#### **CHAPTER 2**

#### **PROJECT DESCRIPTION**

#### 2.1 **Problem statement**

The Pearl S. Buck International: PSBI at Chonburi is an NGO working to improve the quality of life in PLWHs, PLWAs, and children affected from HIV/AIDS, and their families. The main strategy of the organization is strengthening capacities of the clients including support to PLWHs, through self help groups in the four districts with the highest density of AIDS cases. Home based care is one of the approaches that the organization uses to respond to the needs of PLWAs. In 2000, PSBI nurses and community health workers carried out home based care activities for 68 patients, during their 384 visits.

The main obstacles in home based care services are the high numbers of PLWAs and the distance to PLWAs' home in the four districts. Thus, to reach out from the central office in Muangchonburi to each of the PLWAs is not cost effective and not efficient. In addition, the number of staff is too limited to cover all PLWAs. Moreover, professional staff cannot address all needs of PLWAs.

Focus group discussions were arranged in February 2001 to assess the actual needs of PLWAs. It was found that while the majority of PLWAs at home need mainly primary care physically and mentally such as giving medication, peer support, and personal help such as bathing, toileting, feeding, meal preparation, household chores, and simple medical care, professional staff tends to provide

mainly physical nursing care such as health check up, wound dressing, providing medication, and to some extend mental support. Other care and personal help, which are time consuming tasks for professional staff, were left out to be duties of families who were not well prepared.

In early 2001, there was a policy change and strategies within the organization, both worldwide and nationwide. One of these new strategies was the shift from direct services to indirect services, aiming at increased cost effectiveness and sustainability of the program. This change had led to the consideration of a new approach, which aimed to fulfill the needs of the PLWAs and fitted with the organization's direction. Currently, PSBI has been strengthening the formation of PLWH groups in Muangchonburi, Sriracha, Banglamoong and Sathahip districts. The groups provide peer counseling and peer psychosocial support to PLWHAs in their area. A meeting with the four self-help groups was arranged to discuss the problems and the plan of action to respond to the problems. In conclusion, a project on enhancing capacities of PLWH volunteers in providing home based care to PLWAs was proposed. The PLWH volunteers recruited from four self-help groups were trained in implementing home based care in the four districts. The project consisted of two phases. The first phase focused on training to build capacity among PLWH volunteers to provide home care while in the second phase, PLWH volunteers focus on building ability among family members to provide care to PLWAs.

## 2.2 Rationale

As the number of people infected with HIV rises, the number of people developing the disease will also rise which mean that more PLWAs will need someone to care for them during their illness (Songwathana et al., 1998). Over the years, the number of PLWAs requiring care have multiplied rapidly (Piot, 1997). According to the Thai Red Cross (1995), PLWAs do not require staying in the hospital at all time. If all PLWAs were required to stay in the hospital, the number of hospital-beds in the whole country would not be adequate, therefore home based care is an appropriate alternative. Beside that, the expenses for hospitalization of PLWAs could be a burden especially for low-income families. Home based care proved to be on average five times less expensive than hospital care (Kitheka, 1999). The WHO (1999) found that almost 90% of patients preferred home care to hospital care. In addition, Piot (1997) provided more support by stating that whether home care is highly cost effective or not, it is a way to ensure that the person maintains a better societal interface, families are more able to carry out other duties easily, and the most important is that sick people are comforted by being in their homes and communities with family and friends around.

In the early years of the epidemic, fear, hatred, and prejudice became AIDS victims' ferocious enemies along with their own bodies (Burke, 1999). HIV/AIDS had imposed a legacy of ignorance, shame, and stigma (Public Media Center as cited in Beaudin, 1996; and Ganesh, 1999). PLWHAs were generally regarded as social misfits. They were stigmatized because of the misperception that AIDS is a disease of promiscuity, the disease of high-risk groups, and a terminal disease (Songwathana and Manderson, 1998). Additionally, there are numerous misunderstandings on transmission such as AIDS can be transmitted through social contact like touching

6

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patient's body or patient's belongings, sharing food or eating utensils, using a common toilet, or from a cough or sneeze (Ungphakorn & Sittitrai, 1994 as cited in Songwathana, 1998; Songwathana, 1998). This results in unreasonable phobia of contagion.

