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## **Response to AIDS at Individual, Household and Community Levels in Thailand**

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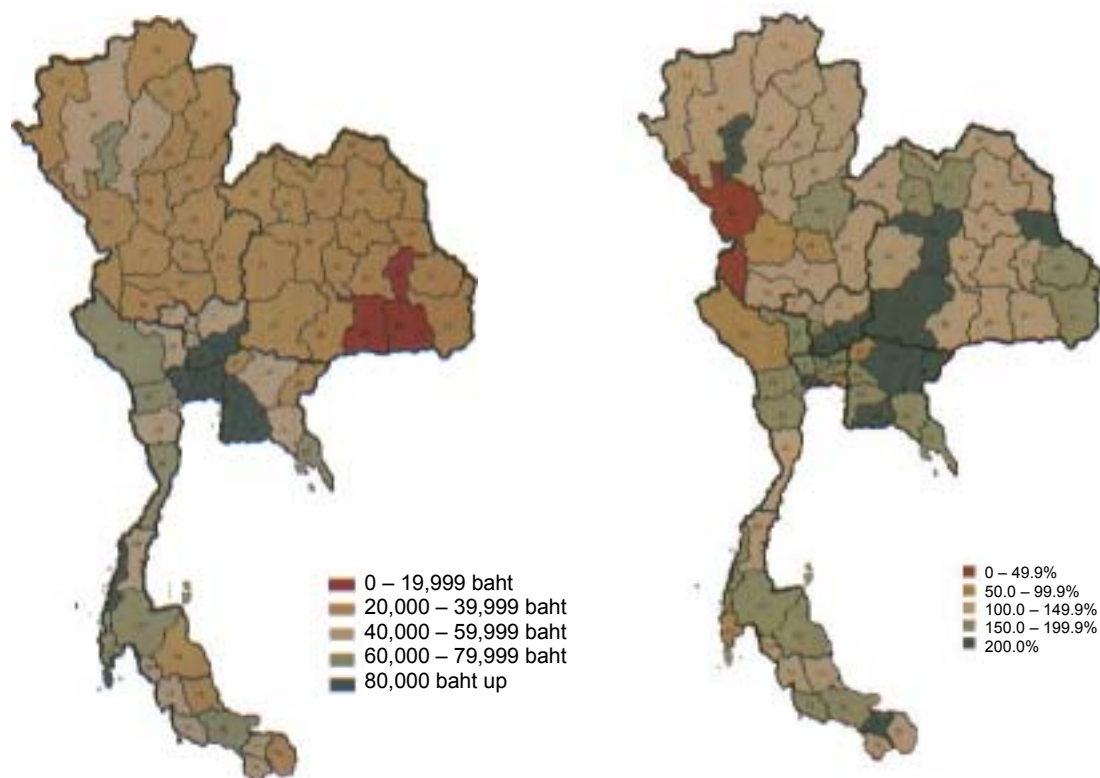
**Response to AIDS at Individual, Household and Community Levels in Thailand***Wassana Im-em and Gary Suwannarat***Background**

Thailand's response to the HIV/AIDS epidemic, globally acknowledged for confronting the basic issues, nonetheless was slow out of the starting gate and remains uneven. Not until several years after the epidemic emerged did the government undertake a national program, including the establishment of National HIV Sentinel Surveillance surveys to monitor the progress of the epidemic and guide subsequent government policy and actions. While the national response to the epidemic is well documented (see Poocharoen, 1998 and Porapakham, n.d.), less is known about how individuals, families and communities cope with and respond to the challenges presented by HIV/AIDS, particularly outside the much-studied Northern Region. This paper attempts to redress this gap. It begins by briefly reviewing the influence of the on-going social transformation in relation to the AIDS epidemic in Thailand. Subsequently, the paper explores the situation of AIDS by region and argues that limited information is known about Thai responses to HIV/AIDS outside the Upper North region where the epidemic is severest. The paper next explores changes in behavior undertaken by individuals to prevent infection, how people living HIV/AIDS (PHA) respond after being infected, and addresses how families adjust to infection of family member(s) with HIV/AIDS. The concluding section describes how communities react and respond to PHAs and how the communities utilize resources to support people affected by HIV/AIDS.

**Social Transformation and Mobility**

During the decade beginning in the mid-1980s, HIV/AIDS entered and spread in Thailand roughly in parallel with the rapid growth of foreign investment. Rapid economic growth, largely based on the emergence of peri-urban export industries, produced imbalances across provinces, with the relatively better-endowed Bangkok and Eastern Seaboard areas enjoying higher growth than other parts of Thailand (see Figure 1). High growth in turn fueled a snowballing social transformation.

Figure 1 Per capita income by province (1996) and change of per capita income (1988-1996)  
 Source: UNDP, 1999 (Map 1&2)



During this period, rural Thai villages experienced an intensification of connections with urban areas and with the opportunities and challenges of integration with global markets. The attraction of regular pay in jobs less physically demanding than farming, the excitement and diversity of cities, and schooling which prepares rural students for non-farm jobs are among other factors pulling youth out of villages. Indeed, migration for schooling is an important aspect of mobility. Rural children attend district and provincial schools at the secondary level, in many cases living in private dormitories near school. With the emergence of residential universities outside Bangkok over the past 35 years, dormitories have flourished, often offering little or no supervision.

The out-migration of young adults for urban employment has increased the shortage of farm labor. Traditional labor exchange has been replaced by hired labor, rationalizing the system but loosening community solidarity. Contributing to the reduction of farming during the boom years, land speculation enriched some farmers, but left fields idle. Many farmers lack their own land and have to rent land for farming (Im-em, 1996; Im-em, Phuangsaichai, 1999).

Migration, historically a cyclical phenomenon as rural men seek wage labor during the off-farming season, has become increasingly long-term. Of some 3 million people who migrated at least once over the two-year period from September 1995-September 1997, about 30 per cent contribute to families through regular remittances (National Statistical Office, 1997: Table 23), which constituted the major source of cash income for some elderly parents. Rural men from throughout the country seek jobs in construction work, as taxi drivers in Bangkok, as fishermen in the Gulf of Thailand and beyond, as guards of businesses and private homes, and increasingly during the boom years of the late 1980s and early 1990s, in industry. Rural women have joined the exodus and constitute some 80 per cent of the export industry workforce in the textiles and foods industries. Among 11-19 year-olds, twice as many females migrant to Bangkok as males (Gender and Development Research Institute, 1995). Women

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and men have also migrated abroad to work in the Middle East and in wealthier Asian nations (including Taiwan, Malaysia, Brunei, and Singapore).<sup>1</sup>

Meanwhile, the attraction of higher wages in Thailand has led to increased migration from neighboring countries.<sup>2</sup> Episodic reports indicate that cross-border migration increases the likelihood of infection, due both to ignorance of risk and to physical and sexual abuse of migrants.<sup>3</sup> However, sero-prevalence rates in border areas are among the highest in the region. For instance, the 1997 Sentinel Surveillance survey indicated that the sero-prevalence rate for Koh Kong, along the Thailand-Cambodia border, is alarming (52 per cent of commercial sex workers [CSWs] surveyed, 21 per cent of police, 10 per cent of the military, 19.5 per cent of pregnant women). In 1999 the rates were 42 per cent for CSWs, 24 per cent police and military (combined) and 8 per cent for pregnant women attending antenatal clinics (CARE International, nd).<sup>4</sup>

**Poverty**

The proportion of people in poverty in Thailand has declined rapidly over time. In 1962-1963, 57 per cent of the people were living in poverty and twenty years later the percentage had declined by half and stabilized at this level for another 10 years. The period around 1970s-1980s was the time that increasing number of people from the rural areas sought overseas employment, often in the oil-producing countries of the Middle East, for higher income. Many migrant workers returned home rich.<sup>5</sup> With the stimulus of wealthy returned migrant workers and the economic boom of the 1990s, the percentage of people in poverty further declined to 11.4 per cent in 1996. In 1999, the percentage of people living in poverty increased to 15.9, a result of three years of economic crisis (Meesuk, 2000).

While mobility increases risk across different socio-economic groups, the majority of Thais reported to be infected with the HIV/AIDS virus are poor. The poor have less access to information and services which might protect them from sexually-transmitted infections; poor men are probably somewhat more likely to patronize sex workers who do not insist on condom use, and poor women are less likely to have the bargaining power to protect themselves against infection in relations with a regular partner. Poverty, the relative status and power differentials associated with being poor, and mobility interact to heighten vulnerability to infection. Being female increases risks, with some researchers indicating that women factory workers face vulnerability of two sorts: public perceptions of "sao rongngan" (factory girls) as loose and ready to experiment sexually, and power realities in the workplace, where women are largely workers, not managers, and sexual advances and rape by male supervisors are known but go underreported because of fear of job loss (Thaweessit, 2000).

<sup>1</sup> The reported number of Thai working overseas from 1995-2000 was about 200,000 per year, and between 14-18 per cent of them were women (Overseas Employment Administration Office, cited in Soonthornthada, 2000; National Economic and Social Development Board (NESDB), 2001).

<sup>2</sup> In the mid-1990s, it was estimated that one million migrant workers were in Thailand. The vast majority of them were from Burma (Archavanitkul, 1996).

<sup>3</sup> Based on the first author's experience to evaluate the HIV/AIDS Prevention Project in Keng Tung Province located in northeast Burma or above Upper North Thailand, the AIDS situation there was devastating in 1998 and 1999. It was found that a large number of PHAs living in the villages there were young women returning from commercial sex work in Thailand. See also Duangdetaweerat (1998) and Oppenheimer (1998).

<sup>4</sup> Even though the commercial test kits for HIV were new to Thailand, blood testing for HIV was widely carried out in the country beginning in 1986 because the receiving countries at that time required all workers to be certified AIDS-free before going there to work. Of over 172,000 overseas workers tested for HIV in 1986-1988, only 19 persons were tested positive for HIV. The laboratory service for the HIV test had been expanded dramatically beginning in 1987, largely because of the demand for blood tests among the overseas workers. More than 30 laboratories were available for the HIV test in major cities in the year 1987, only three years after the first AIDS case was reported in the country (Thongcharoen et al., 1991: 19; Weniger et al., 1991: Table 5).

<sup>5</sup> Many returned migrant workers from the Middle-East countries in the 1980s were well recognized among Thais as 'setthi sa-u' or 'Saudi (Arabian) millionaires' who enjoyed spending money for new houses, electronics goods, drinks, and women. The number of overseas contract workers from Thailand has increased overtime and the total number reported for the year 1999 was 202,416 persons. Half of them were those going to work in Taiwan (Ministry of Labour and Welfare Report, 2000).

**Response to AIDS at Individual, Household and Community Levels in Thailand***Wassana Im-em and Gary Suwannarat***Transformation of Social Institutions**

Both emblematic and causative of larger social transformation, migration and mobility more broadly cannot be ignored as a major element in Thailand's rapid social change. The growing significance of the nuclear family, evidenced by the mushrooming of single-family housing developments both in Bangkok and in most provincial centers, is confirmed by census data which indicates that the proportion of one to two person households increased from 11.6 per cent in 1980 to 16.4 per cent in 1990<sup>6</sup>. This shift in family living patterns contributes to an erosion of the extended family and the social support and constraints which it provides.

