

# Coping with Love

**Older People and HIV/AIDS in Thailand**



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**HelpAge International** is a global network of not-for-profit organisations with a mission to work with and for disadvantaged older people worldwide to achieve a lasting improvement in the quality of their lives.

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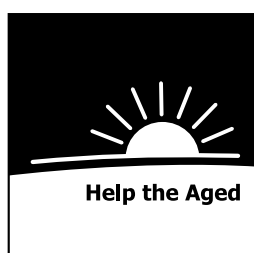
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## Coping with Love: Older People and HIV/AIDS in Thailand

### Summary

Thailand's AIDS epidemic has received a lot of attention over the last decade. However, little information exists about the impact of HIV/AIDS on older people. HelpAge International has worked with older people affected by HIV/AIDS in Northern Thailand since 1996 gaining first-hand knowledge of the negative effects of HIV/AIDS on the older population and the multiple roles older people play to mitigate against the impacts of the epidemic on their families and communities.

This report presents the findings of research carried out in Sankampaeng, Mae Wang and Muang districts in northern Thailand. It highlights the issues faced by older people affected by HIV/AIDS, the contributions they are making to their households, and the lack of services and support available to older people affected by HIV/AIDS. The report is intended for policy makers in government, donor organisations, civil society and age care organisations to help them better understand the links between old age, poverty and HIV/AIDS in Thailand. It aims to bring about appropriate responses to support the needs and roles of older people in the fight against HIV/AIDS.

The report is divided into seven sections. It provides background information on HIV/AIDS in Thailand (including the number of older people affected) and research methodology. Interviews and focus group discussions demonstrate the range of ways in which older people are affected by HIV/AIDS, their significant caregiving role and the affect HIV/AIDS has on household income. The report highlights older people's concerns, including lack of knowledge about the epidemic, lack of income security, the burden of caregiving and the strain HIV/AIDS places on family and community relationships, and looks at how older people are perceived in the community. It examines community projects, looking at the reasons why there are so few programmes that target the older population. The report concludes with key recommendations to form the basis of an agenda for action to improve the lives of older people affected by HIV/AIDS.

## 1. INTRODUCTION

People aged 60 and over represent about 10.5 per cent of the 64 million total population in Thailand.<sup>1</sup> This age group is expected to increase to over 15 per cent by the year 2020. The northern region of Thailand has the largest proportion

This report highlights the issues faced by older people affected by HIV/AIDS, the contributions they are making to their households, and the lack of services and support available to older people affected by HIV/AIDS.

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<sup>1</sup> Population Division of the Department of Economic and Social Affairs of the United Nations Secretariat, *World Population Prospects: The 2004 Revision* <http://esa.un.org/unpp>.

of the older people and is also the second most economically disadvantaged region in the country. The percentage of older people in this region is expected to grow from 11 per cent in the year 2000 to 20 per cent by the year 2020.<sup>2</sup> Thailand is one of the more developed countries in Asia, but there is an increasing disparity in income levels between the rural and urban areas. 81 per cent of the country's older population live in the poorer, rural areas.<sup>3</sup>

Thailand has one of the highest prevalence rates of HIV infection among countries in Asia. The prevalence rate for adults aged between 15 and 49 is currently 1.8 per cent.<sup>4</sup> It is estimated that in the last 20 years one million people have been infected with HIV/AIDS. Of these, 600,000 are currently living with HIV/AIDS and 400,000 have died.<sup>5</sup> From the beginning of the epidemic, the northern region (particularly the six, upper northern provinces) has been the most severely affected and, to date, maintain the highest prevalence rates of the virus.

### **Older people and HIV/AIDS**

Reported cases in Chiang Mai Province indicate that about 5 per cent of people infected with HIV/AIDS are aged 50 and over.<sup>6</sup> Extrapolating from this data and national population figures it is estimated that there are approximately 50,000 older people infected with HIV/AIDS in Thailand. Because of much higher levels of stigma and discrimination, the numbers are less well known as less people are willing to be tested or admit to the illness. This is partly due to the perception that older people are not sexually active. Even more disturbing for older people is the estimate that between 2001 and 2004, over 240,000 older people lost their adult children to AIDS. This figure is expected to rise to over 550,000 by the end of year 2010<sup>7</sup> For older people, this represents a great deal of heartache and burden of responsibility that will not subside in the near future.

HelpAge International's experience in Thailand and globally shows that HIV/AIDS has had far-reaching economic, social and psychological effects on older people, destroying their hopes and security for the future, and bringing new

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<sup>2</sup> Northern Region Economic and Social Development Office, 2003.

<sup>3</sup> Fact sheet - Family planning and Population, 1999.

<sup>4</sup> ASEAN Work Programme on HIV/AIDS, 2002-2005.

<sup>5</sup> 9<sup>th</sup> Thailand National Seminar on AIDS Report, 2003.

<sup>6</sup> Provincial Public Health Office, Chiang Mai Province, 2004.

<sup>7</sup> These figures were calculated using data from two sources: the number of persons estimated to die of AIDS in each age group of the population aged 15 and over, based on the projections for HIV/AIDS in Thailand between 2000-2020 (Thai Working Group on HIV/AIDS Projection (TWG) 2001, Ministry of Public Health), and the average number of living parents for the population of each age group aged 15 and over based on the Survey of Elderly in Thailand, (National Statistics Office, 1994). The projected number of deaths were multiplied by the average number of living parents age 50 and above to estimate the number of older people who will have lost an adult child due to HIV/AIDS.

responsibilities as household breadwinners and carers. The risk of infection of older people has also been consistently underestimated. By hitting the middle generation, HIV/AIDS strikes at the heart of how families and communities provide for the older and younger generation. HIV/AIDS deepens the poverty of already poor older people; especially as older people are now primary carers for those with HIV/AIDS and their grandchildren. Often they carry the burden of three generations when HIV/AIDS strikes: *themselves*, without support from now sick children; their *sons and daughters*, who they must now care for; and their *grandchildren*, who become their responsibility when their parents are too ill to look after them or have died.

The concerns and pressures faced by older people as carers have not been adequately recognised by the government and non-governmental organisations (NGOs) implementing HIV/AIDS programmes, mainly due to lack of awareness. The significant contribution of older people as carers and their potential as educators for both the children in their care and others in their communities has also been overlooked. Although there are a large number of agencies implementing activities and projects on HIV/AIDS in the three districts covered by this study in northern Thailand, very few of them specifically focus on older people. None of the Thai Government's HIV/AIDS policies, programmes and services make explicit reference to older people, and very few of the NGOs and community-based organisations in Thailand include older people as a target group within their programmes.

### **HelpAge International and HIV/AIDS**

HelpAge International is a global network of not-for-profit organisations with a mission to work with and for disadvantaged older people worldwide to achieve a lasting improvement in the quality of their lives. Some network members started work on HIV/AIDS and its impact on older people in the early 1990s in Africa. In 1996 HelpAge International developed a pilot project in Sanpatong, Thailand, using participatory research to identify community needs and the impact of HIV/AIDS on older people. This project was designed to improve the social and economic conditions of older people caring for people with HIV/AIDS, thereby improving the quality of home-based care. It was implemented in partnership with a local NGO.

Based upon this project experience, HelpAge International expanded its efforts to support a number of local NGO and People Living With AIDS (PLWA) groups for the purpose of initiating small-scale, community-based activities to sustain and support affected older people and enable them to make contributions to their communities.

In addition to its work at the community level, HelpAge International has worked with local partners to raise awareness about the impact of HIV/AIDS on older people and to advocate for the inclusion of older people in HIV/AIDS policies and

This research was undertaken to gain more knowledge about how older people are affected by HIV/AIDS in the areas where HelpAge International is currently working with local NGOs in Northern Thailand.

programmes at the community level, national and regional levels. HelpAge International facilitated the participation of older people from Thailand and staff and partners from Africa and Asia in the 15<sup>th</sup> International AIDS Conference held in Bangkok in 2004, which provided a forum for affected older people to express their views in relation to the ways that HIV and AIDS affect their lives.

### **Purpose of the study**

This research was undertaken to gain more knowledge about how older people are affected by HIV/AIDS in the areas where HelpAge International is currently working with local NGOs in Northern Thailand. Some efforts have been made to research older people and HIV/AIDS in Thailand,<sup>8</sup> but there is still a lack of national data. There is little information concerning the number of older people affected by HIV/AIDS as well as its impact on their lives and families in northern Thailand.

