Expanding community through ARV provision in Thailand

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Abstract

Anti-retrovirals (ARVs) have altered the complexion of HIV/AIDS management in Thailand. In 2005, ARVs were included within a subsidised health scheme making provision widespread. Increased access has been brought about through the legal and political advocacy of the Thai Network for People Living with HIV/AIDS (TNP/C²⁷) who now play a central role in expanded ARV provision. HIV-infected volunteers help the state deliver comprehensive services and assist with follow-up and adherence programs. Alongside improvements in drug provision, a focus on pharmaceutical treatment has left other issues, such as community support of orphans and the social responses to living with HIV, less central within community responses. As they take on new responsibilities, people living with HIV/AIDS (PLHA) groups move from activities focused on reversing local stigma to constitute a new social movement that is increasingly prominent in Thai civil society. Networks of PLHA confront new social and political challenges as they also seek to broaden access to marginalised groups who remain excluded from these services. Many ethnic minority groups without full Thai citizenship have been denied access to subsidised health services including ARVs. As part of a broadening advocacy profile, the PLHA movement is now engaging in a politics of difference defined not simply by presence or absence of HIV but also by wider issues of national identity and belonging.

Introduction

Thailand is regularly cited as a success story in the global battle to halt damages wrought by HIV and AIDS. Through intensive media campaigns, progressive government policies and constructive collaboration with international agencies, local non-government and religious organizations, HIV infection levels decreased dramatically in Thailand from the mid-1990s (Lyttleton, 2000; UNDP, 2004). Thai army conscripts, brothel sex workers, pregnant women and blood donors all showed declining levels of infection throughout the mid-late-1990s (Brown, 1998).

Between 1990 and 2000 annual new infections dropped from roughly 140,000 to less than 30,000 per year.

While prevention efforts by state bodies and non-government organizations (NGOs) have radically changed the pattern of susceptibility, as people make selective decisions on preventive behavior, they have not completely removed ongoing transmission. As government spending on prevention programs dropped, with prevention activities comprising only 8% of the AIDS budget by 2000 (Ainsworth et al., 2003), signs of ongoing volatility in levels of infection re-emerged. Increasing rates of infection have been found among young people (Thianthai, 2004) and men who have sex with men (Thanprasertsuk et al., 2005). Injecting drug users have shown consistently high rates of infection over 15 years, hovering near 40%, with little or no reduction despite years of programming (Verachai et al., 2005). In addition, migrant groups and ethnic minorities who have historically been excluded from intense programming cause concern over undetected levels of infection (Beesey, 2000).

Accompanying effective fear promotion in early HIV/AIDS campaigns, stigma and discrimination became entrenched aspects of personal and institutional responses (Lyttleton, 2004, Lyttleton & Amarapibul, 2002; Sringernyuang et al., 2005). Significantly, stigma has lessened markedly due to the widespread presence of local community support groups, but it still shapes the impact of HIV/AIDS in many sectors. Relevant to this paper is the role ARV provision plays in processes of normalisation that further reduce social discrimination as drug treatment redefines the sense of community that has been built over the past ten years for those directly affected by HIV. Just as the effectiveness of education campaigns changed the nature of risk, so too provision of ARVs is changing ways in which
normalisation and community integration take place for those with HIV/AIDS. As drug therapy has become more central, management of HIV/AIDS at individual, community and national levels pose many social and personal issues that go beyond simple drug distribution.

**Provision of anti-retroviral therapy**

The Thai Public Health Ministry (MOPH) began to provide antiretroviral mono-therapy in 1992 and, by the late-1990s, triple-therapy. Uptake remained minimal for both ARVs and medication for opportunistic infections due to the prohibitive cost of medicines and, by 2001, only 3,600 patients had received ARVs. But by early-2005 National Access to Antiretroviral Program for PLHA (NAPHA) and Global Fund had expanded uptake to 52,593, while a further 10,000 people received ARVs through government social security insurance schemes and NGO funded projects for migrants and pregnant women (Kiatying-Angsulee et al., 2005). These rapid increases came about largely due to activism of civil society groups, specifically NGOs (ACCESS, MSF and Thai Foundation for Consumers, and TNP+). In 2000, when a request for compulsory licensing was refused, a lawsuit was filed at both Thai and international trade courts. While PLHA groups in Thailand had gained public profile prior to this (Duongsa et al., 2000), spearheading legal action was a significant milestone in their political evolution. It was the first time that ‘people infected with HIV braved stigmatization to stage public demonstrations and proved to be a watershed event in terms of awareness and self confidence for people with HIV/AIDS’ (Ford et al., 2004: p. 560).

