

Supporting community action on AIDS in developing countries



## POSITIVE PEOPLE'S GROUPS:

The story of people living with HIV mobilising to improve their lives in Upper Northern Thailand

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**Front cover photo:** Peer educators at their office in Chiang Khong district, Chiang Rai

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# Summary

Nearly five million people live in the six provinces of Upper Northern Thailand: Chiang Mai, Chiang Rai, Lampang, Lamphoon, Mae Hong Son and Phayao. Most live in tight-knit rural communities. With little money and seldom more than primary education, they earn a living off the land or through other manual labour. Many migrate, seasonally and long term, in search of work.

In the late 1980s and early 1990s HIV spread rapidly throughout the six provinces. Although less than 8 per cent of the country's population live in the region, by 1992 it was home to over 50 per cent of Thais who had developed symptoms of HIV/AIDS. However, Positive People – people who know they are living with HIV/AIDS – did not find themselves in a supportive environment. Government policy focused on fear tactics and promoting condom use in the country's sex trade, and ignored the needs of people living with the virus. In the Upper North, increasing numbers of people fell ill and found themselves shunned by their communities and denied adequate medical care. Many died and many more suffered deep depression and withdrew from society.

But a few Positive People refused to be defeated by the virus. They established groups that fought for better care for men and women living with HIV/AIDS, and for an end to the stigma and discrimination that excluded them from their own communities. These groups followed a long-standing tradition in the Upper North, where people with similar interests come together in community self-help groups. Meanwhile, a few government and non-governmental organisations in the region, recognising that the epidemic could only be overcome by working closely with Positive People, began to offer these new groups technical and financial support and to advocate for a new national strategy.

In the mid 1990s, in recognition of the severity of the epidemic and in response to advocacy from concerned organisations across the country, national policy changed. Rather than being ignored or excluded through fear, people living with HIV/AIDS would be at the heart of the new strategy. Positive People would be encouraged to come together in self-help groups in every district,

and through these groups receive appropriate medical and psychological care. At the same time, ongoing training and education of communities and community leaders would combat stigma and discrimination. Although the strategy applied to the whole of Thailand, it has been most successful in the Upper North. By the end of 2005, 309 Positive People's groups were active in the region, compared to approximately 920 in the country as a whole.

A key function of Positive People's groups is helping members access services such as health care, psychosocial support, children's education and income generation. However, Positive People themselves and professionals working in HIV/AIDS differ in how they define essential services. Positive People's groups in Upper Northern Thailand tend to identify a relatively small number of services – in particular health care, psychosocial support and assistance for their children – and believe that on the whole their needs are being met. Professionals identify additional areas, such as legal assistance and reproductive rights, which they believe are neglected. Similarly, understanding of who should provide services also differs. With the exception of medical services and their children's education, Positive People look to themselves and the community more than to outside agencies.

If success is measured in terms of service user satisfaction, then most members of Positive People's groups are accessing the majority of the services they need. Nevertheless, not everyone living with HIV/AIDS in the Upper North is able to gain access to services equally. Factors that can reduce access are related to self-exclusion – notable among positive people who have relatively higher incomes, are younger or male – and exclusion of people belonging to marginalised groups, such as ethnic minorities, drug users or men who have sex with men. Overall, however, a much higher percentage of Positive People in the region have access to services than in poor rural communities elsewhere in the world.

Some of the factors behind this success are found in many other countries: individuals living with HIV/AIDS who are determined to fight for the

rights of all those living with the virus, supported by local or regional government bodies and non-governmental organisations (NGOs). But two factors appear unique to the region. One is a very strong sense of community and a long-standing tradition of self-help groups. And the other is strong determination by the national government to place people living with HIV/AIDS at the heart of the response.

## Glossary/abbreviations

<i>amphur</i>	district	<b>Positive People</b>	people who know they are living with HIV/AIDS (also known as PWA, PWHA, PLHA)
<b>AIDSNet</b>	AIDS Network Development Foundation ( <i>formerly</i> Thai-Australia Northern AIDS Prevention and Care Program: NAPAC) – non-governmental organisation	<b>serostatus</b>	the status of someone’s blood – in HIV/AIDS, whether or not they have contracted HIV
<b>ARV, antiretrovirals</b>	drugs that prevent HIV from replicating in the body	<b>tambon</b>	a sub-district – there are often 8-10 tambons in a district, and several districts in a province
<b>CDC -10</b>	Office of Communicable Disease Control Region 10 – a department of the Ministry of Public Health covering the six provinces of Upper Northern Thailand ( <i>later</i> DPC 10)	<b>TNP+</b>	Thai Network of People Living with HIV/AIDS
<b>DPC 10</b>	Office of Disease Prevention and Control Region 10 ( <i>formerly</i> CDC 10)	<b>TNP+/UN</b>	Thai Network of People Living with HIV/AIDS/Upper North Office
<i>jangwat</i>	province	<b>Upper Northern Thailand</b>	the provinces of Chiang Mai, Chiang Rai, Lampang, Lamphoon, Mae Hong Son and Phayao
<i>mubaan</i>	village		
<b>NACC</b>	Northern AIDS Coordination Centre (government organisation)		
<b>NAPAC</b>	Thai-Australian Northern AIDS Prevention and Care Program ( <i>later</i> AIDSNet)		
<b>NGO</b>	non-governmental organisation		
<b>NNCA</b>	Northern NGO Coalition on AIDS		

# Section 1 – HIV/AIDS in the Upper North

Almost five million people live in the six provinces of Upper Northern Thailand: Chiang Mai, Chiang Rai, Lampang, Lamphoon, Mae Hong Son and Phayao. Most live in small rural communities, earning a living from the small plots of land they own and from manual labour.

With little money and seldom more than primary education, many people migrate, either seasonally or long-term, in search of work, usually within Thailand but sometimes abroad. Work can be found in construction or service industries, such as shops, restaurants and hotels and the sex trade. Meanwhile, the lives of those who remain are closely interlinked. Each year the rice is communally harvested. Every day people meet and interact in the fields and market. The Buddhist temple in the centre of each community is a focus not only of worship but also of education and sometimes even income generation. Many host social welfare funds, rice and buffalo “banks” that villagers can draw on in times of need.

Self-help groups are common in Thailand, a tradition perhaps strongest in the Upper North. Long before HIV/AIDS, villagers with similar interests, such as housewives, disabled people or young people, formed associations that support their members. These groups are recognised components of community life. Their office-holders are part of decision-making processes intended to ensure that the community as a whole benefits from proposed changes. Positive People’s groups are a more recent development in a tradition that has long helped members play a full and active role in their communities.

## The sudden epidemic

The first case of HIV in Thailand was detected in the capital, Bangkok, in 1984. In the Upper North the virus did not appear until 1988. It spread rapidly. Although less than 8 per cent of the country’s population live in the region, by 1992 it was home to over 50 per cent of Thais who had developed some symptoms of HIV/AIDS. Why did it spread so fast? Nobody knows for certain, but a combination of factors seems likely, including the sex industry, recreational drugs and mobility.

Although illegal, sex work has long been widespread in Thailand. For decades, poor families in the Upper North made money by sending a daughter into sex work. Today, young women (and some young men) still leave to work in the sex trade elsewhere in Thailand or abroad, sending a considerable proportion of their earnings back to their parents. Once they have made money, many return home. In the late 1980s and early 1990s, many of those who returned – and many who worked in the sex trade at home – contracted HIV, as did their clients.

