daughter finish college. I have no worries after that."
– an HIV-positive mother

Planning a Response

There is no one-shot cure for the impact HIV/AIDS has on families. Just as AIDS erodes the body's defences against every passing disease and infection, so HIV/AIDS erodes a family's social and economic security. Isolated, weakened and impoverished, families lose their ability to cope with a swelling flood of problems. Responding to the needs of affected families means helping them rebuild their defences, cope with their immediate problems and plan for those that are coming.

Action for children affected by HIV/AIDS must be:

- Responsive, because each case's needs are different and changing,
- Holistic, because the problems come from all sides, and
- Continuous, because affected families need constant support.

A Continuum of Care

A national response to the problems of children affected by HIV/AIDS must operate at many different levels and include cooperation and coordination across sectors. We can ensure legislation protects the rights of widows and orphans, particularly to inheritance. We can ensure teachers, community leaders, health and social services staff, the media are knowledgeable about HIV/AIDS and understand its impacts on families and children. But most responses need to be dealing directly with the affected families and children, as every one is hit in different ways and at different, unpredictable times.

To be most cost-effective and sustainable, the response needs dynamic partnerships between all stakeholders. Central and decentralized government agencies, international organizations, NGOs, local authorities, the private sector, community-based organizations and anyone else at community level who has the willingness and the opportunity to offer assistance should cooperate towards common goals.

Don't Single Out AIDS Orphans

From *Children on the Brink*

HIV/AIDS causes serious problems for children. But singling out for assistance those children whose parents have died of AIDS stigmatizes the intended beneficiaries. The needs of individual children are not necessarily greater than those of children orphaned by other causes or vulnerable for other reasons, and the problems may begin long before their parents become ill or die from HIV/AIDS. Because of increased economic stress on households, many children who are not themselves orphans also will experience these problems.

For these reasons, interventions should be targeted in two stages. They should be directed to the communities where the impact of HIV/AIDS is greatest and where it significantly affects the ability of families to meet their children's needs. Within these communities, assistance should be targeted to the children and families identified by residents as the most vulnerable (without making HIV/AIDS a criterion).

Strategic Action to Help Affected Children

1. Mobilize political will and reallocate national resources:

- Invest in poor communities;
- Allocate resources more fairly;
- Increase investment in basic social services; especially education
- Involve all sectors;
- Coordinate action centrally.

2. Bolster the capacity of families and communities to care for and support orphans:

- Ensure access to basic services;
- Provide assistance through specially targeted programmes
  - childcare services,
  - income generation,
  - credit/loans,
  - food production,
  - psychosocial support.

3. Stimulate and strengthen community-based responses:

- Support NGOs and community-based partners with
  - technical assistance,
  - policy and planning guidance training,
  - resources;
- Identify and strengthen community-based care and support to:

(continued next page)

The box running down the side of this page and the previous page gives an outline for a national response for children affected by HIV/AIDS, showing what can be done at the different levels.

Focus on the Family

What happens in the family directly affects the child. Thus action to help the family – income support, psychosocial counselling, reuniting them with estranged relatives – can go a long way to reduce the pressures on affected children.

Other elements of family strengthening programs, such as raising awareness on children's rights and counselling/support on good parenting, are particularly important in the response to children affected by HIV/AIDS

Focus on the Community

If the community in which an HIV/AIDS-affected family finds itself is hostile or unsupportive, the family will have few places left to turn, and its children's suffering will be maximized. If the community and its institutions can be mobilized to help affected families, they can provide responsive spiritual and practical support to ensure the welfare of children affected by HIV/AIDS.

Scholarship funds and other material support for affected families and children are better distributed by community-level bodies who know the particularities of each case. Follow-up of orphans in new households, monitoring how affected children are coping, and many other important tasks are most effectively done at community level and by community members.

Giving them "ownership" in this way will ensure communities are more motivated to give support and find solutions over the long term.

"My House", drawn by Nai, 6. Her father is dead due to AIDS. "I wish I could become a doctor and go and treat my dad in heaven."

- substitute or foster care families,
- child-headed households,
- orphanages, which play a transitional role;

- Make use of the formal welfare system;
- Promote exchanges of information about experiences;
- Bring small initiatives to larger scale.

4. Ensure that governments protect the most vulnerable children:

- Obtain political commitment;
- Promote and protect children's human and legal rights;
- Review and reform laws and policies dealing with children;
- Provide protection and care services.

5. Build the capacity of children to realize their rights and fulfil their needs:

- Support psychosocial and family counselling;
- Enable children to obtain education and training through
  - sponsorship programmes developing non-formal and alternative education programmes,
  - empowering children through Lifeskills programmes.

from *Children Orphaned by AIDS* (UNICEF)

Raising Awareness

Discrimination accounts for a great deal of the suffering of children affected by HIV/AIDS. Ironically, it is largely based on misinformation that is easily rectified.

What most people learn about HIV/AIDS is a germ of truth fleshed out with myths created by sensationalist reporting and the overactive imagination of the rumour mill. The scare tactics still used in public information about HIV/AIDS in some areas must take a good deal of the blame.

People believe AIDS is contagious, and people with HIV are victims or deserve to be punished;. all children of HIV-positive parents have AIDS.

A little education can go a long way in reducing discrimination and in increasing acceptance of people affected by HIV/AIDS. Several cost-effective ways of disseminating accurate information are available to us. In terms of communications, our aim should be to ensure that society's opinion-formers are presenting a consistent, positive message.

Mass media: Messages broadcast on radio and, increasingly, television have the potential to reach even the remotest areas. Existing HIV prevention campaigns can be expanded to dispel the myths, to elicit sympathy for people with HIV/AIDS and their families, and to provide information on homecare. News media should be given awareness-raising training. Producers of popular dramas and documentaries should be asked to look at the issues of affected children and families.

Alternative media: Folk music and folk drama continue to play an important role in shaping people's ideas and attitudes in the Mekong subregion, and may still be more influential than more formal media.

If people affected by HIV/AIDS and their families are willing to talk about their experiences publicly, they can do much to generate more positive attitudes.

Influential figures, such as teachers, religious leaders and community heads, can be targetted with awareness-raising activities. As well as being familiar and respected in the communities, they can also answer people's questions.

Limitations of the Rights Approach

The violations of children's rights that many children affected by HIV/AIDS suffer give us a clear entry point for programming and for high-level advocacy. But they may not be the best place to start when we approach communities themselves.

Awareness of children's rights is still far from universal in the Mekong subregion, and even those who know about them are often ambivalent. Likewise, the process of bringing legislative systems in harmony with the CRC is long and slow. It takes even longer for the new or revised legislation to filter down to community level.

Child rights, for all the formality of the CRC, are really just what our hearts tell us we owe to our children. We can appeal to people's better nature without waiting for the child rights message to filter through.

Dream Diary

The *Dream Diary* is the fruit of a series of one-day painting sessions for children affected by HIV/AIDS, organized by AIDSNet and hosted by local self-help organizations of people with HIV.

The *Diary* reproduces many of the children's pictures – on topics such as "My House", "My Family" and "My Thoughts About AIDS" – along with each child's commentary and information on their life.

The sessions helped children explore and express their feelings, as well as strengthening the self-help groups. The *Diary* itself is an attractive and eloquent record of the feelings of children affected, and has proved a useful tool in advocacy and awareness raising.

Children's pictures from the *Dream Diary* are reproduced throughout this document.

"Sipy's Legacy"

Sipy's Legacy is a film produced by the National AIDS Program in Cambodia with UNICEF support. The film tells the true story of Sipy, a Cambodian soldier, who died of AIDS. Sipy contracted HIV whilst visiting sex workers and refusing to wear a condom. He then passed it on to his wife, who died before him.

The film uses the style of popular TV drama totell Sipy's story. It has been shown on national television.

By the time he died, Sipy was destitute and had nothing to pass on to his children. His real legacy was the story he allowed to be told, and the real footage of his last hours alive, incorporated into the film.

Guidelines for Dealing with Discrimination

from the Thai Department of Social Welfare

Community Level:

1. Educate community members about HIV transmission. Children of parents who have HIV/AIDS can be involved in this. The message needs to be sent that most children of HIV-positive parents are not infected and that HIV cannot be contracted by simply playing or studying with an infected child.

2. Arrange study tours for community leaders on care of HIV-positive children. The tours should show them how HIV positive and negative children are cared for together in exemplary communities.

3. Arrange discussion groups following study tours, allowing those who went on the tour to compare what they saw with the situation in their own community. This continues to build understanding.

4. Arrange for those who have been on study tours or those who have attended training sessions to disseminate information to other community members.

5. Help establish community volunteers who can serve as representatives and can counsel and advise villagers, parents and officials in communities experiencing problems.

6. Arrange activities involving both the general village population and people with HIV/AIDS and their families. This can help create a deeper understanding and a willingness to consider others' points of view.

Organizational level:

1. Educate teachers, local community governments, childcare centre coordinators and the Community Development Department officials to understand the issues of affected children. Teachers are often highly respected in communities. If they understand the issues and can explain them to others, it can help build acceptance.

2. Establish community networks, with teachers and the village's Committee for Population and Social Welfare as leaders. The networks can create understanding and provide services to children.

"My Family" drawn by Pha, 11."This is the way I dream of my home. My dad is sweeping up leaves and my mum is watering flowers ... Sometimes I sit with Mum and cry. Both of us cared for Dad when he was ill..."

Dealing with Discrimination

Pla, a six-year-old girl, lived in a village household of four people. Her grandfather was the head of the household as the two other family members, including her grandmother, were disabled.

The villagers refused to accept Pla as a member of the village, because Pla's mother had had AIDS. Pla wasn't allowed into the village child care centre. As the family wase also very poor, Pla's grandfather took her to the Children's Welfare Home, where Pla seemed subdued and not very happy.

Social welfare staff talked to Pla's grandfather, who told them that if he could get some money to help with Pla's living expenses and if she could go to the village day care centre, she could come back to them.

After this discussion, social welfare staff joined with health workers in educating the community, to show them that they could safely continue to use the village child care centre along with Pla. The team also answered questions the villagers had.

After the team's visit, the villagers talked further, and in the end they agreed that they would accept Pla into the child care centre.

At this stage, the Welfare Home staff were able to send Pla back home to her family, with a small amount of benefit from the Division of Social Welfare.

Today, Pla is a happy, cheerful little girl who is enjoying living in the warmth of her family.

Case study supplied by the Office of the Division of Social Welfare, Chiang Mai

Don't Just Say No – Say Why

"Teachers sometimes intervene to stop schoolchildren teasing the children of people living with HIV/AIDS. This approach works in eliminating the more immediate problem, but we must consider carefully the students' understanding.

"Are the students who are being teased really happy after their peers stop such behaviour? Do they understand their own problems? And in the future, will they understand how to prevent HIV/AIDS transmission? Do the students who do the teasing now really understand this issue?