A major victory was gained in 2002 when two HIV-infected Thai won a court case against Bristol-Myers Squibb overturning a patent on the ARV drug didanosine (Kumphitak et al., 2004: 2). This verdict allowed MOPH to produce generic drugs without fear of breaking TRIPS regulations. It meant the government’s treatment program could expand rapidly. The success of PLHA lobbying didn’t stop with production of cheaper drugs. In 2005, the Thai government included provision of ARVs into its subsidised health scheme. This universal healthcare program, established in 2001, entitles eligible patients to hospital care for 30 baht (approximately US$75 cents) per visit regardless of the ailment. While this scheme has come under scrutiny for its practicality and sustainability, it has without doubt dramatically increased access to medical care and to ARVs at minimal cost. It has also created a programmatic and practical demand for increased involvement of PLHA groups in the distribution of ARVs.

Anti-retrovirals are now, with some notable exceptions, available to all who need treatment. By early 2006, roughly 70,000 individuals were receiving ARV treatment. District hospitals can provide these drugs almost free of charge under the universal coverage scheme and it is projected that as many as 200,000 infected people will receive ARVs in coming years. Whether Thailand can achieve its ambitious goals will depend on many things; ongoing commitment, political willingness to challenge World Trade Organisation rulings and adequate budget (national and international). It will also depend on the active participation of people living with HIV/AIDS. In this context, PLHA groups have become central players in how HIV/AIDS is managed in Thai society.

In many countries, the GIPA (Greater Involvement of People Living with HIV/AIDS principle) pledge for ‘full involvement’ of PLHA in the response to HIV/AIDS has not lived up to projections (International HIV/AIDS Alliance, 2005: 29). Thailand is a notable exception. Here PLHA groups have become central to planning and facilitation of ARV treatment outreach. While many still receive additional funding from NGOs and external donor bodies, as well as organizational assistance from local health institutions (phi liang), in parts of Thailand the support groups have become the key unit of coordination, activity orchestration and information relay in the national response to HIV/AIDS, standing out in some provinces above other civil society contributions.

A recent review notes that, ‘The PLHA movement in Thailand is a movement of the rural poor, most of whom are farm or factory laborers, housewives or unemployed people’ (Kumphitak et al., 2004: 1). While technically true, the symbolic association is equally significant. It aligns PLHA networks with other community-based movements in Thailand. Grassroots activism has gained an increasing profile since the Assembly of the Poor (a loose coalition of disenfranchised groups) first made substantial political advances in the late 1990s. This was at a time when Thailand had just adopted a constitution that gave considerably more leverage to popular participatory representation. Whereas previously PLHA collectives were oriented to local community acceptance rather than a larger order of socio-political activism (Lyttleton, 2004), this growing mood of empowerment underscored demands from PLHA for increased rights to treatment. It has also prompted subsequent engagement in broader arenas of political and moral exclusion. Thus, at recent demonstrations over free trade agreements, PLHA group members joined in solidarity with thousands to collectively voice their concern over agriculture subsidies, trade imbalance and restrictions on production of ARVs.
Following strategic directions orchestrated by the TNP+, in constructive collaboration with the state, HIV-infected volunteers have now taken on a range of new responsibilities. Anti-retroviral treatment has linked PLHA support groups more closely with government as they mobilised within local hospitals. For many who rely on state provision of these drugs, it provides an impetus to join support groups whose number is growing dramatically. Currently, there are about 20,000 members of HIV support groups throughout the country. As the growth in membership expands the public face of HIV in Thailand, it also increases the collective weight for community and political activism. On the one hand, PLHA groups play a key role in ARV provision—they assist the state in expanded uptake. At the same time, PLHA leaders advocate for increased access. This directly challenges the state and international trade agreements through confrontations over affordable medication. Increased access is not simply negotiated through cheaper drugs. One important initiative is to expand ‘community’ to include PLHAs from ethnic groups formally denied access to support and health services.