Meanwhile, the region bordered by Myanmar (Burma) and Laos, and close to China, formed the heart of the “Golden Triangle”, where opium was harvested and processed into heroin. Although cultivation has dropped sharply and much of the processing has receded over the border, drugs in one form or another have played an integral role in communities over many generations. The drugs and the methods by which they are consumed vary. However, all of them can result in direct infection – when HIV is transmitted in contaminated injecting equipment – and indirect infection – when drugs that are ingested or inhaled relax inhibitions, so that the consumer may be more sexually active and less likely to use condoms.

## Fear and discrimination

In the late 1980s and early 1990s, national AIDS prevention campaigns in Thailand had two major themes: fear-inducing images of HIV intended to encourage people to protect themselves and a campaign to promote 100 per cent condom use with women sex workers. The women, and other groups at high risk of infection, were also targeted for obligatory HIV testing.

The campaigns were highly effective in raising awareness of the virus among the general public, and the rate of new infections among women sex workers and their clients fell dramatically. However, a side effect of the AIDS awareness campaign was to stigmatise and marginalise the men and women directly affected by HIV/AIDS.

Most people who contracted HIV in the Upper North discovered that they had the virus only after they had fallen seriously ill. For many, a diagnosis with HIV/AIDS was the beginning of a downward spiral. Doctors and nurses offered inadequate or inappropriate treatment and little hope. On returning home, they were shunned by neighbours and workmates. Many were weak and unable to work. Those who were fit found themselves excluded from community events such as the rice harvest or funerals, while their children were turned away from school, irrespective of whether they too were living with HIV.

“When one of my relatives died from AIDS,” Aim-on from Dok-Sarapee group remembers, “nobody wanted to eat the food at the funeral.” “And whenever we used the bathroom,” Wanda from the same group adds, “they wanted us to clean it thoroughly afterwards.” Others found that they were excluded from the community funeral fund – an act of great symbolic and financial importance.

The virus affected whole families. “My husband felt tired in the evening and took medicine,” says Bualuang. “I thought it was malaria, but when he died I knew it was AIDS. Later my youngest child was ill, she got thinner and thinner. I thought it was malnutrition but they said it was AIDS. When she went back to the community people didn’t want to talk to her or me. Then she passed away.”

Told they were going to die and rejected by the communities they lived in, many Positive People fell into deep depression. Some died having lost the will to live. Suicide rates rose. In the words of Wanda from the Dok-Sarapee group: “We didn’t know what to do. We just stayed at home. It was very stressful.” A few, however, refused to accept the fate that others predicted and started searching for a cure.

## Coming together

By the early 1990s, several NGOs, such as the Church of Christ of Thailand-AIDS Ministry, Norwegian Church Aid, the Red Cross and World Vision, had begun to offer support to Positive People in the Upper North. In 1993, the Thai-Australian Northern AIDS Prevention and Care

Program (NAPAC – later re-named AIDSNet) established a unique project designed to build the capacity of and fund non-governmental and community-based organisations – including groups of people living with HIV/AIDS – to respond to the virus. It was also designed to promote multisectoral collaboration – collaboration not only between government and non-governmental organisations but also with other sectors of society, such as faith-based organisations and academic institutions. Advocacy – raising awareness of the need for a positive, pro-active response to the epidemic – was also key. Meanwhile CDC-10 (the office of the 10th region of the Ministry of Public Health’s Communicable Disease Control programme) had established programmes that reached a few people living with HIV/AIDS.

The services available were limited. In Aeung Peung there was a clinic that provided anonymous testing, counselling and healthcare. In Chiang Mai city there were weekly meetings for Positive People and home visits for some who were ill. Overall, the government’s response to the epidemic was slow and bureaucratic. HIV/AIDS remained shrouded in stigma and discrimination. Many who knew they were living with the virus withdrew from community life. And many people who were at risk were reluctant to be tested.

Meanwhile, a less orthodox activity was attracting the attention of many people with HIV/AIDS. In Chiang Mai in 1993, Vichai Vicchunilobol claimed to have found a cure for the virus, which he distributed through a membership scheme. Some members met informally, calling themselves the New Life Friends group. When Vichai was charged with unlicensed production and distribution of medicine, New Life Friends submitted a petition of protest to the Prime Minister of Thailand.

More than a decade later, Samran Tagun, one of the founders of New Life Friends and still its president, says that the primary importance of the petition was not to obtain “medicine” but to make the point that Positive People had the right to make their own decisions about health care. State-run hospitals offered few treatment options, and when it appeared that a viable alternative was available, the government seemed determined to ban it.

# Section 1 – HIV/AIDS in the Upper North

The principle of self-determination was important. Perhaps Vichai's "cure" did not eliminate HIV, but there were other ways in which people living with HIV/AIDS could take care of their health. And there were other actions that they could take to improve the quality of their lives, including protest against widespread discrimination. There was much to do and New Life Friends would be the focus of that activity.



Samran Tagun, the New Life Friend Center's chairperson, performing at an International AIDS Conference

## Reaching into the community

New Life Friends grew quickly. But for rural members, meeting in Chiang Mai city cost money, time and energy. More importantly, it did not respond to their need to be accepted by their own communities. With New Life Friends' support, many members established groups in the districts or sub-districts where they lived. By the end of 1994, there were 13 Positive People's groups in the Upper North. Ten, including Doi Saket Widows, Amphan, Clear Sky and Thung Satoke Hearts Together, were in Chiang Mai province; two – Warmly Love and the Tapestry of Friendship – were in Chiang Rai province; and one was in Phayao. A year later, there were 35 groups in the region.

The groups were truly community-based organisations, although the community was social (people living with HIV/AIDS) rather than geographic (based in a village or sub-district).

The impetus to establish them came from Positive People themselves, not external government or non-governmental organisations. However, the groups could not have survived without such resources as small grants, a meeting place, capacity-building and administrative support. This essential support came from NAPAC, other NGOs, CDC-10 and a few hospitals and health centres.

Positive People's groups had two primary goals: to help members maintain good health for as long as possible, and to combat the widespread stigma and discrimination that many members faced. These goals were closely related. Discrimination leads to stress and poor health, while poor health frequently leads to discrimination. In the words of Taweesak, former co-ordinator of the Network of Positive People, one of the first tasks was to insist on receiving the best medical services. Antiretroviral drugs were not yet on the horizon, but "We still had hope and opportunity."

## The government response

The alarming speed with which the virus had spread in the Upper North, together with advocacy by NAPAC, other NGOs and CDC-10 staff, encouraged the government to rethink its HIV/AIDS strategy. In March 1994, the Upper Northern HIV/AIDS Prevention Committee was established, with the deputy health minister as its chair. The committee aimed to encourage the establishment of Positive People's groups and to develop networks that would play a key role in meeting their basic health and social needs.

In 1995, 60.5 million baht (US\$2.4 million at the time) was allocated to a range of government departments in the six provinces. It was the first time that government funds were given to a programme not tied to a specific ministry. In the same year, 75 million baht (US\$3 million) was allocated to NGOs working in HIV/AIDS – a significant increase from the 11.5 million baht (US\$460,000) distributed in 1992, the first year that NGOs received support. At the same time, the government was preparing the Eighth National Economic and Social Development Plan (1997-2001), at the heart of which was a programme of

decentralisation to strengthen the ability of communities, in particular sub-districts, to respond to the challenges of human development.

Meanwhile, in September 1995 the Third International Conference on AIDS in Asia and the Pacific was held in Chiang Mai. NGOs across Thailand, including Positive People's groups, collaborated closely to prepare for the event. This collaboration led to the publication of *Policy Recommendations to Protect the Rights of People Living with HIV/AIDS to be Submitted to the (Thai) Government* – a document commonly known as the Yellow Paper. Among the recommendations were provision of treatment and care services to people living with HIV/AIDS without stigmatisation and discrimination, and participation of people living with HIV/AIDS in the delivery of services. Although it was only one of many submissions and programmes reviewed by the government, the fact that it came from a nationwide coalition of Thais directly affected by HIV meant that the Yellow Paper undoubtedly had a strong influence on national HIV/AIDS policy.