In the present day, no PLWHAs are free from discrimination. The impact of AIDS includes stigmatization such as negative attitude toward PLWA, discrimination by family members, and negligence (Fischer, 1994). Some family members discriminate PLWAs because they believe that they could be "contaminated" with AIDS as a result of proximity and social exchange (Khadka, 1999; and Songwathana, 1998) and this resulted in the denial of providing care and supporting to the PLWAs. If the PLWAs receive appropriate care and treatment, their lives could be prolonged and they can live more happily in the last period of their lives (Beaudin, 1997). Family members, therefore, should be knowledgeable on how to provide care for PLWAs as well as to be corrected on misconceptions and misperceptions in order to remove the stigma and unreasonable fear of PLWAs (Songwathana, 1998; Burke, 1999).

In normal practice, there are different ways in providing home based care for PLWAs. The PSBI, Chonburi has been providing home based care by using nurses and community health workers to reach out to PLWAs houses in the four districts. The PSBI project is not cost effective, does not address to major needs of PLWAs, and is not sustainable. Therefore, there is a need for an approach, which responds to the needs of the PLWAs and is more appropriate in terms of cost effectiveness and sustainability.

In Chiangmai province, the Northern Thailand, the Home Care Project of the Rejoice Charity offers full medical treatment at the PLWA's own homes and provides PLWAs and family members with basic medical training to enable them to care for themselves and the PLWAs. The advantages of the project are, besides providing medical information to the home based caregivers; it is an important step towards reducing the stigma and isolation of PLWAs from their families and communities. This results in the provision of care to the PLWAs by their family members.

Sanpatong Family Care Project is another project implemented in Chiangmai to help caring for PLWHAs at home by family members. The project's efficiency appears to be relatively high, by providing education and skill training for family members in the assumption that primary health care can indeed be provided at home by family members and through self-care (UNAIDS, 2000). Through this project, care provided by family members is proved to be an appropriate model for home based care for PLWHAs in the Thai society.

The importance of involving PLWHA for the effective responses to the complex challenges of the HIV/AIDS epidemic has been recognized and supported by the Paris AIDS Summit (1994) and all international conferences on HIV/AIDS (UNDP). The UNAIDS provided support to "The Greater Involvement of People Living with HIV/AIDS" (GIPA) by opening the possibility of involving PLWHA in policy and decision making, and target action against the epidemic including provision of care and peer counseling. Furthermore, the WHO has recommended to

8

include family, friends, neighbors, trained volunteers and others to provide home care and community care for PLWAs. The UNAIDS also reported that action initiated by persons infected or affected by HIV has always played a major role in the response to AIDS. Further more capacity building of the resources and ensuring sustainability of the project is recommended.

It has been recognized worldwide that PLWHA are able to understand and accept other PLWHA better than non-infected persons. This has been proved by the appropriateness of using the buddy system as the model of care for PLWAs (Motsepe and Perry, 2000). The model is designed to provide a care, referral, and a support system for PLWAs and their families as the families always face the crisis of managing terminally and critically ill people without the skills and resources required.

The UNAIDS (1999; 2000) reported on key elements of home care projects that involve HIV positive people and PLWH self help groups as implementors. The strength of such projects is that projects achieve a high degree of continuity in services. Essential for this approach is that projects have an efficient strategy using two levels of training activities including a formal, resource-intensive training to PLWH volunteers and a less formal training of PLWAs and affected persons.

Hansen, Woelk and Jackson (1998) reported that community members, if receiving appropriate training, should be able to undertake the bulk of care and support to PLWAs at home. The care provision by the community would be more affordable, sustainable and with expanded coverage. Teerakanok (1999) offered further evidence that community based care could be effectively carried out with encouragement for PLWH group network. The strategy showed greater ability to gaining strength in their own group to give support to one another. Khatoon (1999) had a successful pilot project that has been replicated to 10 more groups. The project involved PLWH women into community care for PLWAs. The project that involves PLWH for provision of care to other PLWAs does not benefit only to the PLWAs but also the PLWH volunteers themselves from their knowledge, attitude, and skills that they are able to take care of themselves and their families.

#### 2.3 Conceptual Framework

The conceptual framework used in this project is derived from the Orem's Self-Care Deficit Theory (Orem, 1991 as cited in George, 1995). In this model, self-care is the practice of activities that individuals initiate and perform on their own behalf to maintain life, health and well being. If there is a self-care deficit, it means there is a gap between what the individual can do (self-care agency) and what needs to be done to maintain the optimum functioning (self-care demand). In HIV infected people, care is required when the infected people are incapable of, or limited in the provision of continuous effective self care resulting in self-care deficit. There are five methods of assisting people to deal with self-care deficit (Orem, 1991 as cited in George, 1995)

- 1. Acting for or doing for another
- 2. Guiding and directing
- 3. Providing physical or psychological support

4.Providing and maintaining an environment that supports personal development

5.Teaching

This project is based on the theory and concepts of Orem. After a certain period,

most of the PLWAs become self-care deficit and require compensatory care and support. By applying the concepts, a four-step project was developed (Figure 1):

Step 1: The PLWH volunteers recruited from the four self-help groups are trained on peer counseling and support but not on home care. Even some of them have experienced care for their spouses but the knowledge, attitude and skills (KAS) are identified as deficit. Therefore, they are unable to provide care for PLWAs. With a supportive-educative approach (teaching, guiding and directing), the volunteers will build sufficient KAS to provide care. In the continuation phase, volunteers may come from affected persons or non-HIV infected persons.