Methods

To explore tensions implicit in these positions, research was carried out in the northern province of Chiang Rai between December 2005 and February 2006. Chiang Rai was chosen for its high level of HIV prevalence and for its many agencies working on prevention and support initiatives. It has a strong PLHA network with the most support groups of any province and it has a large minority ethnic population.

We used two teams of researchers each consisting of western, Thai and Akha researchers. We chose five districts in Chiang Rai to examine the community level functioning of PLHA groups. Our informants included health officials at central, provincial, district and sub-district (tambon) levels and representatives from key NGOs with HIV/AIDS and ethnic support programs in Chiang Rai. We interviewed leaders of TNP+ at regional and provincial levels, we spoke with PLHA volunteers and support group members at district and sub-district level in each of these districts as well as members of local communities. It should be noted that much of the data we report comes from PLHA members within support groups who have disclosed their status. Their experiences are relevant to group membership and do not cover the experiences of a broad spectrum of HIV-infected who have not joined groups.

Qualitative data was collected through open-ended discussions. This was augmented by documents and research reports from NGO and government bodies. With material from public health officials, NGO workers, PLHA members from lowland and highland communities and local community members we were able to gain a clear picture of the evolving trends faced by the PLHA groups and the communities in which they are both working now (lowland) and those in which they are seeking to be more active (highland).

Results

The growth in PLHA groups

During the 1990s, activities within PLHA groups were primarily geared to income generation, shared moral support and knowledge about medical and self-care techniques, including traditional medicine and alternative therapies such as massage and meditation (Tanabe, 1999). People living with HIV/AIDS found enormous solidarity through these groups. While somewhat structured around class and gender distinctions, the groups have fostered a crucial process of ‘redemption’ for those that joined (Lyttleton, 2004). Their formation assisted in social normalisation of HIV infection by creating the social platform and moral support for public disclosure of HIV status and marked the establishment of a public space from which self-admission of HIV infection could lead to a “recovered” sense of self-worth and self-reliance’ (Duongsa et al., 2000: 4).

The number of support groups in Thailand jumped from just over 400 in early 2002 to 920 in early 2006. This recent increase is closely linked to the provision of ARVs. Further, the notion of community support has changed from one that was oriented to social and psychological assistance to one that includes drug treatment as its central platform. Through the 1990s, the growth of groups was concentrated in the north, a product of the relatively advanced stages of epidemic in the north and productive relationships between NGOs, PLHA leaders and state bodies (Im-em & Suwannarat, 2002). Groups have organised themselves into stratified networks linking sub-districts (in the upper north), districts, provincial, zonal, regional and national levels. Their functioning as a coordinated structure representing tens of thousands of members has allowed expansion of the TNP+ into increased social and political advocacy.

Since 2002 group numbers have doubled. While there has been minimal increase in the upper north (see Table I), increases elsewhere have been dramatic. District hospital groups increased from 495 in 2003 to 688 in 2005 (see Table II). Nearly 200 new hospital-based groups have emerged due to the necessity for PLHA groups to assist with ARV distribution. An earlier review of PLHA groups in north Thailand noted that ‘their mobilisation has
strategically functioned as a move to engender societal acceptance of PLHAs and their ability to live in harmony with the rest of society' (Duongsa et al., 2000: 23). During their rapid growth in the north the groups’ primary function was to allow exchange of emotional support and facilitation of shared therapies between members.

Since 2000 and the battle to make ARVs available, PLHA informants indicate that the tenor of group mobilisation and functioning has shifted. The focus of activism for PLHA rights has moved from engaging community acceptance and support to a political terrain. Now the contested rights are access to medication rather than local integration, although the two are still related. The shift is evident in the declining role of village level AIDS committees but can be detected most notably in the changing focus of PLHA networks, group activities and volunteers. Leadership within the PLHA network has taken a larger role in national and provincial advocacy for basic rights to health and social equity. At the more local level, the profile of PLHA groups is increasingly defined by the public responsibilities of a core group of volunteers in each district. These responsibilities come from agreements between TNP/C27 and MOPH. They are enacted by the commitment of scores of PLHAs who give up time (and possibly their health) to further a cause.