A group meeting to draft the Yellow Paper

## A new strategy

By the end of 1995, the government's new policy towards HIV/AIDS was clear, acknowledging that prevention and care were two sides of the same coin. The national care strategy now stood on twin pillars: improved health care for people living with HIV/AIDS and a significant reduction in stigma and discrimination. In the words of Chonlisa

Chariyalertsak, head of STI/AIDS Prevention and Control in Chiang Mai Provincial Health Office: "We had to prepare society to understand AIDS."

Positive People's groups were to be the focus of treatment and of reintegration into the community. Existing groups would be supported and new ones encouraged to form. These would be based at district hospitals and sub-district health centres, where they would be helped to write proposals applying for funds. Meanwhile, across the region school teachers, public health workers, tambon (sub-district) administrative organisations, medical staff and community leaders were given training for raising awareness of HIV/AIDS and ensuring a better understanding in the community about people living with HIV/AIDS.

Money was made available for different purposes and from different ministries, the primary source being the Social Investment Fund Menu 5, which initially came from the World Bank. Funds were distributed for treatment, financial support for Positive People's groups, emergency funding for individual members, vocational skills training, saving schemes and education campaigns. Decisions on who would receive the money were made by regional committees that represented a broad section of the community, including Positive People's groups. In the Upper North, some members of the regional committee also served on NAPAC's multi-sectoral committee, reinforcing a community-based response to the virus.

The new strategy was not always successful. Individuals and organisations at sub-district and district level were not always fully aware of the issues facing Positive People. Sometimes they lacked the resources to respond or assist them. Groups were not established in every sub-district or district, and not every group was successful. But the principle had been established that a reduction in stigma and discrimination and the support of the Social Investment Fund were essential elements in HIV/AIDS prevention and care. As a result of that support, by the end of 1996 there were 78 groups, by 1999 there were 224 and 309 were functioning by the end of 2005.

## Section 2 – A typical group

A typical Positive People's group in the Upper North has 50 to 100 members. Every month the group meets to share information on health issues – in particular, access to antiretroviral drugs and other treatments – discuss problems facing individual members or the group as a whole, deal with internal administrative matters and respond to initiatives from the provincial or regional network. A doctor or nurse may attend to answer questions. Most meetings are also social events. When the business of the day has finished, there is a chance to talk to each other and sometimes to eat and drink.

Groups are managed by a committee of 10 to 12 members, who may meet several times a week to run or oversee different activities. Committee members and other volunteers are almost always unpaid. Most are women, partly because there are more women members and partly because men are more likely to be working and unable to give their time.

Groups may be involved in a wide range of activities, such as home visits to members who are ill or to their carers and families, advocacy and campaigning, fundraising and credit and income generation schemes for individual members.

Most groups provide regular workshops on health. These can range from basic medical knowledge, including first aid and taking antiretroviral drugs, to massage and information on managing a good diet. Training is also usually offered to family members. Srithorn from the Mae On group points out that her teenage son and daughter came to a workshop to learn how to look after her if she were to fall sick.

Most groups are based in a district or sub-district. District groups tend to meet in or near the district hospital. Sub-district groups usually meet at the health centre or, as in the case of Hearts Together, the local temple. Some groups have an office that is open on a daily basis. These premises serve as an administrative centre, a place to hold workshops and meetings and a location for income-generating activities. Members can drop in and meet each other – something that is particularly important for those who live alone and are unemployed. And members of the public can

visit and get information if they are concerned about their own health or that of a family member or neighbour.

Not every district or sub-district has a group. Alternatively, groups may overlap, and in some communities people may join a sub-district group, a district group or both. It is possible to be a member of a district group without neighbours learning you are HIV positive, but it is much more difficult to keep that information confidential at sub-district level.

### Life is better today...

Members of the Mae On group now have friends, moral support ("if you are alone, you think a lot"), access to regular medical checkups and antiretroviral drugs and information. "Life is much better, our mental and physical health has improved and our members are strong," says a group member. "Nothing needs to be improved," says another; "only one or two members feel they are not receiving quality medicines."



A local housewife learns about condoms in a community demonstration activity organised by peer educators from the Kiang Kim Khong Positive Peoples group

### The average member

In the average group, two out of three members are women. Most are in their thirties and forties, few have had more than primary education and almost all live directly or indirectly off the land or from manual labour.

New members usually have learnt about the group from their neighbours or medical staff. Not everyone who hears about the group is immediately enthusiastic about joining, and members often spend time telling HIV-positive friends and neighbours about the benefits of membership. Women are more easily persuaded than men, and poor people are more likely to join the group than those who have relatively higher incomes or are educated.

People join for different reasons. For many, in the early days the greatest benefit was quick and easy access to health care, including antiretroviral drugs. Others join to gain access to the government emergency fund of 500 baht a month (US\$12.50). For many, psychosocial support remains key: the opportunity to meet others in the same situation who have overcome their anxieties about living with HIV/AIDS and who have regained their physical and mental health and standing in the community. Initially, such support is likely to come in formal counselling sessions, which cover such issues as antiretroviral drugs, information about HIV itself, scholarships for children and staying healthy. Over the long term, support comes from the ordinary interaction between members during or after meetings or in social gatherings.

Not everyone who joins a group is living with HIV. Parents, siblings and children are often members too. Saifon in Amphan group tells how when she first heard about the Positive People's group she wanted to join but was unable to because she was working. So her mother joined first to learn how Positive People can live healthily, and then passed the information on to her.

## Men and women in Positive People's groups

One reason why most members of Positive People's groups are women could be that it is often easier for men to find work so they are less likely to get involved. And some men are not attracted by activities such as sewing associated with many groups.

However, most groups say that there are fewer male members because the men have died. Mae On group started with equal numbers of men and women but the men passed away earlier. Many people believe that the men were infected first and fell ill before there were drugs available. Amarin Nawchaiwong, who works with the Dok-Sarapee group, says that when men have HIV they stay at home and are looked after by their wives. When the men die the women are alone and come to the group for support.

Many Positive People point out that women are more likely than men to disclose that they are living with HIV/AIDS. Since disclosure in the group leads to strong psychosocial support, women are likely to maintain their health for longer. Children also provide women with an incentive for taking care of themselves. Men, on the other hand, are more likely to quit work and continue drinking and smoking, all of which lead to poorer health.

Some groups are convinced that men and women have different needs. Sunrays group say that men need more intensive, long-term counselling than women. They also have a greater need for occupational training and support, specifically to help them find work.

Men and women are more equally represented in provincial and regional committees. In early 2004, the Upper Northern TNP+ Committee comprised six men and six women. Phayao Network of PHA Committee points out that although the core work of most groups is carried out by women, men are more likely to be office-holders because it is easier for them to travel since women have children to look after.

## Back in the community

One of the greatest problems facing Positive People is exclusion from the community. This may result from the stigma that leads others to avoid them, from their own withdrawal from the community or a combination of both. Many members recall how badly they were treated when others first learnt that they had HIV. Often they did not leave their homes for many months.

## Section 2 – A typical group

That is why reintegration into the community is a key goal of Positive People's groups. This can take many forms. Groups may organise a fundraising event for the local temple. They often establish links with other groups in the community. Hearts Together works so closely with a housewives' group that it sometimes seems like they are all one big group. The Amphan group makes a particular effort to bridge the gap between elderly members of the community and people living with HIV/AIDS.