Industrialization has taken both women and men out of home-based commerce and industry (including agriculture) and into formal workplaces – offices and factories often distant from home. The rapid development of high-quality roads throughout Thailand has made commuting to work possible. Many rural teachers live in larger district towns and commute to outlying schools, a development which in itself has been criticized as isolating teachers from the smaller communities in which their schools are located and depriving the community of important resources in the broader development process. Vehicle ownership<sup>7</sup> nearly tripled between 1989 and 2000 (calculation based on statistics from National Statistical Office, 1990: Tables 5&80; 2000: Tables 1.1&5.7). The parallel growth in numbers of children in day care programs is indicative of the decline in family care of the very young as economic opportunities (and necessity) have absorbed increasing numbers of parents into the workforce.

Social change has touched religious institutions, as well. In a series of highly publicized cases, Buddhist monks have broken their vows of celibacy, thereby eroding the legitimacy of religious figures, and to some extent, religion itself. Buddhist strictures on contact between lay women and monks, compounded by social views of women's sexuality as both dangerous and degrading, restricts the ability of monks to address intimate matters (Thaweesit, 2000).

**Economic Crisis and Its Impact on HIV/AIDS**

East Asia experienced severe economic crisis, starting in Thailand in July 1997. The root cause of the Thai economic crisis was excessive, foreign debt-financed investment by the private sector together with declining demand for Thai exports in the world market. In the aftermath of the crisis, businesses closed, resulting in massive unemployment, under-employment and a 14.5 per cent increase in poverty incidence, from 6.9 million in pre-crisis in 1996 to 7.9 million in 1998. The crisis resulted in loss of employment, household income contraction, changing expenditure patterns, child abandonment, and poor mental health, furthering the difficulties of families in addressing the needs of PHAs (see Tangcharoensathien et al., 2000).

Anecdotal reports of PHAs themselves and of some health professionals indicate that the sharp fall in the value of the Thai Baht (from Baht 25:\$1 pre-crisis to Baht 45:\$1 late in 2001) has greatly reduced the ability of PHAs to access drugs to counter opportunistic and fungal infections. While this can be hypothesized to have reduced the quality of life and accelerated death rates, no study of this aspect of health impacts of the economic downturn has yet been undertaken.

Tangcharoensathien and others (2000) reported that the crisis has had little effect on HIV/AIDS and STI prevalence. HIV prevalence rates since 1997 have further declined, consistent with stable levels of regular condom use in commercial sex, despite significant reductions in both the total national AIDS budget and free condoms distribution in brothels by the Ministry of Public Health. Total condom distribution fell from 60 and 50.2 million pieces in 1995 and 1996 to 11.2 and 14.2 million pieces in the following years (Pothisiri et al., 1998). In non-free condom distribution brothels, condoms were paid for by clients or charged inclusive with sex services. This suggests that if messages about personal responsibility for safe sex are maintained and sex workers urge clients to

<sup>6</sup> The census data does not give information about the family structure, i.e. nuclear versus extended families. The full results of the 2000 census data are not available to the public as of late 2001.

<sup>7</sup> Refers to all registered vehicles.

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always use condoms, a high level of consistent condom use would continue despite the lack of free condoms.

Public speculation that the number of women entering sex work may have increased during the economic crisis period appears to be supported: the annual census of commercial sex establishments shows an increase from 7208 in 1997 to 8016 in 1998, with a small increase in sex workers from 63,526 to 63,941 in the same period (Tangcharoensathien et al., 2000). Furthermore, recent sexual behavior changes, including a diversification to smaller, informal arrangements, mobile brothels, and casual sex contacts possibly obscure the real scope of the sex industry.

Return migration of those who lost jobs in the wake of the financial crisis provided a potential source of further spread of the HIV/AIDS virus. Indeed, Thailand's Northeast experienced the largest numbers of returnees, amounting to about one million workers. The Northeast is now experiencing an increase in HIV prevalence even though the level is lower than that reported in other regions (World Bank Report, 2000: Table 11).

Post-crisis job loss is credited by some with fueling the rapid spread of amphetamine sales throughout Thailand. Although increased vigilance by law enforcement authorities has no doubt contributed to increased arrests of drug offenders and drug seizures, reports from village-level informants in a number of communities indicate a major increase in drug dealing and drug use has occurred. Along with the increase in amphetamine sales, the growth of child prostitution, both boys and girls, has been evident in the main tourist destinations as recently reported by UNDP of Thailand ... "UNICEF studies confirm the seriousness of the risks (for child prostitution). They have shown the correlation existing between child prostitution and such factors as dire poverty, increased family indebtedness, the growth of poor single parent families, the lack of educational and employment opportunities, and broken homes and divorced and separated parents. All of these risk indicators have undoubtedly increased in Thailand since the crisis (UNDP, 1999, pp.142-3).

**Changing Conceptions of Sexuality**

The rapid economic and social changes provided the medium for behavioral changes that increase vulnerability to sexually transmitted diseases. For instance, there is a prevailing social attitude that men can be sexually experienced, but women should be virgins at marriage. Thai family law historically viewed women and children as chattels, although the 1997 Constitution has changed this. The freedom associated with one's own paycheck and the absence of parental or community restraints provided young workers, both male and female, with the opportunity for radically different lifestyles than would have been the case in their rural homes. The other side of the coin, the hollowing out of family and community support capacity, partially shapes the current rural response to HIV/AIDS.

Peer influences on risk behavior have been well-documented among a number of groups (Bond, 1997). Friends who experimented with drugs, alcohol, and sex were likely to induce others in their group to follow suit. Belonging to a group whose members do not indulge, on the other hand, extends a protective influence on behavior. Group norms among males, whether local to the community or migrants, often encourage drinking and brothel-based sex.

Upon return home, infected returnees form a bridge for further transmission of HIV or other sexually transmitted diseases within rural communities. Since many of these return visits coincide with major holidays and festivals at which alcohol plays an important role, risk of sexual transmission of disease is high.

The Thai belief that it is natural (in fact, imperative) for men to achieve sexual release legitimizes the sex industry, as highlighted by public opposition to government policy to close brothels on the grounds this would lead to an increase in rape and the destruction of the lives of "good" girls and women. As AIDS risk has become better understood, men have adopted a range of behaviors to reduce risk, including fewer men patronizing sex workers and condom use becoming the norm in commercial sex (Chamrathirong et al., 1999). While young men are less likely to engage in paid sex

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than the previous generation, casual (unpaid) sex has increased. Educated youth tend to postpone sexual initiation and to have sex with a girlfriend, with a small proportion continuing to have paid sex (VanLandingham, et al., 1997; van Griensven et al., 2000). Indeed, young men now say that visiting commercial sex workers is “not modern,” and is for “*tao hua ngu*” (literally, old snake-heads, a Thai term for dirty old men). However, there are reports of more clandestine sex workers and of an increase in (unprotected) casual sex with colleagues, schoolgirls or others assumed to be risk free.

Older men are increasingly likely to have sex with ‘informal sex workers’, waitresses, colleagues, or others. A recent survey of over 2,000 women found that 6 per cent of reproductive age women believed their husband paid for sex in the last 12 months. One-fifth reported their husband had ever had another wife or long term partner within their marriage (Archavanitkul et al., 2001). Nevertheless, little is known about the pattern of overlap or concurrent partnership in Thailand, which may have amplified the risk of HIV transmission as suggested in Africa (Morris and Kretzschmar, 1997).

Concepts of female sexuality are changing in Thailand, concomitant with changing views of women’s place in the world. Young women are choosing the single life in increasing numbers particularly among those received tertiary education<sup>8</sup>, as a response to concerns partly about HIV/AIDS, partly about family and career responsibilities, and reflecting a growing acceptance of same sex relationships or sexual abstinence.<sup>9</sup>

Among single women, whether in short-term or steady relationships, evidence abounds that prevention of infections from sexual intercourse is low on the list of priorities.<sup>10</sup> Despite the known risk behavior of single men involving paid sex and/or casual relations, newlywed couples rarely obtain counseling including HIV blood test prior to marriage. Hence, a number of women learn they are infected with HIV when an antenatal clinic conducts blood tests, including HIV, in their first pregnancy.

Married women reported various responses if they find that their husband were involved with paid partners. Abstinence until the husband obtained an HIV blood test is the principal method of protection. A few reported in focus group discussions that they would ask their husband to use condoms (Im-em, 1996). In reality, prevention of HIV within marriage is more difficult and the level of condom use within marriage remains low. Wives of taxi drivers and fishermen who return periodically to their rural homes in the northeastern provinces indicate a bit of desperation in addressing their concerns regarding HIV/AIDS. Requesting condom use could be turned against them as (presumed) evidence of their infidelity. A recent survey of more than 2,000 Thai women suggested that only 18 per cent of women report ever using a condom with a spouse to prevent STI, 6 per cent ever asked their partner to use a condom to prevent STI, and about half of those who ever asked said their partner refused condom use (Archavanitkul et al., 2001). The female condom has gained little public interest and has not been promoted for general use. Microbicide trials are currently being conducted in Thailand, and may provide promise of acceptable protection within long-term relationships.

<sup>8</sup> Based on census data, the proportion of never-married Thais increased substantially from 1970 to 1990. The increases occurred in all age groups and were greatest for women. In 1970, 8 per cent of women aged 30-34, 5 per cent aged 35-39 and 4 per cent aged 40-44 were never married. By 1990 these per centages had increased to 14, 10, and 7 per cent, respectively. However, the celibate are not distributed equally by level of education. At ages 40-44 in 1990 about 5 per cent of women with no education or with a primary education were celibate. For the same age group, 12 per cent with a secondary education and 19 per cent with tertiary education were not married. In 1990 28 per cent of men and 33 per cent of women with tertiary education have never been married by the ages 30-34 (Guest and Tan, 1994). Another study by Jones (1996) based on 1990 census data of various countries reported that 29 per cent of women aged 30-34 in Bangkok were still single compared to 22 per cent of those in Singapore and smaller proportions in Kuala Lumpur, Hong Kong, Manila, Taipei and Jakarta.

<sup>9</sup> Marjorie Muecke, Thai Health Project, 1973-2000. Personal communication, September 5, 2001.

<sup>10</sup> Warunee Fongkaew, Faculty of Nursing, Chiangmai University, personal communication, September 6, 2001.



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Young women appear to be more likely to engage in premarital sex than their mother's generation, and both males and females may have a series of partners over the course of a year, although virtually none would define these relationships as promiscuous or risky. Hence, they are less likely to expect that they would be infected with HIV despite inconsistent condom use.<sup>11</sup> The World Bank suggests the need to make condom use the norm for all sex among youth (World Bank, 2000, Box 8), although the design of interventions for this purpose is not always as straightforward as it might seem.