**Changing roles of PLHA groups**

The involvement of PLHA in care and support predates the arrival of ARVs (Del Casino, 2001). Their active involvement in uptake of biomedical regimes is more recent. In 2000, TNP+, ACCESS and MSF launched a campaign to increase access to prophylaxis and treatment of opportunistic infections. This set the stage for the institutionalisation of PLHA groups within medical service provision. In 2002, the MOPH invited PLHA volunteers to join multidisciplinary teams providing ARVs based on the assumption that PLHAs would readily recognise symptomatic HIV-infection and be able to refer ‘friends’ for appropriate treatment (Kumphitak et al., 2004: 5).

In Chiang Rai, the Thai MOPH-US CDC collaboration (TUC) created daycare centres at the district and sub-district (tambon) level based on provision of holistic health services including ARVs. This model dovetails with the MOPH Centres of Comprehensive and Continuous Care program that, at the time of writing, has expanded to 160 hospitals nationwide. In both instances, PLHA groups are essential to these programs due to the ethos of active participation and the pragmatic recognition that health staff are overburdened and cannot provide adequate follow-up to the growing number of ARV recipients. It is a model that is likely be further replicated, depending on funding and the ability and readiness of the hospital staff and PLHA volunteers to work together.

The PLHA volunteers we spoke with confirmed the basic elements. The district hospital runs a daycare centre where PLHA group members come for monthly meetings. During these meetings updated knowledge of ARVs is presented, CD4 counts

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### Table I. Number of groups of PLHAs in the upper-north, 1993–2005.

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### Table II. Numbers of support groups nationwide, 2003–2005.

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<th>Region</th>
<th>Upper North*</th>
<th>Lower North</th>
<th>Central</th>
<th>East</th>
<th>West**</th>
<th>North east</th>
<th>South</th>
<th>Total</th>
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<td>77 (229)</td>
<td>80</td>
<td>105</td>
<td>52</td>
<td>195</td>
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<td>803</td>
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<tr>
<td>2005</td>
<td>77 (232)</td>
<td>97</td>
<td>89</td>
<td>54</td>
<td>43</td>
<td>245</td>
<td>83</td>
<td>920</td>
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*groups in brackets are the number at the sub-district level, all other groups are hospital-based at district level.

**the west became a regional classification subdividing from central region in 2005.

taken and ARVs distributed. Sometimes social and/ or psychological issues are raised but this is rare, as technical aspects of ARV provision are time-consuming. Medical staff suggested that where possible such discussions were best carried out at the sub-district level.

It is possible to receive ARVs from the hospital under universal coverage without being a member of a support group but there are a number of pressures to join. Firstly, it is strongly advised to incoming PLHAs so that the medical staff can co-ordinate medical check-ups and ARV provision (which are only distributed in monthly amounts) on a regular schedule when all PLHAs attend. Secondly PLHAs must pay extra for outpatient costs if they do not come as part of the regular hospital meeting. Those who do not wish to disclose their HIV status to other group members through public attendance at day-care centres pay substantially more for ARV drugs privately from clinics. Virtually free ARV provision is the core rationale for attendance. This raises ethical issues of the extent to which poor people are being forced to disclose their status as they have no option to join these groups if they wish to receive ARVs. While hospital meetings are ostensibly confidential, clearly some degree of disclosure to other members takes place at group events. The same ethical questions arise over the need to join groups at the tambon level to receive social welfare assistance administered through groups by the tambon council.

Volunteers as ‘change’ agents: exclusion into inclusion

The role of PLHA volunteers is paramount at hospital meetings. A group of between seven and thirteen volunteers assists with logistic demands of administering drugs. They act as key resource people in giving counselling and training to new patients about to enter ARV regimens. Before anyone begins ARV treatment, he/she must sign an agreement with a list of conditions. The potential recipient must understand the possibility of side effects and that this is a lifelong commitment. Most importantly, if the patient does not attend the monthly meeting or omits to take ARVs for more than seven days, he/she automatically relinquishes any right to their ongoing (monthly) provision. Volunteers ensure these details are adequately understood, important for patients who do not have the language facility or background to readily comprehend the medical requirements of daily lifelong adherence.