<u>Step 2</u>: The PLWAs, who are ill at home, face health deviation and self care deficit. Therefore, the supportive-educative approach (teaching, guiding and directing) is required. It includes partly or complete compensatory care, which the volunteers will be acting for or doing for the PLWAs. The PLWAs will be satisfied if the volunteers provide appropriate care.

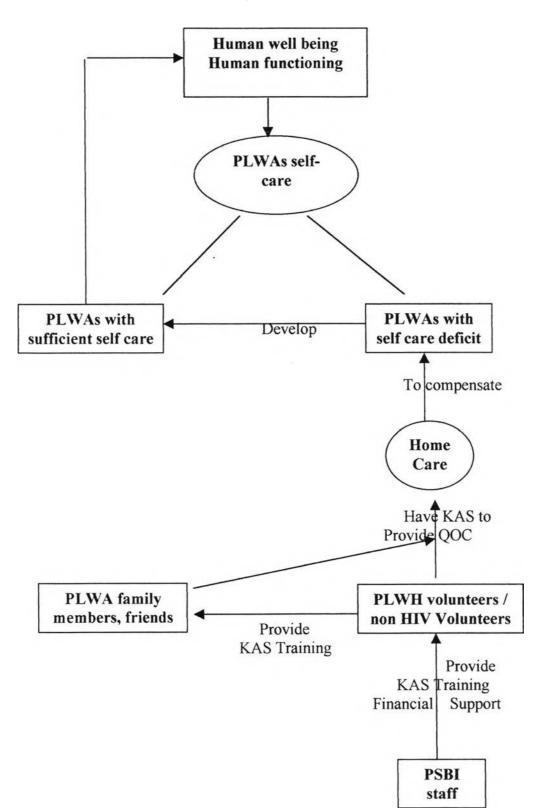
<u>Step 3</u>: The family members or friends or neighbors, who fulfill caregiver roles at home, can be assumed to have a KAS deficit. Therefore, they require a supportive-educative approach (teaching, guiding and directing), which will be provided by PLWH volunteers. Upon receiving appropriate knowledge, skills and attitude, they will be able to provide care to the PLWAs at home.

Step 4: The PLWAs, who after a period of time, remain ill, or have more health deviation and self-care deficit, require partly or complete compensatory care from someone. If the family members or friends or neighbors have KAS and are willing to act for or do for the PLWAs in providing physical or psychosocial support and maintaining an environment that supports personal development, the PLWAs will receive good care. The PLWAs will then live in a supportive environment. During this step, families who do not stigmatize to the PLWAs will be supported and strengthened to be a role model to other families.

All four steps require a supportive-educative approach, which will be provided by using problem-based learning and a partly compensatory approach, which means the provision of compensatory care from volunteers and families after gaining KAS. Therefore, if the project proves to be successful, continuous recruitment of new PLWH and other volunteers should be considered during the continuation phase.

# Figure 1 : Conceptual Model: Self Care Deficit and Provision of Care to PLWAs

(modified from the Self-Care Deficit Theory: Orem 1991, 1995)