**Variations in Responses to the HIV/AIDS Epidemic**

The AIDS epidemic emerged in Thailand at a time that sexually transmitted infections (STIs) were a nation-wide health problem. The reported annual prevalence for all venereal diseases nearly quadrupled from 1967 to 1987. Treatments for STIs were available at public and private clinics. Self-treatment using over-the-counter drugs and antibiotic injection was common. The government's initial response to the emergence of AIDS in the mid-1980s was to integrate AIDS prevention and control into ongoing STI control activities (see details in Thongcharoen et al., 1991), but this move had little impact on the spread of HIV. In 1989 the Government implemented a more vigorous national approach to control the spread of the epidemic, surveys to monitor HIV infection among selected high-risk groups and mandatory screening of all blood units (no paid donors have been used since 1992.) In 1991-92 the government implemented its national "100 per cent Condom Use Programme" to promote universal use of condoms in the commercial sex industry. At the same time, it launched massive public information campaigns AIDS. NGOs and groups of people living with AIDS (PHA) then emerged (see more information in the World Bank, 2000).

Close to one million people have been infected with HIV, largely through sexual transmission, and 289,000 of them died of AIDS since the report of the first AIDS case in 1984 (Thai Working Group on HIV/AIDS Projection, 2001). As interventions have succeeded in addressing sexual forms of transmission, the nature of the epidemic has changed: historically, needle sharing among intra-venous drug injectors accounted for around five per cent of new infections. With the continuing success in reducing sexual risk, new infections arising from IV drug abuse has risen to 25 per cent.

**Regional Variations in the HIV/AIDS Situation**

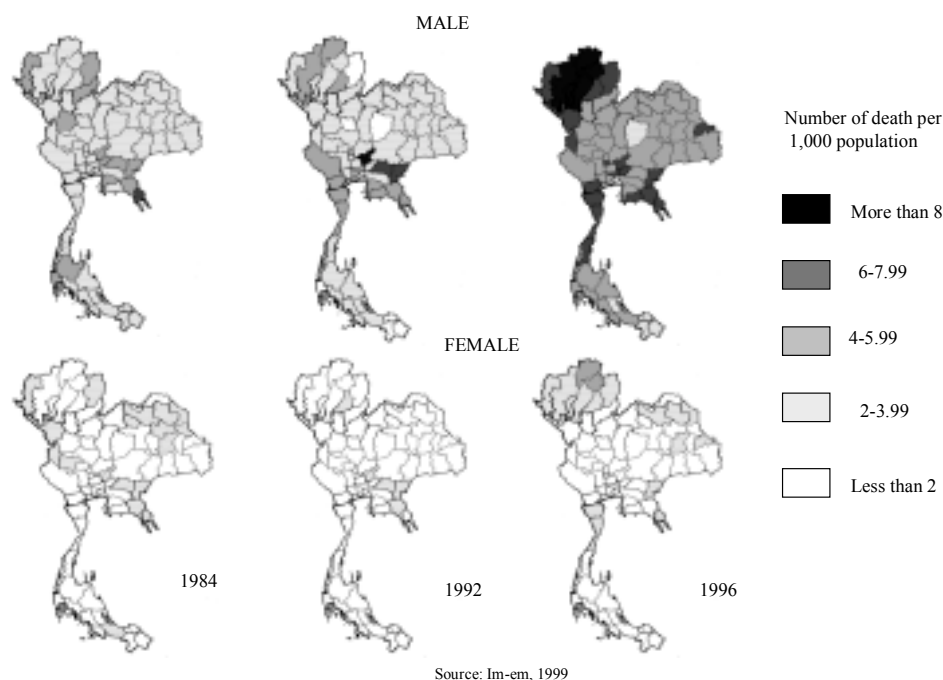
The prevalence of HIV infection and AIDS-related deaths are consistently highest in the Upper North. (See Figure 2.)<sup>12</sup> From 1984 to 1997, five Northern provinces (of 76 provinces nationwide) accounted for 40 per cent of reported AIDS deaths (Im-em, 1999 based on National AIDS Case Reports). Several explanations of regional variation in HIV infection rates have been forwarded, including disproportionate numbers of both male and female commercial sex workers originating in and returning to the region, rapid socio-economic change and sexual subcultures which increase vulnerability. In the early years of the epidemic, the Ministry of Public Health (MOPH) designated AIDS as a notifiable disease. As a result, a number of HIV positive sex workers were sent home for follow up by health authorities in the province of origin as part of AIDS-control policies which focused on HIV testing among selected high risk groups, often without consent or counseling, followed by notification of positive results. However, as asymptomatic carriers in a context of limited knowledge about AIDS, a number of returned HIV positive male and female sex workers continued

<sup>11</sup> A six-month intervention study among secondary school students in Songkhla resulted in marked increases in the percentage of students, *particularly female*, indicating that condom use implied promiscuity (Chandeying, 1998).

<sup>12</sup> Two studies in Thailand attempt to overcome the problem of the underreporting of AIDS deaths by relying on a data source that has almost universal coverage - mortality data from vital registration system (see van Griensven et al., 1998; Im-em, 1999). The argument is that the levels and patterns of AIDS mortality can be indirectly estimated through the use of mortality data from the vital registration system. This is not done through using the cause of death information, but rather through assessing changes in death rates over time comparing between the period prior to and the period after the rising AIDS deaths. The correlation between the registered death rate and reported AIDS statistics are highly significant and have increased for both sexes after 1990 (Im-em, 1999). The figures used to draw the map in Figure 1 are based on death registration statistics at the provincial level overtime adjusted for under registration of death. The mortality patterns described in this study with a focus on the place of residence are useful for planning to deal with the burden of care and resource allocation for PHAs.

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Figure 2 Death rates of adult men and women aged 15-49 by province from 1984-1996 based on death registration statistics



working regardless of their knowledge of being infected with HIV, in turn accelerating the progress of the epidemic compared to the rest of the country (Thongcharoen et al., 1991; Brinkman, 1992; Pradabmook, 1994; Im-em, 1996). Less is known about the relationship between socio-economic change and the spread of the virus, although a non-rigorous examination of the distribution of AIDS infections suggests that Northern Thai rural communities experiencing high out-migration and high turnover of farm lands underwent a more serious epidemic than more settled communities. The observed high levels of infection in communities ringing Chiang Mai and lying along major inter-provincial roads appears to coincide with the high levels of land speculation. Ex-farmers who sold their farms for fortunes beyond their dreams quickly spent their fortunes on the good life – new pick-up trucks, brothel visits, and the taking of minor wives. Official HIV/AIDS data are not desegregated at a level to allow quantitative confirmation of this observation at this time.<sup>13</sup>

### Regional Variations of Responses

The concentration of HIV infections and AIDS-related deaths in the North drew a significant share of HIV/AIDS related resources to the region, including research and interventions of both government and non-governmental organizations (NGOs), and contributing to the emergence of relatively strong community-based responses to HIV/AIDS challenges. The efforts of NGOs and PHA groups have contributed to the development of a remarkable civil society response to the challenges of HIV/AIDS in Thailand, creating a strong and growing network of organizations which integrate prevention, care and support.

Collaboration is strongest in Thailand's Upper North. There, in the context of a strong recent history of NGO activism and a concentration of development NGOs at work, NGOs confronted the AIDS epidemic as the key challenge to development work, beginning in the early 1990s as AIDS-related deaths began to take their toll. The assistance of the Australian government created the Northern AIDS Prevention and Care project, led by several social activists who nurtured community response through weekly seminars and work with PHAs, educators, health workers, NGOs, monks and other religious leaders, community leaders and the general public. These seminars were followed by

<sup>13</sup> Chayan Vaddhanaphuti, personal communication, January 1996. The same observation was also reported in Rayong (Im-em, fieldnote, 1997).

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funding support for activities, and a continuing engagement in a public and private dialogue on the epidemic and how to address it. The support of key medical personnel, NGO leadership and ties with academia greatly enhanced the development of a collaborative relationships and a strong civil society response to the HIV/AIDS challenge in the North.

Funding by the European Community aimed to replicate the same model in Northeastern Thailand. While the Northeastern expansion met with less success initially, apparently due partially to the diffuse nature of the epidemic at that time, it has made strides in recent years as it established trust and a record of working well with PHA and other groups. The confluence of leadership, congenial and supportive relationships with the Ministry of Public Health and the respective CDC Centers; and the level of perceived urgency of the epidemic have greatly influenced the differing levels of response observed in the Northeast and North.<sup>14</sup>

Nearly 190 Thai non-governmental organizations reported working on HIV/AIDS in 1995. About 40 per cent of them were based in Bangkok, one-fourth in the North, about 20 per cent in the Northeast and the rest in the Central and Southern region (Rojanavet and Chinchotikasem, 1995). As the numbers of people living with HIV/AIDS increased, they developed their own structures and forms of cooperation with both NGOs and government (this is discussed in more detail below). By the year 2000, 304 PHA groups were reported throughout Thailand, in all but 14 of the 73 provinces. The Upper-North region alone (covering six provinces) reported 140 PHA groups. By contrast, only a few groups were reported in the high-prevalence Rayong Province in the East (Smitaketarin and Paowanaporn, 2000). Table 1 gives details about cumulative AIDS deaths and number of PHA groups by region.

**Table 1: Cumulative AIDS deaths (1984-1997) and number of PHA groups by region (1999-2000)**

Region	No. of provinces	No. of AIDS deaths*		% of AIDS deaths		Number of PHA groups**	Number of provinces without PHA groups**
		Male	Female	Male	Female		
Upper North	6	12772	3110	40	46	140	None
Northeast	19	3242	854	10	13	73	2
Central	17	5182	904	16	13	18	5
Lower north	11	2852	624	9	9	42	1
Bangkok	1	3088	416	10	6	3	None
South	14	2090	446	7	7	16	5
East	8	2312	380	7	6	12	1
Total	76	31538	6734	100	100	304	14

\* Reported cumulative AIDS deaths for 1984-1997, National AIDS reports cited in Im-em, 1999.

\*\* From a study conducted by Smitaketarin and Paowanaporn (2000) for 1999-2000. Attempt was made to obtain information from all PHA groups in every province. However, some PHA groups may be missing from the report as the number of new PHA groups turns up every year.

PHA mobilization was in part triggered in the early 1990s by MOPH sanctions of a herbal practitioner with hundreds of clients in Northern Thailand, bringing strong protests from those using his preparations. The PHAs then coalesced into the nation's first PHA group, from which has since

<sup>14</sup> Personal Communication, Scott Bamber, UNICEF/Thailand and ex-NAPAC staff member.

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emerged a national network of locally based PHA groups. The PHA response has expanded into a broad involvement of PHAs in counseling, home visits, home and community care, as well as advocacy on a range of issues, such as access to medications (herbal, modern antibiotics and antifungals, and increasingly, antiretrovirals), access to unprejudiced clinical care, and stronger protection of human rights of those infected and their families. Some also spoke about HIV prevention to school children and community. Some PHA groups are based in district hospitals, depending upon the willingness of the hospital director to provide space, some in the homes of PHAs. The New Life Friends Center in Chiang Mai has a simple office in a modest home on the edge of the city, and has been provided a room at the Provincial Administrative Offices. At both sites, PHAs respond to phone queries and meet with walk-in clients who seek someone to listen to them. Other PHAs make home visits within their respective communities, talking with families about general health concerns and prevention of sexually transmitted diseases. While most groups focus on addressing the needs of PHAs in the local community, it is not uncommon for PHAs to cross district and provincial lines in order to benefit from PHA group activities without revealing their HIV status at home.<sup>15</sup>

Many civil society responses include the participation of public health personnel, with a number of MOPH staff having established commitments to supporting a flexible, highly diverse community-based response. The work of NGOs and, to a lesser extent PHA groups, depends upon external funding to support personnel and other costs. As external donor assistance decreases, the future fate of these groups and the role they have played in maintaining the spotlight on AIDS issues is unclear. The ability of NGOs and PHA groups to contribute to policy making hinges to some extent on the willingness of MOPH leadership to engage with them. This has varied over time, depending upon the personalities leading the MOPH Center for Communicable Disease and the AIDS Division.