Sanchai Chasombat, chief of the HIV Care Unit in the Ministry of Health, points out that HIV/AIDS is usually seen as a community problem rather than an individual problem. This means that community leaders such as monks and health centre administrators play a key role. If they are sympathetic, they can initiate discussions and activities that help the process of reintegration. Sometimes formal meetings or training is required; for example, when schools are reluctant to accept the children of parents living with HIV/AIDS.

Reintegration is also partly the result of improved health among Positive People. Almost every group mentions that people living with HIV/AIDS became accepted when they regained their health and became active in the community once more. Improved health also leads to greater self-confidence. Positive People who once closeted themselves at home are more likely to take part in community life with improved health. As time passes, more members of the community understand the nature of HIV/AIDS and become less afraid of people living with the virus and less judgemental. So, regardless of their health, Positive People are now more likely to be welcomed back into the community.

**Urban groups** may have different profiles from those based in rural areas, even though their purpose and structure are usually similar. New Life Friends in Chiang Mai city, for example, has over 300 members, three full-time staff members and at least 20 regular volunteers. Activities are focused around specific groups, such as young people and men who have sex with men. According to Samran Tagun, the group's president, many members are those with relatively higher incomes or city dwellers, who are often reluctant to join local groups because they fear that others will learn they are living with HIV/AIDS.

New Life Friends Centre works in both prevention and treatment, offering education programmes for young people, a counselling service and a 24-hour hotline, advice on antiretroviral and other drugs, and a recuperation programme for members to regain their physical and mental strength.



New Life Friends group participating in a HIV/AIDS campaign organised by Chiang Mai provincial Ministry of Public Health

### Partnerships

Most Positive People's groups depend on external support from an NGO or government hospital or health centre. Support can come in the form of small grants, training in administration, financial management and the skills needed to respond to the needs of people living with HIV/AIDS. Groups also benefit from and contribute to a range of networks and partnerships.

Thai NGOs work directly with Positive People's groups in many different ways. Both AIDS Network

Development Foundation (AIDSNet) and AIDS Access Foundation (ACCESS) provide small grants, capacity-building and training, while encouraging multi-sectoral involvement and networking. The NorthNet Foundations provide technical support to people living with HIV/AIDS working on organic farming as an income-generating programme, while the Christian AIDS Ministry gives technical support to groups of people living with HIV/AIDS and HIV-positive volunteers involved in the home-based care-related programme. The Thai Network of People Living with HIV/AIDS is a member of the Northern NGO Coalition on AIDS, which brings together 50 organisations in Upper Northern Thailand working in HIV/AIDS prevention and care.

Groups also have relationships with political institutions, in particular the tambon organisation. In Mae On, the tambon provides scholarships for affected children and sends representatives to the monthly meetings. In Thung Satoke, where the Hearts Together group is situated, the tambon supports the income generation fund and home visits, and provides food for the monthly meetings. Representatives of the group have joined the tambon organisation, the village health volunteer and the village leader to form a community-based group that works to involve the whole community in responding to HIV. In some cases, however, groups have little formal contact with the tambon, particularly if the administrative organisation is seen to be incompetent. Another source of support may be the local Member of Parliament (MP). At least one group reports receiving rice, dry food and blankets from their MP.

Positive People's groups usually work closely with others in the community too, such as traditional healers, housewives and youth groups. School teachers and principals often work with Positive People's groups, particularly to help get scholarships for children. Many groups have strong links with their local temple, which plays a key role in community life – a few, such as Hearts Together, are actually based in the temple. The Amphan group has a monk on their advisory board, and one of the temples in Mae On provides meditation sessions for group members and assistance at funerals.



The Hearts Together group and the local housewives group are making bags, scarves and clothing for export to Japan

## Thai Network of People Living with HIV/AIDS

In 1996, Positive People's groups across Thailand established the Thai Network of People Living with HIV/AIDS (TNP+). TNP+ plays a critical role in supporting and reflecting the views of Positive People's groups. It was one of 11 networks that campaigned for the Universal Health Care scheme, which was implemented in 2000. Under the scheme, a visit to a government hospital or doctor, including treatment, costs a fixed fee of 30 baht (US\$0.75). Initially, ARV treatment was excluded from the scheme. However, continued campaigning by TNP+ and partners led to their inclusion in 2005, with the aim of universal access for all Thai citizens.

District TNP+ committees assist co-ordination between individual groups and NGOs, relay information from the provincial network to the districts and set budgets for groups in the district. Provincial TNP+ committees disseminate information from the regional network and confirm budget allocation to the districts, and co-ordinate with other organisations at provincial level. In early 2004, activities identified by the Phayao Provincial Committee, for example, included liaising with the provincial prosecution office, health office and radio station, and setting up holistic networks to increase Positive People's access to traditional healers as well as hospitals and health centres.

## Section 2 – A typical group



Groups in TNP+ working together – people from the New Life Friends Centre support a new group of people living with HIV/AIDS



Hard at work in the TNP+ Upper North office in Phayao province

### What makes a group successful?

After ten years, there are more than 300 Positive People's groups in Upper Northern Thailand. So how do groups start and what makes a group successful?

Some groups are formed by strong-minded individuals living with HIV. Others are started by staff at a medical centre who believe that membership of a group will help their patients. In both cases, the end result is the same: a community-based organisation in partnership with a professional organisation that either provides small grants, training, premises or other administrative support, or helps the group to find the resources it needs.

Strong leadership can help to build the group and carry it through difficult times: for example, if key members fall ill. However, many groups do not have natural leaders. Then, the government or non-governmental partner organisation has the essential role of helping to build leadership. Members of the Dok-Sarapee group point out how difficult it can be to find a chairperson: "Most of us are not very good at reading or writing. Sometimes we think a particular person should be chair, but they don't want to because they think they cannot do it."

Success stems from dedication and mutual support. Committee members and other volunteers have to contribute significant time and energy. They should also be supported by friends and family members who recognise the importance of the group. The Dok-Sarapee group survives partly because of the dedication of individual members and partly because of the support it receives from the hospital where it is based.

And almost every group points out that their first priority is ensuring the physical and emotional wellbeing of their members. Many people say that their own good health depends as much on supporting other members as in taking care of themselves. Many feel that income should not be the group's primary motivation. As Komsan of Sunrays says, "Money is the grease of the group, not the wheels." Srma from Phayao Network of People living with HIV/AIDS Committee warns that if money is the objective the group will finish when the funds dry up. For many, even access to antiretroviral drugs is seen as less important than ensuring that members' basic physical and emotional needs are met.

Another key element is training in a range of skills, both HIV/AIDS related and administrative. Training is best provided in workshops, but skills can then be passed on to members who either cannot attend or who join when the workshops have ended.

Not every group is successful. Some have difficulties in sustaining themselves because there are few people living with HIV/AIDS in their community or because people are reluctant to disclose their status. Sometimes the external

support is insufficient or inappropriate. If the relationship is with an NGO, the group may not receive sufficient funding, particularly since NGOs often restrict funding to one to three years.

While some groups fail, others close for “positive” reasons. Taweesak Wangthan, former co-ordinator of TNP+/Upper North, says that some groups disband as a result of improved health and reduced discrimination. When people are able to return to work because their physical strength has returned, or they are welcomed back by the community, they may not have time to attend group meetings. Then membership falls below a critical point and the group closes. Alternatively, a group may compromise, as Sunrays has done, meeting monthly instead of weekly because many members have less time now they have been able to find work.

Meanwhile, other groups emerge. The Doi Luang district group in Chiang Rai province encouraged its members to meet and organise at sub-district level to ensure that they could access community assistance. Most of the group’s activities have been devolved to these newer groups. And overall, the number of groups in the Upper North continues to rise.