"Most people certainly know that the ways HIV can be transmitted are by blood, from mother to child and by sexual intercourse. However, this information is much too general and in daily life, especially if people are sharing a house with a person living with HIV/AIDS, questions are always arising and there is nobody available to provide sufficiently detailed answers to reassure them that they are safe. As long as they have no access to clear information, the fear of getting AIDS will not be erased and discrimination will continue.

"If we can overcome discrimination, communities can play the focal role in solving the problems of children affected by HIV/AIDS."

– Ratana Matsumura, assistant project officer with the UNICEF EAPRO HIV/AIDS Program

A New Home

One of the most important decisions to be made concerning children affected by HIV/AIDS is who will look after them once their parents are dead. The earlier this issue is confronted, the greater the chance that a loving and supportive home will be found for the child. Too often, affected children become orphans without any clear idea of where they will go next.

The norm in most parts of the Mekong subregion has been for orphans to be taken in by the extended family – by aunts and uncles or, most often, by grandparents (usually maternal).

The situation is more complicated in the case of children affected by HIV/AIDS. The poorest and most vulnerable have been hit hardest by the epidemic, families for whom another mouth to feed may seem an intolerable burden. Massive rural–urban migration has separated many poor rural families and people with HIV/AIDS may already have lost contact with relatives – especially drug users or sex workers, who are particularly vulnerable to HIV infection. Finally, fear and discrimination makes many families reluctant to take on the care of even close relatives with HIV/AIDS.

Another consideration is that many orphans, even when they are looked after by close relatives, are put low in the family pecking order and treated as free labour, another source of income or worse, rather than as true family members. Placement within the extended family is generally the preferred option, but the child's best interests are always the first consideration. The child's own wishes should always be taken into account.

Supporting HIV-infected mothers in re-establishing contact with their families and planning ahead can do much to ensure substitute care is the best possible for the child. With time, it is possible to quell the potential carers' fears about taking on an "AIDS orphan" and assess their suitability. It may be necessary to offer support – including scholarships and vocational training – to make the family more able or willing to take on a new member.

Options for Substitute Care

A ranking of care options for children orphaned by AIDS:

1. Children live within extended family (the best option)
2. Children live in a foster home which has a monitoring system to make sure that children get good care.
3. Many children live together with one foster parent to care for them as a family group in the community.
4. The eldest child leads the family and takes care of the younger members under the support of the community.
5. Send children to an orphanage only as a last resort.

From conclusions and recommendations from the seminar on children affected by HIV/AIDS and the community, in the 12th World AIDS Conference in Geneva, Switzerland, 1998.

UNICEF/HQ97-0074/Jeremy Horner

Living with Granny – like many orphans of HIV/AIDS, these Akha children now live with their grandmother

A Different Kind of Adoption

A Church of Christ congregation in Lampang, northern Thailand, is exploring an innovative way of supporting families looking after children orphaned by HIV/AIDS in their community. These families normally consist of a young child or children living with elderly relatives. Church of Christ members are encouraged to "adopt" an orphan. In this case it does not mean actually taking over care of the child: the adopter visits the child regularly, helps with housework, brings home-cooked food or just drops in for a chat.

Because of the need for prolonged direct contact, and the individuality of each case, identifying and supporting substitute carers, and following up the progress of the orphan, are best done within the community, or by organizations with good local contacts.

Institutional Care

Strong family and community safety nets in the past meant orphanages, temples and other institutions took in only the exceptional cases. Today they are rapidly filling up with children orphaned by AIDS. The immediate reaction is often to build more orphanages.

However, institutional care should be considered a last resort. Institutions cannot offer the level of support, attention and human contact that a family can. Moreover, while institutions might be able to cope in the short term, the inevitable massive rises in numbers of orphans due to HIV/AIDS will stretch them far beyond their capacity. Stimulating and supporting family care is the only feasible way forward.

Pun Rak

The Viengping Children's Home in Chiang Mai, Thailand, makes sure that children in its care spend as little time in an institutional setting as possible. Even while they are waiting for adoption, the Home tries to put them in a family environment.

Under the *Pun Rak* program, foster families volunteer to take an abandoned or orphaned child from the Home temporarily, with financial support. The adoption process can take a long time, and the Department of Public Welfare recognizes that institutional care is not really suitable for children.

Overall, Pun Rak, which has been running for over a year, has proven to be highly successful. Children placed in temporary foster homes have suffered from fewer illnesses, particularly ear, nose and throat infections. They have also eaten better, slept more soundly and grown more than those children who stayed in institutional care.

In some cases, children orphaned by HIV/AIDS have been placed with foster families while arrangements have been made to return them to the care of their own extended families.

Psychosocial Support

The psychological and emotional needs of children affected by HIV/AIDS are no less real than their more tangible practical needs – welfare, education, health care, new homes etc. Yet they are often overlooked

If we want affected children to enjoy the same opportunities as other children, we cannot ignore these needs. A scholarship will not help a child who fears being tormented in the playground. A child who believes she is of little value will do little to protect or advance herself.

There are many types of emotional and psychological pressure an affected child may feel. Among them are:

- Grief at the loss, or impending loss, of a parent or carer
- Distress at a parent or carer's illness
- Confusion at the change in a parent or caregiver's behaviour towards the child
- Exhaustion and helplessness at having to cope with new responsibilities and pressures
- Frustration and anger at the restrictions on play and other childhood activities enjoyed by a child's peers
- Loss of self-worth because of discrimination in society and lack of attention from parents or carers
- Fear of what will happen once their parent or carer dies
- Feeling unwanted or a burden, particularly as an orphan in a new household
- Frustration at the attitudes of elderly carers, particularly grandparents.

All of these will be exacerbated by a fear that the child cannot or should not talk about these feelings – common in the Mekong subregion – and that they may be in some sense "wrong".

Any action to help affected children and their families will help to reduce the pressures to some extent. But building capacity for direct emotional support is still an urgent necessity.

Suffering in Silence

Aree is in her first year of high school. Aree's mother recently died of AIDS, but Aree has never talked to anyone about the suffering of her or her family.

Aree and her sisters are teased and ostracized at school because of their mother's illness. When the mother got sick, Aree's elder sister had to quit school to take care of her and of their one-year-old brother. Even though they all know what's happening, none of the sisters ever discusses it.

Aree is still studying, but the treatment she receives from her schoolmates makes life at school intolerable.

She has no friends and nobody to talk to. She eats lunch alone. When the teacher sets group activities, "nobody asks me to work with them," Aree says. Instead she has to wait until the teacher assigns her to a group.

Aree lives with her five sisters, her grandmother and father-in-law. She hasn't even told them what happens at school. When she has problems or feels very low she stays alone in her bedroom, reading a book or sometimes just crying.

Even though she enjoys studying, she plans to quit after she finishes Grade 9 (in two years' time). She doesn't know what she'll do after that.

Adapted from "Tackling Discrimination Against Children" by Suthida Malikaew, in *AIDSNet Newsletter Vol.1 No.3*

Memory Books

Memory books are a good, simple way to help children cope with the loss of a parent. They are scrapbooks filled with photos or pictures, messages, a diary of activities the child and parent have shared and of changes in the parent's condition. When the parent is dead, these help the child summon up good memories and understand what has happened.

"My Family", drawn by Song, 10

Simply encouraging the child to express their feelings is a good start. Structured play, painting and drama are all ways children can be invited to explore their feelings, especially those they are not yet comfortable articulating in words. Camps can provide an ideal setting for this, and are discussed more fully on page 14. Encouraging and supporting networking between affected children (and other orphans or disadvantaged children) helps them to feel their problems, and their feelings, are shared and understood.

Confidential Counselling

Counselling for affected children is probably the most important type of emotional support. Because affected children are geographically scattered, and may be from linguistic or cultural minorities, local capacity must be built up. Teachers and volunteers in the community, perhaps from village women's groups, make ideal counsellors. Monks, nuns and other religious figures often already play a role as spiritual and pastoral advisers and can thus be useful allies.

Counselling should be sensitive and its pace dictated by the child. Counsellors should be carefully trained and fully knowledgeable about HIV/AIDS and the problems of affected families. Sometimes it will be useful to talk to the child and family together, but this should be the child's decision.

A mobile counselling service, such as that provided by the Thai NGOs Hotline, can cover a large area cheaply when local counselling capacity is low. Some children may also feel more comfortable talking about very personal matters with someone they do not see outside of counselling.

Human Rights Often Denied to Children Affected by HIV/AIDS

1. The right to freedom from discrimination (Convention on the Rights of the Child Article 2);
2. The right to life, survival and development (Art. 6);
3. The duty of the State to support parents or legal guardians in child-rearing (Art. 18);
4. The right to the highest standard of health and medical care attainable (Art. 24);
5. The right to an adequate standard of living and access to social welfare (Art. 27);
6. The right to education and access to information (Arts 28 and 13);
7. The right to be heard in all matters affecting the child (Art. 12);
8. The right to protection from abuse and exploitation (Arts 19 and 34);
9. The right to receive appropriate alternative care where the family is unable to provide this (Arts 20 and 21).

From "AIDS and Children's Rights" in *AIDSNet Newsletter* Vol. 1 No. 3

A Mother Steps in

Noo's daughter was being teased by her schoolmates, so Noo decided to go and talk to a teacher at the school. It worked. The teacher talked to the other children, and they stopped their teasing.

However Noo is still not confident enough to take her younger daughter to the day-care centre. While most people in her own village now accept her situation, Noo says, at the day-care centre there are children from another four five villages.

"There is no problem with the staff at the centre, they just want my daughter to come because she is now three years old," says Noo. "But I'm afraid that the other parents cannot accept the situation. I think I should get the director of the centre to clarify things with parents of the other children first. If they are OK, I'll take her there."

Noo has been infected with HIV for four years. She gained self-confidence and knowledge about HIV/AIDS after she joined a self-help group for people living with HIV/AIDS in her district.

Telling Your Children That You Are HIV Positive

Telling your children that you have HIV/AIDS can be one of the most daunting experiences for an HIV-positive parent. They may well be deeply upset for days, even months. In addition, parents fear that their child will blame them and reject them.

Jittra, a 30-year-old mother from Yasothon province, Thailand, contracted HIV from her husband, a deep-sea fisherman. When she and her husband both had their blood tested and found out they were HIV-positive, they told their nine-year-old son.

Jittra believes families affected by HIV/AIDS should make time to get together and tell their children.

"The sooner the better," Jittra adds. "We have to prepare them for their future. If we let time just pass by, we may lose the chance to understand each other."

Jittra found it hard to muster up the courage to tell her son, but eventually managed it. Although the news was hard to take, her son felt good that she told him. Now he understands her situation and can do all he can to help her.

Timing may be worth considering, however. Somsri, a 35-year-old Thai mother, warns against revealing your status before you are ready.