The central government provides financial support to a limited number of PHAs, who may request a monthly allowance from the Department of Public Welfare in their province. In 1997, 1,661 PHAs from Chiang Mai province received allowances, amounting to about one-third of PHAs nationwide receiving the DPW allowance (Im-em, field note, 1997).<sup>16</sup>

<sup>15</sup> Terms of Reference, Community-Based HIV/AIDS Prevention, Care and Support Activities. Prepared for Channel 1 of the World Bank Social Investment Project, WHO/Ford Foundation, September 1998.

<sup>16</sup> The only parallels for these allowances are for the elderly and the physically handicapped; those living with other chronic illnesses do not receive government transfer payments.

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The combination of government and civil society interventions, active research and the severity of the epidemic have combined to enhance the level of resources within the region, exposing people to clinical

**Main characteristics of HIV/ AIDS situation and responses by region**

- While the high concentration of infections and illness in the **Upper North** have contributed to changes in behavior patterns, these shifts conceal continued risk behavior as unprotected sex continues with partners *assumed* to be risk-free. The most highly developed NGO/PHA/ community response, focusing largely on care and support, exists within the region.
- The **Lower North** presents lower prevalence and illness, with a weaker NGO/PHA/ community response. Active interest of medical workers, businessmen, civic groups and the military have resulted in the development of an excellent model of cross-sectoral collaboration in Pitsanulok province.
- The **Northeast** exhibits low reported prevalence, accompanied by reports of increasing new infection rates. The initial response of NGO/PHA/community groups was slower to take hold than in the North, apparently due partially to the diffuse nature of the epidemic at that time. Expansion of the community response has proceeded faster in recent years as a key regional actor established trust and a record of working well with PHA and other groups, and as HIV in has become more apparent and the urgency of the epidemic becomes more clear in the region.
- The **Southern peninsula** presents cultural challenges (including both Buddhist and Muslim populations and a culture less open about private affairs than found elsewhere), with a high HIV prevalence, uneven coverage of NGO/PHA/community groups, and reports of high risk behavior among ethnic minorities and migrant workers.
- **Central** (including Eastern Seaboard and Western provinces) region has a high prevalence and an uneven coverage by NGO/PHA/community groups.
- **Bangkok** is noted for fragmented care and support mechanisms, prevention efforts. Behavioral studies indicate high-risk behavior continues.

(Adapted from World Bank, 2000)

trials and intervention research at a significantly higher level than elsewhere in Thailand, and further increasing the likelihood of individuals, households, communities, and organizations in the Upper North region responding to the epidemic than elsewhere in the country. Regional variations in response to the epidemic appear to reflect differing socio-economic contexts and dynamics, the severity of the epidemic and the presence or support for the creation of a local response. Some argue that NGO and PHA activity has been supply-driven, that is, resulting from the availability of funds rather the objective needs of the PHA population. The truth probably lies in some combination of demand and supply factors, and is moderated by both the urgency of the epidemic and by local capacity.

Regional variations aside, the emergence of national networks of both PHA groups and NGOs working on HIV/AIDS has facilitated coordinated advocacy on a range of issues. These include, for

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example, the need for a minimum standard of care, access to care, protection of anonymity, workplace rights, and health reform.

**Provincial Variation: Chiang Mai and Rayong**

Both Chiang Mai and Rayong provinces have high HIV prevalence levels, but illustrate differences in levels of response.<sup>17</sup> Selected characteristics of Chiang Mai and Rayong are given in Table 2. Sakhonnakorn, a northeast province, as a basis for comparison with a low-prevalence province.

**Table 2: Selected characteristics of Chiang Mai and Rayong Province**

	Provinces with high prevalence of HIV		Province with low prevalence of HIV
	Chiang Mai	Rayong	Sakhonnakorn
<b>GENERAL CHARACTERISTICS</b>			
Population (persons)	1,552,766	477,895	1,057,674
Urban & rural population	11% & 89%	20% & 80%	5% & 95%
Per capita income (Thai Baht, 1999)	49,614	168,324	21,206
Gross provincial product (%)			
Industry	17	23	6
Agriculture	11	17	21
Service	22	5	14
Others	50	55	59
Number of sex establishments	183	96	66
Number of tourists			
Thai	1,545,138	973,334	Not available
Foreign	891,209	225,678	Not available
<b>AIDS STATISTICS</b>			
Reported number of male AIDS deaths <sup>a</sup>	3,550	950	54
Reported number of female AIDS deaths <sup>a</sup>	854	202	14
Male AIDS deaths per 100,000 population <sup>a</sup>	477.5	369.6	10.6
Female AIDS deaths per 100,000 population <sup>a</sup>	120.1	80.4	2.8
Average HIV seroprevalence among pregnant women (reported in %) <sup>b</sup>	4.32	4.94	0.41
Average HIV seroprevalence among military conscripts (reported in %) <sup>c</sup>	8.32	7.50	1.57

Sources: Chamrathirong et al., 1999, Appendix A. and Im-em, 1999, Appendix B.

<sup>a</sup> AIDS statistics covering the period 1984-1997 only.

<sup>b</sup> Average of HIV surveillance among pregnant women round 1 (June 1989) to round 15 (June 1997).

<sup>c</sup> Average of HIV surveillance among military conscripts round 1 (November 1991) to round 12 (May 1998).

<sup>17</sup> Chiang Mai and Rayong are numbered 46 and 19, respectively, on the maps in Fig. 1.

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Chiang Mai, bordering Burma to the north and west, is among the three provinces in the Upper North where HIV/AIDS infections are consistently highest over time. The province is rich in agriculture and attracts many tourists. Annual average per capita income was Baht 54,000 in 1996 (UNDP, 1999: Table 2; about the equivalent of US\$1,000 at the time). A HIV prevalence in 1989 of 1 per cent among pregnant women in Chiang Mai increased eight-fold to 7.98 per cent by 1995. The mean prevalence from fifteen rounds of the HIV sentinel surveillance surveys of pregnant women over the period 1989-1997 was 4.3 per cent in Chiang Mai, four time greater than the national prevalence (National HIV Sentinel Surveillance Survey, cited in Im-em, 1999: Table 23). Among military conscripts, average HIV prevalence of 8.3 per cent exceeded by a factor of three the national level for the period 1991 to 1998 (Armed Forces Research Institute, cited in Im-em, 1999: Table 24). By 1997, 3,550 men and 854 women in this province were reported to have died of AIDS-related causes.

The response to AIDS in Chiang Mai began in the late 1980s. Joint interventions in brothels and with pharmacies conducted by international NGOs, the Provincial Health Office and the regional office of the national Communicable Disease Center focused largely on high-risk groups. The establishment of a non-profit clinic providing anonymous testing and counseling generated important insights into the scope of infections outside high-risk groups, and provided the impetus for key health official to encourage and cooperate in the development of a broader civil society response. This extended to the inclusion of NGOs and community-based organizations (CBOs) in official committees and working groups of the Upper Northern HIV/AIDS Prevention Committees (Rojanapithayakorn et al, 1997).

In 1990, several NGOs shifted their programming to include AIDS-related interventions in response to the rapidly escalating numbers of PHAs and AIDS-related deaths. By 1995, more than 20 AIDS-related NGOs operated in Chiang Mai Province, compared to less than five in other provinces outside Bangkok (Rojanavet and Chinchotikasem, 1995). The high prevalence levels of HIV, a strong NGO community, and the presence of several universities and research infrastructure in Chiang Mai have fostered HIV/AIDS related research and activities. As a result of the intensive research and intervention activities over the past fifteen years, selected risk groups and the general population in Chiang Mai have been exposed to HIV/AIDS interventions and prevention campaigns at a much greater level than the rest of the country. As a consequence of these interventions and of the density of infections, risk behaviors had decreased by the mid-1990s and new infection rates have declined<sup>18</sup>

Rayong province is located in the eastern region of the country, bordering Cambodia and the Gulf of Thailand. The province is home to the government-promoted Eastern Seaboard Development Project, designed to attract industrial investment. In turn, increasing numbers of workers migrated to the province from throughout Thailand and beyond. Land prices have escalated. Prior to industrialization, the province was known as a local holiday site, with white sand beaches, productive fruit orchards and fisheries—the latter two forming the main source of income in pre-industrial days. As Fig. 1 indicates, Rayong GNP grew nearly twice as fast as that of Chiangmai during 1992-1996.

Rayong is one of the few high HIV prevalence provinces outside the Upper North region. The average HIV infection rate from the fifteen rounds of HIV sentinel surveillance surveys over the period 1989-1997 among pregnant women was 4.94 per cent, the second highest prevalence in the country after Chaing Rai and exceeded the average prevalence of 4.32 per cent in Chiang Mai (the National HIV Sentinel Surveillance Survey cited in Im-em, 1999: Table 23). Surveillance reports show HIV infection rates among military conscripts consistently near the level found in Chiang Mai over time. However, during the period 1984-1997 AIDS-related deaths in Rayong occurred at roughly two thirds the rates reported in Chiang Mai. Possible explanations for the lower rate of AIDS-related deaths in Rayong include the less advanced stage of the Rayong epidemic, better health associated with a wealthier population, the return of migrant workers to their province of origin after becoming ill, and, possibly, greater reliance on anti-retroviral treatment among PHAs. Despite Rayong's high HIV

<sup>18</sup> See Chamrathirong et al. (1999) for report about high consistent use of condom with commercial sex workers among Thai men in late 1990s.

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prevalence and proximity to the capital city of Bangkok, the province is underrepresented (compared to Chiang Mai) in HIV/AIDS research and interventions.