The key aims of the study include:

- To better understand the ways that HIV and AIDS affect older women and men, including their needs, risks and concerns, and how these are currently being addressed;
- To produce relevant information for future project implementation;
- To raise awareness and advocate for the inclusion of older people among organisations working on HIV/AIDS.

## **2. DATA COLLECTION AND METHODOLOGY**

### **Research sites**

Fieldwork was conducted during the last quarter of 2004 and involved 26 villages in rural and semi-urban areas in three districts in the northern Thai provinces of Chiang Mai and Lampang. These districts – Sankampaeng, Mae Wang, Muang – were selected for inclusion in the research due to:

- the high rate of HIV/AIDS infection;
- the large proportion of the older population;
- the intensity of interventions by government and NGOs working on HIV/AIDS in this region due to the higher HIV/AIDS prevalence levels.

Another reason was that HelpAge International's local partners have worked in these areas for a number of years and plan to expand their programmes on HIV/AIDS and older people in the future.

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<sup>8</sup> See John Knodel et al <<http://www.psc.isr.umich.edu/pubs/>>



## Methodology

With the participation of community leaders, active older people, people living with HIV/AIDS and concerned government staff, three research teams were able to interview older people affected by HIV/AIDS in over 240 households.<sup>9</sup> 380 older people were identified in these households and 211 of these older people participated in the focus group discussions. Staff members from HelpAge International's three local partners organised themselves into teams of two or three researchers. Approaches used to collect information included a survey, focus group discussions and participatory consultations and interviews with service providers and older people affected by HIV/AIDS, people living with AIDS and children being cared for by older relatives.

The survey was conducted using a structured questionnaire to interview over 240 older people affected by HIV/AIDS about the make-up of households affected by HIV/AIDS, types of roles the respondents have, main sources of household income, respondents' opinion about their health status and social life, and information on the number of adult children and grandchildren affected by HIV/AIDS.

Fifteen focus group discussions were conducted involving 211 older people and 136 other key stakeholders. The discussions provided a first-hand view of the needs and concerns of older people affected by HIV/AIDS, and gave the key stakeholders an opportunity to express their opinions and experiences concerning the situation of older people affected by HIV/AIDS. NGO stakeholders were asked about the services provided to older people in the communities and their impressions of the situation of older people affected by HIV/AIDS. In addition, eight in-depth interviews were undertaken with older people affected by HIV/AIDS to lend greater insight into their lives.

## Participants

The criteria for the selection of older people affected by HIV/AIDS and their participation in the research was based on them or another household member being infected with the HIV virus. Older people are affected by HIV/AIDS through a variety of circumstances including:

- having a family member (adult child, spouse or close relative) living with HIV/AIDS
- caring for grandchildren whose parents are living with HIV/AIDS
- having an adult child or spouse who has died of AIDS
- caring for grandchildren whose parents have died of AIDS

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<sup>9</sup> Older people affected by HIV/AIDS refers to those aged 50 and above who are themselves infected or had or have a member of their household infected with the HIV virus.

Only one older person affected by HIV/AIDS was interviewed per household, and therefore there are more older people affected by HIV/AIDS than represented in the number interviewed. The head of the household, typically the oldest male, was the person who was usually interviewed and thus the reason why men make up the majority of the affected older people who were interviewed.

Table 1: Number of older people affected by HIV/AIDS interviewed in each district

Districts	No. of villages	No. of older women	No. of older men	Total
Sankampaeng District, Chiang Mai	9	21	38	59
Mae Wang District, Chiang Mai	10	41	85	126
Muang District, Lampang	7	25	36	61
Total	26	87	159	246

The other key stakeholders participating in the focus group discussions included people living with HIV/AIDS, children affected by HIV/AIDS, formal and informal community leaders and concerned government and NGO staff.

Table 2: Participants in focus group discussions

	Sankampaeng district	Maewang district	Muang district	Total
Affected older people	57	72	82	211
People living with HIV/AIDS	22	15	11	48
Formal and informal community leaders	17	9	8	34
Affected children <sup>10</sup>	16	10	18	44
GO and NGO personnel	4	1	4	9

## Scope and limitations

The scope of this research project was to identify and document the following areas:

- Identification of older people affected by HIV/AIDS and their role in their household.
- Perceptions and experiences of older people affected by HIV/AIDS (the contributions they make to their families and communities and the impact of HIV/AIDS on their lives).
- Perceptions and experiences (including their opinions of older people) by people living with HIV/AIDS, children affected by HIV/AIDS and under the

<sup>10</sup> These are children aged 18 and under who had or have a parent infected with the HIV/AIDS virus.

care of older people, community leaders, and concerned GO and NGO staff.

- Programmes and services offered to older people affected by HIV/AIDS.

This study covered only a limited number of districts in two provinces in the upper northern region. It may not fully reflect the situation of older people affected by HIV/AIDS in other parts of the country with differing social and economic contexts. This needs to be taken into consideration when using the results.

The number of older people affected by HIV/AIDS that were identified may not reflect the actual number of older people affected by HIV/AIDS in the selected villages. It was observed and recorded by the research teams that older people in approximately 15 per cent of the affected households did not want to be interviewed due to fear of discrimination.

Although previous research has revealed that older people are also at risk and are infected like other age groups, the research teams were unable to identify older people living with HIV/AIDS. In Thailand, older people infected by HIV/AIDS face higher levels of discrimination than younger age groups (this is largely because of the cultural perception that older people should not be sexually active). Due to the lack of information about this group, their situation is not explored or presented in this report.

### 3. OVERVIEW OF SURVEY FINDINGS FROM HIV/AIDS AFFECTED HOUSEHOLDS

#### Older people are affected by HIV/AIDS in a range of ways

Around 380 older people affected by HIV/AIDS were identified in the households that were surveyed. The average age of the respondents was 66 and the oldest was 91. The ratio of male to female among older people was similar in all three districts, approximately 1 male to 1.4 females. This is because more women than men are involved in caregiving activities among older people affected by HIV/AIDS.

What is clear from a review of the data is that older people are not a homogenous group. In some cases older people are assisting in the care of the grandchildren after one of the parents has died. Others have no one to care for them as all of their adult children have died. Some older people are actively caring for an adult child living with HIV/AIDS, while others are caring for orphans. Because of these varied circumstances, it is difficult to group older people affected by HIV/AIDS into precise categories. The table below separates them into three major groups in order to better understand their general predicament and common experiences.

In Thailand, older people infected by HIV/AIDS face higher levels of discrimination than younger age groups (this is largely because of the cultural perception that older people should not be sexually active).

The role taken on by the older women and men is not only care for their adult children, but also one of guardianship and caring for grandchildren.

The survey results confirm that a significant number of older people have been affected by the debilitating effect of HIV/AIDS. 83 per cent have lost an adult child from HIV/AIDS. 22 per cent are currently caring for an adult child. In both these cases, there are grandchildren in nearly half of the households.

Table 3 – Older people and their adult children

Description	No. of cases	Percentage
OP whose adult children have died due to HIV/AIDS	192	78
OP who have an adult child infected with HIV/AIDS	41	17
OP whose adult children have died due to HIV/AIDS and who have an adult child infected with HIV/AIDS	13	5
Total	246	100

Older people and children are both left behind when a person dies of AIDS. In the households surveyed, the number of affected older people far outweighs the number of affected grandchildren, although there may be more affected children than the surveys could capture.

Table 4 – Number of affected older people and grandchildren

	No. of villages	No. of households	No. of older people affected <sup>11</sup>	No. of grandchildren affected <sup>12</sup>
Sankampaeng District, Chiang Mai	9	59	94	43
Maewang District, Chiang Mai	10	126	198	49
Muang District, Lampang	7	61	87	33
TOTAL	26	246	379	125

### Older people have a significant caregiving role

The data illustrate how the infection and loss of adult children has resulted in additional responsibilities for the remaining members of those households. All of the older people surveyed provided care to their children who were or are currently living with HIV/AIDS. The role taken on by the older women and men is not only care for their adult children, but also one of guardianship and caring for

<sup>11</sup> This number reflects the number of older people aged 50 and over in a household where a member of the household has been infected with HIV or has died from AIDS.