## Section 3 – Identifying and accessing services

Positive People have the same needs as the rest of the population: food, clothing, shelter, basic medical care and education for themselves and their children. They also have other specific needs arising from their infection, such as for information and health care appropriate to HIV or opportunistic infections. But poor health, severe depression and discrimination may all prevent Positive People, their carers and children from receiving appropriate services.

There is general agreement about what these needs are, but there are different ideas about the basic services that are required and who should provide them. Professionals who work with HIV/AIDS in different communities tend to identify a greater number of services than those living with the virus, who have little experience outside their own communities. People who live in wealthy societies often assume that services are best provided by government or non-governmental organisations. While those in middle- or lower-income countries look to family members and neighbours or friends to provide certain services, such as child care.

Positive People in Upper Northern Thailand identify a limited number of services and suggest that many of these can be provided by the groups themselves rather than by outsiders. Most appear satisfied that their needs are being met. This section discusses services both from the perspective of Positive People themselves and from others working in HIV/AIDS.

### Life is better today...

Members of the Hearts Together group feel they have no conflicts. They meet regularly in temple grounds, talk over problems and have strong connections with the monks who help them to resolve problems. They have a good income generation scheme and all of their children go to school, where they face little or no discrimination. At the health centre where other people were once uncomfortable about Positive People using the toilet and other facilities, such issues are long resolved. Now the only serious problems group members have is when someone falls sick – and most of them are healthy most of the time.

### Medical services

The primary service identified by Positive People in Upper Northern Thailand is medical care. People living with HIV/AIDS want quick access to a knowledgeable and friendly doctor or nurse, a hospital bed, medical tests and appropriate treatment, including antiretroviral drugs and medicines for opportunistic infections. Accurate information on how HIV develops and what steps can be taken to delay or halt progression to AIDS is also essential.

Most groups have strong links with hospitals and health centres, many of which have staff or even a clinic specialising in HIV/AIDS care. Mae On hospital, for example, has a dedicated HIV/AIDS clinic where drugs are dispensed twice a week, herbal and traditional medicine is available, and members can receive and give massages. Volunteers from the Positive People's group also measure blood pressure, temperature and weight, and help dispense medicine. Health centres offer a narrower range of services, but are usually more involved with the groups on a day-to-day basis; for example, offering premises or helping to apply to the tambon for funds.



Mae On HIV clinic

Sometimes medical services are available but difficult to gain access to. Doi Luang district, for example, does not have a hospital, and so members of the New Life Friends group have to “compete” for services at hospitals in other districts. Patients who are not members of a group

or who do not attend regularly might not have the information they need. For example, they may go to a hospital not knowing that the HIV clinic only operates on specific days. Sometimes poor training, ignorance, discriminatory attitudes or overwork leads medical staff to offer less than ideal care to Positive People. Overall, however, most members of Positive People's groups appear satisfied with the medical services they receive.

## Antiretroviral drugs

Antiretroviral drugs attack HIV and significantly prolong the lives of most people with the virus. They are an essential component of medical services, but currently reach only a fraction of the people who need them worldwide. The high cost of antiretrovirals meant that in the early days they were not universally available in Thailand. However, access has been increasing since 2000, when a pilot programme was introduced involving 69 Positive People's groups.

The programme ensured that antiretrovirals were available to group members. Doctors, health officers and nurses were trained to prescribe and dispense the drugs, and monitor their impact on individual patients. By 2002, 250 million baht (US\$6.25 million) had been allocated annually for the purchase of antiretrovirals. They were available free of charge to any member of a Positive People's group in the Upper North with a CD4 count of under 200<sup>1</sup> or with a higher CD4 count but symptoms or an illness indicating AIDS, such as tuberculosis.

In October 2005, the government announced the roll out of a 2.8 billion baht (US\$68 million) plan to include antiretrovirals as well as prevention for infections common among people living with AIDS in the 30 Baht health care scheme. More than 900 hospitals were designated as providers of the drugs, with the aim of reaching 80,000 people living with HIV/AIDS country wide.

A number of concerns remain, though. Some have raised the issue of which drugs will be included in the scheme. The almost universally prescribed combination is called GPOvir, a generic brand

manufactured in Thailand by the Government Pharmaceutical Organisation. However, resistance to this is becoming more common and "second-line" treatments are only available on the scheme on a quota system. This means that during 2006, a maximum of 288 people with drug resistance in the Upper North can get second-line medicine.

Concerns have also been raised over the distribution of drugs through hospitals, which has led to comprehensive care becoming less available for people living with HIV/AIDS. The development of Comprehensive Continuum of Care Centres (CCCs) in some areas has helped address this concern.

### Life is better today..

Antiretroviral drugs are not easy. They must be taken regularly for the rest of your life and they can cause unpleasant side effects. However, they make people strong and confident, say members of the Mae On group, and that helps them regain the respect of the community. Improved health and being seen to be capable of work is a major factor in the reintegration of Positive People into community life. "Volunteering at the HIV/AIDS clinic provides a good example, showing that we can work," says the Mae On group.

## Comprehensive Continuum of Care Centres

CCCs were conceived as a model for involving Positive People in antiretroviral provision at government hospitals. They were initiated during 2002 to 2003 through collaboration between TNP+, a Thai NGO called ACCESS and Médecins Sans Frontières (Belgium), and funded by the Global Fund to fight AIDS, Tuberculosis and Malaria. There are now 53 CCCs in the Upper North, each run by three to five staff from the Positive People's groups. The centres are run in collaboration with hospital staff. People living with HIV have now become an integral part of the HIV/AIDS teams, working together with nurses, counsellors, technicians, pharmacists and doctors in the hospitals. There are three main activities of the CCCs: individual counselling, group activities and home visits. Combined, these inputs for Positive People cover issues such as adherence to the drug regimen, nutrition and safer sex.

<sup>1</sup> CD4 is the name of a molecule that forms part of the body's immune response. A low number of CD4 (measured per cubic millimetre) is an indication that HIV has progressed to the extent that the body is highly vulnerable to opportunistic infections.

## Section 3 – Identifying and accessing services

### Psychosocial support

Equally important as medical care is psychosocial support, which can be defined as ensuring an individual's emotional wellbeing and mental health.

A key tool in helping people living with HIV/AIDS regain their emotional wellbeing is formal counselling, particularly in the period immediately after they learn they have contracted the virus. In the Upper North, counselling is offered by hospitals, health centres and dedicated HIV/AIDS clinics, and also by Positive People through CCCs and through the groups.

Home visits<sup>2</sup> for those unable or unwilling to leave home are essential. Group representatives often visit not only fellow members but also others in the community living with HIV. Home visits can also be made to the families of people living with the virus or who have died, in particular to grandparents and children. Depending on the group's resources, visitors may be able to take food and even small amounts of money.

While formal counselling is undoubtedly beneficial, many members say it was informal support from others in the group that brought them back from the brink of despair. "Being part of the group means that we are not the only people going through this situation," says Wanda of Dok-Sarapee group. "It gives us strength." Wannapa of the same group tells how Aim-on, also in the group, helped her when antiretroviral drugs were causing severe side effects. Without Aim-on's help, Wannapa might not be with the group today.



A home visit by New Life Friends Centre

### Life is better today...

There is still discrimination, say members of the Amphan group. Not everyone understands how the virus is transmitted. Some hospital staff discriminate and dental staff scrub everything with alcohol. Even group members themselves may be hesitant. "I don't join in every activity," says one. "I join community activities but not when they are cooking," says another.

But none of the members regrets disclosing their status. "Many years ago I had problems, but after public officers gave us information, I could join in community activities, such as attending a funeral or building a new house." "In the past I couldn't touch things in the community, but after an officer came and explained about HIV/AIDS everything became easier." "When people feel lonely they can come to the centre [where the group meets]." The local community has now asked one of the group to become leader of the housewives' group.