Despite a level of HIV infections in Rayong roughly equaling that of Chiang Mai, the community response to AIDS in Chiang Mai far outstrips that in Rayong. The international NGO focus is on Rayong's large fishing fleet, and to a lesser extent, commercial sex workers. In 1995, two PHA groups were reported in the province (Rojanavet, B. and Chinchotikasem, 1995; Smitaketarin and Paowanaporn, 2000), although this has since doubled.<sup>19</sup> Rayong PHA groups undertake income generation projects, home visits, support group meetings, and some HIV prevention activities. A Buyers' Club (established with the support of Medicin Sans Frontiers, which continues to assist with the procurement of low-cost anti-retrovirals) distributes medications to PHAs at a 40 per cent saving over the cost of the same medications at local government hospitals. Club clients require a prescription from a physician and must come in person monthly to receive medications (usually AZT and ddi, although some PHAs with lower CD4 levels have been prescribed a triple cocktail). PHAs availing themselves of this service, numbering over 50, largely are married factory workers making Baht 8,000 to 10,000 (US \$178 to \$222 monthly, using 2001 exchange rates of Bhat 45 to \$1), for whom the monthly cost (Baht 3,000 (US\$67) for AZT/ddi; Baht 5,000 (US\$111) for triple therapy) is seen as an affordable necessity. Buyers' Club clients prefer to meet one on one rather than joining a group in order to protect their anonymity, partly because businesses remain reluctant to continue to employ PHAs, despite regulations intended to protect their right to work.<sup>20</sup> No PHA is willing to go through a lengthy court battle and the related publicity in order to establish a court-supported precedent for enforcement of the law. The Thai NGO, Center for AIDS Rights, works in Rayong with employers to increase understanding of legal, social and medical dimensions related to HIV positive employees and create more favorable workplace attitudes to workers living with HIV/AIDS.<sup>21</sup>

PHAs in Rayong comprise three distinct groups: local long-term residents, who may be somewhat more likely to reveal their status and to join the full activities of PHA groups; those working in industry, generally less willing to take actions which would reveal their HIV status, including joining a PHA group or requesting PHA subsidies from the government; and fishermen, whose work and recreation patterns (including short shore leaves characterized by patronage of brothels, and extensive periods at sea where drug use is reported common) complicate interventions.

The differential responses to AIDS in Chiang Mai and Rayong result from a number of factors, although prioritizing potential factors requires more rigorous study. Among the important factors are:

- The epidemic in Chiang Mai is more advanced, as demonstrated by the higher death rates. As Table 2 indicates, AIDS-related deaths among males are some 30 per cent higher in Chiang Mai than in Rayong; among females, some 50 per cent higher.
- The higher number of AIDS-related deaths in Chiang Mai both has created a sense of urgency among Chiang Mai-based governmental and non-governmental agencies and communities and motivated individuals to change high-risk behaviors.
- Chiang Mai is a major Thai tourist site, resulting in a large share of income from service jobs, including commercial sex.
- While Chiang Mai is both a 'sending' and 'receiving' province for sex workers, Rayong is developing as a 'receiving' province as the number of sex establishments rises with the recent industrial transformation of the province.
- The response in Rayong has been driven by concerns regarding "high risk" groups, principally commercial sex workers and fishermen.

<sup>19</sup> Paripat Dommom, Chair, Eastern PHA Network, personal communication, September 6, 2001.

<sup>20</sup> When the general public started to realize about the existence and the widespread of AIDS in early 1990s, a number of PHAs, particularly those in service works, were asked by their employers to go for HIV blood test. A number of HIV infected workers were asked by their employers to quit or to change the job when they found to be with HIV. Others resigned by themselves as they felt that their peers would not accept them.

<sup>21</sup> Paripat Dommom, Chair, Eastern PHA Network, personal communication. September 6, 2001.



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- PHAs in Chiang Mai are more motivated to participate in PHA group activities than those in Rayong, which can be attributed to a complex set of factors, including financial and emotional support from government and non-governmental organizations and also from people in the community. The level of external support given to PHAs in Rayong is low, although this would appear to be partly a result of the greater stakes for higher-income industrial workers in revealing their HIV status.
- Chiang Mai has been exposed to more HIV/AIDS research, interventions, activities and campaigns than Rayong. Therefore, the province is better prepared in terms of infrastructure and human resources to deal with the epidemic.
- The Chiang Mai response built on a stronger presence of development NGOs, whose work in a number of communities provided a base of experience in addressing local issues, organizing activities, and undertaking attitudinal change interventions.
- The 1994 establishment, direct budget earmark, and active role of the Northern HIV/AIDS Prevention Committee, has encouraged an active response in Chiang Mai together with availability of large sums for HIV/AIDS interventions, both from government sources and external donors (Rojanapithayakorn et al., 1997).

The comparison between Chiang Mai and Rayong suggests the need for greater understanding of the differential responses to HIV/AIDS in Thailand. Out of 76 provinces, existing documentary information largely focuses on the six Upper North provinces. However, as illustrated in Figure 2, the AIDS situation in other provinces is worsening and several provinces will reach the level observed in the Upper North in the future. Although this paper suggests some tentative hypotheses regarding differential response by region, more could be done in documenting experiences both at provincial and regional levels. The next part of this paper explores responses of individuals, families, and communities, discussing differential response by region to the extent possible based on available information.

**Individual Responses to AIDS**

After dealing with the initial reactions shock, disbelief, anger, fear and confusion of learning they are HIV positive, three stages of response are found among PHAs: seeking a cure; achieving peace with living with the virus; and dependency (Im-em and Phuangsaichai 1999). During the first stage, denial and fear tend to drive attempts to find a cure, lengthen life, or suppress symptoms—despite the awareness that there is no cure for AIDS. Drugs are anxiously sought and traditional therapies such as meditation, massage and herbal medicines are followed, even though some of these treatments can be costly and involve high travel costs to distant provinces. PHAs at this stage are easy prey for all kinds of charlatans. Many Thai PHAs firmly believe that dietary supplements have helped them, while acknowledging they do not constitute a cure.

During the second stage, achieving peace and living with HIV/AIDS, PHAs no longer incur debt in the search for futile and expensive treatments. Many adopt natural therapies to promote good health, including more selective diet and daily activities, restricting alcohol and tobacco use, taking herbal medicines or meditation. Food taboos play an important role for some PHAs, including macrobiotic diets and avoidance of foods seen as “hot”.

During this period, PHAs adjust to live with chronic illness. Many seek supplemental income activities to support themselves. A number join PHA groups to meet and share experiences with others in similar situations, and to exchange information about how to live with HIV/AIDS. About one-third of PHAs, mostly members of PHA groups in the upper-north region, have lived for longer than three years after first developing symptoms and over one-fourth reported their current health status to be excellent or good (VanLandingham and Im-em, 2001, Table 2).

PHAs progress to the dependency stage when advanced illness strikes. Many return to their homes, if working away, when they can no longer earn a living or live independently. Close to 40 per cent of PHAs moved to the current residence after becoming ill and the majority of them move in with

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parents or adjacent to them. Some wait until illness is very advanced before moving back; about one-third of those who returned when ill live only a few months; some die after just a few days or weeks following their return. This is the period of terminal illness, requiring either or both hospital and home based care provided by their family members (Knodel et al., 2001; VanLandingham and Im-em, 2001). Northeastern PHAs are reported to be particularly likely to delay their return until shortly before death, influenced both by a reluctance to be a burden to their parents, and by the real poverty which faces many northeastern families, where incomes still lag well behind the national average.

**Determinants of PHA Response**

The ways people living with HIV/AIDS respond after learning that they are infected with HIV is both more complex and less linear than this characterization suggests. Various socio-economic and cultural factors including the level of family and community support would appear to determine how individuals respond to a positive HIV test. While some individuals are able to acknowledge and quickly adjust to living with HIV/AIDS, others are less likely to do so. PHAs may shift from the dependency stage back to the acceptance stage, depending upon the effectiveness of treatment of opportunistic infections. Differential response of individuals to the knowledge of HIV status is likely, although information is too fragmentary to understand the implications of some of the following dimensions.

*Source of infection:* It is common for the Thai man to be the first infected, through paid sex or other sexual relations, then passing the infection to his unsuspecting wife. Many couples learned of their HIV status when pregnant wife received antenatal care, which usually includes HIV blood test. Thus, the presumed low risk wife is usually the one to receive counseling about their HIV status in the absence of her husband.<sup>22</sup> How women respond to their husbands after learning that they are infected with HIV is little known. Some husbands refused HIV blood testing after learning of their wives HIV positive status because of awareness of high-risk sexual behavior, denial, and fear. While a number of couples divorced or separated after learning that one spouse was HIV infected, some continued to live together. In the Upper North provinces, the deaths of many men left a number of widows, several of who became key members of PHA groups there.

*Circumstances of learning of one's HIV status:* The stage of disease, the voluntary or involuntary nature of HIV testing, the availability of pre- and post-test counseling are believed to impact subsequent behavior of PHAs although the nature of these impacts is not well understood (Im-em and Phuangsaichai, 1999).

*Socio-Economic Background:* PHA leaders both in Chiang Mai and Rayong indicate that PHAs from wealthier or higher-status families are less likely to participate in PHA activities than poor PHAs, but likely to access telephone counselling. Expensive private treatment for PHAs, with costs borne by the individual and/or family, probably provides greater anonymity than would treatment at a public facility.

**PHA Health Care Behavior**

A pioneering study conducted in four villages of Chiang Mai reported that PHAs combined modern and traditional treatments in various permutations, and that those who had died tended to be dependent on institutional treatments more than those who were living with HIV/AIDS, reflecting the stage of illness (Im-em and Phuangsaichai, 1999). About half of PHAs who had died sought provincial hospital treatment, followed by private clinic, community hospital, herbal medicine, drug store, health center, and other local traditional remedies. People living with HIV/AIDS in the same study reported that the treatments they most often sought were from existing community health facilities (including community hospitals and health stations) and traditional treatments including herbal medicines and sauna, massage, and meditation. The apparent decreased dependency on provincial hospitals is probably due to public health policies to promote home based care and care at

<sup>22</sup> Siriwan et al. (1998) report that among married couples where one partner is infected and the other not, infected women account for 20-25 per cent of cases.

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local health facilities. Many community health facilities have been improved and both staff and community volunteers have been trained in home based care of PHAs. Also, there are a growing of number of traditional treatments available for PHAs.

A larger number of men are more likely to receive clinic or hospital-based treatment than women for several reasons. First, it may have more to do with the more advanced stage of illness among infected men than women surveyed, rather than reflecting gender bias in treatment or in seeking treatment (VanLandingham and Im-em, 2001). Second, community and home based care for PHAs are being developed in many rural villages to serve the increasing number of PHAs, an increasing number of whom are women, and allowing them to use local health facilities and services. Hence many HIV-infected women are more likely to find low cost community- or home-based care available than did the men who died in the earlier years when more expensive institutional care and treatments were the norm. Third, surviving widows often had little money left to address their own treatment needs, as much of the family assets had been spent in treating the husband before his death (Im-em and Phuangsaichai, 1999)<sup>23</sup>. Fourth, anecdotal evidence suggests that women are more likely to take care of themselves (avoiding alcohol and tobacco, eating adequate diets and otherwise adopting healthy lifestyles) after learning of their HIV status than are men. Clearly, more information is needed to determine if further supports of female PHAs are needed to enable them to care for themselves and the growing number of children living with an infected mother.

The average cost of treatment for a person who died of HIV/AIDS in the mid-1990s was reported at 30,000 baht per person<sup>24</sup>, depending upon the socio-economic status of PHAs and their families (Im-em and Phuangsaichai, 1999).<sup>25</sup> In another study based on health key informants<sup>26</sup> representing over 200 deceased PHAs, 40 per cent reported that total treatment expenses were substantial, another 45 per cent reported the amount was modest with insurance covering most costs, and the rest reported the burden was modest because little treatment was received. The economic status of PHAs or of their parents prior to illness also determined the treatment burden to family: the more well-off they were, the less treatment was a burden to their family (Knodel et al., forthcoming, Table 3).