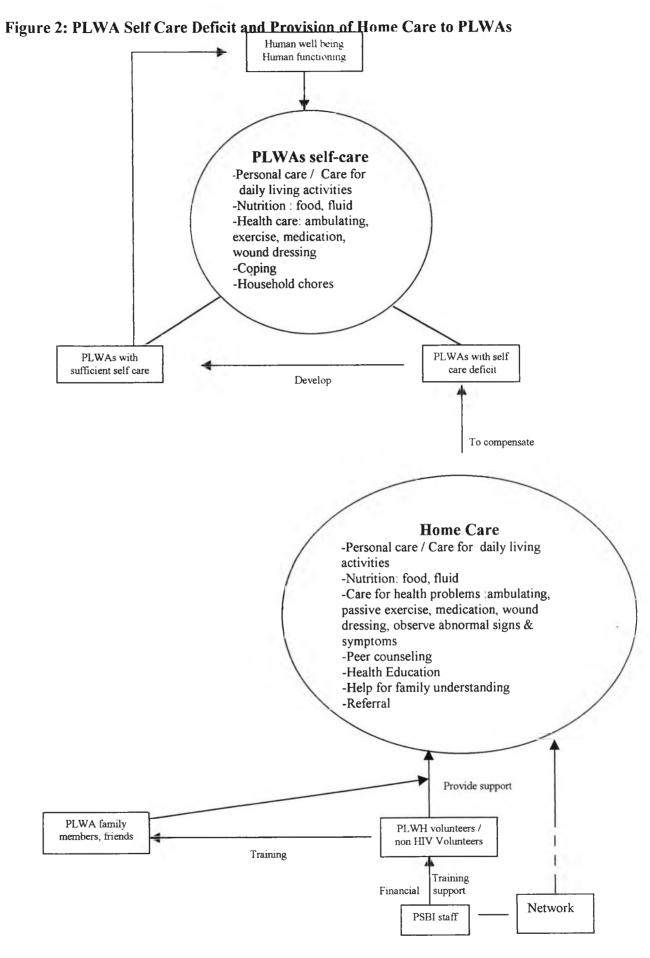
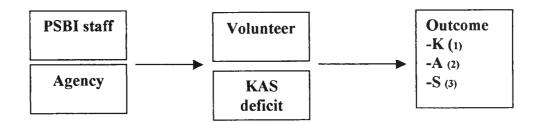
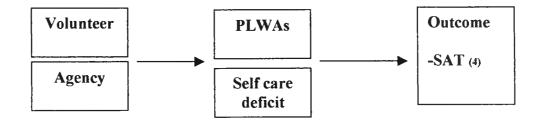


Figure 3: Operational Framework (Modified from Self-Care Deficit Theory, Orem, 1991, 1995)

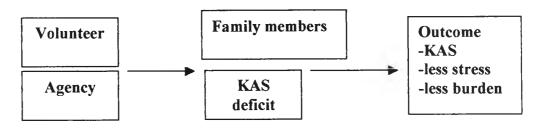
# Step 1: PSBI Provide Training to PLWH volunteers (or volunteers)



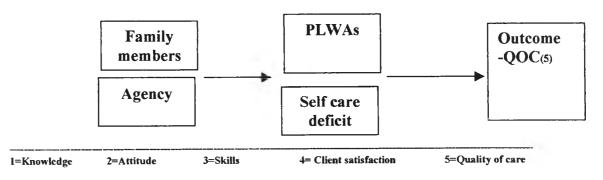
# Step 2: PLWH Volunteers (or volunteers) Provide Home Care to PLWAs



# Step 3: PLWH Volunteers (or volunteers) Provide Training to Family Members and or Friends



# Step 4: Family Members, Friends Provide Care to PLWAs



## 2.4 GOALS AND OBJECTIVES

The ultimate goal of this project is to improve care for PLWAs at home in the four districts of Chonburi Province.

#### 2.4.1. General Objective

To establish family care to PLWAs at home in the four districts of Chonburi province.

#### 2.4.2. Specific Objectives

- To strengthen the capacity of PLWH volunteers in providing care to PLWAs at home. To achieve this objective, the plans were (a) 91%<sup>1</sup> of the target PLWH volunteers' capacities will be strengthened in providing care to PLWAs at home, and (b) 83% of the target PLWH volunteers will provide care on a weekly base to PLWAs at home within eight months.
- To improve the willingness and capacity of family members to provide Home Care. The target was set that seventy percents of the 120 PLWAs will have at least one family member willing and able to provide care to them at home within 10 months in the second phase.
- To provide a support mechanism for families to continue care of PLWAs at home. For this objective, the systems and mechanisms to support for

<sup>&</sup>lt;sup>1</sup> 91% is equivalent to 11 out of 12 volunteers, this was defined based on the previous training arranged in the Counseling program

family members to continue care of PLWAs at home in the target districts will be functioning within 10 months.

# 2.5. Target Groups

The project covered the four districts in Chonburi province named as Muangchonburi, Sriracha, Banglamoong and Sathahip; each district has a PLWH self help group.

The main target groups were:

1). Twelve PLWH Volunteers.

Table 1:	Numbers	of PLWH	Volunteers
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Name of PLWH group	Number of volunteers / Total volunteers
Sai Yai Chonburi	5 / 20
Sriracha Friends	3 / 15
Friends Help Friends Banglamoong	2 / 8
Sathahip Ruam Jai	2 / 5
Total	12 / 48

2) 120 PLWAs in PSBI/support group list for home care.

3) Family members of PLWAs in PSBI /support group list for home care.