### Children and grandparents

A further priority for Positive People's groups is ensuring their children's access to education. In the early to mid-1990s, many children of people with HIV/AIDS were denied schooling in the Upper North and elsewhere in Thailand. At a roundtable meeting in 1993, representatives of the government, TNP+, AIDSNet and others outlined a strategy to work with schools and local communities to reduce stigma and discrimination. As a result, the number of cases of discrimination in schools fell considerably. Now, when problems occur, the Positive People's group can talk to community representatives or the health centre, who will approach the school to resolve the issue. Alternatively, says Taweesak Wangthan, ex-coordinator of TNP+'s Upper Northern Committee, the network has a mobile team that talks to the village traditional leader, pointing out that education is both a right and a government policy, and there is no danger that others will contract the infection.

A number of problems remain. Although their children's education is free, not all Positive People can afford the extra expenses of lunch, sports activities, transport and uniform. A scholarship fund has been set up to help those parents,

<sup>2</sup> Home visits should be distinguished from home medical care, provided by medical or paramedical staff. Some hospitals, such as Mae On, provide home medical care for members of Positive People's groups.

although mothers from the Sarapee group point out that the fund tends to go to the cleverest children, while theirs, who are average students, lose out. Taunts from other children, such as “Your mother has AIDS!” persist and some children have problems making friends. Camps are occasionally organised for such children by NGOs in collaboration with Positive People’s groups, although less frequently than the organisers would wish.

Child care outside the extended family is available in some Positive People’s groups, such as Dok-Sarapee, which runs a child care centre for children up to five years old.

Almost always it is the mother who survives or stays to take care of the children. If she falls ill or dies, it is usually her parents who take responsibility for her children. Elderly grandparents are often living on reduced incomes and have few formal services to support them. Positive People’s groups try to assist them and further help may come from NGOs such as HelpAge International.

### **Life is better today...**

Nataporn of New Life Friends in Chiang Mai used to live in Bangkok. Ten years ago he was very ill and went to hospital. Although he got better, his health was still not good and he wanted to improve his life. His brother and sister suggested he come to Chiang Mai to talk to people at the New Life Friends Centre. In the two years since he has been a member, his weight has gone up from 42 to 56 kilograms. He gets antiretroviral drugs and has a good relationship with everyone in the centre, which he now considers as his family.

## **Income**

One priority for Positive People – although not mentioned by all groups – is income. When members feel healthy and want to work, this is not always available. Some groups say that everyone in the region has the same problem finding work. Others believe that their poorer health overall limits their opportunities.

Some group members look for the same kind of work that they had before they fell ill. This tends to

be temporary, even on a daily basis. Construction is one type of work that is suitable for people who can be active when they are healthy but need to stop when they are ill. Forestry is another option.

Most group members do not apply for jobs in the formal employment sector for several reasons. These include lack of qualifications, a sense that such jobs are beyond their reach and fear of being sick and unable to fulfil their role. “One of our members has problems because she has a job in a sewing factory and she is not always able to go to work,” says the Mae On group.

The fact that some companies and the government are believed to test job applicants for HIV does not seem to concern individual members, although at a national level, TNP+ continues to lobby against the policy.

Various income generation schemes have been tried by different groups. These include herb and mushroom farming, sewing and basketry. The Dok Ta Lom group in Mae Chan, Chiang Rai, received 60,000 baht (US\$1,500) from the tambon to buy sewing machines to make clothes and to set up fisheries. Not all schemes are successful, however. Mae On reports that sewing brings in only 20 to 30 baht (under US\$1) a day. And for many groups interviewed, income generation does not appear a priority.

One of the most successful income generation schemes is in Thung Satoke. The Hearts Together group, together with the housewives group, has a contract with a Japanese company to produce bags, scarves and other clothing for export. The products are made by members from both groups in a workshop in the temple grounds. This scheme grew out of a visit from a Japanese professor and monk in 1999, who asked what support the group needed and paid for appropriate training.

Another form of income generation is micro-credit, where small sums of money are loaned to individuals. The Amphan group has a long-running credit programme for purchases such as seed, littering sows, catfish and fertiliser. A typical loan of 3,000 baht (US\$75) is offered for four months, with interest of only 100 baht (US\$2.50) charged. The group also offers instruction and advice on the activity the money is

## Section 3 – Identifying and accessing services

being loaned for. The money is also available to people who are HIV negative, providing they have good credit.

Positive People who are destitute can apply for the government's emergency grant of 500 baht (US\$12.50) a month. To receive the money, applicants must register with the tambon, which means disclosing their HIV-positive status. Some tambons are more efficient at distributing this grant than others.

### Life is better today...

After learning she had contracted HIV, Ariya from Hearts Together did not leave her family's home. Her husband had died, she had lost weight, and she was no longer able to work in the rice and vegetable fields. She thought she would die within three months and was very unhappy and unable to explain how lonely she felt. Then she joined the group, who had heard she was living with the virus. They counselled her and invited her to join the sewing workshop, where she earns 300 baht (US\$7.50) a day – five times more than her previous earnings. Her 12-year-old daughter now has a scholarship. Thanks to the group, Ariya herself has visited many places and even been to the sea. She has learnt a lot, trained to help others live with HIV and understands how other people think. Altogether, she is very happy and believes she is a typical group member.



An income generation programme run by the Amphan group

### HIV prevention

Until recently, HIV prevention services for Positive People in the Upper North were provided mainly by professionals. Positive People's groups did not feel that active involvement in HIV prevention on others' behalf was their priority. However, several said that when they took part in community activities they would talk about HIV and how people can protect themselves. For instance, members of Sunrays group formed a band that played for several years at community events. However, it is not clear whether this sort of participation was really more concerned with reducing stigma and reasserting members' rights to participate in community events than with prevention education.

However, the scaling up of antiretroviral provision is undoubtedly leading to a reduction in deaths among people living with HIV/AIDS and to improved wellbeing. Positive People are increasingly able to return to a "normal life". In this context, the need for HIV prevention in its widest sense has become increasingly recognised by groups. As people become healthier, they begin new relationships and start to think about having children again. This leads to the re-emergence of questions about disclosing their HIV status, especially to new partners and to children. Positive People groups can become an important support around the questions raised by these changing circumstances.

In response to this, prevention services for Positive People began in 2005 through TNP+/Upper North, with the support of AIDSNet and the International HIV/AIDS Alliance. Peer educators from 13 groups in three provinces have been reaching people living with HIV with a programme of participatory education, both through the CCCs and through outreach work. This has initiated problem-solving discussions on primary prevention options, curable sexually transmitted infections, disclosure of HIV status and issues related to community rejection and self-acceptance. These will be followed by a new module on family planning for Positive People. The programme will also be scaled up to all the CCCs in the Upper Northern region, with the aim of positive prevention becoming a core component of the services provided.

TNP+ groups say that the initial programme strengthened both the peer educators at an individual level and the network of groups. Peer educators reported that the exchange of experiences led to an increased openness and trust among Positive People and with other service providers, especially hospital staff. With links to hospitals improved, new members are now being referred to the groups.

### Life is better today..

Among the communities of Positive People in Mae Taeng district, Chiang Mai, those reached by TNP+ peer educators have found discussion groups to be very useful. They report that they never had the opportunity before to share experiences with their peers on health, family life and social concerns. These exchanges allow participants to take a problem-solving approach. As a result, they report greater awareness of the need for condom use with spouses or steady partners, and confirm that they now use condoms to protect themselves and those they love.



Peer educators at their office in the Chiang Khong district Chiang Rai

## What's missing?

Positive People's groups that were interviewed say that members have access to most of the services they need. However, professionals working in HIV/AIDS identify additional services that they say are not being provided. These gaps include housing, legal services and reproductive health.