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<sup>23</sup> Due to small sample size in this study, this situation can not be quantified. However, on-going work with a bigger sample size by Knodel, Im-em and others will quantify this observation.

<sup>24</sup> About US\$1,200 (exchange rate of 25 baht to 1 dollar at that time).

<sup>25</sup> The duration of illness determines the cost of treatment. This community based study obtained information about 47 people who had died of HIV/AIDS and 29 who were living with HIV/AIDS in four villages of Chiang Mai. An on-going study with a much larger sample size covering provinces out of the Upper North region is being investigated by Knodel, Im-em and others.

<sup>26</sup> In this study the health key informants were village health volunteers, local community leaders and community health volunteers who provided information about persons dying with AIDS in the three years prior to survey.

The following case studies illustrate large investments in HIV/AIDS treatment.

#### Case 1

Mr. Somkit was a construction worker, earning 300 baht a day (exchange rate at the time was Bhat 45=US\$1). He suspected that he had AIDS but didn't go for a blood test. He didn't tell anyone and tried every kind of treatment. He spent all of his savings, a total of 180,000 baht, on treatment for several months. He first sought herbal treatment at a far away district in a southern province, spending 40,000 baht. Subsequently, he went for nine more treatments in several provinces, one after another, paying no less than 10,000 baht per treatment. Eventually, he confided in his parents and stopped looking for different kinds of treatment. He later joined the local PHA group and learned to look after himself. He went to see doctors at the local hospital and a health card he purchased for 500 baht then covered most of the treatment costs.

#### Case 2

Ban and Air were recently married. Air became pregnant but had a spontaneous abortion, after which the doctor told her she was HIV positive. When they found out they were both HIV positive, they began to look for treatment together. Ban bought and sold longans and garlic, earning around 80 000 baht per year, and they had some savings. Not long after his diagnosis, Ban became very ill and was hospitalized five times at a cost of between 3,000 and 100,000 baht each time. The most expensive treatment was in private hospitals, where the medicine was very costly. Apart from that, he went for treatment at private clinics three times, and traveled to find herbal treatments in distant provinces, spending 35,000 baht on transport and these treatments. In total, he spent 253,000 baht on his treatment over the three year period of illness. All their savings were spent, and Ban's parents also contributed, hoping their son would recover. When Ban died, Air went back to live in her parents' home. At this time, she could still earn a living by sewing. Air couldn't spend the same amount of money on her treatments because all their savings had been used up on Ban's treatments. Air bought a health card that entitled her to low cost treatment. Every month, Air visits the doctor at the community hospital and attends the health centre. She went to see a doctor at a private clinic four times a year, and bought bottles of herbal medicine at a cost of 600 baht per bottle, taking one bottle per month. Five years have passed since Air was diagnosed HIV positive.

(Source: Im-em and Phuangsai, 1999, p. 35).

### **Family Responses to AIDS**

The majority of PHA households had low family incomes and high expenditures<sup>27</sup>; more than half had no savings and 80 per cent were in debt, compared to some 60 per cent of Thai households. The main occupation of heads of households and the major source of family income was wage earning, forcing

<sup>27</sup> Although a number of PHAs were from wealthier households, the information obtained from them is limited, as PHAs from better-off families are reluctant to give detailed information.

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many households to forgo income when the household head becomes ill. Another portion of household income was lost when one or more family members left the workforce to care for the sick person. (Im-em and Phuangsaiachai, 1999; Brooker Group, 1999).

Most families employ various strategies to cope with these problems. Whether the effects are far reaching or not depends largely on the initial family situation. A wealthy family with a large pool of resources will be less affected than a family with few resources at their disposal. While a family with several wage earners will be less affected than a family with only a few, a family with several dependants will be more affected than a family with only a few. Table 3 shows the socio-economic status of the households with PHAs comparing households in which a person died of AIDS-related illness, households including a person living with AIDS, and those with a person living with other chronic diseases. About half of PHAs lived in extended families (three or more generations living together) and another one-third were nuclear families, of husband and wife and children living together. The number of wage earners in HIV/AIDS-affected families is less than in families of people with other chronic diseases, possibly because the presence of a PHA in the family requires more people to help care for the patient. A small proportion of PHAs lived alone, but usually near parents or other relatives (Im-em and Phuangsaiachai, 1999).

**Table 3: Economic situations in households where a family member is a PHA or a person with another chronic disease**

	Deceased PHAs N=45	Living PHAs N=29	Living with other diseases N=37
Average number of household members	4	4	4
Average number of wage earners	2.8	2.7	2.9
Living conditions (%)			
Alone	7	10	-
Nuclear family	35	37	70
Extended family	54	50	30
Others	4	3	3
Main profession of head of household (%)			
Not working	24	33	11
Farming	28	23	27
Selling	-	3	11
Employee in private business	4	7	-
Wage earning (general, farming, construction)	43	40	51
Family assets			
Legal ownership of house and land (%)			
None	7	3	-
Legal owner	89	80	92
Others	4	7	8
Legal ownership of rice field (%)			
None	74	63	56
Legal owner	24	27	32
Rents	0	3	3
Others	2	7	9
Legal ownership of farm/orchard (%)			
None	72	77	32

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Legal owner	22	20	62
Lays claim to	7	0	3
Others	0	3	3
Annual average family income (in baht)			
From farming	5,645	4,810	6,980
From other occupations	43,971	41,933	4,334
From business	3,973	4,283	483
Other supplementary occupations	10,611	12,590	35,803
Total average annual income	64,522	63,617	91,027
Average annual family expenditure (in baht)			
Food	33,573	31,113	27,809
Clothing	2,013	1,486	2,682
Travel	3,607	3,248	3,653
Entertainment	586	461	937
Merit making	1,319	1,013	1,574
Education	7,787	7,176	5,054
Hospital treatment <sup>a</sup>	3,499	3,664	5,652
Funeral fund payments	2,303	1,992	2,514
Others	3,235	1,533	2,037
Total average annual expenditure	57,919	51,689	51,916
Average annual income that exceeds expenditure	6,603	11,928	39,111
Percentage of families with no savings	65	76.6	56.7
Percentage of families that are in debt	80	86.6	56.7

Source: Im-em, Pongsaijai, Panitchaphak, 1999.

Note: Information from adults who died with diseases other than AIDS was also obtained, but information is not given here due to small number of cases.

<sup>a</sup> Cost of hospital treatment for adults with other illnesses is higher than those reported to be with AIDS because some persons had long term chronic illnesses which require high cost treatment costs. The illnesses reported by these 37 cases were: kidney, bone, and heart diseases, goiter, typhoid, gallstone, stomach ulcer, paralysis, gout, thyroid, cancer, anemia, asthma, sinusitis, jaundice, diabetes, neurosis, leprosy, hepatitis, hypertension, alcoholism, tuberculosis, and allergy.

The presence of a PHA in a family affected the household's well-being is complicated and interconnected to various life events of several individuals and the living arrangements of PHAs, which change over the course of illness. Many married PHAs subsequently separated or divorced although little is known about how marital problems influenced mental or physical health. Some women who were HIV positive and sick had to care for children on their own, and they need urgent attention for external support. Some AIDS widows remarried, and subsequently infected their new husbands suggesting that safe sex practice and premarital counseling need to be promoted among both the newly married and remarried couples. Some young children were infected vertically, and died of AIDS along with their mothers and fathers suggesting that the HIV infected couples should be adequately informed to make their own decision whether or not they would like to terminate or continue the pregnancy.<sup>28</sup> Other children were not infected, but their parents had both died from AIDS and were left to the care of other family members. However, their quality of life and their future are insecure. Anecdotal reports suggests that some AIDS orphans are the targets of sexual and emotional exploitation by neighbors or their relatives. Many PHAs, both single and married, moved back to co-reside with or live next to a parent when ill as lack of income and/or lack of a care-giver reduced them to dependency.

<sup>28</sup> The Ministry of Public Health has introduced low cost AZT treatment to prevent vertical transmission of HIV from mother to child, thus it is hope that less than 10 per cent of the babies born to HIV infected mothers will be HIV infected.

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The level of family support is hypothesized to depend upon importance of the PHAs to the family.<sup>29</sup> Those considered to be important to the family in terms of financial support provided to the family, their social status related to education or work, and their companionship are believed to be more likely to receive family support.

**Coping with Financial Consequences of HIV/AIDS**

About one-third of PHAs were poor prior to illness; of these, treatment expenses posed a serious burden to nearly 60 per cent of families, compared to only 19-34 per cent suffering a serious cost burden among those with good or average economic status. Families of those who died of AIDS related causes in the earlier years of the epidemic paid more for treatment than families affected by a death in recent years due to limited support available to PHAs at that time (Knodel et al., forthcoming: Table 3). The costs of treatment, including medicine, traveling costs and any other additional costs for an AIDS patient up until death was around 30,000 baht, one-tenth of which supported travel and other treatment related expenses (Im-em and Phuangsai, 1999).<sup>30</sup> The most expensive form of treatment was hospital based, especially at a private hospital. The fact that most PHAs now buy a health card, which entitles them to free medical treatment at government hospitals, helps to reduce these costs.

Households employ a range of strategies to cope with the rising costs of treating a family member with AIDS. First, PHAs use their own savings or joint family savings to pay for hospital treatment, usually getting money from parents and close relatives to help towards the costs. The PHA often has to adjust his/her way of life in order to cover expenses, such as looking for extra income, or economizing in everyday life. Other strategies include borrowing money privately or from a financial institution, or selling assets. Table 4 shows most-frequently reported consequences on families of adults who died of AIDS-related illness.

**Table 4: Percentages of families of adults who died of AIDS who experienced selected consequences**

Consequences	All persons who died of AIDS	
	%	N
% whose family sold property or possessions	11.2	206
% whose family went into debt	12.1	206
% whose family sold property or possessions or went into debt	23.3	206
% for whom a family member had to reduce or stop working	33.3	248
% for whom a parent had reduce or stop working to care for PHA	16.5	248
% for whom a family member had to increase work to earn extra income to cover expenses	11.6	242
% for whom a parent had to increase work to earn extra income to cover expenses	3.3	242

Source: Knodel et al., forthcoming, Table 6.

The presence of a PHA in the family creates a burden of caregiving in the family. Close to 80 per cent of households reported caregiving was a serious burden, including the emotional, financial, physical and time strain. The spouse provides care for about 60 per cent of currently married PHAs, followed

<sup>29</sup> An on-going study will shed the light on this issue (see Knodel and VanLandingham et al., 2000).

<sup>30</sup> This figure is larger than the figure reported in a study by Phitayanon et al. in 1992-1993, which quoted a figure of 3,000 baht (at a rate of exchange of US\$ 1 = 25 baht).

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by parents, usually their mothers. The burden of care for single, divorced or widowed PHAs largely depends on their parents (Im-em and Phuangsaichai, 1999; Knodel et al., 2001). AIDS widows usually returned to their parents, particularly if they had not been married long. A few chose to continue living with their in-laws after the death of a husband.