# 2.6.Strategy and Approach

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The project was part of a larger PSBI program. PLWH volunteers from the four self help groups within the PSBI program were recruited (selection criteria as described in appendix 3). The project approach was the mobilization of PLWH self help groups and family members. This approach aimed to strengthen the capacity of the PLWH volunteers in order to set up a home based care program for PLWAs and to support family members in coping with home based care needs. In order to ensure credibility of PLWH volunteers, the PLWAs were informed during the monthly group counseling, individual counseling, and telephone calls to introduce the PLWH volunteers. For those who could not be contacted prior to the home visit conducted by volunteers, PSBI staff facilitated to establish the relationship between the PLWAs and the volunteers by accompanying the volunteer during the first home visit.

The two main strategies used in this project were supportive-educative assistance and provision of compensatory care. For supportive-educative assistance, due to the limited educational background of the volunteers, problem-based learning was used as a strategy to facilitate effective learning. The training consisted of practical and theoretical sessions. Firstly, the problems during the practice exposure were brought to the classroom for discussion and demonstration. Then, a series of training (workshops) were arranged according to the problems identified throughout the implementation period.

When the PLWH volunteers were determined to be able to start home care practice, they would provide care to PLWAs at home under supervision. Each volunteer was scheduled for home care to PLWAs in their district, with a minimum of two days per week. Each PLWA received care on a daily, weekly or biweekly basis, depending on the needs identified by the volunteers. In order to expand the coverage of care and increase the sustainability of the program, the family members or friends or neighbors (identified by PLWAs) will be trained at home during the visits and care in the second phase.

Small incentives in cash for lunch and transportation cost were provided to PLWH volunteers throughout the project period. During the training, there was financial support from the Praboromrajchanok Institute and the PSBI. After the training, the PLWH self-help groups with partial financial support from the PSBI, MOPH, and other support from networks continue to run the home based care project. The volunteers were recognized by networks as Home Based Care providers. A life and accident insurance were arranged by the PSBI for all volunteers. Six volunteers were sent to two meetings, a national AIDS conference, and a workshop to increase their dignity and opportunities to share and learn from the others. Further financial support to the project was arranged, with assistance from the PSBI Chonburi Program Manager. PSBI will continue to take an advisory role to the functioning of the project after completion of the training in July, 2002.

#### 2.7. Human Resources

The PSBI professional staff (one nurse and one community health worker) were responsible to prepare the curriculum and training materials as well as to provide training both formal and informal, supervision, and evaluation of progress and performance of the volunteers. The staffs from the hospitals of Banglamoong and Ao Udom provided support with technical assistance in basic nursing, and

medical care, while the academic staffs from the Faculty of Public Health and the Faculty of Nursing, Burapha University provided consultation for the training curriculum, training material development, and the project evaluation.

#### 2.8. Activity Plan and Timetable

#### 2.8.1 Activity Plan:

The project consisted of two phases. Phase I was implemented in the first eight month and phase II continues up to date.

#### Phase I: Strengthening capacities of PLWH Volunteers (8 months)

## Step 1: Preparation (2 months)

• Needs Assessment:

Since the PLWAs, families, volunteers and self-help groups can provide an important insight of how to address problems and how to empower them, they were involved through PLWA focus group discussions and volunteer nominal group discussions.

• Activity plan:

Based on the needs assessment an activity plan was developed with the participation of PLWH self help groups.

• Review the plan:

A consultative meeting with four PLWH self-help groups' committees was organized to share the needs assessment findings, review the plan of action, and agree on collaboration for the project.

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# • Collaboration:

The activity plan was discussed with resource hospitals (referral clinics) as well as the request for collaboration.

• Training material development:

A training curriculum, training materials and the measuring instruments such as prepost test and a skill checklist were developed in consultation with the local hospitals and Burapha University. The referral networks (health centers, hospitals) were informed on Home Based Care services by volunteers and procedures for referral discussed.

# Step 2: Implementation (6 months)

• Pretest:

A pretest was conducted as baseline information before training was provided.