"I'm sorry for telling my children too soon about my being HIV infected", says Somsri. She found she was infected in 1996, a few months after her drug-addicted husband became so sick that he had to be admitted to hospital. She was very confused when she learned that she had HIV/AIDS. All she could do was cry.

"My Family" drawn by Jin, 12. Jin's mother died of AIDS. Her father has it nowand is sick. Nobody has told Jin, but she and ehr siblings are taunted at school as "AIDS kids", and when Jin hears the word "AIDS", she cries.

Her children, a son of 15 and a daughter of 11, found her one day and asked why she cried so much. She decided to tell them the truth, even though she hardly understood HIV/AIDS herself. Both children became quiet and depressed. All they could think of was that their parents would die. "It took them a year to get over it", says Somsri.

Somsri believes she hurt her children by telling them too soon. If she had another chance, she says, she would have waited until she was emotionally ready and had more practical knowledge. However, she still thinks that telling her children herself was better than letting them hear from somebody else.

There are still many cases where parents have no idea how to tell their children of their HIV-positive status. Sometimes the children are too young to understand. When interviewed, 90 percent of mothers of children under five said they did not know how to do it.

Mothers with HIV/AIDS, meeting at the 8th International Conference for People Living with HIV/AIDS (November 1997, in Chiang Mai, Thailand) made the following suggestions for how to break the news. These included:

1 Tell the children when you yourself are in good health;

2 Take your time, providing information on HIV/AIDS bit by bit before revealing your own condition;

3 Have some other HIV/AIDS education materials on hand;

4 Consider using songs, play or role play to communicate the news, rather than just telling straight out.

5 Remind children that there are other adults they can talk to about their feelings, such as grandparents or relatives.

However you break it to them, some children will cope better than others with the news that their parent is HIV-positive, depending on their age, situation and individual character. If, when and how to tell your child about your own HIV infection is one of the most difficult choices you can face as a parent. A lot of people will be eager to offer you advice, but don't be pressured. It is your family, and you know your children – and yourself – best.

Adapted from "Communicating to Your Children than You Are HIV+" by Suthida Malikaew in *AIDSNet Newsletter* Vol. 1 No. 2

"Children of AIDS patients are the most vulnerable group. Many companies will fire employees who are HIV positive the second they find out. Without a decent income, parents are forced to take their children out of school."

– Chanida Liangthorachon of Pearl S Buck International (Thailand)

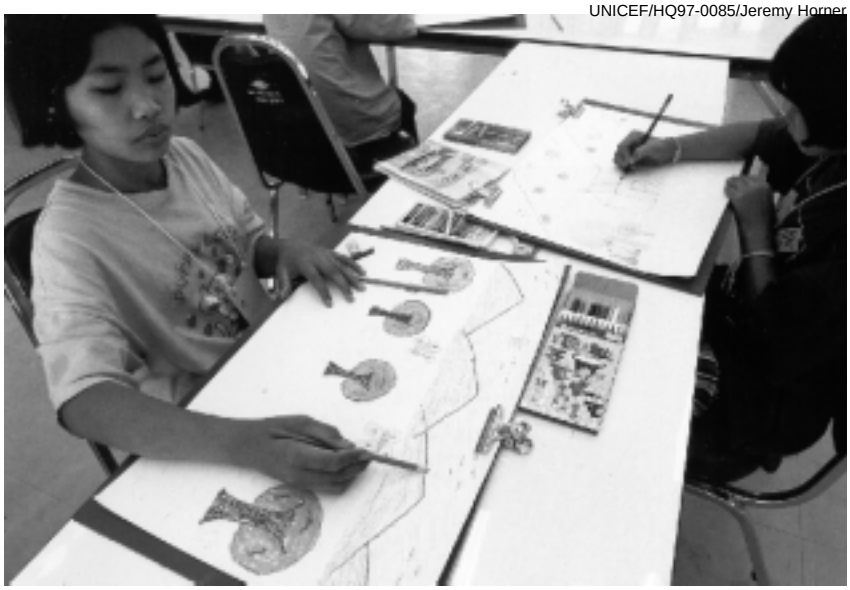
Camps for Children

Camps provide ideal opportunities for intensive work directly with affected children and their carers. They can be used for psychosocial counselling and for encouraging the participants to reflect on their situations; for lifeskills and child rights training; for strengthening relations between children and their carers and helping them to plan for the future.

For the participants, camps can combine a break from their difficult, stressful lives with an environment of open discussion free of fear and discrimination – something many may never have experienced before. Meeting others with similar problems shows them that even though they may feel isolated in their communities, they are not suffering alone.

Camps need not be expensive. Local state-owned recreation facilities are often available at low rates. A camp can even be held in the community itself.

UNICEF/HQ97-0085/Jeremy Horner



Affected children at a day camp in Thailand

Dhamma Camps

Monks connected to the Sangha Metta Project (see p. 20) have put an innovative spin on the children's camp format, organizing "*Dhamma* camps" for local children, both those affected and those not.

At these camps, meditation training and teaching of Buddhist scripture synergizes with HIV/AIDS prevention and awareness activities. In particular, the children – mostly teenagers – are introduced to other children of their own age who are HIV positive, and can learn from them and interact with them.

The spiritual aspect of the camp makes the children more attentive and receptive, while meeting their HIV-positive peers allows them to put into practice key Buddhist virtues. Dhamma camps are conducted in local temples, with participants sleeping on floor mats or in visitor accommodation, making them very cheap to run.

Rainbow Camps

The Life Skills Development Foundation in Thailand runs "Rainbow Camps" with UNICEF support. In October 1999, the Foundation held a camp for children from the three northern districts where UNICEF is developing an area-based response for affected children (see p. 19). The children were asked if they would like to nominate a carer to accompany them. Around half of the 60 children were from families affected by HIV/AIDS – the others being orphans from other causes or other disadvantaged children.

The Rainbow Camps focus on lifeskills education for communication, with the aim of improving understanding between disadvantaged children and their carers, encouraging life planning and raising rights and HIV/AIDS awareness. Another key aim of the October 1999 camp was to develop support networks among the disadvantaged students in the three districts.

"My Dream Occupation" by Pii, 13. Pii's father recently died of AIDS. Pii thinks there is little chance he will be able to study further

Education – Every Child's Right

The most damaging impacts of HIV/AIDS for children affected can be on their education. Having a parent with HIV/AIDS can make a child underachieve academically, miss long periods of school, or even drop out entirely. Missing out on a good education can cut off a child's opportunities throughout a lifetime.

Three main factors influence affected-children's attendance and performance at school:

- economic pressure
- the need to care for sick parents
- discrimination.

Even when schooling is free, families must bear the cost of uniforms, food, school books and materials. For an impoverished family – or a family which considers a child's education a low priority – this can be too much. Poor parents may also want a child to work. Even when this does not entail the child leaving school, heavy workloads during evenings and weekends can leave little time for home study and little energy for the school day.

In some cases, counselling the family about the importance of education may be enough to keep a child in school. More often, scholarships, other direct support or vocational training for a healthy parent are also needed.

Care of sick parents can be another drain on a child's time and resources. During bouts of illness, there may be little choice but for the child to miss school, a fact which schools should recognize and compensate for.

No-one to Play With

Vuth is 10 years old. He is in Grade 4 in primary school. He likes fishing and finding things from the forest to eat. These days he'd rather do that than go to school.

Vuth's schoolmates call him "AIDS kid" and won't play with him. One day he had a sore on his mouth. They called it an AIDS sore.

Vuth's mother, Bua, contracted HIV from her third husband six years ago. Now he is dead. It took years for her neighbours to get over their fear and disgust and start to treat her as a normal person again.

Vuth has two younger sisters, one in Grade 2, the other in kindergarten. The younger of the sisters gets teased about AIDS too, both at kindergarten and at home, as her schoolmates are also her neighbours. At five years old, she has no one to play with.

Bua has talked to other parents in the village, educating them about how HIV is transmitted. She's asked them to let their children play together again and to tell their children not to tease hers. The situation has improved a lot. But not enough to make Vuth and his younger sister look forward to school again.

Adapted from "Tackling Discrimination Against Children" by Sutthida Malikaew, in *AIDSNet Newsletter*, Vol 1 No 3

School-based Tracking

Expansion of the school-based monitoring system developed by Mahidol University Institute of Nutrition's CHILD Project, which links data about students' school performance and attendance, nutrition, health and self-reported changes in family situations, means Thai child-friendly schools receive early warning of emerging problems and can stimulate a family- or community-based response before they become too serious.

Myanmar
Drawing on the experience and successes during the previous programme cycle, the community-based data collection mechanism will be established as a component of the Education Management Information System (EMIS) in all child-friendly schools in all townships. This system will emphasize on school mapping and monitoring of the Education for All (EFA) goals. Plans are underway to train the parents teachers association members and village authorities on baseline data collection regarding the population of school age children, out of school children, children in need of special protection, potential drop-outs and children with various kinds of physical and emotional disabilities.

Discrimination

Discrimination in school is a different matter, being largely outside the family's control. Almost every affected child at some point becomes the butt of cruel jokes. They may also be excluded from games and groupwork or even completely shunned by the other children. The psychological and emotional toll is incalculable. All too often, the victim drops out of school, becomes depressed, angry or delinquent.

And discrimination is not limited to the schoolyard. Teachers' discriminatory behaviour can reinforce the attitudes of other children. Some schools, worried for their reputation or under pressure from other parents – or simply believing that all affected child have AIDS, will die and are therefore not worth educating – expel affected children.

As with all services for children, raising the understanding of teachers and school administrators of the problems of affected children, and mobilizing them to play a positive role in addressing those problems, is essential.

Child Friendly Schools

UNICEF and the Royal Thai Government's Office of the National Primary Education Commission (ONPEC) are cooperating in a vigorous national Child Friendly Schools initiative.

UNICEF's global Child Friendly Schools movement aims at making schools powerful partners in realizing children's rights – both inside the school grounds and in the community at large. As experiences in Thailand have shown, child-friendly schools can do much to mitigate the problems of children affected by HIV/AIDS.

The district primary schools of the three prototype "HIV/AIDS-friendly" districts in northern Thailand (see p. 19) are all actively promoting atmospheres of acceptance and mutual support for disadvantaged children, as well as training their teachers to provide counselling, particularly for bereavement, and build students' self-esteem. In addition, the schools have organized "Rainbow Camps" , and been visited by the Hotline mobile counselling service. In self assessments, the schools reported great improvements in the behaviour of at-risk students.

Lifeskills education, one of the foundations of the Child Friendly Schools movement, may help affected children to cope with extra emotional and practical loads and to avoid risk.

Child-friendly schools also root themselves more firmly in the community, forming and revitalizing parent-teachers' associations and keeping up dialogue with community leaders and local officials so that school curricula and activities reflect community priorities – which often include HIV/AIDS and its impacts.

