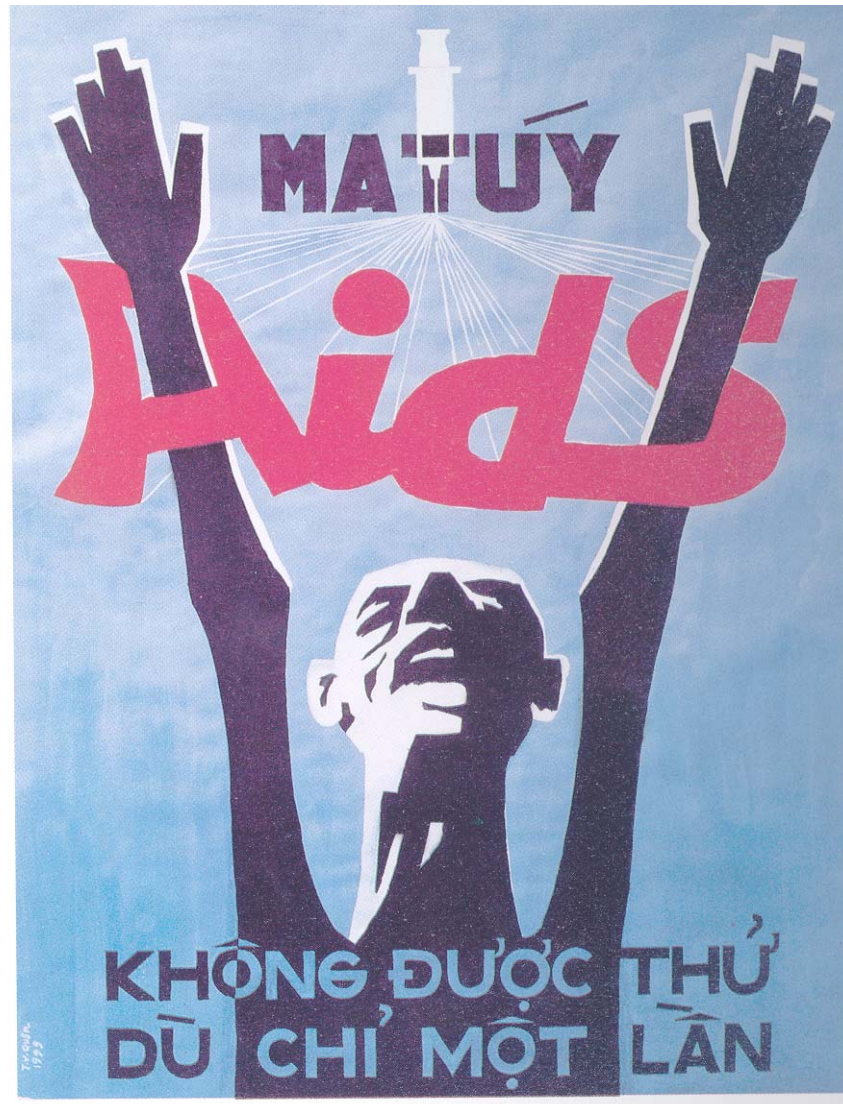


MOVING FORWARD:

OPERATIONALISING GIPA IN VIETNAM



**FINAL STUDY REPORT
OCTOBER 2003**



Table of Contents

EXECUTIVE SUMMARY AND RECOMMENDATIONS	p.3
SECTION 1: STUDY BACKGROUND & METHODOLOGY	p.5
SECTION 2: FINDINGS OF STUDY	p.9
2.5 SUMMARY OF FINDINGS	p.27
SECTION 3: DISCUSSION & STUDY RECOMMENDATIONS	p.28
APPENDIX ONE: POLICY MAKER INTERVIEW GUIDE	
APPENDIX TWO: STUDY PARTICIPANTS	
APPENDIX THREE: PLHA INTERVIEW GUIDE	

List Of Acronyms

GIPA	Greater Involvement of People Living with HIV/AIDS
IEC	Information, Education and Communication
IDU	Injecting Drug Users
MSM	Men who have Sex with Men
PLHA	People Living With HIV/AIDS
STIs	Sexually Transmitted Infections