• Training:

The training consisted of two parts (theoretical and practical) with the aim to improve knowledge, attitude, and skills (KAS) of the volunteers as follow: (a) a theoretical part using problem-based learning was employed and arranged in eight training sessions. The KAS curriculum based on provision of care components and the knowledge supporting the provision of care such as :

# 1.Physical care

- 1.1. Personal care
  - Bathing, personal hygiene care and skin care
  - Toileting
  - Body fluid disposal

# 1.2. Nutrition

- Food for PLWHAs
- Meal preparation and feeding
- Oral rehydration
- 1.3. Health problems and health cares
  - Basic information on HIV/AIDS, and care for

**Opportunistic infections** 

- Ambulating help, passive exercise
- Medication: preparation, ensuring taking medication, simple medication for palliative care
- Dressing: simple wound dressing
- Tepid sponge for fever
- Observation for signs and symptoms requiring referral for medical care including assisting in referral process
- Health education and teaching technique
- Terminal care
- Alternative cares such meditation, traditional medicine

# 2. Emotional support

- Communication with PLWAs and family members
- Peer counseling and support including coping with stress and anxiety, disease progression, stigmatization and dying
- 3. Social support

- Increase understanding between PLWA and families
- Correct misperception and misunderstanding that lead to stigma, discrimination and fear of PLWAs
- Refer to medical and social welfare resources

# 4. Household chores:

- Light housekeeping work such as bed making, and sweeping

The training curriculum for the eight days training was based on the prioritized problems and needs identified by PLWH volunteers. The less priority topics were discussed during the monthly meeting or during supervision of skill practice.

## (b) The practical part was arranged as follow:

1. Home visit:

During the first two months, volunteers visited PLWAs at home to learn about PLWAs and families' needs. The volunteers performed home visit two days per week. In order to gain more confidence dealing with PLWAs and families and to facilitate learning, six teams consisted of two volunteers each.

2. Home Care:

After the completion of the training sessions, the volunteers received a home care bag and schedule to practice actual home care for a minimum of two days per week. Two volunteers continued to work in small teams. Each volunteer was individually observed and supervised for a minimum of two times in each month (25 percent) by the two professional staffs from the PSBI. Their skill performances were recorded in the checklist form as a part of the evaluation.

• Meeting:

A monthly meeting was arranged after the completion of the theoretical part. The purpose of these meeting was to provide opportunities to discuss activity reports and plans including identification of problems in each district, case discussions and refresher training.

• Referral:

A referral system was discussed with resource hospitals including referral guidelines. Copies of referral forms are to be used for feedback for volunteers in the monthly meeting during the second phase.

• Post-test:

After completion of the training the knowledge and attitude posttest was conducted. A home care certificate was provided to PLWH volunteers who past the competency post-test.

#### **Step 3: Evaluation**

A training evaluation was done after completion of the training (phase I). The volunteers were evaluated from two perspectives: (a) the supervisor (PSBI staff) and (b) the clients (PLWAs). Indicators for evaluation are detailed in the evaluation part (Chapter 3).

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#### Phase II: Initiation and provision of support in care by families (10 months):

This phase commenced after the completion of phase I and is currently ongoing. There are two steps in the implementation:

### Steps 1: Empowerment of families:

Each volunteer provides individual informal training at home to PLWA family members during their home care services. In this informal training, the family members learn how to provide care tailored to the needs of PLWAs. The informal training aims to increase the KAS among family members with the expectation that care would be provided to PLWAs if family members (caregivers) have ability to do so. At the same time, the workload of the PLWH volunteers would be reduced. This series of informal training are done during home visits for five consecutive visit days. The family members are encouraged to practice together with the volunteers.

## Step 2: Families provide care:

After the family members have learned and gained more confidence in providing care, the families would carry out continuing care. Home care supplies and other social support is arranged from the PSBI. At this step, the PLWH volunteers take a supportive role to family care by offering a visit to the PLWAs and families on a regular basis and offer peer consultation and peer counseling via telephone or faceto-face counseling in the office and hospital clinics. Trained PLWH volunteers in each district are responsible for the Home Care Project in their districts, and help

26

bridging the gap between the families and the networks in the district / province.

They also facilitate referral of PLWAs to network services as required.

# 2.8.2 Timetable

# Phase I (February 2001-September 2001)

No.	Activities	Dates	Duration (days)	2	3	4	5	6	7	8	9	10
1	Needs assessment	9/2-23/2	10	x								
2	Needs analysis and plan of action	26/2-6/3	7	x	x							
3	Contact self-help groups	16/2,20/4	2	x		x						
4	Contact hospitals and Burapha U.	5-7/3, 23-27/4	8		x	x						
5	Literature review, proposal writing	12/2-11/4	60	x	x	x						
6	Consult experts	18-27/3,	5		x		x					
7	Develop training curriculum, materials	19/4-8/5	20			x	x					
8	Develop instruments	22/4-10/5	20			x	x					
9	Pretest	11/5	1				x					
10	Theoretical training : problem based learning	17/5-29/6	8				x	x				
11	Field Study: home visit	24/5-22/6	6				x	x				
12	Home care practice	2/7-21/9	60				-		x	x	x	
13	Supervision	2/7-21/9	30						x	x	x	
14	Monthly meeting	27/7-21/9	3						x	x	x	+
15	Case discussion	27/7-21/9	3					1	x	x	x	
16	Posttest	24/9	1					+			x	
14	Certification	24/9	1								x	
15	Evaluation	17/9-12/10	15		-						x	x
16	Evaluation report	24/9-26/10	10			-			+		x	x