Groups do not identify housing as a problem presumably because in this rural region, where people have strong roots in their communities, most people find somewhere to live. However, some Positive People do have housing-related problems, particularly if a woman and her children have to live with her parents or dead husband's family. Lack of space or poor personal relationships can make sharing very difficult. Some groups are aware of legal abuse related to HIV/AIDS, such as children's rights being overlooked when their parents die. Most, however, do not identify the need for legal services. Some professionals also note that reproductive health services are inadequate, leaving many women living with HIV/AIDS unable to decide whether or not to have children and whether or not to terminate a pregnancy. However, this issue was not raised by Positive People's groups.

Some services are provided at provincial rather than district or tambon level. The provincial committee of Positive People's groups in Phayao works closely with an NGO to address questions of human rights and law affecting rural communities. An estimated 50 per cent of the organisation's work concerns people living with HIV/AIDS.

### Life is better today..

When Somsak fell ill in 2001, his morale plummeted and he stayed at home all the time. One day, Praparatt, a member of Sunrays, was visiting Somsak's father who was also ill. Praparatt learnt that Somsak had HIV and recommended he join the group. Since then, his life has changed completely. His health has returned to normal, he is physically stronger and, after a period of buying antiretrovirals himself, which he could not afford, he now gets the drugs for free.

And best of all, he says, he got married – to Praparatt.

## Section 3 – Identifying and accessing services

### Who's missing?

Several sectors of society are under-represented in Positive People's groups. Since funds and support for people living with HIV/AIDS are channelled through groups, it is more difficult for people living with HIV/AIDS but who are not members of a group to gain access to appropriate services.

Those who often have greater difficulty include people with relatively higher incomes, young people, drug users, men who have sex with men, ethnic minorities, migrant workers and currently active women sex workers. Each of these groups of people face specific obstacles. For example, men with relatively higher incomes appear more reluctant than poorer women to be openly HIV positive. Young people are less likely to learn they are HIV positive. Ethnic minorities have uncertain legal status, speak different languages and have different social structures. Migrants living away from their home districts cannot register locally for public services.

Many people living with HIV/AIDS who are more educated and have higher incomes are less likely to join a Positive People's group. This has implications for access to services. While some with higher incomes can afford to buy drugs privately, several groups tell of members who spent all their money buying antiretroviral drugs before they joined.

Some Positive People's groups recognise that they have, or have had, one or two members of marginalised groups such as drug users and men who have sex with men as members. But only New Life Friends in Chiang Mai city appears to address their specific needs. Several NGOs in the Upper North work with these and other populations. However, they reach relatively few people and the focus may be on prevention more than the needs of those living with HIV/AIDS.

# Section 4 – Learning from the experience of Positive People’s groups

The key conclusion from this report is that a high proportion of people who know they are living with HIV/AIDS in Upper Northern Thailand are accessing the services they believe they need. Furthermore, unlike in many other communities across the world, it is the least privileged – the rural poor with little education – who have been best reached and involved in this grassroots response.

This situation arose after what one expert has described as a paradigm shift in both government and Thai society. In the mid to late 1990s, perceptions of HIV/AIDS and people living with the virus in Thailand changed from one of fear and rejection to sympathy and support.

## Qualifications and questions

However, some areas of concern remain. As discussed in section 3, some people living with HIV/AIDS are under-represented in Positive People’s groups and may find it more difficult to gain access to services as a consequence. Essential services may be defined differently by experts and Positive People’s groups.

Questions of confidentiality are also important. It is possible theoretically to be a group member without other people learning your HIV status. However, this is more achievable at district than at tambon sub-district level. Although it is only the names of people applying for the emergency financial fund that are officially registered, communities are too tightly knit at sub-district level for membership of Positive People and other self-help groups to be kept confidential. Furthermore, the fact that groups do not exist at every administrative level means there may be no choice over disclosing their HIV status if someone wants to gain access to services.

It is arguable that confidentiality is no great concern in rural communities where everyone seems to know everyone else’s business. However, despite the ongoing efforts of government and NGOs, the stigma of HIV/AIDS persists and many people remain reluctant to tell others that they are HIV positive.

Concerns over confidentiality in connection with the provision of antiretroviral drugs have been addressed now that access is available directly through public hospitals. Previously, access was channelled through Positive People’s groups. But this was challenged by TNP+, who called for the system of distributing antiretrovirals to be changed to encourage those who need them to come forward without risking loss of confidentiality. This change in policy now enables Positive People to gain access to antiretroviral drugs without needing to join a group, although this raises new concerns about the provision of comprehensive care and support.

Focused prevention for Positive People is a new area with specific challenges. There is a need to overcome the compartmentalisation of systems and thinking. Worldwide, prevention programmes are usually aimed at key populations such as sex workers, men who have sex with men and injecting drug users, but services for people living with HIV fall under care and support, or access to treatment. There is also a need to avoid creating further stigma and discrimination through poor targeting and ill-conceived prevention information for Positive People. Finally, there is a need to recognise openly that Positive People have sexualities just like everyone else, and to provide tools for dealing with complex questions about sex, intimacy and relationships for people who are living with HIV.

### **Life is better today...**

The Phayao Network of PHA Committee is proud of the changes it has helped to bring about in the rural communities where its members work. Attitudes have moved on from distrust and discrimination to support. Seven or eight years ago, people were dying of AIDS. Now they are living with HIV. Positive People participate in community life, and the community participates in their lives.

# Section 4 – Learning from the experience of Positive People’s groups

## Why the success in the Upper North?

Groups of people living with HIV have been created in rural communities in other countries, but seldom as many as in Upper Northern Thailand, where one in a hundred adults is a member of Positive People’s group. Elsewhere in Thailand, the policy of supporting Positive People’s groups appears to have been less successful. So what is the secret of the Upper North? There appear to be a strong combination of four essential factors.

The first is the leadership offered by a few individuals living with HIV/AIDS. Strong early leaders were determined to have access to the best possible services for themselves and others with the virus, and to challenge HIV/AIDS-related stigma and discrimination. These leaders were supported by NGOs and local government agencies; a key factor in their success. Government commitment and funding helped ensure that Positive People and a reduction in stigma and discrimination became central planks of national policy. Finally, the Thai tradition of self-help groups involved in community life was the model for groups of Positive People – a tradition that is strongest in the Upper North.

Other factors undoubtedly make the task of promoting access to services easier. These include: a high level of literacy across Thailand; a comprehensive and relatively free media, which allows widespread dissemination of HIV/AIDS-related information; the policy of decentralisation that encourages local decision-making; and a technically competent medical establishment and government health network.

### Life is better today...

Saengchan of Dok-Sarapee group fell in love with a man in her village who does not have HIV. Some people said they should not be together. But he came to the hospital for counselling and they have now been married for three years.

## Who should we thank?

Who should take credit for improved access to services in the Upper North? “Everything started with the Positive People movement,” says Komsan of Sunrays. “We lobbied the government and the government responded. Then the groups lobbied for cheaper medication and the price has come down. So it’s a combination of our lobbying and the government.”

There are two stages in ensuring access to services. The first involves drawing attention to those services that do not exist or that are poorly executed. The second involves ensuring ongoing access. The first stage happened in the early to mid-1990s, and can be attributed primarily to the small number of Positive People’s groups, NGOs and government agencies that drew the national government’s attention to the needs of people living with HIV/AIDS. Once it had acknowledged the problem, the national government deserves credit for responding aggressively, implementing a policy that prioritised support to Positive People and allocating significant sums of money to ensure access to medical care and other services and to reduce stigma and discrimination.