The responsibility of PLHA volunteers moves well beyond monthly meetings. In addition to staffing a counselling centre and helping with the monthly meetings, they provide crucial follow-up to assist with side effects and ensure compliance to drug regimens, in particular during the first month of prescription. People living with HIV/AIDS volunteers are the first line of action if an enrolled ARV patient does not appear at the monthly meeting. There is substantial concern over compliance; not simply for the health of the individual but to prevent drug resistance. Additional counselling is needed when lypodystrophy (fat redistribution) takes place calling for a change in drug usage. At present, only first-line drug treatments are subsidised, and patients face difficulties in accessing affordable alternatives when drug regimens must be changed. According to volunteers this is a particularly difficult period for individuals who have become used to a sense of physical normality (from ARV treatment) and are again reminded of the dilemmas posed by HIV infection. Volunteers spoke to us of the stress they face taking on responsibilities to both the health departments and ARV recipients. As one volunteer noted: ‘It's fine for people on ARVs—their CD4 count goes up. But for us volunteers, our CD4 barely changes even with ARVs because of the sheer demands of our work. Sometimes it is hard to carry on.’

It is not just home visits that form part of volunteer’s collective responsibility, regardless of implications for their own health. A further key role for volunteers (and other group members) is ongoing political agitation for ARV provision and, nowadays, for broader areas of social change. In a 2006 demonstration against the free trade agreement being negotiated between Thailand and US, hundreds of PLHA descended on Chiang Mai to publicly voice concerns about potential impacts on patent rights and drug costs. They slept on streets for several days joining with thousands of others raising concerns over agricultural subsidies and trade deals. The volunteers we spoke with felt this was part of their mission as core PLHA group members. Their work thus proceeds in two directions: one (funded by NGO or Global Fund assistance) is to help ‘friends’ access and adhere to medical treatment. The other, for which they wish to remain free from state control, is to participate in public action against state controls and policies, such as challenging the proposed free trade agreements and application of drug patents. Volunteers told us that this dual work was satisfying, exhausting and, above all, fundamental to their current identity as PLHA spokespersons. At the district level, group leaders indicated that while their work with local hospitals seemed to be integrating them within the state bureaucracy, they would staunchly refuse becoming employees as this would remove their ability to act independently and to actively challenge state policy.

There are a number of issues relevant to such changing roles of the PLHA groups and their volunteers. We highlight two. Firstly the increased importance of PLHA work with local hospital
programs removes them from an earlier focus on community integration. Secondly, increased political profile of PLHA networks have prompted attention to marginalised individuals and groups who are unable to access ARVs for structural reasons that go beyond practical availability.

The ‘medicalisation’ of PLHA groups

The necessity of attendance at the district hospital on a monthly basis brings the chief focus of PLHA group’s activities back to a medical setting. While the functioning of tambon and district groups has always differed, a more definitive set of linked activities is emerging. The district (hospital) level groups are now focused almost exclusively on CD4 assessments and ARV provision. In the past tambon groups have mainly been engaged in assisting with community acceptance and integration by seeking to dismantle stigma and discrimination. Now their activities are increasingly linked with nearby hospitals, as they become an organisational conduit to assist ARV provision rather than a source of locally generated activities. While this structural shift is noticeable in upper northern provinces that have tambon groups, the recent rise in hospital groups across the country consolidates the trend. As the district hospital level becomes a key nexus of HIV and AIDS management, control and assistance, the tenor of activities is centred on vertical articulation of biomedical initiatives, rather than community based psycho-social assistance. As one NGO worker described the changes: ‘In the past groups were concerned with health in broad terms of well-being, now they focus on ARVs.’

Clearly this is not categorically negative. Many of those with HIV, together with NGO and government staff that we interviewed, felt that the health and longevity provided by ARVs was a godsend. Likewise the presence of ARVs has further reduced stigma to a point where, in some lowland communities, PLHAs felt it was of minimal concern. People living with HIV/AIDS suggested that pity rather than fear was becoming a more common emotional response to those with HIV. But, at the same time, NGO and PLHA members also cited shortfalls in community focus on significant issues of partner notification, disclosure to children, new partners, discordant couples and more broadly oriented health practices such as nutrition and alternative therapies. In other words, ARVs are now seen as the key to physical and social normality, while other strategies to reduce dependency on drug therapy receive less attention. Several long-term PLHA group leaders noted that as the impetus to join groups has moved from emotional support towards medical help, the hospital has replaced local level village structures such as AIDS committees as the key focus of the response to AIDS and the sense of responsibility amongst village structures established by an earlier generation of PLHA initiatives is waning.