# Phase II (October 2001 – July 2002)

No.	Activities	Period	Duration (days)	10	11	12	1	2	3	4	5	6	7
1	Provision of care by vvolunteers	1/10/01- 19/7/02	200	х	x	x	х	x	x	x	x	х	x
2	Training of families of PLWAs	3/1- 19/7/02	140				x	x	x	x	x	x	x
3	Volunteers provide supervision and support	7/1- 19/7/02	138				x	x	x	x	x	x	x
4	Monthly meeting PSBI and volunteers	26/10/01 -22/7/02	10	x	x	x	x	x	x	x	x	x	x
5	Meeting with 4 self help groups	22/10/01 -28/6/02	5	x		x		x		x		x	
6	Meeting with networks	29/10/01 -24/6/02	3	x				x				x	
7	Final evaluation	24/6/02- 24/7/02	22									x	x
8	Final report	1/7/02- 31/7/02	15										x

# 2.9. Expected outputs and outcomes:

# Phase I:

- 1. The PLWH volunteers are able to provide home care appropriately.
- 2. The PLWAs are satisfied with the care provided by PLWH volunteers.

# Phase II:

- 1. Network is active in supporting the PLWA care.
- 2. The improvement of quality of care provided by the family members as perceived by the PLWAs.
- 3. PLWH volunteers are able to guide and support families to do home care.

#### 2.10. Assumptions, risks and possible means for resolution

1). Assumption: There is collaboration from the four self-help groups for this project.

**Potential problem**: All self-help groups receive partial financial support from the PSBI, however, the management committees are independent. To create a home based care project run by PLWHs groups is a big issue for them since an increasing number of capable volunteers and further financial, and logistical support are required, self-help groups may not want to have extra burdens in addition to their existing activities.

**Resolution**: The PSBI committed to provide technical, logistical, and financial support in the initial phase and to facilitate the continuation of the program in terms of technical support and fund raising.

**2).** Assumption: The PLWH volunteers are motivated, willing to learn and to provide care and support to PLWAs and their families.

**Potential problem**: The current roles of the PLWH volunteers are providing peer education and peer counseling in clinics. The outreach care to PLWAs at home, which will be between 3- 30 kilometers from their workplace, is a major change. The volunteers might prefer sitting in the office instead of going out. Another uncertainty would be whether volunteers are willing to provide care to terminal stage-symptomatic patients.

**Resolution**: Incentives can boost motivation for starting the project. The PSBI and the MOPH had approved funding support for this project from May

2001 to July 2003. During this period, the volunteers built up their relations and sympathy with PLWAs and their family members. This is a good motive to continue the project afterwards. Besides, the volunteers have had KAS to do self-care and provide care for their own families. The volunteers, who continued to perform home care role, received a life insurance package from PSBI starting July 2001. Another motivation is the recognition as community resource persons from the hospitals and other networks. In case of burnout or facing difficult cases, emotional support and debriefing were provided by the PSBI staff. Another motivation is the PLWH volunteers' opportunities to report and present the home care activity to the MOPH and other NGOs.

**3).** Assumption: The PLWAs and families agree to receive PLWH volunteers' care and support.

**Potential problem**: The PLWAs and families, who need care, request the PSBI nurse and community health workers whom are perceived as professional staff. The change from care provided by health staff to those PLWH volunteers could be perceived by PLWA as unprofessional. Further PLWA may not want to disclose their HIV status for outsiders such as PLWH and other volunteers.

**Resolution:** The problem was resolved by informing PLWAs on the change and the request for permission prior to visits. In addition, PSBI staff accompanied PLWH volunteers in their initial visits to facilitate a positive relationship and trust.

31

**4). Assumption**: There is a commitment from the PSBI in providing financial support to the first phase and the ability to mobilize the MOPH fund and other resources to the second phase of the project.

**Potential problem:** The self-help groups are newly established, and have limited resources. To commence a home care project is costly compared to in-house peer counseling. If there were a lack of financial support throughout the implementation period of the project, the continuation of the project by the self-help group budgets would not be possible.