<sup>12</sup> This number only refers to the number of grandchildren between the ages of 1 and 18 who have or had a parent or parents infected with HIV and are cared for by older carers. It does not include other vulnerable children not affected by HIV/AIDS who may be cared for by older people.

grandchildren. Table 5 below shows that in 51 per cent of the households, older people are caring for a grandchild or grandchildren who have lost one of their parents and in 21 per cent they have lost both parents. 37 per cent of households showed older people as sole guardian or carer for the orphaned grandchildren.

Table 5 – Older people caring for grandchildren

Description	No. of cases	Percentage
OP caring for grandchildren who have lost one parent	125	51%
OP caring for grandchildren who have lost both parents	52	21%
OP who are the sole guardian or carer <sup>13</sup>	90	37%

### Adult children are a key income support for older people

It is evident that there was a considerable, adverse financial effect on those households, which have been affected by HIV/AIDS, and these households were marginalised in comparison to the average household in Chiang Mai region. Most of the households affected by AIDS are either in poverty or near the national poverty line for households in Thailand.<sup>14</sup> The average combined household income for the respondents in the three districts varied considerably, but were all markedly less than the average income for Thailand. The average combined income for Sankampaeng District was 8,000 baht per year (US\$200), followed by 20,000 baht for Maewang District (US\$500), and 25,000 baht (US\$625) for Muang District. When compared to the average income per year for a household in the northern region of Thailand, 114,000 baht (US\$2,850),<sup>15</sup> the household income of the respondents in the survey falls into a much lower segment.

Most of the older people interviewed did not receive any income from employment in the formal commercial sector. They took on odd jobs and daily wage work in order to provide some income for the household. In some cases, there was a retirement fund or a sale of assets, such as land, that provide income to support the household.

The results showed that in all three districts, the main source of income was through the employment of the older person's adult children.<sup>16</sup> 63 per cent of the

The results showed that in all three districts, the main source of income was through the employment of the older person's adult children.

<sup>13</sup>This refers to households where the adult children are infected and there is only an older person or older people remaining to provide care and possible guardianship to the dependants should the adult children pass away, and cases where the older person is left to care for themselves.

<sup>14</sup> The official poverty line in Thailand is 12,764 baht per person per year in urban areas and 8,336 baht per person per year in the rural areas.

<sup>15</sup> Statistical Reports of Chiang Mai Province, 2004. National Statistical Office, Ministry of Information and Communication Technology.

<sup>16</sup> When referring to adult children in this report, the spouse of the adult child is included in this category.

households that took part in the survey had one or more healthy adult child. Most of these adult children were involved in farming, construction work, or running a small business.

### **Size and composition of households determines income earning capacity**

The average size of the households surveyed was 3.5 people, which is the same as the national average.<sup>17</sup> One would expect the figure to be somewhat lower in the districts surveyed, given the number of deaths from HIV/AIDS. However, it is likely that the addition of grandchildren to the household offsets the number of deaths affecting the middle generation.

The household composition varied between districts (see table 6) and can explain some of the differences between incomes in the districts. Those households with more adult children of working age compared to the numbers of older people and children have larger combined household incomes, than those where the ratio of older people and grandchildren is greater.

Table 6: Composition (averages) of households in three study districts

District Composition	Sankampaeng	Maewang	Muang
No. of older people	1.6	1.6	1.4
No. of adult children	0.9	1.1	1.5
No. of grandchildren	1	0.8	0.6

It is evident that the households where a healthy adult children remains have a definite advantage because they are able to assist with caregiving, provide emotional support to their parents and to their nephews and nieces, and provide financial support. In households where an older person is the sole guardian and carer they experience more stress and responsibility.

### **Older people play important roles in community groups**

Nearly all of the respondents reported that they were involved with community groups, such as savings groups or associations of older people (OPAs). In Sankampaeng and Muang District, older people were active members of at least two or three community groups. However, only in a very limited number of cases did the older people have a leadership role in the community group. The respondents in Maewang District were more active in community groups, being active members in at least three or more. In only four cases did the older person have a leadership role in the community group.

<sup>17</sup> Statistical Reports of Chiang Mai Province, 2004. National Statistical Office, Ministry of Information and Communication Technology.

#### 4. EXPERIENCES AND CONCERNS OF OLDER PEOPLE AFFECTED BY HIV/AIDS

This research shows that while circumstances may vary, older people are dealing with similar issues. These issues include lack of knowledge about HIV/AIDS, limited livelihood opportunities, lack of social interaction, discrimination and social status and personal health concerns.

##### Older people have little knowledge about HIV/AIDS

Many of the older people surveyed have limited knowledge about the virus and its transmission; they only know that it is difficult to transmit to others. They know a little about how to properly care for patients, but they do not know how to protect themselves when caring for infected family members. Older people were not aware that the illness could only be transmitted when infected blood, semen or vaginal fluid gets into another person's body, or through breast-feeding. Many of them said they do not know how their adult child became infected.

*"I don't know what it is, and I also don't know where my child got it from."*

Male carer, 70 years old

*"I don't know; people said AIDS is AIDS. I have no idea where it is from."*

Female carer, 69 years old

There are also misconceptions about how to treat the illness. For example, in focus group discussions one older carer thought that leeches applied to the body would heal her adult child. In some cases older people purchase the wrong type of medicine or treat their children with methods that are ineffective and a waste of money.

*"I felt sad for my child that is infected by HIV/AIDS. I had no idea what to do, I also have spent a lot of money; I have sold cows and buffaloes in order to help him, but he has never been healed. Whatever medicine that people said was good, I would try to find it and buy it. It cost 5,000 baht for one container, but it didn't help at all."*

Male carer, 54 years old

They are also unaware of what services are available to support them in their role as carers.

*"I don't know where to get support; they came and wrote down my name, but nothing has happened since then."*

Female carer, 64 years old

Many of the older people surveyed have limited knowledge about the virus and its transmission; they only know that it is difficult to transmit to others.

As well as providing basic needs, older people also try to provide for the education of their grandchildren.

### **Older people find it difficult to make a living**

Older people are from a generation where education was not considered important and they lack basic skills and have few employment opportunities in the formal sector. Many of those surveyed are farmers and daily labourers, which makes it difficult for them to earn a good salary to take care of their family. The survey showed that many older people are earning as little as 5 to 100 baht (US\$13 to US\$2.50) per day, some are engaged in selling vegetables and crafts, and some have no means to earn at all. Others may have the skills, but because of their age they are seen to be too old to work. Household income from their children has disappeared because they have died or are too sick to work. Many resort to selling assets in order to pay for medicines, funeral expenses and to support the household. If they do not have assets they usually borrow money, often from relatives to avoid paying interest. Poverty is a serious issue for older people caring for people living with AIDS (PLWA) and their grandchildren.

*"If I don't do it [pick fruit and vegetables] then I will have no food to eat."*

Female carer, 78 years old

*"Beside all the expenses from the hospital care, I had to borrow 70,000 baht from other people for the funeral after my child passed away."*

Male carer, 58 years old

*"The hospital expenses were getting higher and higher until we ran out of money. We finally had to sell the land that we had bought for our child."*

Female carer, 52 years old

As well as providing basic needs, older people also try to provide for the education of their grandchildren. Even though primary school tuition is free in Thailand, older carers have to pay for uniforms and other school requirements for children under their care, besides trying to raise their grandchildren and teach them morals and about being responsible. This only serves to add to their stress.

*"I take him to school and he always asks for money. All expenses, everything, money for the gas, for food. It's very tiring!"*

Male carer, 70 years old

*"I teach him, find him food, money, and do whatever I can; I pick vegetables to sell, and do everything people hire me to do. Just to have money to give to my grandchild is something that makes me very happy. I also try to teach him and keep my eyes on him all the time just to keep him on the right track."*

Female carer, 74 years old



*"I don't want to borrow money, and I don't want to be in debt. I have no one to help; they have all died and left me alone. I have only my grandchild. Even today I have no money to give him for school at all."*

Female carer, 64 years old

### Strain on intergenerational relationships

Some of the older carers faced a difficult time in their role as guardians, and in mentoring and teaching the children in their care. Some complained that the generation gap affected their relationships and many viewed their grandchildren as disobedient and disrespectful. Others felt that their children didn't fully understand the situation their families were in; they only cared about themselves and what they wanted. In some cases, though, the grandchildren understood their situation and were willing to work extra hard and help their family as much as they could.