This changing focus appears to be associated with a shift in membership. In one district, while the number of groups had not changed, the numbers of members had dropped markedly, to the point that virtually only those taking ARVs regularly attend meetings. Now, in early 2006, in Chiang Khong district 169 members attend meetings; of these, 156 take ARVs. In previous years, according to group leaders membership numbered closer to 400. No longitudinal data exists to chronicle the changing make-up of district groups making generalisations difficult. However, for the larger groups where data has been recently collected, the majority of group members are those who have reached symptomatic AIDS stages or with low CD4 counts and are taking ARVs. According to TNP+ data, Chiang Rai has 4,185 adult HIV-infected group members—of these 3,065 (75%) are on ARVs. The proportion is higher in the upper northern region, where, of 9,594 adult members of support groups, 8,359 (87%) are on ARVs and nationally, where 79% of the 20,162 adult members receive ARVs.

PLHA groups have always functioned as a resource for those who become sick. When ARVs were not available, groups also functioned as a panacea for stigma and alienation and many joined for this, regardless of their physical symptoms. Nowadays the majority join the groups when they need to access ARVs. One PLHA leader described associated changes: ‘Before if you didn’t take herbal remedies you were seen as “out of touch”, now if you don’t take ARVs you are seen like this.’

The symbolic weight of ARV provision is evident in other ways. An evaluation conducted by TUC Collaboration showed that, amongst PLHAs (n = 477) participating in daycare centers, health and social outcomes were notably better for those taking ARVs (71%) than those who weren’t (29%). Those taking ARVs scored better in health improvement, psychological improvement, ability for self-care and ability to care for others (Lolekha et al., 2006). In other words, taking ARVs figured significantly in a range of well-being variables that related more to caring than direct medical support. For example, people taking ARVs felt they were better at taking care of others than those not yet in need of ARVs and the PLHA groups, by extension, were perceived as less valuable by those not taking ARVs.

Echoing trends in the west, several Thai researchers that we spoke with are calling this ‘the re-medicalisation of HIV in a post-ARV ‘Thailand’. Certainly the PLHA role in follow-up visits to ensure compliance does give PLHA volunteers roles as...
agents of the state. But while this is partially driven by practical requirements, it is also driven by the PLHA themselves. People living with HIV/AIDS told us that a number of HIV-infected people in their communities came to the hospital to receive ARVs and then carried on with their ‘normal’ work lives without needing assistance in any other context. Thus ARVs are allowing a normalisation of HIV-status through medical means that in the past the PLHA groups had to battle for through more social maneuvers.

While the widespread availability of ARVs is a significant achievement, there are issues that remain problematic. For example, the number of orphans who receive little or no social welfare benefits is of serious concern. The regional PLHA network lists 5,202 children infected or affected by HIV/AIDS in the upper north. Drug treatment is complicated as the subsidised drugs are not always suitable for children. It is often beyond the capacity of PLHA groups and/or PLHA volunteers to provide the kind of material and psycho-social support children affected or infected require without a broader level of community assistance. And as the tambon groups themselves become less engaged with community mobilisation, far less pressure is placed on local communities to maintain a level of social welfare that is not state provided. Care and support for HIV-infected individuals not yet on ARVs thus receives less attention and issues such as how to delay progression towards AIDS through holistic health strategies, such as nutrition and meditation, do not have the forum they had in the past.