Child Friendly Schools in Thailand is being implemented by ONPEC with UNICEF support. Save the Children USA, the Thailand Life Skills Development Foundation and the Maya Group provide technical support.

Action from People with HIV/AIDS

Among the most motivated and effective actors in the response to HIV/AIDS are groups made up of people who are themselves living with the virus. Around the world, people with HIV/AIDS are active in prevention, awareness raising, support of affected families, counselling, treatment and advocacy.

One of the most important aspects of self-help groups is the message they send out, particularly to those who have only just learned that they are HIV-positive: that people with HIV/AIDS can be positive, useful and strong.

Affected children themselves, too, should be given opportunities to speak out and encouraged to form their own groups.

Some self-help groups in northeastern Thailand now run monthly "lunch and games" sessions for children of parents with HIV/AIDS. In other groups, such as New Life Friends Association in Chiang Mai, children of people with HIV/AIDS are invited to participate in the work, particularly during school holidays.

"My Family", drawn by Nii, 12. Nii's mother is HIV positive and has made the family house a centre for people with HIV/AIDS.

Burapha House

After finding out she was HIV positive, Malee tried to take her own life. The first thing she saw when she awoke a day later was her daughter sobbing by her hospital bed.

"My child's tears hurt me deeply. I promised I would never hurt her again, and that I would fight the disease until my last breath," Malee says.

Malee became one of 20 volunteers at Burapha House in Chon Buri, Thailand. Run by Pearl S Buck, a non-profit organization, social workers and volunteers at Burapha House offer counselling, home visits and help with the essentials of daily life for people with HIV/AIDS, as well as prevention education for high-risk groups.

The volunteers, all HIV positive, call their group Saeng Song Jai, meaning "Light for the Mind".

Saeng Song Jai run a hotline and counselling service, along with monthly meetings of people with HIV/AIDS. With assistance from the volunteers, Burapha House provides home-based care for living people with AIDS who can no longer help themselves. They also teach the families of people with AIDS basic skills for home care.

from "Positive Action" by Ukrit Kungsawanich, in *Sangha Metta Newsletter*, Vol. 6

Learning to Care

In families affected by HIV/AIDS, children are often the only ones available to care for parents when they are sick with AIDS. This need is exacerbated by the fact that in many hospitals in the Mekong region, non-clinical care such as feeding and washing is generally regarded as the responsibility of relatives rather than nurses.

People with AIDS tend to have continuing periods of illness, with healthy periods in between, before death. During these bouts, they may need constant attention. If a school-age child is responsible for care, they may have to take time extended periods out of school, making it hard to keep up. Alternatively, they devote much of their free/homework time – or time when they could be working, as in many rural households – to providing care.

Ideally, care should be performed by adults in the extended family. Efforts to reunite people with HIV/AIDS with their families can also spare affected children the burden of care. Even in such cases, the family may not be able to bear the loss of an adult's income and a child may have to share or even adopt full responsibility for care.

With Hope and Help (see box, left) and Medicins du Monde's *Taking Care of Your Loved Ones at Home* by Katharine Landfield, developed with funding support from UNICEF Viet Nam, 1999, are both useful training tools and resources for AIDS home care.

With Hope and Help

With Hope and Help is a counselling and awareness-raising kit for the Mekong subregion featuring the voices of people living with HIV/AIDS, their families and carers.

Each country-specific kit features a short film made up of interviews with local people with HIV/AIDS, their families and others who work with them. The interviews cover people's experiences, coming to terms with HIV/AIDS and how to stay healthy.

A set of manuals in local language complement the video, turning it into a workshop tool for people living with HIV/AIDS, their families and carers,and general audiences. One manual is designed for people living with HIV/AIDS and their carers who have no access to the video. It covers care, treatment, diet and how to avoid infection.

Coordinated and funded by UNICEF, film-makers Living Films have produced videos for Thailand, Lao PDR and Viet Nam. Another for Yunnan, China is in production and films for Cambodia and Myanmar are planned. The manuals were developed by the Albion Street Centre in Australia and Bamrasnaradura Hospital in Thailand, in collaboration with EAPRO, and with support from UNICEF, UNAIDS and the EU.

Balancing School and Care

Chai is aged 15 and is in Year 10. His mother has just died of AIDS. She was very ill before her death. She had to got into hospital several times, culminating in a two week stretch before her death.

When she went into hospital, Chai would sleep under her bed at night so that he could be there to take care of her. In the morning he would wait for another relative to take his place, then go home, bathe and change into his school uniform. He often arrived at school late. If a relative was not available to take his place by his mother's side, Chai had to take a day off school.

Chai missed many days of school in this way. In fact, his poor attendance record could have barred him from sitting the end of year exams, but his teachers were well aware of his situation and allowed him to sit the exams and move up into the next grade with the rest of his class. Chai's teachers was trained in counselling and sensitized to the problems of children affected by HIV/AIDS through the Child Friendly Schools Program.

"My Family" drawn by Ace,13. Ace's mother and stepfather both have AIDS. "In the picture ... I'm taking care of my stepfather who is sick. He has AIDS. ... My friends are playing in the yard ... I want to play with them but I can't."

Some Sample Projects

Thailand's Area-based Response

In 1998, UNICEF Thailand launched a new project to make three districts in the North of Thailand into models of cooperative, community-led response to the problems of children affected by HIV/AIDS.

The districts selected were all in the badly affected Upper North: rural districts with high numbers of affected families along with some known level of commitment and activity in the area of affected children. They are Mae Chan, Mae Ai and San Pa Tong. Mae Ai is home to large numbers of ethnic minority "hilltribes".

The first stage was to create district teams for children affected, comprising district-level officials from the local administration, health, social welfare, community development and education sectors, along with other local people known to be particularly active or influential. Among these were some teachers, police officers, monks and elected members of sub-district administrative bodies (TAOs).

UNICEF supported child rights sensitization for the district teams.

The project in each district is run by specially created committees, which hold monthly planning meetings. As the projects respond directly to local priorities and needs, they have each taken on very different characters. The Mae Chan project is run mostly by health staff, who make use of their existing networks and contacts with local people. In San Pa Tong, the most active group is a local NGO called Women Against AIDS, working chiefly through the local temple and school, though TAOs are likely to play a more active role in the future. In Mae Ai, the district team itself is the driving force behind the project.

Women Against AIDS

Women Against AIDS (WAA) , in San Pa Tong district , Chiang Mai, delivers community-based care for women and children affected by HIV/AIDS.

WAA has a team of trained volunteers, most with HIV/AIDS, providing a variety of services: direct support, counselling, scholarships etc. In addition, WAA:

- Helps identify, trains and supports alternative carers for affected children;
- Provides income generation opportunities for families caring for orphans of AIDS;
- Encourages partnerships between community-based organizations, local officials, health staff and community leaders.

WAA has also recently:

- Set up a database of affected families and children in San Pa Tong, to be updated through volunteers' surveys;
- Identified a lawyer willing to provide free advice and support to affected women and children on ensuring they are not cheated out of their rightful inheritance;
- Held a workshop to sensitize community leaders about child abuse and discuss ways they can intervene. This is important for protection of affected children.

Who Are Orphans?

UNAIDS, WHO and UNICEF define AIDS orphans as children who lose their mother to AIDS before reaching the age of 15 years. .. Because reliable data on the number of orphans are not available in many countries, the orphan statistics used by UNAIDS and UNICEF do not include children who have lost only their fathers.

from *Children Orphaned by AIDS*

"We've found income generation schemes have worked well with elderly carers, who are happy with small-scale projects like raising a few ducks and chickens or a pig. They have those farming skills and they make a success of it. Often, it's younger people in these village income generation schemes who have ambitious money-spinning ideas that they can't see through."

– Ben Sawasdiwat, Women Against AIDS

A substantial part of project funds each year has gone into direct support for children affected. These funds are channelled through the district committees, who give it to the most deserving cases they have identified. Direct support is to be gradually replaced by livelihood support.

One of the main strengths of the project was that it built on existing commitment, networks and activities. It has also taken advantage of some existing UNICEF-supported projects, particularly Child Friendly Schools (see p. 16).

Temples Join the Response

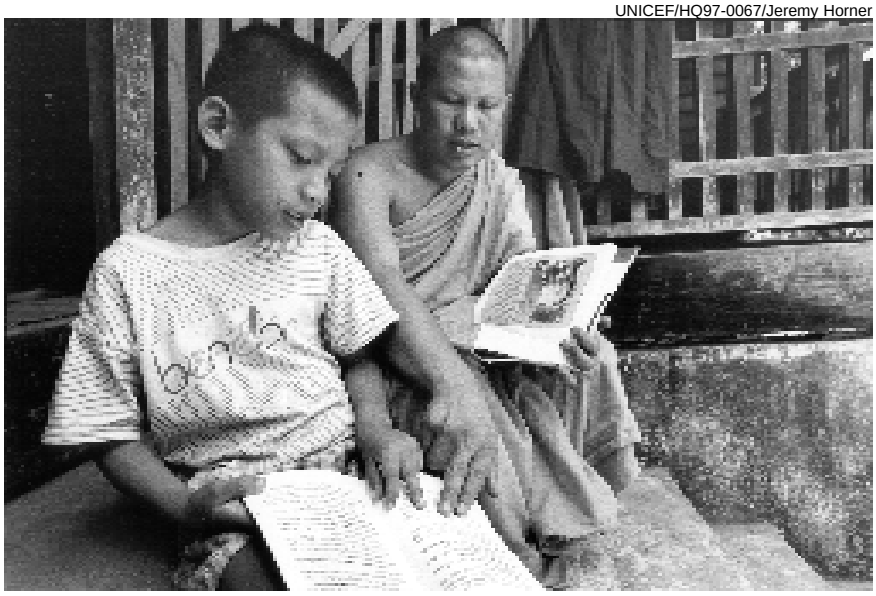
Temples are one of the pillars of rural communities in the mainly Buddhist Mekong subregion. They are the community's social hub and spiritual heart, a haven for those with nowhere else to turn. Buddhist monks and (to a lesser extent) nuns command respect as spiritual and pastoral advisers. Temples can be powerful allies in the response for children affected by HIV/AIDS.

Sangha Metta is a UNICEF-supported project that breaks new ground, helping monks and nuns join in the HIV/AIDS response. The project (whose name links the Buddhist virtue of compassion – *metta* – with the world name for the Buddhist institution of monks) is based at Thailand's Mahamakut Buddhist University, and trains monks and nuns in HIV/AIDS awareness-raising, participatory rural appraisal and other useful skills. It also supports their own initiatives in their home temples.

Using what they have learned through their training and experience exchange, Sangha Metta monks and nuns help community leaders to assess and plan for the impacts of HIV/AIDS and organize a range of awareness-raising activities.