*"It was difficult, he is naughty and stubborn, and drives me crazy. When I don't give him money, he will try to find a way to steal it. When he gets the money, he will go and spend it on computer games."*

Female carer, 62 years old

*"It's quite tiring taking care of my grandchild because he is very naughty and does not listen to me at all. When he goes to school, I give him 5 baht, but he asks for 10 baht."*

Female carer, 60 years old

*"I told my grandchild to focus on school and be a good person, and stay away from bad friends."*

Male carer, 72 years old

### Social relations are an important source of support to older carers

For those older people having to cope with grief and poor emotional health, personal health issues, time constraints, and financial stress, it is important to maintain social relationships as a strong source of support. Social networks are very common in Thai society, and are especially strong in the rural areas where people work together to help each other in building a house, harvesting a field, financing an enterprise, and caring for each other's children. However, an older person affected by HIV/AIDS may find it difficult to maintain their social network given the considerable time spent caring for the person living with AIDS, especially those in the later stages of the illness. This leaves much less time to interact socially. In cases where other family members or friends assist with caregiving, older people are able to find time for rest and for social interaction.

Some of the older carers faced a difficult time in their role as guardians, and in mentoring and teaching the children in their care.

Some older people feel too ashamed to join in activities as a result of their decreased social status due to having AIDS in their family.

Older people affected by HIV/AIDS have to adapt to their new responsibilities and a positive social network can be vital to support older people. Part of the social network can be older people themselves; they can be part of the solution by volunteering to help care for others, by leading a group to educate the community about HIV/AIDS, and how to properly care for the sick. There are many who have gone through the grieving process and understand the sadness, can share their experience and help others to overcome their own situation. Moreover, they can also be active in an older people's club or association that is helping to encourage and mentor their grandchildren and other teenagers in the village to be aware of AIDS and prevent risky behaviour. In short, they can be a voice to improve other's ability to cope and to reduce the level of problems associated with HIV/AIDS in their communities.

*"We can teach people in the village to avoid behaviour that puts them at risk of infection. We also help to give advice to the patients about eating healthy food, and we help teach and mentor the orphans to be good people."*

Older male carer

*"For the ones who have experience, they can use their knowledge and maturity by visiting people in the village and teach them to understand and know more about AIDS."*

Village leader

### **Stigma and discrimination lead to isolation and depression among older people**

Stereotypes and discrimination affect social networks, and lead to the exclusion of affected older people and family members from participation in community activities because others fear contracting the illness. Some older people feel too ashamed to join in activities as a result of their decreased social status due to having AIDS in their family.

Focus group discussions highlighted the fact that stigma affected the livelihoods of these households as community members would not associate with or use the businesses of those affected by the illness. At community events, others would stay away from them and not let them join in group activities, resulting in social isolation.

The stigma of HIV/AIDS gives rise to a considerable feeling of shame associated with what is viewed as irresponsible behaviour. Those who are infected are considered by society to have engaged in promiscuous sexual relations, and parents are blamed for not teaching their children proper morals. In many cases the wife of an infected man is viewed as not being a "good wife", as the husband

has engaged in extra-marital affairs. The stigma and shame associated with the illness can disrupt relationships and social networks, resulting in isolation and depression among older people. Older people who continue to have positive relationships with their family, community and through new relationships from concerned individuals working with HIV/AIDS programmes, have better coping abilities and emotional health.

*"I normally have my own restaurant, but after people found out that my husband was infected with AIDS they stopped coming to my restaurant. Even though I was not infected, they were still afraid of me and they stopped using my business."*

Older female carer

*"There might be some people who do not accept us; sometimes when I go to wash clothing on the upper part of the river, they will go to the lower part. There are some that do not accept us. Sometimes I hear them gossip about us, but I don't do anything."*

Female carer, 56 years old

*"People don't come to visit my house anymore; they said that they don't want to go to someone's house who has AIDS."*

Older male carer

*"People in the village are afraid of anyone who lives in the same house with a person living with HIV/AIDS. When these people go to events in the village, people will not interact with them nor will they eat with them."*

Older female carer

Levels of discrimination varied, however, and some older people said discrimination is no longer a major problem because so many people are affected by HIV/AIDS. Community members are able to help each other both emotionally and in the physical care of the sick.

*"I don't see anyone afraid of us, but we don't know what they think. What I see is that people are very accepting of us."*

Female carer, 57 years old

Education about the illness and how it is transmitted has improved the situation in the communities that were surveyed, but incidents of discrimination were still reported.

### **Older carers feel the strain**

The research shows that older people already have age-related illnesses, which become more pronounced when they are having to work hard and are anxious

It is a huge challenge for these carers to take care of not only their adult children but also their grandchildren

about the future. Their emotional health is also affected, especially after their children are sick and pass away. They themselves report that they are very sad to learn their child is sick and depressed about what the future holds for themselves and their grandchildren. Some of them are too anxious to get a proper night's sleep and others are working so hard that they do not get enough sleep. Some have high blood pressure, diabetes, and other ailments due to fatigue and stress. For the older ones, arthritis becomes a factor in their ability to provide care as they have poor mobility which affects their ability to walk or carry out physical chores.

It is a huge challenge for these carers to take care of not only their adult children but also their grandchildren, some of whom are orphans as a result of both of their parents dying from HIV/AIDS. In many cases, older people must alter their lifestyle considerably to accommodate caregiving responsibilities. For example, older females usually look after the sick and their grandchildren, while older males seek other employment opportunities to provide additional income for the family. Some have to quit their work in order to spend time caring for their children. Their new responsibilities include finding food and feeding their adult children with AIDS, washing and changing their bedding, and looking after their dependant's children. Moreover, they need to find money to purchase medicine for the sick in order to extend their lives. The increased workload puts a huge strain on older people.

*"I had no idea what would happen; I couldn't sleep at all. When I feel very terrible, I go get medicine at the hospital to reduce my stress. I am very worried and it causes me to have stomach pains."*

Female carer, 62 years old

*"It's me who helps her to take a bath and feed her the food. If I cannot carry her, I will ask her dad to help. I am also responsible for washing clothes."*

Older female carer

*"It's always me. If my grandchild is sick, I always take care of him, and if my own child is not well, then it's only me who is there to take care of him. Who will take care of them if I am not there?"*

Female carer, 62 years old

*"Their [grandchildren's] parents all died. I just have to take care of them, but it is more difficult now because their parents used to be the ones who earned the money and took care of them. I am now very old and weak, and I can't do much anymore."*

Older female carer

## Women provide most of the care

The survey results show that women make up the majority of those caring for PLWAs and for grandchildren. A total of 58 per cent of the older people in the affected households were women. The focus group discussions showed that women take on the responsibility for care, such as attending to the health needs of those in their households and taking care of the housework. The most common complaint from the women was being tired from physical exertion. The men in the survey were mostly involved in finding additional income and their most common complaint was insufficient resources for supporting the family and the grandchild's education.

A total of 58 per cent of the older people in the affected households were women.

*"Some of the older carers survive by making baskets, and feeding the cows. These are pretty much the male's responsibilities, but the older females are responsible for the housework and taking care of the children."*

Headman

*"Of course, it is tough. I have to wash clothes, and find food for her every day. When I go to look for work, I have to prepare everything for her or sometimes I ask my neighbour to take care of her for me".*

Older female carer

Given the conservative nature of rural communities, women commonly fall into taking on the traditional roles of carer and housekeeper, whereas the men are more likely to take on the role of provider. Service providers need to design programmes with this in mind.

## Older people's hopes for the future

Older people provide hope for their children and grandchildren. They are doing what they can to provide and care for their families. They have lived a full life and want their children and grandchildren to have a better life. In discussions, older people said they hoped their spouses, sons and daughters would get better and their families return to normal. They hoped that their grandchildren who have lost one or both of their parents would grow up to be good people and contribute to the society. They also wanted them do well in school and achieve the highest level of education so that they would be able to find a good job and take care of themselves in the future.

In spite of taking on such a wide range of responsibilities, older people who took part in the survey were rarely discouraged by the challenges facing them.

*"I really hope that they will give some money or scholarship for my grandchildren for school, so that they will finish school. That's what will make me satisfied."*

Male carer, 59 years old

*"I hope that he [grandchild] will have a higher education, but I don't have money to support him. I want him to have good future like other people. For now, all I can do is send him to the local school."*

Female carer, 52 years old

Some of the older carers said they find satisfaction and continued hope in taking care of their sick children. Their one wish is that their children and grandchildren will stay healthy and live as long as they can, in spite of how difficult it is to care for them.