A further set of social issues relates to the significant extension of life expectancy brought by ARVs. The numbers taking ARV has grown rapidly and, barring changes in the patent laws, is expected to reach 200,000 in the next few years. This has raised a new set of issues around the requirements of lifelong compliance. The government has asked PLHA members to help in dealing with these, based on concerns for the well-being of HIV-infected individuals and the need to reduce drug resistance and the transmission of resistant strains of the virus. These issues go beyond medical compliance: as people’s lives become normalised by longevity, this affects their social choices and relationships. Desire for domesticity replaces the alienation and stigma facing those with HIV in a pre-ARV era. Families are (re)formed, new partners taken and children born. Life proceeds. While these topics are mentioned in ARV training sessions, it is often not specific technical help that is required but rather careful consideration of both the physiological implications of lifelong drug-taking and support for adapting social relations to endemic HIV. These issues are included in some tambon group activities but, according to NGOs and PLHA members, they lose precedence to a focus on expanding correct ARV uptake. The onus thus falls on the volunteers as ‘counsellors’ to address all these psycho-social issues, rather than on broader community-based support mechanisms, mobilised through local village committees. And, as ARVs become more central in the management of AIDS, the imperative to expand community is shifting attention to a further advocacy requirement—the inclusion for those marginalised in ways other than HIV infection alone.

**Expanding the community of PLHA**

The intent to broaden terms of inclusion became clear at a recent TNP+ (northern region) meeting in late 2005. An agenda item was raised: ‘What to do about our friends who are less fortunate than we?’ Friends in this instance meant those who were having difficulty benefiting from the recently won advances in accessing ARVs for most PLHAs in Thailand. More specifically, ‘friends’ meant ethnic minority peoples and migrants who were unable to be part of NAPHA for reasons to do with lack of Thai citizenship. A plan of action was ascertained and questionnaires prepared. In 2006, district groups in northern provinces have begun collecting data to ascertain how many support group members are without Thai citizenship.

This initiative fits within an operating philosophy that intends to build on past success in political advocacy. The TNP+ (north) specifies four central strategies that highlight the focus on ARVs; preparation for new PLHAs entering the system (primarily ARV training); hard to access populations (persons without an ID card); long term side effects management (fat replacement, diabetes etc) and appropriate regimens for children. Listing ‘hard to access populations’ is a key development: this category includes migrants and ethnic minorities. While TNP+ has yet to compile the data on ethnic PLHAs in support groups, it is already apparent there is a problem. As the battle to have ARVs included within the national health subsidy was won in 2005, this success immediately created a new boundary of exclusion. Since NAPHA began, hospital staff were usually able to manipulate operating budgets to provide ARVs to those without funds to buy them. When ARVs became subsidised, formalised rules of access meant that hospitals could no longer provide free treatment to PLHAs without full Thai citizenship.

Around one million highlanders from a number of ethnic groups live in Thailand, the majority in northern provinces (Srettachau et al., 1999). A further 2–3 million migrants have entered Thailand from surrounding countries in the last 15 years, some of whom are from highland groups that live
throughout the upper Mekong. Until 30 years ago, highlanders in Thailand were largely ignored by state modernization programs—they existed in remote areas as stateless individuals. Attempts to officially bring hill-tribe populations into regimens of state governance began in 1975 and while many have been registered and carry highlander ID cards, they remain second-class citizens ineligible for rights taken for granted by most Thai. ‘Despite being born in Thailand, almost half of the country’s hill tribe people lack Thai citizenship and are unable to vote, buy land, seek legal employment or travel freely’ (Lynch, 2004:1). Thus, HIV has, and continues to, spread through hill-tribe communities as forms of exploitation and marginalisation dominate their lives. Although data is not aggregated in national surveys, case studies show high levels of HIV sero-prevalence amongst ethnic groups (Gray, 1998; Razak at al., 2003). Discrimination and stigma is prominent and lack of disclosure common in highland villages.

The obstacles that preclude minorities from accessing health services are multiple: cultural, geographic and economic. In Chiang Rai, there are noticeably fewer support groups in areas with high ethnic populations. Leaders of PLHA groups are aware that HIV-infected people from minority groups seldom join PLHA support groups. Ethnic highlanders with HIV that we interviewed listed language, remoteness, cultural difference and difficulties with health staff as primary reasons. Likewise PLHA volunteers noted that exactly the same reasons preclude them from regularly making follow-up visits to ethnic communities that have PLHAs who have disclosed their status.