Public donations to the temple are being used to give scholarships or material support to families affected by HIV/AIDS. Temples are striving to become "AIDS friendly" and to bring temple schools, where many poor, abandoned

UNICEF/HQ97-0067/Jeremy Horner



A nine-year-old boy orphaned by AIDS studies with a Buddhist monk who is his teacher and surrogate father.

and orphaned children receive their education, in line with the national Child Friendly Schools Program (see p. 16).

Sangha Metta's network already includes temples all over Thailand and in Myanmar, Lao PDR and Yunnan province in China. Contacts have been made with temples in Cambodia, Viet Nam, Malaysia and further afield.

Continuing Care from Siam-Care

The work of Siam-Care, an NGO based in Bangkok, is a good example of comprehensive and continuous support for children affected by HIV/AIDS, achieved through cooperation with a multi-sectoral network.

Hospitals and health clinics in Bangkok, where many people are first generation migrants, refer HIV-positive pregnant women and new mothers to Siam-Care. Siam-Care provides counselling and HIV/AIDS education. It provides practical support (such as helping the mother or her partner to find income), information on how to stay healthy and treat illness, temporary accommodation, and introductions to other people with HIV/AIDS.

Siam-Care also helps the mother to plan for the child's future as early as possible. Often, mothers who have left a home village fear that if they return they will face discrimination; however, the alternativere is to grow poor and sick in Bangkok without support. Siam-Care helps mothers re-establish contact with their relatives, who can care for her when she is sick and take over care of her children. Siam-Care also provides counselling and support for orphans' new carers.

When the mother returns home, Siam-Care provides scholarships for children's education and care, and uses local health facilities, officials and NGO partners to monitor the family's progress. Where a school is not happy with taking an affected child, Siam-Care will talk to school administrators.

UNICEF/HQ97-0080/Jeremy Horner

An HIV-positive man sits beside his wife and their 10-month-old baby. The wife and baby have not been tested for HIV, fearing they might be positive

Lek and Bomb

The story of Lek and her son Bomb illustrates the type of continuous support Siam-Care provides:

Lek found out she was infected with HIV one morning nine years ago, when she was selling noodles at her stall. Five uniformed health officials sat down and asked her to join them. They told her that her ante-natal blood test had come back positive. Lek was shocked – and so were the other customers, who overheard it all.

Lek and her husband were forced to leave her husband's village, and in desperation came to Bangkok. A hospital referred them to Siam-Care. Siam-Care helped Lek's husband find a job so Lek could stay home and look after her newborn son, Bomb.

When Bomb's father died a year later, Lek's mother asked her to come back to her home village. Siam-Care kept in touch with the family. When Bomb started school (after Lek had already succumbed to AIDS), Siam-Care provided a scholarship.

Now Bomb is in Primary Grade 3, and doing well.

Estimating Numbers of Children Affected

Trying to get even a rough idea of the number of children affected by HIV/AIDS in most cases relies a good deal on "guesstimation". The most reliable figures (notably those arrived at by the US Agency for International Development and UNAIDS) are those for the number of children already orphaned by AIDS. These are based on the number of AIDS deaths among women of reproductive age and fertility rates. We can also predict how the number of orphans will rise based on our understanding of the current epidemic and its likely course.

However, these figures are subject to inaccuracy, and are most valuable as advocacy tools. This inaccuracy reinforces the need to improve HIV surveillance and correct diagnosis and reporting of AIDS in all of the Mekong countries apart from Thailand.

Below is the formula used by a USAID-supported research team to estimate numbers of children orphaned by AIDS in 23 countries:

Formula for Estimating Numbers of Living AIDS Orphans

AIDS deaths among WRA	X	Fertility rate	▪	No. of children orphaned by AIDS	▪	Deaths from MCT	▪	Deaths from other causes	=	Total number of AIDS orphans

WRA = women of reproductive age (18–49) MCT = mother-to-child HIV transmission

From *Children on the Brink*

The Global Orphans Project

The problem with only looking at the number of children orphaned by AIDS is that it ignores those children whose parents have HIV/AIDS. In 1998, the Global Orphans Project carried out an international study to estimate more accurately the number of children (under 14) affected by HIV/AIDS in Thailand.

The study recognized three categories of risk: tertiary (children whose mothers had already died of AIDS), secondary (those with mothers now showing AIDS symptoms) and primary (with mothers living with HIV but not yet showing symptoms). The basic steps are:

Tertiary risk:

1. Estimation of the number of women of reproductive age who had died from AIDS, 1984–98;
2. Estimation of the number of children under 14 (in 1998) who were born to women in the first category;
3. Adjustment to account for child mortality (including paediatric AIDS deaths).

Secondary risk:

1. Estimation of the number of women of reproductive age living with AIDS in 1998;
2. Estimation of the number of children born to these women;
3. Adjustment for child mortality (including paediatric AIDS deaths).

Primary risk:

1. Estimation of the number of women of reproductive age living with HIV but not symptomatic in 1998;
2. Estimation of the number of children born to these women;
3. Adjustment for child mortality.

The study used raw data from the Thai Ministry of Public Health, and made adjustments guided by some earlier studies of under-reporting in Thailand.

Results of the Global Orphans study for Thailand

Children With HIV/AIDS

Only a small number of children affected by HIV/AIDS are infected with the virus themselves. About half of those born with HIV will develop AIDS rapidly and die before they turn two years of age; the others will not develop full-blown AIDS for years.

All children have the right to life, survival and development. We must therefore speed up our primary prevention activities as well as prevention of mother-to-child transmission to stop children becoming infected in the first place.

For those children who, in spite of prevention activities, become infected, efforts should be stepped up to guarantee that their rights to education, family care or appropriate alternative care, the best available health care, freedom from discrimination, an adequate standard of living and protection from abuse, are all being respected.

Life Beyond Choosing

My daughter was five years old in 1996. She was often sick. She had fevers every evening. She went to hospital so often that she wondered why she had to take medicine all the time. Why didn't her friends have to go to the hospital? I couldn't answer. Even though she was sick she wanted to go to school. She woke up early and got dressed. I didn't know what to do but prepare her medicine to take to school.

My daughter was talkative. Many times she talked about her future while lying in the hospital. She said she wanted to be a singer. ... Whenever I heard my daughter talking about her future, I secretly shed tears. I knew it was impossible ... but I couldn't destroy the dreams of my innocent child. ...

It is now a year and eight months (since she died) but she is still always in my memory. The more time passes the more I miss her.

From "Life Beyond Choosing" by Lamai Dechabun, in *AIDSNet Newsletter* Vol. 1 No. 1

Care for Children with HIV/AIDS

The Royal Thai Government has recognized that children with HIV/AIDS should be guaranteed the same rights as those who are not infected. Thailand's law protects these rights.

Most children with HIV/AIDS in Thailand are being cared for by their immediate or extended families at home. A much smaller number are being cared for in institutions, and efforts are being made to place them in adoptive or foster care. At the moment, there are some expatriate adoptive families and it is hoped that there will be more local families willing to adopt children with HIV. A recent case in which a Thai family fostered a child with HIV for the first time turned out to be a huge success.

Efforts are being made to ensure that those children still in institutions receive the same care as their non-infected friends. They participate in the same activities, eat together and are encouraged to play together.

A Mother's Story

My name is Kry Chanthy. My husband died of AIDS last year. I am HIV positive. I was married in 1993 when I was 20. I adhered to Cambodian traditions and saved myself for my husband before marriage and remained loyal to him throughout...

Our son was born in 1994. When he was one year old, he was often sick ...The hospital ran many tests and concluded that my son was infected with HIV. He was immediately sent out of the hospital.

My husband was also often sick and I begged him to go for testing. He ignored my pleas at first; however, he finally agreed to be tested. When he learned that he had HIV, he cried... I took care of my husband ... until he died last year.

I take care of my son throughout his many periods of illness. He is a good boy, very friendly, very clever. He brings me much joy – and great sadness. ... I am an orphan so I have no family to turn to. Who will care for me and my son when I can no longer care for myself?

I believe it is important to share my story with others. (It) helps (others with HIV/AIDS in the community) accept their illness and see that is is possible to continue doing things.

My message to government: Please help us. My message to the people of Cambodia: please don't bring AIDS home.

Told by Kry Chanthy of the NGO WOMEN at the National Workshop on Women and AIDS in Cambodia, December 1999

Cambodian Options

Responses

- Increase community prevention education;
- Start destigmatization activities;
- Increase community access to testing and counselling to assist families in obtaining appropriate treatments (not spending all family finances trying to "cure" AIDS);
- Introduce PFMCT programs;
- Scale up interventions;
- Mobilise communities
- Provide legal protection to ensure inheritance by orphans;
- Build capacity of Monks and Pagodas.

(Suggestions made by survey participants in the KHANA report)

The problems faced by children affected by and infected with HIV are becoming highly visible in Cambodia. The Ministry of Social affairs has noted an increase in the number of children admitted to government centres all over the country, whose parents have died of AIDS. Many other children are being cared for by relatives. Some are cared for by monks in Buddhist temples. Others are on the streets. NCHADS estimates that there are currently 40,000 children orphaned due to AIDS in Cambodia.

The solutions are not so clear. Recently, the Khmer HIV/AIDS NGO Alliance conducted a qualitative appraisal of Children affected by HIV/AIDS, interviewing 900 people including 413 orphans. Preliminary findings showed that the majority of adult participants suggested that orphanages were 'the answer'. The orphans interviewed felt that a family environment was preferable.

Home Care teams[1] have been finding "huge numbers" of orphans in communities. In the course of an evaluation, the teams reported on 100 patients with children. Of these children, half to a third were disadvantaged by their parent's illness: 21% of children had had to start working since the parent's illness, 30% were providing care, 40% had to 'go without' things, 40% had to leave school and 28% had to leave home.

Orphanages

In Cambodia, many government orphanages were set up to respond to the emergency conditions in 1979, when there were large numbers of orphaned and displaced children. There is a government orphanage in every province in the country. Government orphanages have been augmented by a number of private institutions run by NGOs and charities. The KHANA report estimates 21 children's centres in Phnom Penh alone, caring for 1798 orphans.

A factor contributing to the perception of orphanages as a solution for children affected by HIV may be the high rate of overseas adoptions. In 1999 the US Embassy alone approved 240 visas for adopted Cambodian children (*Phnom Penh Post, May 26-June 8, 2000*).

Children infected by HIV present a difficulty to advocates of orphanages as these children can require constant medical nursing care. The management staff of the Nutrition Centre, a government orphanage in Phnom Penh, have noted with concern the increase in HIV positive children in admissions to the Centre.

Children infected with HIV

Numbers of new admissions of HIV positive orphans to a Government Centre in Phnom Penh increased from 17 children in 1996 to 48 in 1999. HIV positive children are generally not available for inter-country adoption as many countries and individuals will not accept an HIV positive child. As the children become sicker, they need more and more intensive care. In an institutional environment with limited resources, babies, two, three, four and five year olds can die after months of suffering and illness with insufficient individual care.