**Resolution:** The request for financial support had been submitted to the PSBI for the support of the first phase and to the MOPH for the second phase. Both agencies had approved the financial support covering the whole period. Other resources are being mobilized for future continuation of the project.



# 2.11. Project Budget

No.	Budget Category	Phase I	Phase II	Total (Baht)
1	<b>Personnel</b> 1.1 1 Nurse 1.2 1 Community Health worker 1.3 1 Trainers	In kind contribution from PSBI 4,000	In kind contribution from PSBI	In kind and 4,000
2	Equipment and materials for training and providing care			48,000
	<ul><li>2.1 Training materials</li><li>2.2 Lunch, break</li><li>2.3 Home care supplies</li></ul>	5,000 7,000 10,000	In kind from PSBI 6,000 20,000 plus in kind from CDC 3, resource hospitals	
3	Field expenses			49,000
	<ul><li>3.1 Travel cost for training</li><li>3.2 Travel cost for meeting</li><li>3.2 Travel cost for home care</li></ul>	5,000 2,000 10,000 plus vehicle service from resource hospitals	6,000 20,000 plus vehicle service from resource hospitals	
	3.4 Travel cost for supervision	3,000	3,000 plus vehicle service from PSBI	
4	Administration / logistics			12,500
	4.1 Transportation and communication	1,500	3,000	
	<ul><li>4.2 Project documentation</li><li>4.3 Other logistics</li></ul>	3,000 2,000	3,000	
5	Incentives 5.1 Lunch / incentives	5,000	10,000	15,000
6	Monitoring and Evaluation			3,000
	<ul><li>6.1 Mid-term evaluation</li><li>6.2 Final evaluation</li></ul>	1,500	1,500	
7	Other incidental expenses	2,000	5,000	7,000
	Total	57,000	77,500	138,500

#### 2.12. Sustainability

From May 2001-until 2003, there is financial support available for the Home Based Care project from the PSBI and the MOPH. Future financial support is required in order to assist the PLWHs self-help groups to continue the activities after this 18 months project period. The proposals for the MOPH financial support for the period from August 2002-July 2003 have been approved. During the first 3 years of the project implementation, the PSBI Program Manager is responsible to assist in fund raising to support the Home Care project. Funding support will be raised from the MOPH, the Japan Embassy, The Lions Club, the Tambol Authority Organization and other funding agencies including local communities.

Most of the PLWHs volunteers appointed to this project are infected for more than 5 years; it is possible that the volunteers themselves may become symptomatic or ill in the next few years. A replication of training, after completion of the first group would allow more volunteers providing home care. Involvement of noninfected people is considered in order to have more sustainable resources.

Many programs faced difficulties to rely only on unpaid volunteers because poverty does not allow much voluntary work. Therefore, an incentive either in kind or in cash needs to be considered. This project provides cash for lunch and transportation and a life insurance for the volunteers. To make the project more sustainable, there should be community mobilization to assist the PLWH self-help groups in term of finance, affected or non-infected volunteers recruitment, and logistical support. Resource hospitals and network should continue their supportive role to the groups.

As the project is a joint project of the four PLWH self-help groups, in the beginning of the project, the groups require a lot of input from the PSBI. Thus, it is the PSBI's responsibility to take a role in identifying potential volunteers who could be strengthened for leadership. Capacities of the potential volunteers' leaders need to be built on facilitating and monitoring the project and mobilizing resources for support. This is currently integrated into the process by building PLWH networks in Chonburi province.

During the first eight months period, the PSBI took a leading role in monitoring the project. At the same time, potential volunteer leaders were looked for. During the second phase, the potential volunteer leaders will be trained on maintaining and monitoring of the project while the leading role and responsibilities will be gradually handed over to the potential volunteer leaders. It is expected that at the end of the second phase, the volunteer leaders would take up 50% of the responsibilities. After completion of this project, a 10 more months period would be required for the volunteer leaders to take up the total responsibilities while PSBI and networks will provide support for technical advise, referral and fundraising. The diagram for transition of responsibilities to volunteers is illustrated as follow.

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# Figure 4: Diagram illustrated the transition of responsibilities to volunteers.

Phase-1	Phase-2	Post project
8 months	10 months	10 months
PSBI	Volunteer leaders	Volunteer leaders
	PSBI	PSBI/network

# 2.13. Ethical issues

The confidentiality of the PLWAs who request home care services is respected. Therefore, the PLWAs were informed prior to beginning of the services provided by PLWH volunteers. The PLWAs were able to choose whether to allow the PLWH volunteers to provide care. In case that the PLWAs did not agree to receive services from the PLWH volunteers, they would remain to be a member of the groups and continue to receive care from the PSBI.