EXECUTIVE SUMMARY AND RECOMMENDATIONS

- The official government position of support for GIPA was reinforced and supported by the senior policy makers and programmers interviewed. Whilst knowledge of the term "GIPA" was low, particularly amongst professionals outside of the Ministry of Health, the idea of people's participation and the involvement of those infected and affected by HIV/AIDS was more common.
- The perceived rationale for GIPA among policy makers and programmers in Vietnam was varied and included:
 - a reduction in stigma and discrimination associated with HIV/AIDS;
 - increased effectiveness of policy and programs;
 - and improvements in the lives of PLHA.
- The conclusion that can be drawn then in terms of ranking PLHA involvement, is that they are primarily 'target audiences', and occasionally 'contributors' and 'speakers'.
- The results show that stated support for GIPA has not yet been translated into action. Some of the key barriers to operationalising GIPA include the following and are explored fully in Section 2.:
 - lack of capacity among PLHA and service providers;
 - high levels of stigma and discrimination especially related to IDUs;
 - insufficient funds;
 - lack of a legal framework for civil society groups; and
 - high levels of poverty among most PLHA.
- Whilst barriers to implementing GIPA clearly exist, policy makers and programmers believed that a more enabling environment is emerging in Vietnam. One of the frequently mentioned positive factors was the growth of a more democratic and transparent policy making process. Interviewees believed that the Government of Vietnam was creating a more open and participatory system for policy and strategy development that would benefit the HIV/AIDS program and PLHA.
- This study has highlighted that in Vietnam, political will and commitment to GIPA exists among both PLHA and senior policy makers and administrators. The primary means by which the GIPA principle is being operationalized so far is through local level involvement of PLHA and other marginalized groups in specific projects, in ways that enhance their visibility.
- However, in order to move beyond this point, consideration must be given to a range of reinforcing strategies that place GIPA within the wider picture of people's participation. This needs to be done in the context of a socialist-turned-market oriented economy and the changes such transition brings. As such the following recommendations are made to progress GIPA in Vietnam and are explored fully in Section 3.

RECOMMENDATIONS (fully described in SECTION 3)

1. Creation of an enabling environment

- *Reduce stigma and discrimination through the promotion of positive and productive images of PLHA*
- *Increase access to treatment for PLHA*
- *Develop a GIPA Policy, budget and guidelines for all sectors*
- *Mobilise financial support for PLHA participation.*
- *Provide training and support for people working with PLHA*

2. Building capacity and supporting PLHA to be involved in the response

- *Create self-help groups linked to civil society*
- *Build skills*
- *Provide disclosure options in GIPA responses*
- *Co-opt and target well-educated PLHA to participate*

3. Mobilise support

- *Network formation*
- *Clarify government position*
- *Document GIPA Projects in Vietnam*
- *Mobilize donors to support and provide funding for GIPA*
- *Demonstrate value-added of GIPA*

SECTION 1: STUDY BACKGROUND & METHODOLOGY

1.1 The Importance of GIPA in an effective response to the HIV/AIDS epidemic

In December, 1994, the Head of Governments or Representatives of 42 States declared that the principles of greater involvement of people living with or affected by HIV/AIDS (GIPA) were crucial to ethical and effective national responses to the epidemic.

One of the major rationales for GIPA is that it can facilitate a reduction in stigma and discrimination against people living with and affected by HIV and AIDS. Stigma and discrimination not only have powerful negative psychological consequences to HIV/AIDS positive people but they also undermine the progress of the National AIDS program in preventing the spread of the epidemic. For example, if people are uncomfortable discussing the risk of infection with health care providers, due to concerns about discrimination or a lack of confidentiality, they may avoid HIV testing or treatment of symptoms, and may go on to infect others.

For HIV-positive individuals, involvement in the response can lead to overall improvements in their health and quality of life. It can provide greater knowledge of HIV/AIDS, particularly in the areas of treatment and care. Moreover participation can lead to increased feelings of confidence and self-value for PLHA.

Anecdotal evidence has shown that stigma and discrimination against PLHA have been reduced through their visibility and involvement in local, national and international organizations. Their participation in policy design and program implementation has been instrumental in reorienting priorities, ensuring relevance and increasing the effectiveness of interventions.

Nevertheless, the role of GIPA in fighting the AIDS epidemic is far from optimal. In many developing countries, the HIV epidemic is still considered “low level” and restricted to groups who are at high risk, such as injecting drug users, commercial sex workers or men who have sex with men (MSM). Policy makers have often been reluctant to involve such groups in policy dialogue. Despite the global commitment to GIPA principles, the challenge for organizations, governments and networks of PLHA to operationalise these principles has yet to be met. This is acknowledged by UNAIDS:

“GIPA is not reflected in national policies and programs in any concerted or large-scale way, and there is an almost total lack of mechanism permitting or encouraging PLHA’s experience, perceptions or skills to be considered”¹.