For Affected Children

The number and condition of these children, and the resources required to care for them constitute a powerful argument for the widespread start of PFMCT Programs; better prevention programs for women of reproductive age and improved care and support through capacity building for communities and GO and NGO workers alike.

Alternatives to Institutional Care
The Cambodian Government acknowledges that it is in the best interests of the child to stay with their extended family or community. Despite stigmatization of HIV/AIDS, the majority of children affected do stay in their community and only those who have no alternative or whose relatives are too poor end up at orphanages. Currently, the Government can provide for children in orphanages, at a rate of US $4 a month. Non-Government organisations provide the only financial support for families caring for orphaned children. In year 2000, NGOs provided support for thousands of these orphaned children.

Models of Care
At present one government centre in Battambong has moved to a house parent model of caring for children with assistance from an NGO. This centre also utilises foster families. NGO centres are more likely to focus on re-integration of children into communities, offering counselling, educational and vocational training and income generation schemes for carers or foster families. Such centres have been devoted to reintegrating street kids, sex workers and trafficked children. Many of these NGOs, such as AFESIP and Krusar Thmey, are now finding they have HIV positive children and youth in their care.

Obstacles to Community Care
As a result of war and limited life expectancy there are fewer older people left in Cambodia than Thailand. While grandparents are deemed the best carers, children often end up with other relatives with limited resources and, in some cases, are exploited for their labour. Parents may themselves be orphans or have been displaced from their community of origin. Poverty means that it is hard for relatives to take more than one child, yet fertility rates in Cambodia are high (4.1) and orphaned families of four and five siblings are common. Foster families and local adoptions are rare.

NGOs facing HIV/AIDS infection in Children
NYEMO, a French NGO providing support/vocational training to sex workers, many of whom have young children, now has a number of young women with HIV. Kruasar Thmey, an NGO which run 3 residential centres for children in provinces, two reception centres in Phnom Penh and group homes for homeless children has also noted a number of children with HIV coming into its centres. Initially some children were tested but this resulted in stigmatisation so this is no longer done.

This information emerging from Cambodia constitutes a call for action by community, government, NGOs and UN agencies.

[1] Dissemination of Findings of An Evaluation of the MoH/NGO Home Care program for people with HIV/AIDS supported by the International HIV/AIDS Alliance, Thursday 25 May, Phnom Penh

Pagodas

The Role of Monks

A recent sub-regional seminar of Buddhist monks provided Cambodian monks with an opportunity to reflect on their role in relation to communities affected by HIV/AIDS . The monks clearly demonstrated their commitment and potential to assist local communities struggling with HIV/AIDS.

Monks' Care & Support

- setting an example of anti-discrimination,
- caring for the sick through hospital visits and home visits
- sheltering orphans.
- counselling
- training in Dhamma and meditation

Obstacles

- Need for further training on HIV/AIDS and related opportunistic infections;
- Need to build skills and capacity in pagodas;
- Need for government ministries to support and encourgate involvement of monks in AIDS interventions.

Networking and Liasion Secular and Religious:
Monks said they needed support from many sides, including:

- local authorities, schools and hospitals.
- nuns who could reach young women with prevention messages, care for sick women and teach and care for orphaned girl children.

Lao communities & families

Affected Families Care & Support Project

The Lao Youth Union, with the support of the Provincial Health Office and the Provincial AIDS Council, has proposed a plan for a UNICEF funded project in care and support in Savannhakhet Province.

This includes:

- home-visiting affected families;
- income generation schemes for families;
- scholarships for affected children; and
- capacity building for people living with HIV/ AIDS, traditional doctors and Governement and Mass Organisation representatives.

Savannakhet, a province bordering Thailand, has one of the highest rates of HIV/ AIDS infection in Lao PDR. Currently the Ministry of Health in Savannakhet has contact with ten affected families, in most of these, children have lost at least one parent to AIDS.

Orphans in Savvanakhet are generally cared for by members of their extended families. A survey of village head men in Savannakhet over 1998-99 reported 4,111 children who had lost at least one parent from a variety of causes, and 772 children who had lost both parents. Over the past two years only 5 of these children were sent to an institution, the nearest one, Pakse Children's home in Champassak Province, after the Ministry had been notified by village headmen that the children were living with relatives who were unable to care for them or pay for schooling.

Support for community care

While community care through the extended family is the norm for orphans in Laos there are no government mechanisms for supporting these children apart from provision of clothes, blankets and school supplies, supplied by the Ministry of Social Affairs or through the Lao Red Cross. The main role of the Ministry to date has been in emergency relief such as fire and floods.

Main problems for orphans cared for in extended families

Maintaining their school education and, in some cases, labour exploitation were perceived as major problems faced by orphaned children in Savannakhet Province.

Children were often unable to continue in school as there was no-one to pay the fees or for books etc. In some cases they were treated coldly and had to work hard in difficult conditions as relatives grudging required that they earn their keep.

Schooling problems for orphans were compounded by the fact that small villages often only had grades 1-2, so children had to travel further for higher grades. Children who lacked parental support and transport to attend school up to four kilometres away were often absent, (particularly in the rainy season,) fell behind, performed poorly and became too ashamed to resume schooling.

However, in some cases, orphans were perceived as achieving a better life rather than a worse one, as in the case of orphans adopted by childless relatives. It is a mistake to assume that familial adoptions inevitably disadvantage children. In Lao PDR and neighbouring countries, there is a long tradition of childless relatives bringing up one or more children from a family with too many children.

care for orphans...

The Impact of HIV/AIDS on Children
HIV/AIDS affected families in Savannakhet have encountered some problems including familiy break-up, with siblings going to different homes and children developing behavioural problems. The two family case histories on this page represent two extremes of the many different outcomes possible for children in extended family care.

Khoumkeo's Family
Khoumkeo and her husband and family lived in Phonsavanh village. Phomma, Khoumkaew's husband had been to Thailand. While Khoumkao was still alive she faced some discrimination from her neighbours. Now, both she and her husband have died from AIDS and left five children orphaned - the eldest child is19 years old. The children are being cared for by their 74 year old grandmother. Khoumkeo's brother is a worker and his wife sells meat at the morning market. The children's food is meat left over from sale.

Currently, three of the five children are still living with their grandmother. The second eldest didn't want to study, dropped out of school and went to live with his father's parents in Atsaphangthong District. The youngest aged 13 went to stay with her step sister (from Phomma's first marriage) in Sekong province. The children, who were born before their father became infected, were all tested for HIV but were found negative. The three children living with their elderly grandmother have started to have problems in their daily life. The grandmother isn't able to discipline the children who don't listen to her.

Dai's family
Dai is 26 years old. She lives in Pakkha village. Her husband died from AIDS. Dai contracted HIV from her husband. Both she and her husband had worked in Thailand. She has a 2 year old child who is currently under observation to see if she has infected HIV from her parents. At the moment the child is living happily with her uncle (Dai's brother) who has a close and warm family and can support the child if Dai dies.

In Lao grandparents and older relatives care for children when parents are absent, ill ,or have died.

Sibling Support

Children who lose parents, often lose brothers and sisters, and neighbours and friends too, as families are split up and moved around to be less of a burden on relatives. In countries like Lao PDR and Cambodia, big families are not uncommon.The break-up of the family may begin with the mother's death.

"When the mother dies, the father is often unable to care for kids and families have to be split up" said a Lao Youth Union representative for Savannakhet.

This may have an impact on children who are seperated from their siblings. From African experience, it seems that sibling support is a significant force for family survival.

Vietnam: street children

Street Children

Numbers of street children are growing in Viet Nam. The rapid development of industrial and tourist areas combined with other factors, such as break down of traditional family structures and poverty, is drawing youth away from their homes in poor rural provinces. The Viet Nam committee for Protection and Care of Children reported 21,400 street children in 2000, concentrated in the two major cities of Ha Noi and Ho Chi Minh City. Around half of these young people use drugs, (a bit less than half of young drug users inject heroin) and about 40% are sexually active: as sex workers, in relationships and in some cases sexually abused.

Children have tested HIV positive in Government Rehabilitation Centres, Reformatory Schools and Social Protection Centres. In April 1999 Reformatory School No. 2 tested 276 students who engaged in high risk activities: 49 were HIV positive. In 2001, out of 400 students tested, 78 were HIV positive. In 2001, at School No. 4, of 150 students engaged in drug use and prostitution, 75 were HIV positive.

Currently, children affected by HIV in Vietnam present a rather different profile to those in other countries in the region. The most visibly affected children fall into two groups, street kids and children in conflict with the law, who acquired HIV infection through intravenous drug use and sexual transmission; and, babies abandoned in hospital by their HIV positive mothers. (Of course, not all these babies will turn out to be HIV positive). Because these two groups of children have high rates of HIV infection and are often in state care to begin with, they are visible and prominent. Most government policies to date have focused on services to such children in institutional care in urban centres. The process of developing community and family support in rural villages is just beginning.

Institutional Care

There are a number of government institutions involved in the care of orphans and street children, these include Reformatory Schools run bythe Ministry of Public Security, and Social Protection Centres administered by the Ministry of Labour, Invalids and Social Affairs (MoLISA). There are 290 Social Protection Centres caring for 10,787 children nation-wide. There are also ten SOS children's villages[1], offering a family-like environment in which children are cared for by "mothers' in families of seven to nine kids. SOS villages now care for about 1,400 children at a cost of 200,000 VND a month but have been reluctant to take HIV positive children. There are also some social organisations caring for HIV positive and HIV affected children on a small sacle.

One major problem facing HIV positive children in institutions is the budget for health care which is inadequate for the treatment needs of children with AIDS. Children and youth in rehabilitation centres generally have their sentences reviewed in the light of their health. Sometimes they are sent back to hospital or to their communities for care at home, once they become sick. In one recent case a boy had to be returned to the centre after his father refused to care for him at home.

In Vietnam, as elsewhere, institutions solely for children infected with HIV have been considered by government.The model of an institution exclusively for children with HIV/AIDS has been hotly debated and has not been widely applied.

The Go Vap child Care centre in Ho Chi Minh City cares for 22 HIV positive children. Go Vap makes the following recommendations for care of HIV positive children:

- There must be no discrimination.The childen must be cared for and loved, able to live in the same centre with normalchildren.
- They enjoy playing, entertainment, clean and ventilated rooms.
- Food must be nutritious and suitable to their age group.
- Their health must be checked regularly.
- Avoid other people's discrimination, so that children are not upset about their health conditions.

1 From 1987 SOS Kinderdorf International has worked with the government to set up SOS children's villages and schools in Vietnam.

and abandoned babies?

Community Care
Around 32,916 orphaned children are reported by MoLISA to be living in communities along with a surviving parent or other relatives. Displaced orphans in communities are entitled to an allowance of 24,000 VND a month. Government legislation states that displaced orphans and children in difficult circumstances are supported by the state to achieve primary education.