## **5. COMMUNITY PERCEPTIONS OF OLDER PEOPLE AND EXPERIENCES OF THOSE AFFECTED BY HIV/AIDS**

Focus group discussions explored how others affected by HIV/AIDS including grandchildren, adult children in the household and the leaders of the villages and districts viewed older people and the problems they face.

### **Grandparents are children's first choice carer**

Children whose parents were infected with HIV and who were living in a household with their grandparents expressed a clear desire to stay and live with their grandparents rather than with a relative who may have a more comfortable place to live. This appears to be because of the love and compassion they receive from their grandparents. Because of this close relationship, they would rather stay with their grandparents even though they might face future difficulties, as they do not know who will take care of them or where they will live if their grandparents pass away.

*"They [grandparents] are kind to me and are good people, especially because they love me."*

Female child, 10 years old

*"I don't want to live with my relatives because they all have families, and I don't want to bother them."*

Female child, 15 years old

*"If my grandmother died I think I would die as well."*

Male child, 11 years old

It is evident from the discussions that the children want to belong to good, warm families, where family members help each other with their responsibilities. They also want their grandparents to punish and teach them, which shows the vital role that older people are playing in raising up these children. Most of the children seem satisfied with what they have and whom they are staying with.

*“My grandfather and grandmother are very good and kind people. They love me and help me with everything. They have been helping me since I was young, and I love them very much. When I grow up I want to be a nurse, so that I can take care of them as they have been taking care of me.”*

Female child, 10 years old

*“I want my grandmother to love me until her last minute, and I want her to hug me and give me love. I also want her to help support me to have a higher education.”*

Male child, 15 years old

*“I want my grandmother to love me and I am also willing for her to punish me because I believe that the reason she does it is because she loves me. And I know that everything that she is trying to teach me is good and she wants me to have good future.”*

Female child, 13 years old

Because they are part of the same household, most of the children must deal with similar issues that their grandparents are facing, although not to the same degree. They share similar issues of discrimination, similar hardships and struggles in their lives, such as social isolation, poverty, and concerns about their future. The grandchildren are typically aged between seven and fifteen years old. The female grandchildren play an important role in helping with the daily household chores, whereas the older people feel that the male grandchildren are a little bit harder to control, especially the older ones. Focus group discussions revealed that most grandchildren receive between 3 and 20 baht per day for school, but some receive nothing.

*“I help cleaning up the house, washing clothes, and preparing meals.”*

Female child, 10 years old

### **Stigma and discrimination affect children’s emotional health**

Even when on the surface children appeared to be able to get along well with others, further discussions revealed that many of them have difficulty at school and interacting with their classmates. Some reported being rejected by friends at school and others changed schools so that they would not have to face being isolated and teased.

*“The parents don’t want their children to be with children whose parents are infected with HIV/AIDS. They try to stay away, and some of them even move school because they afraid of these kids.”*

Female person living with HIV/AIDS

Many of them have difficulty at school and interacting with their classmates.

*"I am very sad for my grandchild because he is rejected by his friends, even though he is not infected with AIDS like his parents. Even for me, myself, people also are afraid of me."*

Older male carer

Although, again, not all children face the same negative experiences.

*"They [other students] play with me and they never make fun of me."*

Female child, 12 years old

When the children were asked questions about their parents who had passed away, they had difficulty discussing their situation. Some of them said they could not remember what had happened. Many of the children have not been able to express their feelings about death and have not received the emotional support needed to help them grieve properly and accept the loss of their parent. The responses also show that they found it difficult to discuss the problems they are facing in their lives. Most of the children wanted to be loved and accepted.

*"I think the opportunity that we have gotten to talk today really helps us to feel better. We have gotten to say a lot of things that were hidden inside of us. We also can see that what has happened is in the past and there is nothing that we can do about it."*

Female child, 12 years old

*"When I was at school my friends teased me, and when I came home there was no one there who cared about me."*

Female child

*"I would love to have someone to help me with my homework, but there is no one."*

Male child, 11 years old

These children also expressed their desire for a better future. They talked about what they would like to be when they grow up – soldiers, businessmen/women, nurses, teachers, policemen, doctors – like other children their age. Most children and orphans of the families affected by HIV/AIDS are seeking to live a positive and productive life. The children aspire to have a high level of education and a good career in the future.

*"I want to be a policeman to catch bad people, but I have to study hard."*

Male child, 9 years old



*"I would like to be a teacher, so I can teach and help others to be good people."*

Female child, 8 years old

*"I would love to have a scholarship to continue school."*

Female child, 15 years old

## **People living with AIDS want to contribute to family and community life**

Those living with HIV/AIDS express their gratitude to their parents for the care that they receive from them. The love and compassion shown by older people for their children has a profound affect on those living with the illness.

*"They [parents] are very nice to me and when I am sick they always take care of me; they try to find medicine for me. . . . They are worried about me. They would go anywhere to get the proper medicine in order to see that I am healed."*

Female person living with HIV/AIDS

Most of time, people who are infected by HIV/AIDS live peacefully in the village with other people. They try to lead normal lives and many of them play an important role in helping others and educating community members. PWLAs expressed in the focus group discussions that they are willing to do whatever people ask them to do, and relationships in the communities are improving. They never want to set themselves apart from the community and seek to foster social interaction and activities. They always keep in mind how they can help and serve in an appropriate manner and be a part of the community without being a disturbance or bothering others.

*"I am a vice president of the AIDS committee for the village. If the president is not available, I will be there to help. When they have activities both of us will go and help them."*

Male person living with HIV/AIDS

*"In the past I am sure that people were very afraid of us, but it is better now. When I go selling food they buy it from me; I don't see them complain or say anything."*

Female patient, 36 years old

*“There are just some people that are afraid of us; but, we also have to realise that we ourselves are sick, and we have to be careful, such as if there is anything that we are doing that we should not be doing. When they are cooking we should not try to go and take their place and cook for them. Every time we have a meeting we always emphasise this issue, that we should not do things that may cause other to have a bad view of us.”*

Male person living with HIV/AIDS

*“If our body is in poor condition we should not get close to others, but if our health is good then it is ok. We need to know if we should or should not touch things people are doing, for example, vegetables and rice. People will not tell us; we have to know ourselves.”*

Female person living with HIV/AIDS, 36 years old

The older carers are not only taking care of those who are ill with the virus and their orphaned grandchildren, but the focus group discussions reveal that they also play an important role in educating the community by giving information and attending the meetings of the village where they discuss and share about their situation and the condition of the patients under their care. According to the leaders in the community, this has helped to build trust and create an improved awareness on the part of the people in the village. By reaching out to the community, there is greater understanding, and those who are infected and affected are able to maintain social ties and lead a better life in their communities. In addition, by being a voice in the community, they are advocating for change, acceptance and support.

*“They [older people] will go for the meetings and share information in order to create the ways to solve the problems, which is one way that they can help.”*

Male person living with HIV/AIDS, 35 years old

Some of the adult children could not accept that they had been infected by the virus; they lost control of themselves and became distraught. Those patients who have come to terms with their illness, however, want to do all they can to support their families.

*“I have thought about killing myself before because I was alone and very depressed, but when I thought about my children I was encouraged to live for them again.”*

Female person living with HIV/AIDS

*“I help my family with everything I can, feeding cows, fish and frogs. I am always out there working even though they tell me to stop, but I can’t because I love to do it. I would love to help them as much as I can for the rest of my time.”*

Male person living with HIV/AIDS, 35 years old

## Local leaders begin to recognise the needs and role of older people

Educational programmes started by HelpAge International’s partners have resulted in greater awareness of the problems of older people affected by HIV/AIDS among the general population, and among the leadership of the villages in the survey. The leaders in the three districts are actively seeking solutions. They are trying to find funds to support activities and jobs for older people affected by HIV/AIDS so they are able to sustain themselves. They are also seeking out organisations to educate communities on HIV/AIDS. In order to reduce the stress of the older people, some of the headmen have established clubs for older people. This enables older people affected by HIV/AIDS to join activities in the village, have the opportunity to share and talk with others, and thus improve their emotional and physical condition.

*“These older carers are having a tough time taking care of the patients. They don’t have much money and sometimes they have to turn to their relatives for help. Sometimes we help them by finding money from the organisations in the village or province, and there are also some foundations that target these people. At present, we really need some scholarship funds for children and orphans for their education.”*

Headman of the village

The headmen of the villages and others acknowledge that some organisations provide help to people affected by the illness, but not enough considering the number of the people infected with and affected by the illness. If funds are insufficient for affected people in general, then it follows that funding for affected older people is in an even graver situation.