The second stage – ensuring ongoing access to services – is a joint effort between Positive People’s groups, the non-governmental groups that support them and the various government ministries charged with delivering services. That effort may be seen as a partnership, where both sides are constantly aiming to improve access. In the opinion of Sanchai Chasombat, chief of the HIV Care Unit in the Public Health Ministry, quantity is now assured in Thailand. Almost everyone with the virus who needs treatment gets it. The next goal is to ensure quality: that Positive People get the best treatment available.

### Life is better today...

Statistics show that the rate of new HIV infections among men and women in the Upper North fell radically in the years following the emergence of Positive People’s groups. The rate of other sexually transmitted infections also fell. However, there are indications that infection rates are now rising among certain population groups, such as young people (especially girls), women and men who have sex with men, and that rates of condom use are falling, suggesting that the general population is once again becoming vulnerable to HIV.

## Other issues

Some implementation difficulties remain. These include bureaucracy, stigma and discrimination, and funding.

Bureaucratic obstacles include defects in infrastructure. Some districts do not have hospitals, making it difficult for people with HIV/AIDS in those districts to gain access to adequate health care. Medical staffing levels are not always fulfilled. Training of medical staff and community leaders is not always up to date. And implementation of policy depends on willing individuals. Some Positive People's groups report that village or sub-district leaders do not always see HIV/AIDS as a community priority, restricting the ability of group members to gain access to some services. This may be a matter of indifference, incompetence or HIV/AIDS-related stigma and discrimination. Sunrays points out that without community support, Positive People cannot develop socially and professionally even if they have developed new skills thanks to government funding.

Training to reduce stigma and discrimination among health personnel and other members of the community, including village and tambon leaders and school teachers, is ongoing, but has become less frequent in recent years. Meanwhile, internalised stigma – also called self-stigma, when an individual living with HIV/AIDS fears that others will discriminate against them – is also important and is partly the reason why many people with relatively higher incomes in the Upper North fail to join Positive People's groups.

The budget for HIV/AIDS prevention and care, allocated for the first time in 1992 from the annual national budget via the Ministry of Public Health, was 12 million baht (US\$315,000). Five years later, from 1997-1998, this was increased to 90 million baht (US\$3,260,000). However, this budget assigned to support HIV/AIDS prevention and care implemented by non-governmental and community-based organisations, was cut down to 70 million baht (US\$1,850,000) in 2000. This reduction has not kept pace with the need for a response to HIV/AIDS on the ground. For example, in 2004 there were 987 project proposals submitted to the Ministry of Public Health worth 338 million baht (US\$8,860,000) for non-governmental and community-based

organisation-initiated HIV/AIDS programme interventions. By 2006, the budget had been cut again down to 22 million baht (US\$576,000). The full implications of this remain to be seen at ground level. Undoubtedly it will seriously affect the ability of groups like TNP+ to function effectively without finding new sources of funding.

### Best practice criteria

When this report was drafted, its findings were checked against the guidelines required for inclusion in the UNAIDS (Joint United Nations HIV/AIDS Programme) Best Practice series. A summary of findings is given below.

Is the practice **effective**? Undoubtedly, the involvement in Positive People's groups prolongs life substantially for group members. For several years it also appeared to reduce the rate of new infections in the community. However, there is some indication that the existence of Positive People's groups, where most members are in their thirties and forties, does not prevent increasing rates of new infection among younger community members.

Is the practice **ethically sound**? With some reservations, it is. It depends on voluntary participation and reduces the likelihood of harm to members and others in the community. However, confidentiality is not respected in all aspects of the programme, particularly membership of sub-district groups and when applying for emergency funds.

Is the practice **relevant**? Yes. It meets the needs of the majority of people living with HIV/AIDS in the Upper North. However, it is uncertain whether the policy meets the needs of other members of the community, particularly people with relatively higher incomes and marginalised or semi-marginalised groups such as drug users and men who have sex with men.

Is it the practice **efficient**? Positive People's groups appear to be a good use of financial and human resources, and one that responds appropriately to the circumstances of the majority of people in Upper Northern Thailand.

Is the practice **sustainable**? Although some groups do not survive and others have problems, overall the programme has lasted for almost a decade and there appears no indication that it will run out of steam. Voluntary input appears to be increasing and skills are continually shared between old and new members – between individuals and Positive People's groups. However, government funding may be diverted to other health issues and non-governmental funding would not be sufficient to cover any major government withdrawal.

## Section 5 – Key conclusions

The main conclusion from this assessment is that strong political and financial support for a widespread, effective network of Positive People's groups can be extremely effective, particularly in helping people living with HIV/AIDS in underprivileged rural communities to gain access to the basic services they need to maintain physical and psychological health.

Groups and networks of Positive People are an important mechanism in:

- enabling people living with HIV/AIDS gain access to a range of critical services
- enabling people living with HIV/AIDS gain access to information and advice
- helping to reduce HIV/AIDS-related stigma and discrimination.

Development of widespread Positive People's groups depends to a great extent on the following factors:

- from national government:
  - supportive policy
  - dedicated funding for direct support of Positive People's groups, training for medical staff and community leaders, provision of dedicated medical care, including antiretroviral drugs
  - decentralisation of decision-making in all sectors of administration, including health services
  - an effective nationwide medical care and health monitoring system
- from non-governmental organisations:
  - technical support to Positive People's groups
  - financial support to Positive People's groups
  - advocacy in the community and to national government
- tightly-knit supportive communities, which include (in the context of Upper Northern Thailand):
  - a tradition of self-help groups
  - faith-based organisations at the heart of community life
- high literacy rates
- a comprehensive, competitive media playing a critical role in communication.

The sustainability of Positive People's groups depends on the above points, plus close collaboration through networks and partnerships with:

- other Positive People's groups
- hospitals and health centres
- community leaders and administrative organisations
- schools and education systems
- faith organisations.

Positive People's groups can themselves be service providers, particularly in areas of:

- psychosocial support
- child care
- home visits and care.

Reintegration of Positive People into community life depends on the above points, plus in many cases:

- reduction in HIV/AIDS-related stigma and discrimination
- willingness to accept and disclose HIV serostatus to other group members and often to the wider community
- improved physical and mental health, resulting from:
  - formal counselling
  - psychosocial support from Positive People's groups, leading to recovered self-esteem
  - access to medical services.

# Appendix: Report background

This report was commissioned by the AIDS Network Development Foundation (AIDSNet) in collaboration with the International HIV/AIDS Alliance. AIDSNet is a Chiang Mai-based Thai NGO that provides technical and financial support to non-governmental and community-based organisations as well as Positive People groups in order to build the capacity of and strengthen the responses to HIV/AIDS by local communities.

AIDSNet collaborates with the International HIV/AIDS Alliance, a development organisation specialised in supporting communities in developing countries to tackle the spread and impact of HIV/AIDS. One of the central hypotheses of the Alliance's Frontiers Prevention Project is that empowering key populations such as sex workers, injecting drug users, men who have sex with men and people living with HIV/AIDS can reduce risk behaviour and the prevalence of sexually transmitted infections, which in turn lowers the incidence of HIV. The purpose of the report was to examine whether people living with the virus in Upper Northern Thailand have been able to gain access to the services they need. Such access is taken as an indication of empowerment.

Several techniques were used in drafting this report. These include:

- interviews with Positive People's groups, including one provincial committee (Phayao) and the ex-co-ordinator of the Thai Network of People Living with HIV/AIDS/Upper North Committee, and with representatives of provincial and national health administrations
- an ongoing process of review by representatives of government and non-governmental organisations with regional and national expertise
- a review of relevant documentation over the last ten years.

Those interviewed and on the advisory board are listed in the acknowledgements. The majority of documentation consulted is given in the references.

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