While the Vietnamese Government has had a longstanding commitment to the care and education of orphaned and disabled children, there are currently no regulations regarding those in this group who are HIV positive. Some of these children are of school age and need to be educated. Until recently, most (known) school age HIV positive children in state care did not attend regular schools due to both reluctance of schools to accept HIV positive children on the part of school and the health status of the children. However, advocacy efforts from UNICEF are now helping some children to access mainstream education.

In August 2001, UNICEF, Viet Nam organised a two-day workshop in HCMC on developing a model framework for community and family care and support for children/adolescents who were HIV positive or affected by HIV/AIDS. Participants came from different sectors such as Women's Union, People's Committee, Education, Health, Protection and Care for Children at district and commune levels. Participants shared experiences on the topic, worked in groups to develop a model for care at community level, and used the model to prepare action plans for each participating district.

Viet Nam is beginning to prepare communities to care for their own children with HIV. It is clear that ongoing anti-discrimination programs in communities, schools, teachers colleges and health and welfare institutions are needed to counteract prevailing myths and misunderstandings around HIV transmission and HIV positive people.

HIV positive children in Go Vap Children's Centre

Infants in Children's Centre

Abandoned babies

In 2000, in Tu Du Hospital Ho Chi Minh City, 50 HIV positive new borns were abandoned. Of 116 children with HIV/AIDS in Children's Hospital No 1, only 39% were cared for by their parents. In Hai Phong city from 1998 to April 2001, 47 babies were born to HIV positive mothers and abandoned in Hospital.

Initially some orphanages refused to receive babies of HIV positive mothers on the grounds that HIV positive babies need health care and special treatment that their staff were not able to provide. Now there are several orphanages which accept infants born to HIV positive mothers including HIV positive and negative infants.

Government Policies on care of children with HIV or affected by HIV

In Myanmar, the National AIDS Program aims to increase the awareness and perception of HIV/AIDS in the community by promoting access to information and education leading to behavioral change and adoption of a healthy lifestyle... and to provide effective health care and counseling services for people with HIV/AIDS and to strengthen the potential of the individual, the family and community.[1] At present there are no government policies specifically relating to the care of children with HIV or affected by HIV.

[1] National AIDS Program, Ministry of Health, Department of Health, Myanmar

In Myanmar, as in other South Easrt Asin countries, traditionally temples have cared for orphaned boys, but here nuns are also active in caring for girls.

Myanmar - families, temples

In Myanmar, the extended family has remained largely intact, especially in rural areas. Usually children who have lost their parents are taken care of by other family members, including grandparents. There are no benefits available to families caring for orphans at home. Poor or orphaned boys are traditionally sent to monasteries to be educated. Nuns in Myanmar are more active in education and care for orphaned or disadvantaged girls than elsewhere in the region. As well as the mass ordination of boys for a short novitiate over the summer holidays, (common to Buddhist countries in the region), girls in Yangon secondary schools are also encouraged to ordain as nuns, with up to 500 girls from key schools ordaining at a time.

Social Welfare Provision for Orphans

The Department of Social Welfare or DSW, is the key government department responsible for provision of social welfare services in Myanmar (currently under the Ministry of Social Welfare, Relief and Resettlement). Services include institutional care for orphans, abandoned, destitute, street children and children in conflict with the law. The Department of Social Welfare (DSW) runs six residential nurseries, which provide care for orphans, abandoned and destitute children of both sexes ranging from the newborn period up to the age of five.

At five years of age, these children are transferred to single sex training schools, where they are live together with street children, destitute children and children in conflict with the law (up to age sixteen). The DSW operates eight training schools (of which six are for boys and two are for girls).

Apart from the above, there are institutions run by voluntary organizations, including religious organizations such as church groups, Buddhist monks and nuns and private community based organizations. Institutions with a capacity of more than 50 children need to be registered with the DSW and are subsidized for the cost of rice, clothing, and salary of the warden. The subsidies vary according to the number of children, the resources available, and recommendations made by the respective State and Divisional Social Welfare Officer. A supervisory committee has to be formed in each institution in accordance with the rules and regulations laid down by the DSW in order to provide effective care services. As of December 2001, there were about 142 institutions run by voluntary organizations and registered in DSW, which accommodate about 7730 children. Of those, 5580 are orphans.

A number of institutions caring for less than 50 children, such as small group homes or orphanages run by a single monk/nun or a group of monks/nuns or interested individuals who are keen to help and assist needy children are now emerging due to an increase in the number of orphans or destitute children. Even though they call themselves orphanages, only about 0.7% of the children in these institutions are full orphans. The rest are children from single headed families or children from the poorest families. There is no systematic study or registration system in Myanmar of this type of institution. The exact number of children who benefit from this type of homes or orphanages is difficult to estimate.

& welfare institutions provide...

There are also institutions run by the Department of Progress of Border Area and National Races. These are government institutions for orphans and destitute children from various ethnic groups from border areas. Most of these institutions are situated in remote border areas. The children there are provided with formal education as well as vocational education. As of 2001 December, there were altogether 17 institutions, which accommodated about 1700 children.

Almost all the institutions run by the government as well as non-government organizations are of the dormitory type. The institutions run by the government are closed or semi-closed, whereas the others tend to be institutions of the open type.

In Myanmar, institutionalization is usually seen as a measure of first choice where destitute children are concerned. Alternatives to institutional care for orphans, such as fostering programs, group homes and outreach/ community support are not yet policy or practice of the government. Only one INGO, World Vision, has initiated a fostering program and an outreach community support program. The DSW offers adoption services for children under 5 who are under the protection and care of DSW residential nurseries with the aim of enabling these orphans to grow up in a family, according to the provisions under 'Registration of Kittima Adoption Act' of 1941. The practice of international adoption has been suspended for a number of years. Myanmar has not yet signed the Hague Convention on Inter-country Adoption.

Families in Myanmar continue to be the the major care providers...

Study : Impact of HIV/AIDS on Children

The Ministry of Health has approved a UNICEF Myanmar proposal for a qualitative assessment to be conducted by Research Officers from the Department of Health Planning and Yangon University. The study will be carried out in 3 sites: Dawei, Myitkyinar and Monywa, using key informant interviews, in-depth interviews of affected family members and focus group discussions. This year long study aims to: assess situation of children affected; measure effects of HIV/AIDS on children; and identify infra-structures and networks, and their roles in supporting affected children. The proposal has been approved by the Ethical Review Committee at the Dept of Medical Research at Yangon University and is scheduled for completion early in 2003.

Fostering and big familes...

Children and mothers in PNG

Mary

Mary had six children, many grown up, and two younger ones: a girl, 12 years and a boy, who is 10 years old.

Mary died in November from AIDS. Her husband and three other wives also died from AIDS. Mary had TB and other HIV/AIDS related symptoms.

The children are caught between the different auntie's and uncles. None of them want the burden of an extra two children so these two stay with one group during the school week and with someone else during the weekend. The children are not happy with this arrangement and they seems to wander the streets a bit too much. SCC organized school uniforms for them and will continue to watch over them and assist them throughout the year.

Neglect

Neglect-often an unintentional result of family circumstances such as relatives caring for orphans having to work harder and longer hours to provide for bigger household - is emerging as a problem for orphans elsewhere in the region. The lossof regular, ongoing, personal adult protection and attention seems to be among the things it is hardest to compensate for.

Papua New Guinea, has highest rate of mother-to-child transmission in the region at10.5%, and the highest incidence of reported cases of HIV in the Pacifiic Region. Latest National AIDS Council figures show at least 100 reported infections a month, a quarter of them mothers diagnosed with the disease at ante-natal clinics *(Papua New Guinea Post-Courier 13/3/ 2002)* Big families are common in PNG, as is polygamy. There is a great diversity of cultures, with over 800 languages spoken. At the same time PNG is a country in transition from rural to urban, from subsistence farming to a market economy....

Traditional adoptions

The adoption of children by couples who cannot have children of their own is practiced in all PNG societies, commonly among close relatives. Orphans come under the same traditional adoption and care system. In this situation a close relative of one of the deceased parents tacitly assume full responsibility of the care of the orphan. This traditional system is becoming more sophisticated in urban centers of PNG. Relatives in these areas, formally adopt children from the extended family system, using legal facilities offered by the Social Welfare Department.

Government policies on orphaned and abandoned children

The Government has a policy of fostering children who've been abandoned or orphaned. There are no orphanages in Papua New Guinea. Foster parents can adopt children after they have been vetted and approved by the Director of Social Welfare. In this system, adoption is always supported by comprehensive legal documents. However, these official cases represent a miniscule proportion of all so called "adoptions" that go on all over the country. In rural communities informal adoption of children from the extended family system is the norm.

Problems with adoption

There are also some problems with adoption, including in urban areas with proper, legal procedures, as abuse is very common. These abuses and depravations can take many forms, ranging from taking children out of school to sexual abuse. Cases occur where children adopted outside their families are never again allowed to return to their natural family, even for short visits.

HIV/AIDS and adoptions

The advent of the HIV/AIDS epidemic in PNG has derailed the adoption of children within the extended family. The stigma associated with AIDS in many communities affects both people living with HIV and their children. Children, who are orphaned by AIDS do not enjoy the same traditional care or outright adoption as practiced in PNG societies today. In many cases the immediate family members abandon these children irrespective of their HIV/AIDS status. If the child is suspected of being HIV positive, the situation is still worse.

There are no other government welfare provisions for orphans other than families or fostering/adoption. Before Independence in 1975 and for a

...in Papua New Guinea

few years after that, the Government provided families caring for orphans with financial assistance called 'child allowance'. Basic food rations like rice, tin fish, sugar and tin meat were also given. Currently there are no such benefits.

Policy on Children Affected

A draft Government policy on HIV/AIDS has been drawn up by the National AIDS Committee, but no provision was made in the policy relating to care of children with HIV/AIDS or affected by HIV. However a recent review of the Child Welfare Act by the Social Welfare Division in collaboration with UNICEF, includes a section that deals specifically with care of children with HIV/AIDS or affected by HIV.

NGOs caring for orphans and children affected by HIV/AIDS

There are no private children's homes in PNG. The charitable institutions that come closest to caring for orphans are the City Mission which cares for street boys, and a Half-Way House that rehabilitates ex-prisoners. The Salvation Army provides temporary accommodation for battered wives and their children.

The Simon of Cyrene Centre (SCC) is run by the Catholic church and conducts a range of programs in AIDS education and care, including: awareness programs, counselling (STD's / HIV: pre-test, post-test) on going counselling for people living with HIV/AIDS and their family and friends; food and nutrition, medical examination & medication at St. Therese Clinic, referrals to Port Moresby General Hospital, hospital visiting, home care for people with AIDS and their families, as well as orphan care. The case histories on these pages are taken from Father Jude Ronayne Forde's accounts.