*“We received money from the government only once in the past and only for the first year. Since I became the headman of the village, I have never seen any funding. It’s gone and disappeared years ago.”*

Headman of the village

*“This village never had it [funding for the sick]; I have never seen it at all. They never support us. It has been many years, but I have never seen it.”*

Male carer, 69 years old

Services offered by the public organisations provide an important support base for people affected by AIDS, within Thailand's general welfare provisions.

*"From what I know there are many organisations who give the funds for these people, but it is not enough. My village also has some money, but it also is not enough."*

Headman of the village

The leaders make recommendations for solving the problems through greater levels of intervention by the organisations and foundations that focus on people affected by AIDS. These include scholarship funds for grandchildren, secure employment for older people and more support for older people who are sole guardians or who have their own illnesses to contend with. There is no easy or one-step solution to dealing with the problem of HIV/AIDS; it must be dealt with comprehensively and involve all facets of society, including those older people affected by the illness.

*"It is necessary to find some organisations to help these older people carers whether it will come as money, investment, and/or finding a career in order to support their children's education so it reaches a higher level."*

Male District Governor

## **6. SERVICES AND SUPPORT AVAILABLE TO OLDER PEOPLE AFFECTED BY HIV/AIDS**

From the research and interviews conducted with key stakeholders, agencies were identified that provide services related to HIV/AIDS in the surveyed villages in the three districts. There were as many as 15 agencies providing services in Sankumpaeng and Maewang Districts, and at least six agencies providing services in Muang District of Lampang Province. Those agencies providing services can be categorised into five separate groups: government agencies, PLWA Groups, NGOs, community-based organisations (CBOs) and individuals.

### **Government agencies**

Services offered by the public organisations provide an important support base for people affected by AIDS, within Thailand's general welfare provisions. Key providers in the government sector are healthcare agencies providing public healthcare services at all levels of government structure in Thailand. They include the district and provincial hospitals, the District Public Health Office (DPHO), and the Tambon (sub-district) Health Centre (THC). The government provides a comprehensive range of healthcare services and support for people living with HIV/AIDS. They also provide educational activities aimed at prevention for young people, women of reproductive age and groups at risk such as TB patients and drug addicts. The Provincial Social Development and Human Security Office (PSDHS) is a part of the Department of Social Development and Welfare in Thailand. They run HIV/AIDS education programmes in community schools as part of their welfare programme with children.

The Tambon (sub-district) Administrative Organisation (TAO) organises community fundraising activities to provide financial support to community members infected with HIV/AIDS. The TAO also help to organise the PLWA groups to promote social interaction and mutual support.

Only few of these specifically target older people. In terms of healthcare services a available to older people, the three districts are similar in that the government provides free health care to older people through a network of public health stations and hospitals.<sup>18</sup> This system is effective in terms of basic healthcare services, but food and transportation costs are not covered. Some older people do not have a relative who is able to accompany them so they are unable to participate in the scheme.

The PSDHS also provides financial support to the older population in general, and to children. Because the households affected by HIV/AIDS are often very poor, they qualify for support from the PSDHS office. A subsistence allowance for older people of 300 baht per month is currently being provided to 400,000 people in this age bracket – about 6 per cent of the older population in Thailand.<sup>19</sup> According to the community leaders, these allowances are not enough to cover basic needs and they recommend that a larger budget be allocated for this programme.

### **People living with HIV/AIDS groups (PLWA Groups)**

The PLWA groups are local membership organisations operating as a network at national, provincial, district and sub-district levels to advocate for change. Typically, the groups are organised at sub-district level. The services they offer vary in relation to the level of commitment from the membership. Most PLWA groups have the common goals of providing counsellors for HIV patients and their families through a network of volunteers, conducting meetings with the TAO to work together on AIDS problems, and supporting patients, families and communities in joining in activities to care for each other and build social relationships. They also have ongoing activities that are directed at caring for both patients and people affected by AIDS through home visits, as well as to foster development of children affected by AIDS and general youth education. At monthly group meetings members discuss issues affecting them and coordinate their activities. Other agencies, such as the district hospitals, NGOs and the TAOs,

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<sup>18</sup> The healthcare system is based on a referral system whereby the health centre (Tambon or sub-district health centre) can refer a patient to the district 'Community Hospital'. If treatment is beyond the capacity of the district hospital it will refer to the provincial hospital that is called a 'General Hospital', and if necessary, the provincial hospital can send someone to a central hospital (there is one central hospital in each of the four regions in Thailand). In the north the central hospital is located in Lampang, which serves as the provincial hospital as well. In Chiang Mai, there is the Chiang Mai University hospital and a patient is usually referred to this hospital instead of the central hospital in Lampang.

<sup>19</sup> Ministry of Social Development and Human Security, 2004.

frequently offer support and services to the PLWA because of their ability to bring together a group of people that share similar needs and concerns. Among PLWA groups, older people are often mentioned as an affected group, but when asked about specific data and activities, there is little evidence of PLWA groups targeting older people. For example, a PLWA group at the district level in Muang District, Lampang Province has collected data on PLWAs, affected children, and other affected people and analysed the data based on gender. There was no effort, however, to analyse it based on age. Amphan Group in Maewang District is different in that one of its activities targets older people. This activity focuses on greater knowledge to older people about taking care of their adult children's and their grandchildren's health.

## **Non-Governmental Organisations**

There are seven NGOs working on HIV/AIDS projects in the survey villages, three of which are HelpAge International's partners – the Community Care Network (CCN), Mother Child Concern Foundation (MCCF) and Foundation for Older Persons' Development (FOPDEV).<sup>20</sup> These partners target their activities at older people affected by HIV/AIDS. The other NGOs mostly target young people through information exchange and educational scholarships. This reflects a common situation among organisations working in the HIV/AIDS sector in Thailand, with only a few select organisations working with the older population out of many hundreds of organisations involved in this sector.

One such organisation is the Mother and Child Concern Foundation (MCCF). The MCCF organisation initially began its work with a focus on marginalised women and children. From this experience at the community level, the difficulties that older people were experiencing became more apparent. In the year 1997, with support from HelpAge International, a needs assessment with affected older people was completed, and a three-year pilot project covering 40 villages was started in Sanpatong District to support affected older people and their families.

Activities included:

- community awareness-raising on the impact of HIV/AIDS on older people;
- identification of affected older people and formation of support groups to improve their emotional and physical well being;
- setting up a revolving loan fund, managed by a committee of the Older People Association (OPA) to engage affected older people in income-generating activities (IGA);

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<sup>20</sup> This study is part of the larger proposal to provide support to affected older people and their families by HelpAge International's local partners: CCN, FOPDEV and MCCF.

- training adult volunteers to equip them with the skills and knowledge to provide informal counselling, healthcare advice, and emotional support through home visits to older people affected by HIV/AIDS.

At the end of the project, responsibilities for managing the work were handed over to the communities, and volunteers continued to work with affected older people in the villages.

The achievements of the project are worth noting. The OPA has been able to manage the IGA fund and because of its sustainability, it has been able to reach more and more older people. Older people have expressed positive feedback about the IGA fund, saying it has improved their income and status, strengthened family relationships and enabled them to play a greater role in decision-making. The combined activities of developing a support group and a network of adult volunteers has played an important role in creating a support network for older people and improved their emotional health.

The project model and its successful implementation have been used as an example to raise awareness about the impact of HIV/AIDS on older people and advocate for the inclusion of older people in HIV/AIDS policies and programmes. MCCF, in collaboration with HelpAge International, replicated the Sanpatong project in two other villages (which are part of this research study) in Maewang District, to improve the quality of life for older people affected by HIV/AIDS.

The Community Care Network (CCN) is another local NGO that provides a variety of community services geared toward those affected by HIV/AIDS. They are active in five sub-districts in Chiang Mai and Lumpun Provinces. They provide an extensive range of services including running child development centres, participating in the AIDS Committee at sub-district level, providing income-generating opportunities, and conducting prevention programmes targeting youth. They have targeted three groups to be involved in their programmes: PLWAs, the youth, and older people. CCN's services targeting older people involve developing volunteer networks to make home visits with older people themselves also being volunteers. They provide resources and training for IGA, such as raising cows and making flower wreaths and decorations for funeral services. Training is also provided on older people's healthcare issues, and the health of PLWA and grandchildren. Intergenerational camps for affected older people and children are held to improve communication, strengthen relationships, and provide mutual understanding between family members. Finally, they are building capacity and a network of older people including those affected in order to enable them to voice their concerns and needs, and to better access resources in their communities.