**Care of children orphaned by HIV/AIDS**

Despite the large estimates (several hundred thousand children are believed to have infected parent(s), and some 70,000 are believed to have already lost both parents<sup>31</sup>) of dependent Thai children who lost a parent to AIDS, little systematic information about care of these children is available (Boonchalaksi and Guest 1993; Brown and Sittitrai, 1995). The presence of a person with AIDS within the family unavoidably affects children in various ways: children are themselves infected through vertical transmission; non-infected children live with and lose parents through AIDS-related death; and children live in households where a non-parent is a PHA.

About 75 per cent of the households having lost a family member to AIDS-related causes had children below age 18. About half of the children were younger than five years old and 10 per cent of children were vertically infected with HIV. One-tenth of these households had children who lost both parents because of AIDS, close to two-thirds lost their father and another one-third lost their mother (Im-em and Phuangsaichai, 1999: Table 6.2).

The most common person to care for the dependent child of a person who died of AIDS is the spouse. Multiple fostering arrangements also arise in cases where the person who died of AIDS had more than one child and different persons took responsibility for different siblings. A significant proportion of surviving spouses of persons who died of AIDS are themselves infected by HIV and are likely to die before the dependent child grows up. In many such cases, grandparents are likely to take over responsibility for the orphans with assistance provided by other family members, particularly aunts and uncles (Knodel et al., forthcoming). A number of anecdotal reports indicate that AIDS-affected children in all categories face discrimination, loss of nurturing, and may become early school leavers in response to their problems. Some AIDS-affected children and their grandparents are reported to be involved in Thailand's burgeoning amphetamine trade,<sup>32</sup> although there is inadequate information to determine if the likelihood of such involvement is greater than among their peers.

**Community Response to AIDS**

The following story describes how one rural community has responded over time to the emergence of AIDS.

Baan On is a typical rural village located 45 kilometers away from Chiang Mai city. The village is large with 370 households and 1,400 residents. People in the village earn their living by growing rice and garlic and obtain supplemental income from off-farm work as wage earners in construction or factory work outside the village. The village is located near the main district market where a growing number of tourists stop before entering the nearby national forest. The more developed the market has become, the greater the number of sex workers who serve truckers and villagers from nearby areas. The brothels behind the market became a common place for men from Baan On to pay for sex.

People in Baan On heard about AIDS from the national campaigns on television, radio, and through posters at the health station. However, people were not sure what was AIDS and how to react to this 'new disease', as they had never seen a person with AIDS before. People carried various myths and beliefs about how AIDS can be transmitted. Several men continued to visit sex workers without condom use. However, a large number of PHAs turned up quickly in Baan On. Of about 30 PHAs, only two were women, were reported from 1992

<sup>31</sup> UNICEF estimates, Marc Weitz, personal communication, September 8, 2001.

<sup>32</sup> Personal communication, Usa Duangsa, September 8, 2001.



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to 1998 and most had died. Because of fear of rejection, most PHAs did not admit openly that they had AIDS.

Mixed responses were seen among the people of Baan On. The first few PHAs in the village were young responsible men who were much liked by the villagers, one the assistant to the village head and the others, men who either work hard or who were responsible for a family. Thus, the people sympathized with them and their families when they were ill and passed away. However, as the number of PHAs increased sharply, a growing number of people refused to accept PHAs and their families for fear of contracting AIDS. Men started to change their sexual behavior, stopping or reducing the frequency of paid sex, changing the places they usually go for paid sex and using condoms with commercial sex workers.

Most PHAs sought some forms of treatment after learning about their HIV status even though they knew that there is no cure for AIDS. Several families and individuals burned up their savings for treatment related expenses and also to cover the loss of income. Some families sold their assets or were in debt. Within six years, more than 20 out of 370 households in Baan On had someone die with AIDS. Single PHAs tend to live at home having their elderly mother as the primary care giver. In some cases, their siblings had to quit school to earn extra money to help support the family; some elderly fathers returned to work. Several married PHAs separated from their wife after their HIV status was known, and many of them returned to their parents for care, economic, and emotional supports. The number of AIDS orphans increased sharply and many were cared for by the elderly grandparents and other family members. The village headman was concerned that several families would not be able to continue their agricultural work from the lack of young adults to work and also because some families had already sold their lands.

Fear and rejection of PHAs together with the increasing impact on the family of PHAs stimulated village leaders and the village health personnel to develop strategies to respond to the epidemic. There were calls for volunteers to be trained by the health personnel who would visit PHAs at home and learn how to help families affected with AIDS. A local NGO came to the village to help. The villagers asked for income generating activities to help families of PHAs; elderly village women learned to make artificial flowers. The profits made from selling flowers were contributed to families of PHAs.

*(Source: Fieldnote of a study conducted by Im-em and Phuangsaichai, 1999)*

Community reactions towards PHAs in Thailand are quite mixed. In recent studies of the community and family, community health workers reported sympathy or indifference. Avoidance and/or criticism are reported as the predominant reaction only in a small number of areas (Saengtienchai and Knodel, 2001; Knodel et al., 2001) within the wide range of community response including indifference, sympathy and active support, contempt and fear, all of which are reported in significant proportions (VanLandingham and Im-em, 2001).

However, the reaction to families of PHAs differed somewhat by region, reflecting changes over time as well. Although stigmatization was a frequent problem for PHAs in the early years of the epidemic Northern Thailand, sympathetic reactions and a higher level of openness about the nature of the illness now characterize high prevalence provinces: 77 per cent of families of persons who died of AIDS-related causes in the Upper North were thought to be open with community members about the nature of the illness compared to 49 per cent elsewhere (Knodel et al., 2001). About 20 per cent of those in the Upper North region and 34 per cent of those elsewhere reported having experienced negative community reactions. Members of better off household are less likely to be open with the community about the nature of illness.

### **Utilizing Community Resources in Responding to AIDS**

Although the main source of financial support for PHAs comes family and then from government, communities utilize both financial and other resources to help PHAs and those living in difficult circumstances. The community financial arrangements largely predate the emergence of AIDS, but

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have been adapted to respond to AIDS in four villages in Chiang Mai. Although little is known about the determinants of community decisions to utilize resources to help PHAs and their families, the preference among communities in offering assistance to those viewed as “responsible” community members would appear likely to put the poorest households at further disadvantage (Im-em and Phuangsaichai, 1999).

*Village Savings Fund*

One village has a savings fund that provides loans to fund members. A small amount of money is collected every month from member households. Fund members who are ill, including PHAs, can borrow money at very low interest, the loan amount depending upon prior contributions.

*Village shares*

The village management committee sold shares to villagers at 100 baht per share, and invested the money in activities as decided by the village committee. For instance, investments may include growing mushrooms, buying a weaving machine, or organizing a village fair. Profits were shared amongst members, and consideration was given to using profits to help those villagers in difficulty.

*Village Incomes*

Many villagers carried out activities together to build up a village investment fund. For example, chairs, tents and other equipment considered part of collective village resources were rented out during various ceremonies in order to bring in income for the village. Income was collected from the use of the village hot springs for commercial purposes, such as opening them to soak bamboo shoots to prepare them for sale, and the sale of cut bamboo or fruit collected from public areas. Also, festivals and traditional dinners were organized to generate income for the village. Finally, village funds were invested and the profits used to set up a fund for low interest loans. In one village the housewives’ group had bought 62 pigs, investing the money that they borrowed from the community fund. The profit earned was used to give loans in the village. The villagers are not allowed to borrow more than a certain amount, and the interest is 1 per cent every month. They must repay the loan in 6 months, and those who fail to pay are not allowed to borrow again.

The use of the money from village funds depends on the consideration of the fund committees, and some PHAs receive help and assistance from these funds.

*Rice Bank*

Every year in one village, rice is donated after harvest time. Each family gives 4-5 litres and the total amount collected is about 200 tanks. This is used as a collective village resource, and villagers in need can borrow the rice for their own consumption. Any rice that is left over is sold and the money is put in the village fund.

*PHA Funds*

One village with a large number of PHAs installed a small commercial petrol pump with financial aid given by a non-governmental organization. They were able to pay off the loan and keep a fund to help and assist some of the PHAs in the village.

In the same village the housewives’ group had also joined together to open a shop selling items to offer as alms or to use in merit making ceremonies, to make money to help PHA. The housewives’ group in another village organized merit-making ceremonies to raise money for PHAs in the village. The party was aimed to raise awareness about protection against AIDS and to tackle some of the problems caused by AIDS in the community.

While community consideration of PHA family needs in using such community resources is laudable, it appears episodic at this time and inadequate to respond to income security needs of families either during AIDS-related illness or in taking care of surviving children and elderly persons. Communities in earlier studies were found to need long-term support from government agencies or the nonprofit sector to prevent AIDS fatigue at the local level (Pongsapich, 1997), reflecting genuine financial and

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social challenges facing communities with large numbers of AIDS-affected families. AIDS advocates indicate that communities have little idea of how to use public resources, increasingly being provided as block grants to multi-village *Tambon* Administrative Organizations, to address HIV/AIDS challenges at the community level.

*Financial Assistance from Local Administration*

A small amount of money is given annually by the local health administration to assist PHAs in the community. Both budget levels and activities depend on the area. In some places, PHAs manage their activities, depending on provincial or hospital policies. The management can take many forms, such as using interest accruing to a savings account for loans, for home visit expenses, or to buy health cards for PHA. It is also used to pay for any activities carried out by PHA groups, or to help pay for funeral expenses for people who died of AIDS, to help individual cases, or to invest in order to supplement the income of PHAs.

*Funeral and Cremation Funds*

Death in rural villages involves costly ceremonies: the family of the deceased hosts villagers for the Buddhist rite, which could last 3-7 days. The family of the deceased show their gratitude to guests by serving snacks, to a few hundred guests over the period of ceremonies. A meal for hundreds of guests is usually prepared for villagers prior to the cremation itself.<sup>33</sup> In return, the guests are expected to donate a small sum of money to help the family of the deceased.

The existence of village funeral funds throughout many rural communities serves as a mechanism to help families deal with high funeral costs. Members of the funeral fund pay between 30 and 200 baht or more when a fund member dies. The amount of fund available to the family of the deceased depends on the size of the fund members and the amount of fee collected. The average cost of a funeral for a PHA was about 52,000 baht or almost double the amount of money spent for AIDS treatment, and the amount of money received from the funeral funds and from contribution by the villagers was around 63,000 baht. Less than 10 per cent of PHA families sold assets or borrowed money for the funeral. However, several elderly people in the Upper North region complained about their increasing financial burden due to payment of the funeral funds in recent years as the number of young adults dying with AIDS increases. The case studies describe how the families deal with the funeral costs of PHAs (Im-em and Phoungsaichai, 1999).

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<sup>33</sup> The authors attended a few village funerals of PHAs, which are expensive affairs. Prior to cremation, many villagers help prepare a meal for the guests, with the family of the deceased bearing all expenses. A few pigs, a cow and several chickens are killed to prepare a meal for a funeral of a wealthy person in the village. Several villagers do not cook that day, instead taking home food from the funeral. The myth among the villagers to avoid eating or drinking at the funeral of a person dying with AIDS from fear of contracting AIDS is gradually being replaced by a more realistic understanding.