The questionnaire distribution signals a first step TNP+ is taking to address these obstacles. Once it is known how many members do not have access to the universal coverage health system due to lack of citizenship, how and with what leverage they will be able to subsequently negotiate access remains to be seen (It should be noted in late 2006 the new Thai transitional government proposed significant changes in access to health services for non-citizen minorities and migrants – it is not yet clear to what extent this will be achieved). What is clear is that the extension of care and support services, most specifically access to ARVs, is seen as a crucial part of TNP+ mission. Inclusion of ‘hard to reach’ groups reflects the ways that identity, community, political action and self-motivation have been formative elements of the evolution of PLHA groups in Thailand. It is also a key development within the history of HIV in Thailand and the complex interplay of national policies, community needs and individual responses. It signals an important evolution: on the one hand, it broadens the PLHA responsibility to ‘take care’ of all who belong within a community defined by HIV status; on the other hand, it ratchets up the political challenges facing this initiative. By expanding community to include ethnic minorities without citizenship, HIV is being elevated as the forum for belonging in ways that radically refigure processes of assimilation, while giving the PLHA movement more prominence, and challenge, within civil society in Thailand.

Conclusions
As a product of targeted funding and strategic choices made by TNP+ leadership, PLHAs now have a central role in ARV provision. This is fundamental to a growing profile and influence of PLHA members within a civil society response that supports services provided by the Thai government. This paper highlights that, even as ARVs have dramatically changed the complexion of HIV/AIDS in Thailand and provided staggering benefits, HIV infection and its impact continue to raise highly politicised issues of identity and responsibility. Leaders of PLHA groups and NGOs recognise that community engagement is a crucial form of empowerment that allows those with HIV to negotiate the terms by which the disease is understood and thereby experienced. Anti-retrovirals contribute a degree of control over the virus and thus currently take precedence. At the same time, the evidence we found suggests that pharmaceutical provision has removed a broader understanding and management of the disease away from the individual and his/her community. Support group activities on how to delay progression to symptomatic AIDS through community-based approaches have been somewhat sidelined by a focus on hospital ARV provision. Living with AIDS is coming to mean taking ARVs and little else. Being a PLHA is increasingly defined by stages of infection associated with taking ARVs. These changes are recognized by some PLHA members and NGO staff who are currently seeking to re-invigorate the community level functioning of tambon support groups.

The paper thus points to the changing nature of the collaboration between PLHA groups and government institutions. On the one hand, core PLHA members work closely with health offices and act as vital disseminators of information and personal contact that will ensure adherence. In other words, they extend state functioning in a system designed to help those with HIV. This is a role they willingly and wholeheartedly adopt as it allows direct involvement in self-help to their ‘community’. On the other hand, it draws attention to the wider issues of political inclusion and access to ARVs and the demand to address the forces that keep marginalised groups
from being able to access ARVs in the first place. Given rules excluding those without full Thai citizenship from access to ARVs, the PLHA movement has made expanded access for hard to reach groups a new platform of their activities. This brings quite different relations with members and the state than service provision.

As PLHA groups advocate for minority group access to ARVs they must tackle complicated politics and social norms relating to difference and the historical exclusion of ‘uncivilised’ mountain peoples. The terrain of moral adjudication is one that PLHA groups are intimately familiar with; they too have fought against spurious moral discrimination. Now they are taking on the challenge of exclusion that centres on denial of national belonging and the services that go with this. It further shifts relations with the state away from collaboration towards more active confrontation. This is not new for the PLHA movement as we have already seen in contestations over rights to affordable treatment but it potentially raises tensions in the growing cooperation with the state around ARV outreach. How the implicit tensions between the two positions are resolved will continue to shape TNP presence and effectiveness within the civil society landscape in Thailand.

This situation is dynamic, raising many areas for ongoing assessment and reflection to strengthen both the community of PLHA and the responses to the epidemic. It remains unclear how successful the PLHA networks will be in bringing about increased access to ARVs. It is also unclear how ARV provisioning will change in the future and how this will affect PLHA with different backgrounds and different levels of disclosure. Nevertheless, current TNP maneuvers highlight that the paramount community response in Thailand is currently that of the PLHA networks and their intention to take care of their own ‘community’. While pointing to the challenges, this paper further highlights the ways in which HIV/AIDS and the responses to the epidemic have come to generate one of the more successful community coalitions in the history of social change in Thailand, where groups of people historically marked by stigma and prejudice have become simultaneously central in community outreach and political activism.

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