The project model and its successful implementation have been used as an example to raise awareness about the impact of HIV/AIDS on older people and advocate for the inclusion of older people in HIV/AIDS policies and programmes.

CCN's work has produced positive changes in the following areas: communities have become more aware of the issues of affected older people; the TAO has allocated funds to support affected older people; and one of the Tambon Committee on AIDS (TCA) has initiated activities to address the needs of affected older people, engaging them in IGAs and more suitable and advanced training for older people caring for affected and infected young children.

The Foundation for Older Person's Development (FOPDEV) is a national organisation that specialises in ageing issues. Its mission focus is to improve the quality of life for disadvantaged older people throughout Thailand. It implements a range of activities targeting disadvantaged older people including older people affected by HIV/AIDS, as well as actively advocating for the inclusion of older people in development programmes and services.

In partnership with HelpAge International, FOPDEV started an advocacy and networking programme in Muang District, Lampang in 1999. A survey was conducted in Bankha sub-district that revealed that there are three needs in this district: livelihood development, healthcare and homecare services. Using the results of the survey, several activities for older people were started, including income-generation through OPAs where older people can invest in raising animals and growing crops. They also have trained volunteers for home visiting and assisted in training village health volunteers from the Ministry of Public Health. Finally, they are working with older people to improve domestic sanitation and hygiene. Recognising the impact of HIV/AIDS on older people in Muang District, FOPDEV began to lobby the TCA and the TAO to sensitise them and to pay more attention to this group of older people. This resulted in the inclusion of affected older people in the home visiting work undertaken by the village health volunteers. FOPDEV's efforts have also resulted in TAO seeking more funding to support older people affected by HIV/AIDS as well as for the older population in general.

The other NGO involved in HIV/AIDS work - Rak Thai Foundation – has programs that encompasses older people. One such project, the "Living with AIDS" project, was started in 1998, in four provinces in northern Thailand, and includes the two provinces that HAI is working in – Chiang Mai and Lamphun. In this project, older people were not the target group; however, affected older people could have indirectly benefited from some of project's key activities, such as counseling and training for carers and home-based care. In addition, based upon its interaction with HAI and its experience in conducting community-based projects, the Foundation developed an HIV/AIDS project that directly involves older people. This project, known as "Caring for Family Providers Project," started in 2003 and trains family members (including older people), relatives, community members, and government officials to respond to the healthcare needs of PLWAs. Family members have also benefited from a day care centre, home visits and study visits. This project covers 10 sub-districts in Sankhampaeng district. Three of these sub-districts are also covered by CCN's projects which involved setting up and strengthening older people's groups. CCN started working with older people in 2001 and continue to support older people as part of their on-going work. The Foundation's project, started after CCN's project, has clearly benefited from having active older people's groups as they have helped identify and interact with affected older people. At present, more than 200 affected older people in this district have benefited from the Foundation's project.



## Community Based Organisations

CBOs are development groups working at the sub-district level. They are either religious groups, schools, or private interest groups organised for the purpose of developing and improving the welfare of their communities. The Tambon Committee on Aids (TCA) is a CBO that is made up of the leaders of the community and they are active in all three districts. They are an essential component in providing services to their communities. The committee is made up of key individuals who are very knowledgeable about the HIV/AIDS situation, and therefore the TCA works with a number of different agencies to implement a broad agenda: income-generating activities (in collaboration with NGOs), information and educational materials (in collaboration with religious groups and schools), financial support for PLWAs and scholarship funds for affected children (in collaboration with government agencies, NGOs and schools), and fund-raising activities to benefit the social development of their respective communities. One TCA in Sankampaeng District (through the efforts of CCN) has targeted older people for IGAs and training as part of its work in the community. The religious groups (mainly the development branches of the Buddhist and Christian organisations) provided healthcare materials for those caring for PLWAs, counselling services and emotional support for PLWAs, and production of educational materials for AIDS education among their membership.

Not all OPAs are active at village level, and their activities vary depending on the commitment of its membership.

## Older People Associations (OPAs)

OPAs are membership clubs (people aged over 60) that are promoted by the Ministry of Public Health and the Ministry of Social Development and Human Security, and have a coordinating body at the national level – the Senior Citizen Council of Thailand. Nearly all the villages in Thailand have established an OPA and operate at sub-district, district and provincial level as well. Their purpose is to build mutual support and encourage the well-being of older people in the communities, including activities that promote health, social interaction, and economic support. Not all OPAs are active at village level, and their activities vary depending on the commitment of its membership.

From the experience of the project partners, OPAs in general are not interested in supporting older people affected by HIV/AIDS because they are not aware of needs of this target group. The project partners have found, however, that OPAs can be an effective means of mobilising the older population to provide services directly to older people affected by HIV/AIDS.

## Individuals

The research identified several individuals offering services to the communities in the form of financial support. The individuals are principally foreigners who have been able to raise funds from their contacts in their home countries. Typically, the funding was used to support children's educational scholarships, but there are many cases of direct support for families affected by HIV/AIDS as well. The funds that are raised are usually channelled through village committees, and in many cases directly to those affected and infected by the virus. The community leaders pointed out that support from individuals was typically an informal process where support was offered to a small group of families who came in contact with the individual. In addition, funding could run out at anytime depending on the interest generated and funding secured for specific families by the individuals.

One reason is that there is a general lack of knowledge and skills for working with older people among the service providers.

Another important group of individuals who are providing support are relatives and neighbours. The interviews with affected older people reveal that many older people rely on relatives and neighbours to help them to provide financial support and care for adult children and grandchildren. Further research needs to be conducted to see how prevalent this practice is in reducing the burden of older people. Given the importance of family and community in Thai society, it is likely that relatives and neighbours are a key resource for older people in sharing the workload.

### **Few HIV/AIDS interventions target older people**

Aside from the projects that HelpAge International is implementing in partnership with local NGOs as described above, there are very few agencies that target older people in their activities and many only reach the older generation on a peripheral level. For the most part the problems and concerns that the older people are facing in their lives are not being identified and not met through most HIV/AIDS intervention efforts. Government agencies are actively promoting healthcare, prevention and education, and offering general services to older people but these are not related specifically to the impact of AIDS. This includes the 300 baht cash subsistence allowance as part of the programme for poor, older people in general. Some older people affected by HIV/AIDS may receive this allowance because they are also poor. There is the example of one PLWA Group, the Amphan Group, which holds workshops and training directly for older people in caring for their adult children and grandchildren. There is also the example of one NGO, Rak Thai Foundation, which includes older people in its programme to educate family members in caring for PLWAs. Lastly, the TCA community-based organisation in Sankampaeng District provides training and income opportunities for older people. There are several explanations for why more is not being done to meet the needs of the older generation.

### **Service providers lack skills and knowledge on older people**

One reason is that there is a general lack of knowledge and skills for working with older people among the service providers. They are comfortable in working with adults and children because they are familiar with preparing and implementing activities for these age groups. Another reason for not targeting older people is because many service providers feel that they are already part of the family structure and many believe that targeted efforts are therefore not necessary. Finally, there is a perception among service providers that older people are unable to contribute much to the fight against HIV/AIDS because they are feeble, both physically and mentally, and thus there is no need to make support services available to them or ask them to be a part of providing services.

*“It is more difficult to work with older people than with children in terms of conducting activities. Children seem to have more needs in their lives than older people. Even though we have some assistance come in, it is not enough. That is why we have to focus on the children more than older people. Sometimes the activities are too difficult for older people to join, and when there is an activity in another location, it is too difficult for them to travel.”*

AIDS community leader

*“The reason that we don’t work with older people is because older people are too old and their brains are not able to receive the information we give them.”*

Leader of the district

The experience of HelpAge International’s partners who are working with older people is quite different from that expressed above. Their experience shows that older people are able to make valuable contributions to their communities, especially in implementing the HIV/AIDS intervention programmes. In one project in Sansai District, Clear Sky Project was able to support a group of older people as volunteers, who then successfully engaged in providing mutual support and informal counselling to those affected by HIV/AIDS.