**Response to AIDS at Individual, Household and Community Levels in Thailand***Wassana Im-em and Gary Suwannarat***Community Funeral Funds: Case Examples****Case 1**

Dang's husband died with AIDS and she organized a funeral for him, which cost 90,000 baht. A total amount of 130,000 baht was received as a result of her husband death; a large amount from the Bank of Agriculture where her husband had life insurance and a small amount from the village funeral fund. However, most of the money received was spent to repay her husband's employer, who had lent money for treatment costs while her husband was sick. The family had to sell their pick-up truck to cover treatment costs not covered by the proceeds from the insurance policy and funeral fund, and use the remainder to cover the funeral costs.

**Case 2**

Kham lost two family members to AIDS in three years and has two PHAs in the family, her 6-year-old grandson and her surviving daughter-in-law. Her first son was ill for three months before his death of AIDS-related causes. When ill, he sought treatment three times at government hospitals and also sought treatment at a few private clinics. The total cost for his treatment was about 30,000 baht. A five day funeral was organized when he died, costing a total of 70,000 baht. The family received 30,000 baht from the funeral fund, and another 2,000 from contribution of parents and siblings. They sold a truck to help pay for the funeral. The second PHA who died was a daughter whose husband infected her. She returned to live with her parents when her husband died. She was ill for one year and spent all of her savings of 25,000 baht on treatment. When she died, the family organized a four-day funeral, costing 80,000 baht. They received 30,000 baht from a funeral fund and Kham sold land to make up the rest.

**Mobilizing Non-Financial Community Resources**

With the emergence of HIV/AIDS, NGOs and academics have fostered community movements and strengthening of community capacity to help prevent the spread of HIV and to support PHAs and their families, particularly in the Upper North and Northeast regions, but less outside these regions. Drawing on indigenous traditions and resources, the funding and technical support provided by government agencies, NGOs and academics to community based organizations have helped strengthen responses to HIV/AIDS at the community level in a number of areas.

While national campaigns to raise HIV/AIDS awareness depend heavily on training, distribution of IEC materials, and the dissemination of information via the mass media, the spread of information in rural communities is based largely on informal discussions with networks of friends and families. Several individuals and groups in the community play a crucial role in promoting a better grassroots understanding of HIV/AIDS, either because of their leadership role in the community or because of the vulnerability of the group to HIV. For instance, CARE/Thailand has supported community AIDS interventions by encouraging the formation of youth groups, mostly secondary school students, to address HIV/AIDS prevention needs. A local NGO helped with proposal writing, project planning, implementing activities, and obtaining funds for their activities. These student groups used puppet shows and drama as IEC tools to disseminate the HIV/AIDS information. Some students recruited parents to participate and support their children's involvement in the project. Many other community based interventions aim to encourage the community's involvement in planning and carrying out

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AIDS prevention and care activities (see examples in Elkins et al., 1996). However, community organizations working on AIDS suffer several weaknesses, particularly in following up and evaluating the effectiveness of activities (CARE Chiang Mai, 2000). Nevertheless, the efforts of many NGOs have strengthened community capacity to undertake prevention interventions and to deal with the impact of AIDS on families and communities, enhancing the broad-based response to the challenges at the local level.

**Community Leaders**

Monks, traditional healers, teachers, village leaders, health volunteers, and senior villagers have been tapped to address HIV/AIDS at the community level, although their roles are shaped by personal factors—interest and awareness of HIV/AIDS challenges, skills in addressing sensitive issues, and in mobilizing others community members and local and external resources. Monks not only serve as religious leaders, but some have become informal counselors to PHAs and their families, providing them with emotional support and advice. The limitations imposed by views of sexuality and the status of celibate monks have previously been mentioned. Some monks also act as traditional healers, providing herbal therapy or other non-invasive treatments, and some have developed hospices for those in the final stages of illness. Several kinds of traditional healers provide treatments for PHAs ranging from spirit doctors, herbal therapists, and fortune tellers; treatment costs may range from free to very high cost. Efficacy of such treatments is controversial; PHAs often believe wholeheartedly in such treatments, while health professionals characterize the same treatments as quackery.

One village in Chiang Mai is well known among PHAs in the area for its low cost therapeutic massage and herbal sauna. With community support and acceptance, traditional doctors from nearby areas join in the treatment of PHAs at low cost at the community temple.

Village health volunteers are key in the effort to raise awareness and to promote HIV/AIDS understanding in rural communities. The majority received HIV/AIDS training provided by local health professionals (Im-em et al., 2001). They have a fairly good knowledge about HIV/AIDS and they also help distribute condoms to villagers known to engage in high-risk sexual behavior. Indeed, their knowledge about local situations has made them a reliable source of information about the AIDS situation at the village level, and an important link in monitoring local health concerns, including HIV/AIDS.<sup>34</sup>

The role of village leaders is potentially critical, although in a number of instances villages headmen tend to ignore HIV/AIDS related issues as they pursue infrastructure development. Well-informed village leaders, however, may both direct community resources and influence individual charity to assist PHAs, which is largely based on personal relationships between the PHA and those offering assistance. Some village leaders express the concern over the inadequacy of family supports of elderly parents who have lost children to AIDS-related illness, children who would normally provide income security for their parents in old age. In their view, both government and community should extend financial support to families who have lost adult children to AIDS, particularly if elderly parents provide the sole support for their grandchildren (CARE, 2000).

Community assistance to PHAs exhibits considerable gaps, however. The community is likely to provide assistance to those considered to be responsible members of the society or those who previously contributed to the community (male heads of household are generally perceived to fall in this category). Thus, others who need community assistance like women or elderly parents affected by AIDS, who may not be perceived to have previously contributed to the community, may be ignored in community decisions regarding financial support.

<sup>34</sup> In a study to assess the impact of AIDS on elderly people by Knodel and others (2001), the village health volunteers were able to help identify the households of PHAs. The health station with a small number of nursing staff is the smallest unit of the government health service provided to the rural people covering about 10 villages or over few thousands people. Thus, the village health volunteers become the local key informants to report health situation including AIDS to the health staff.

**Response to AIDS at Individual, Household and Community Levels in Thailand***Wassana Im-em and Gary Suwannarat***Community PHA Groups**

The establishment of PHAs groups in the community has been increasingly accepted by people in the community. PHA groups include those initiated by government health facilities (usually local hospitals; accounting for half of all PHA groups), and those initiated by PHAs with the support of NGOs (20 per cent), GOs (15 per cent), NGOs and GOs (5 per cent), community organizations (1 per cent), or self support (8 per cent) (Smitaketarin and Paowanaporn, 2001).

The impetus to form community PHA groups differ by region and over time. While PHAs from other areas now tend to organize because they fear discrimination, PHAs in the Upper North organize to address financial pressure and the need to raise awareness within the community, although a number of such groups focused on addressing stigmatization at an earlier stage in the epidemic. The top three activities of PHA groups are providing counseling, providing educational campaigns, and making home visits to PHAs.

Most PHA groups would like to introduce income-generating activities to their group members so they could earn a better living. The community response to the establishment of PHA groups in the Upper North community is quite positive. Several villages offer office space for PHAs and many people buy their products or contribute money to support their activities. However, few PHAs groups are able to profit from the income-generating activities organized by their groups, as they struggle with the following obstacles (Smitaketarin and Paowanaporn, 2001):

- Lack of adequate funding to initiate activities
- Lack of skills to produce high quality products
- Lack of markets for products
- Lack of management skill to operate the organization
- Lack of long-term plan for the group
- Deteriorating health prevents members from participating
- Distance prevents some members from regular participation
- Some groups have too few members to initiate income generating activities
- Lack of opportunities to learn from other PHA groups
- Too few government and NGO supporting organizations.

Despite the inability of most PHA groups to profit from their income-generating activities, most continue group participation to support each other and to share their experiences as PHAs.

**Policy Implications and Further Research**

AIDS emerged in Thailand at a time when rural communities were undergoing transformation, as farming became less important economically and young adults migrated for employment elsewhere. The rapid economic growth prior to 1997 brought with it considerable migration and income imbalances between the rich and the poor; both mobility and income disparities are among the forces driving the spread of AIDS in Thailand. The economic downturn brought a wave of return migration to rural areas, possibly contributing to an increase in HIV infection there. It also brought an apparent increase in amphetamine trafficking, sales and use. A number of policy implications and suggestions for further research follow.

**Policy Initiatives**

- 1) As men outnumber women in AIDS deaths, the number of women and children living with HIV/AIDS have increased. Both government and nonprofit organizations should take this into consideration for planning to target appropriate assistance to female PHAs, AIDS widows, and their children
- 2) The premature death of one's adult children and small size of Thai families (averaging two children) jeopardizes income and emotional security of elderly survivors.

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3) Parents, particularly the mother of PHAs bear the burden of intensive home based care. Although PHAs may avail themselves of transfer payments and other benefits, similar benefits are not extended to the families or survivors of the PHA. This issue is especially acute when parents face the responsibility of bringing up orphaned grandchildren.

4) Many available treatments for PHAs offer no benefits. PHA groups and health officials could perform a great service by strengthening consumer awareness among PHAs, to enable them to understand different kinds of treatment, judge suitability of treatments, and avoid exploitation in this regard. Reliable information is not available to help PHAs make decisions about whether or not to use certain services and products.

5) Strong ties within Thai families have lessened the impact of AIDS on individuals and on society. Financial support within the networks of family members is common among Thais to help out family members in difficult situations. However, the ongoing economic downturn may undermine family ability to absorb long-term AIDS burdens. And may require government to review the equitability and targeting of current transfer payments to PHAs.

6) The changing sexual culture among the teenagers has expanded the population at risk of sexually transmitted disease. Continued vigilance in prevention efforts and strengthening of sexuality education appear warranted.

7) The rural community strategies to assist people in difficulty, including people living with HIV/AIDS, remain somewhat spotty. Past development activities carried out by community administrative authorities prioritized infrastructure, such as roads, water, and electricity supplies. Enhanced response to income and other needs of PHAs and their families and improved targeting of resources available to or generated by the community requires continued attention.

8) Rural PHA groups have been formed by the PHAs for emotional support and information sharing. PHA group efforts to earn supplemental incomes are weak and need specialized assistance.

9) NGOs have played a crucial role in development works in the community, particularly to help strengthen the community's capacity in working with AIDS. However, they usually work with limited short term budget so the government should allocate adequate budget to help promote their community activities.

10) Migration increases vulnerability to sexually transmitted disease, including HIV/AIDS. Measures to regularize the status of and reduce exploitation among international migrants, and intensified attention to the prevention needs of internal migrants appear warranted.

**Research Issues**

1) Further research is needed to better understand the factors that contribute to different responses to HIV/AIDS in different population groups and provinces.

2) More information is needed on individual and community responses to HIV/AIDS outside the Upper North and what measures are most effective in strengthening response capacity will be important to the many communities in which HIV/AIDS impacts have yet to peak.

3) Elderly mothers serve as the primary care givers for a large proportion of PHAs, but little is known about their knowledge and practices as home based caregivers.

4) Several villages have mobilized resources to support PHAs and their families. The lessons learned from these communities, and the need for back-up support from other levels of government, should be further investigated and promoted for long-term sustainability.

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