1.2 GIPA and Vietnam

1.2.1 HIV/AIDS in Vietnam

Over the last ten years, Vietnam has experienced a rapid increase in the number of new HIV infections. According to the Ministry of Health, 71 530 cases of HIV were detected nationally as at September, 2003². All 61 provinces have reported HIV/AIDS cases. The true number of HIV cases in Vietnam is estimated to be much higher at around 185,000. Similarly, the number of people living with HIV/AIDS was estimated to be 130,000 at the end of 2001. Of these, women comprised 35,000 cases and children 2,500. The number of children estimated to have been orphaned by AIDS is

¹ Van Roey, J, UNAIDS: From Principle to Practice, September, 1999.

² Dr. Trinh Quan Huan. 5th Draft National Strategy on HIV/AIDS Prevention and Control in Vietnam, October, 2003.

22,000³. However, these are thought to be extremely conservative estimates, and a new UNICEF report estimates that 283 000 children are currently infected or affected by HIV/AIDS in Vietnam.⁴

Research has shown that injecting drug users (IDUs) have the highest rate of infection, with information from behavioral surveys indicating that 28% of users share injecting equipment. The prevalence of HIV/AIDS among female sex workers is also rising, with an increase from 0.6% in 1994 to 3.5% in 2000.

1.2.2 The National Response

In June 2000, the Prime Minister of Vietnam issued Decision No 61/2002/QD/TTg that established the Committee for the Prevention of AIDS, Drugs and Social Evils. The Committee has the task of assisting the Prime Minister in directing and coordinating interventions related to HIV/AIDS, drugs and social evils prevention and control. The Ministry of Health takes the overall leadership for implementing the HIV/AIDS National program. To date the national program has focused on the following areas:

- Prevention strategies to promote safe sexual behavior;
- Voluntary testing and counseling;
- Needle exchange integrated with HIV/AIDS Education;
- Sexual health and life skills education for young people;
- Treatment of sexually transmitted diseases (STIs);
- Blood safety;
- A comprehensive approach to HIV/AIDS care and treatment; and
- Greater involvement of People living with HIV/AIDS (GIPA)

Historically, prevention efforts have remained the strong hold of the Government program. However, with increasing numbers of PLHA, the need for care and support services and the involvement of PLHA in the design of such services has become a priority. Currently, the Ministry of Health is developing specific guidelines for the care and support of PLHA.

1.2.3 People Living with HIV/AIDS and their involvement in Vietnam

HIV/AIDS in Vietnam is disproportionately high amongst groups that already suffer from a lack of human rights protection and from discrimination, or that are marginalized by their legal status. Of those infected with HIV in Vietnam, 65% of all reported cases have been acquired through injecting drug use⁵. The vast majority of HIV infected people are men. However, in recent years there has been a steady increase of HIV among female commercial sex workers and an increasing proportion of these are also injecting drugs. This trend is likely to continue.

The Government has a National AIDS Strategy⁶ and among the five specific objectives identified as necessary to provide care and support to PLHA are that:

- 90% of people living with HIV/AIDS are managed, cared and counseled at all levels; and that
- 100% of 05 and 06 centers [drug use and sex work education and rehabilitation centers], cells, and schools for spoiled people should carry out IEC activities on HIV/AIDS prevention.

Included among the identified solutions for achieving these objectives are:

³ Epidemiological Fact Sheets on HIV/AIDS and STI, UNAIDS, UNICEF, WHO, 2002 Update

⁴ UNICEF Statement to Committee of Concerned Partners, Melia Hotel, 17th October, 2003.

⁵ Vu, Trang. Harm Reduction for IDUs in Vietnam: A Situation Assessment, Macfarlane Burnet Centre for Medical Research, Melbourne, 2001 (<http://www.chr.asn.au>)

⁶ UNAIDS Facts about HIV/AIDS In Vietnam Hanoi June 2001.

- strengthen information, education and communication activities [IEC] – including by extending harm reduction interventions especially in high risk behavioral groups, and by combining the AIDS prevention program with the social evil control program; and
- development of models of self-care amongst HIV infected groups. To apply the “Friend help friend’ model among HIV people.

Whilst the Government of Vietnam is committed to UNGASS principles, which include the meaningful participation of PLHA, their involvement to date has been tokenistic. People who are positive are seen as “passive beneficiaries” who receive assistance and who react to government organized events and initiatives. They play no role in program design or policy development.

Stigma associated with PLHA is believed to be extremely high mainly because prevalence is high among sex workers and drug users who are considered to be “social evils” by most people in Vietnam. Whilst little is known about actual discriminatory practice, given the high levels of stigma it is envisaged that “enacted stigma” or discrimination exists particularly at the community level.