### **Lack of data obscures the impact of HIV/AIDS on older people**

Assumptions by policymakers concerning older people’s limited role in relation to dealing with HIV/AIDS has resulted in a lack of data on the impact of HIV/AIDS on older people. Most HIV/AIDS intervention programmes and policies base their strategic workplans on data from national and international statistics. These statistics do not include data on older people and are externally designed, so programmes and policies are formulated without taking into account the affect of HIV/AIDS on older people, and few HIV/AIDS intervention resources are allocated to the older generation.

One interesting aspect of many of the programmes dealing with the epidemic, is the recognition by the service providers that affected older people are facing extreme hardship. Those involved at the community level have seen first hand the difficulties and burdens that older people are experiencing, and yet few have made adjustments to include older people in their planning and programming. The service providers cite their inexperience with older people, lack of available funding and exclusion of older people within the national policy framework as the main reasons for not designing programs that target older people affected by HIV/AIDS.

Another consequence of having insufficient data is that the services currently being offered might not be meeting the needs that are most important to the older generation. The survey and interviews reveal that the main concern of older people affected by HIV/AIDS is income for basic needs and for education of their grandchildren. A review of the services provided in the communities showed that there were no HIV/AIDS agencies providing financial support for the older generation apart from the work being done by HelpAge International’s partners and the Provincial Social Development and Human Security Office. This is a specific example of how agencies providing services to the communities need to better understand the needs of the older generation, and adopt policies and programmes that address these.

*“There is no one who comes to help us these days.”*

Male carer, 75 years old

The survey and interviews reveal that the main concern of older people affected by HIV/AIDS is income for basic needs and for education of their grandchildren.

From the survey, it is apparent that older people are highly involved in caring for people living with AIDS, grandchildren, or both, and are also busy earning a livelihood and meeting their own needs.

## 7. CONCLUSION AND RECOMMENDATIONS

From the survey, it is apparent that older people are highly involved in caring for people living with AIDS, grandchildren, or both, and are also busy earning a livelihood and meeting their own needs. Older people in Thailand are already in a position of vulnerability because of the lack of social services available to them. Most of the older people look to their offspring as the source of support in their old age. Infection among family members has given them new responsibilities and placed them in an even more precarious situation.

It is also evident from the data, that the majority of the households affected by HIV/AIDS are marginalised and living in poverty. In cases where there are more healthy adult children in the household the household is less likely to be facing extreme poverty. The households where the older person is the sole provider and guardian require the most assistance from relatives, neighbours, and community-based organisations. The health of the older person is also a significant factor affecting their ability to undertake their responsibilities. Many expressed their inability to find money for their grandchildren, and most also expressed that they were exhausted from their work. Their role as guardian was one that provided encouragement and a purpose for their lives; however, it also led to frustration in many cases when the grandchildren did not listen or obey their requests.

Children in AIDS affected households share similar concerns as their grandparents about finances, their education, and the uncertainty of what will happen in the future. In general, most expressed that they wanted to live with their grandparents because of the nurturing and love they receive. Some expressed a need to be able to talk to others about their grief and about their situation in general, and they found this forum to be helpful in that regard. Others were unable to express their feelings or talk about their situation, showing that they have emotional and psychological needs that are not being addressed. The stigma of having HIV/AIDS in their communities was evident, with many expressing social isolation and teasing by their classmates.

The organisations working in the communities are providing a constructive service to those affected by HIV/AIDS. The research shows that there are many different types of agencies working in the communities, both public and private. Only in a few instances, however, are those services targeted at older people affected by HIV/AIDS. If it were not for the programmes being implemented by HelpAge International and its partners, then the needs of older person in the three districts would largely go unnoticed. One benefit from the projects is that communities are paying more attention to the issues of older people. There are also improvements in the skills and knowledge in terms of hygiene and childcare practices, there is more data and knowledge on the needs of older people, and more local resources are being mobilised to support older people.

Community members and workers involved in HIV/AIDS intervention programmes are aware of the multiple stresses that older people are faced with in tackling the problems associated with HIV/AIDS. Most of the older people are doing all they can to support their households. The PLWAs and the grandchildren have experienced first-hand the nurture, love and care that older people are capable of

providing. The agencies that are working with older people in their project activities have seen the benefits of involving older people. The community leaders also view older people as a potential resource, and are seeking ways to help organise them and link more programmes to meet the needs of this group. In the three districts, the community leaders had positive feedback on the programmes that HelpAge International and its partners were providing to older people. As more knowledge of the achievements of the projects directed at older people are disseminated among the larger HIV/AIDS community, it is hoped that more agencies will include older people as a target group for receiving services and for rendering services in their communities.

One can see from the research done in the three districts that older people are highly involved in supporting their households. They are a key resource in enabling their households to function after a member of their households has contracted HIV/AIDS. They have proven to be a very valuable resource in caring for family members infected with the virus, in fulfilling the role of parent and nurturer for grandchildren affected by this illness, and in educating community members and mentoring the youth. Since they are so instrumental in these roles, more needs to be done to make them the target of HIV/AIDS programmes in their communities. In most communities affected by HIV/AIDS in Thailand, they remain an untapped resource for responding to the crisis and for improving socio-economic conditions.

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### **Improving the lives of older people affected by AIDS: Recommendations for action**

As this report has shown, HIV/AIDS in Thailand has affected older people in a variety of ways and has altered their lifestyle considerably. Few programme interventions by the public and private AIDS organisations target older people as the beneficiaries of support or as a potential resource in the fight against AIDS. More needs to be done to involve older people in the HIV/AIDS intervention programmes.

- **Older people must be targeted with information on HIV/AIDS.** Older people associations (OPAs) can be organised to provide the psychosocial support for their emotional well-being, and to provide training sessions to increase their knowledge of HIV/AIDS, healthcare for themselves, home-based care for PLWA and child development and protection. Public education and media campaigns must include and target messages at older people so that they are fully informed about the disease and can serve as educators in their communities.
- **Providing direct income support.** Support can be channelled through the TAO to those affected older people in poverty situations and who require basic needs, such as housing, food, clothing and medicine. The TAO should especially target households where the older person is the sole provider and guardian. In addition older people's associations could establish income-generating activities managed by older people to complement their capacity to make a living.
- **Training public health care workers to educate and engage older people.** Health care workers should receive training to work with older people and transfer their knowledge of what traditional medicine is useful in treating the symptoms of HIV/AIDS and also what anti-retroviral drugs can be purchased commercially to help treat those infected.

- **Capacity building community leaders.** Workshops can be conducted for community leaders on community development with a focus on project management, community mobilisation and planning. Leaders can also be encouraged to be a source of information on available services and resources for older people, and disseminating this information through the TCA.
- **Training community members.** A group of volunteer community workers can be organised and trained to assist older people in caring for their patients, providing the older person with time to rest, emotional support as well as time to interact socially with others in the community.
- **Training for non-government organisations.** A transfer of knowledge, experiences and methods for working with older people affected by HIV/AIDS to the larger HIV/AIDS community can be accomplished through seminars and workshops and will result in more local sustainable project activities through the inclusion of older people.
- **Tackling stigma and discrimination and strengthening social networks.** Continued efforts are needed to take forward progress so far on raising awareness in communities and breaking down stigma and discrimination. People living with and affected by AIDS must be actively encouraged to participate in community groups and social networks of support strengthened.
- **Creating scholarship funds.** Funding can be raised for the grandchildren affected by HIV/AIDS so that they can cover school related costs in order to progress through the education system and gain skills and knowledge to protect themselves and earn a living as adults.
- **Promoting intergenerational relationships.** More activities can be implemented to ensure that there are positive relationships and understanding between older people and their grandchildren. For example, intergenerational events where older people and children in their care can express their feelings in order to improve communication.
- **Collect age disaggregated data on HIV/AIDS.** Data on HIV infection rates and AIDS cases and on carers of people living with AIDS and orphaned grandchildren must be disaggregated by age and gender in order for older people to become a target of policy interventions and programme funding.
- **Older people should be consulted.** Whenever government institutions and other agencies are discussing policy issues and strategy related to HIV/AIDS, leaders from the older people associations should be consulted in order to present their positions and ensure that they are included in development plans and intervention programmes.
- **Older people can play an important social role.** Older people can mentor others and prevent risky behaviour among their peers and the younger generation, especially among their own grandchildren. They can also participate in community groups to build and strengthen social networks for those affected by HIV/AIDS and to prevent unnecessary stigma and discrimination from occurring.

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