Jenny

Jenny is from Kuriva, her husband was from Wabag. He died in 2000 of AIDS. Jenny is a Catholic and has a long relationship with the Church. Jenny was in Port Moresby General Hospital in 2001. She was in with TB but was not getting well. She had a HIV test but did not seem to get the results before she was discharged. When she returned to hospital, some 6 weeks later, she was informed that she was HIVpositive. It rocked her. Her main concern was for her four children.

She and her family are drifting. They have no set place of abode. Her husband's people should look after her but they are not doing so. She was not sure when she was leaving hospital as to where she was going to stay. She is still hanging in there with the Wabag's but they are not feeding her or looking after her. SCC has had the children there many times. When they come, SCC feeds them, washes them and their clothes and sends them home spick and span. Jenny sends them with a list of food she needs. These children are very well mannered, and have a charm and personality of their own. Jenny has not got long to live – maybe 3 months. Who will look after the children then?

.Martha and Anna...

Martha, had 2 adopted children. Her husband died of AIDS in 2000. She was in Port Moresby General Hospital with TB, there she tested positive for HIV. She died in October 2001. Of the two children, her youngest was taken back to the village. Her other girl, Anna was 12-yer-old. She nursed her Mother when Mum was dying. After Mum died, she was brought to SCC one day, by her auntie, who said: ""Her father and mother died from AIDS –test her!" The young girl was obviously suffering from this type of treatment. SCC did the test but she had no symptoms whatsoever. She did not get on with her uncle and cousins so she drifted into a house where two of her friends were living (adopted). That lady took her in. SCC wanted to get her into school. Her new family agreed that it would be good for her to go to school with the other girls. Her father, who had died of AIDS, had left some money so she got the money to go to school. Staff got the impression that the family house also belonged to Anna! No one was looking into protecting her property rights! She is half in and out of school at present but seems much happier. Centre staff meet her a few times a week and assist her in small ways. Sometimes she just pops into the Centre for a cold drink and a biscuit.

China - big numbers -

UNICEF China's "With Hope and Help" postcard features this cheerful man. A widower with four children, he is HIV positive and lives in Yunan Province.

In February 2002 UNAIDS/WHO estimated nearly one million adults and 7,000 children under 14 were living with HIV/AIDS in China. In 2001 alone, one and a half thousand children died of AIDS1[1]. In Yunnan it is estimated that at least 500 children have contracted HIV from their mothers. With an increasing number of women becoming infected without knowing their status and then giving birth, the number of HIV positive children is expected to increase. By 2010, the conservative estimate for Yunan is 16,000 children living with HIV, and 21,000 single or double orphans[2].

While China's success in family planning mean that fewer children will be born to HIV positive parents, existing institutions and services are insufficient to cope with a large and rapid increase in numbers of orphans, especially as currently children orphaned by AIDS are concentrated in poor, rural areas and among ethnic minorities where fertility rates are higher and facilities are fewer. . The case studies on the opposite page describe a number of families in Yunan with 2-3 children.

Existing forms of orphan care

Institutional care is well-established in China with over 47,000 orphans and disabled children in welfare institutions in cities and the countryside in China by the end of 2000. There also nine "SOS" villages completed or in the process of construction, taking in more than 900 healthy orphans. Overseas adoption is approved by the government subject to due processes. There are no national statistics on the number of children living apart from their parents in communities or non-institutional care. In rural areas it is still common for the extended family to take in orphaned children.

Policies on Children living with or affected by HIV/AIDS

China has not yet developed any specific policies for children orphaned by AIDS. However, existing policy in relation to peole living with HIV/AIDS can be assumed to include children living with HIV/AIDS. The "Principles for the Management of People Infected with HIV, and AIDS patients," was issued by the Ministry of Health in April 1999. It is intended to protect people living with HIV/AIDS, and to prevent HIV/AIDS from spreading. The regulations consist of various chapters:

(1) HIV test confirmation and counselling;
(2) Fight against discrimination and promotion of the rights of people living with HIV to study, work and receive social welfare ;
(3) Confidentiality of personal information related to people living with HIV and AIDS patients;
(4) Provision of appropriate medical care to people living with HIV/AIDS;
(5) Provision of education, support and social subsidy if needed;
(6) Provision in prison environments of education, medical observation and medical treatment, if needed outside prisons;
(7) Protection of HIV positive in-country migrant labourers, who should not be sent back to their place of origin without appropriate reasons.

The principles also consider punishment by law for people deliberately transmitting HIV.

[1]*Number from the Report of the People's Republic of China on the Development of Children in the 1990s, NWCCW May 2001*

[2]*Number from the draft report of THE LONG TERM SOCIO-ECONOMIC IMPACT OF AIDS ON CHILDREN AND POLICY RESPONSE IN CHINA'S YUNNAN PROVINCE, Dec. 2001, support by UNICEF*

from poor, rural areas

How villages are affected
The following village and case studies illustrate some of the problems HIV affected families face in the worst affected areas of Yunan.

'A' village in Ruili has a population total of 623: 302 men and 321 women. There have been a cumulative total of 26 HIV-positive people in the village: 24 men and 2 women. Between 1996 and 2001 twenty-one men and one woman have died, leaving behind one 13-year old orphan. Another HIV positive woman has become symptomatic; as her husband died of AIDS three years ago, their three children will become orphans if she dies.

'B' village in Ruili has a population total of 700 and has had 16 identified HIV cases in the village: 14 men and 2 women. Twelve men and one woman have died of AIDS so far, leaving two orphans.

'C' village in Ruili has a population total of 126 and 10 HIV positive members: one couple and 8 single men. Six of the men had died by 2001; the husband of the couple has already died and the wife has been sick in bed. They have two children.

How families are affected

■ " Lao Zhang ", 36 years old. Her husband was an intravenous drug user who contracted HIV through sharing needles. Lao Zhang became infected with the virus through her husband. The death of the husband three years ago has adversely affected the economy at home: her three school-aged children can't go to school because she can't pay for their books; the 13-year old son helps the family herd cattle and work in the fields. Now Lao Zhang has become symptomatic. She is suffering from fever, exhaustion, diarrhoea and other ailments. She has no income as she is n o longer able to work in the fields. She got a loan of 2,000 RMB last year to grow watermelons, but she was unable to pay back any money because of unfavourable weather conditions and poor prices. The rice yield was also affected by poor weather conditions, dropping to only a little more than 500 kilos last year. Rice-planting season has just started this year, but there is only enough grain in the house to sustain the family for two months. Lao Zhang has one older brother and one younger sister: her brother lives in Myanmar and her sister lives in the same village. Her father went to Myanmar long time ago; her mother is still alive. Her father-in-law already died and her mother-in-law lives in another village.

■ "Jingyi Da Jia ", 28 years old. Her husband who contracted HIV through injecting drug use died nine months ago, leaving her with one 13-year old boy and one 7-year old girl. She has been sick in bed with the virus for half a year, suffering from fever and loss of weight. She has no money for treatment or medicine; she has no money to buy rice and cooking oil. Her family now sustains itself on the charity of other villagers. Both her children can't go to school because she can't pay for the "books and other incidental expenses" for them.

■ "Huong", nine year old boy and "Hong", four year old girl. Both their parents died of AIDS, their father at the age of 28 and their mother at the age of 27. They have been under the care of their grandmother since the death of their parents. As their grandmother can't provide for both of them any more because of old age, this year their mother's sister become foster parent to the boy while the girl still lives with her grandmother.

(Case studies from interviews of people living with HIV/AIDS conducted in June 2001, by the research group, reported draft report of THE LONG TERM SOCIO-ECONOMIC IMPACT OF AIDS ON CHILDREN AND POLICY RESPONSE IN CHINA'S YUNNAN PROVINCE, Dec. 2001, supported by UNICEF):

Future studies and projects planned for 2002
(supported by UNICEF):

■ A special survey on the status and issues of children infected and affected by HIV/AIDS in Yunnan, Shanxi and Henan

■ Home-based Care for children infected and affected by HIV/AIDS, *(a cooperative project of UNICEF and Save the Children UK)*

■ Campaign to disseminate video to promote community support and care for families living with HIV : *"With Hope and Help" China*

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"My Home" drawn by Nik, 12, whose mother is HIV positive. "My mum used to sell noodles, but she doesn't do it any more... The owner of another shop said, 'Don't buy noodles from her or you'll get AIDS.'"

Resources on Children Affected by HIV/AIDS

Action for Children Affected by AIDS: Programme Profiles and Lessons Learned, UNICEF/WHO, New York and Geneva, 1994 (includes Thailand)

"Children in Families Affected by the HIV Epidemic: A Strategic Approach", Elizabeth Reid, Issues Paper 13, UNDP HIV and Development Program, New York, 1993 (reprinted 1997)

“Report on Young People's Voices on HIV/AIDS: A Communication and Development Workshop”, 16–19 November 1998, New Delhi, India, published by UNICEF and UNAIDS, 1999

The Impact of HIV on Children in Thailand, Tim Brown and Werasit Sittirai, East-West Center/Thai Red Cross Society/Save the Children (UK), Bangkok, 1996. In condensed and full versions.

Children on the Brink: Strategies to Support Children Isolated by HIV/AIDS, Susan Hunter and John Williamson, US Agency for International Development, Washington, undated

The Potential Impact of HIV/AIDS on Women, Youth and Children, by Sheldon Shaeffer,UNICEF EAPRO, 1994

Children Orphaned by AIDS: Front-line Responses from Eastern and Southern Africa, UNICEF and UNAIDS, New York,1999

Children Living in a World With AIDS, Guidelines for Children's Participation in HIV/AIDS Programmes, Children and AIDS International NGO Network (CAINN), 1998.

Children and HIV/AIDS, UNAIDS briefing paper for the World AIDS Campaign, 1999

Dream Diary (with illustrations by children affected by HIV/AIDS and others), AIDS Network Development Project, Thailand, undated

Newsletters

AIDSNet Newsletter, AIDS Network Development Project, Chiang Mai

Sangha Metta Newsletter, Sangha Metta Project, Chiang Mai

Websites

UNAIDS: <<www.unaids.org>>
UNICEF: <<www.unicef.org>>

Manuals and Videos

With Hope and Help videos, produced by Living Films and UNICEF, currently available for Thailand, Viet Nam and Lao PDR in English (subtitled) and Thai versions. Further films in production or planning for China, Cambodia and Myanmar.

With Hope and Help manuals for working with people living with HIV/AIDS, with communities and for self-care are available in Thai and English (for the Thai version of the video). Similar manuals are being prepared to link with the other country videos. Developed by UNICEF, with Bamrasnaradura Hospital, Thailand and the Albion Street Centre, Australia.

Taking Care of Your Loved Ones at Home: A Manual for AIDS Homecare and training curriculum, by Katherine Landfield for Medicins du Monde and the HCMC AIDS Committee.