Such widespread negative attitudes have been perpetuated through shared social discourse produced and encouraged by the media. Most publicity campaigns throughout Vietnam have emphasized the dangers of HIV and the inevitability of death, which perpetrates fear and anxiety rather than normalization. Campaigns have also focused on the vilification of “core transmitters” such as intravenous drug users (IDU) or sex workers (SW), creating and reinforcing division between “guilty” and “innocent” PLHA. Such campaigns have resulted in people living with or affected by HIV/AIDS facing stigma and discrimination in all spheres of their lives. They find themselves powerless, isolated and marginalized at a time when they are most vulnerable and in desperate need of resources and supports services.

In order for PLHA to be able to live and work with dignity, to erode stigma, to bring a human face to the epidemic and to subsequently facilitate a more effective national response, greater involvement of PLHA is desperately needed in Vietnam.

Anecdotal evidence suggests that so far little has been done to make GIPA reality in Vietnam. To date, there has been no study on the actual impact of the involvement of PLHA, particularly in policy-making and program implementation from either PLHA or policy maker perspectives. With a view to investigating mechanisms to maximize GIPA within HIV/AIDS related policy and program development, Care International conducted applied research to provide:

- an analysis of policy makers and service providers current willingness and capacity to involve PLHA; and
- to make recommendations for programmatic interventions directed at increasing the involvement of PLHAs.

1.3 Study Description and Methodology

The overall objective of the study was to investigate mechanisms to maximize GIPA within the HIV/AIDS policy and program development, implementation and evaluation process in Vietnam.

The specific objectives of the study were:

1. To understand current knowledge and attitude towards greater involvement of PLHA among policy makers and senior programmers; and
2. To provide recommendations to policy makers and programmers to strengthen existing efforts to involve people living with HIV/AIDS in the program development policy making process.

The study was conducted using the following methodology:

- a desk review of Government of Vietnam and UNAIDS reports for monitoring UNGASS was undertaken;
- in-depth interviews with key policy makers and programmers within the National Committee for the Prevention of AIDS, Drugs and Social Evils were conducted; and
- verification with PLHAs of policy maker and programmers' view points and recommendations was undertaken.

Twenty two in-depth interviews were conducted with policy-makers and senior programmers within the Vietnamese Government and administration using a semi-structured guide (Appendix 1). Interviewees were selected based on their responsibility for and experience with HIV/AIDS programming or policymaking, their gender and availability, and are listed in Appendix 2.

One of the limitations with the study sample was the reluctance of the National AIDS Standing Bureau (NASB) to be interviewed. As per the recent promulgation by the Government, the NASB will merge with the AIDS Division of the Ministry of Health. Therefore, HIV/AIDS will become the responsibility of the Preventative Medicine Department. As such, the NASB perceived they no longer had authority to take place in such a study. This is disappointing, given their historical overview of the role of PLWHA in Vietnam.

1.3.5 PLHA group discussions

Information gathered through interviews with senior policy makers and programmers was verified and discussed from the perspective of people living with HIV/AIDS. Two focus group discussions (one male and one female) were conducted in Hanoi, each consisting of 8-10 PLHA. A semi-structured guide was used (Appendix 3) and discussion was tape-recorded. Additionally, PLHA information and experience was also taken from the self-help group meetings convened by the Policy Project, UNAIDS and CARE Vietnam in August 2003.

All data was transcribed and translated. The data was analyzed using the thematic approach, which involves searching for or uncovering the common patterns woven throughout an entire set of data. Themes were identified by general concepts that emerged and which gave the set of data meaning. Thematic analysis is the first step in grasping a sense of the whole, of the regularities and patterns, and this step is essential for the development of a more specific and detailed analysis of the content of the data. The data was manually coded using both English and Vietnamese transcripts against the following themes:

- Commitment and perceived rationale for GIPA in Vietnam;
- Operationalisation of GIPA in Vietnam;
- Barriers to participation;
- Supportive factors for GIPA in Vietnam; and
- Recommendations for advancing GIPA

Findings from the study are reported against these themes and followed by a wider discussion and recommendation chapter.

SECTION 2: FINDINGS OF STUDY

2.1 Commitment to GIPA

The official government position of support for GIPA was reinforced and supported by the senior policy makers and programmers interviewed. Whilst knowledge of the term "GIPA" was low, particularly amongst professionals outside of the Ministry of Health, the idea of people's participation and the involvement of those infected and affected by HIV/AIDS was more common.

"Recently, I worked with the delegation of the Committee of Social Affairs of the National Assembly on the ordinance review. In these discussions, both they and I have a thorough understanding of the need and role of HIV infected people" (Ministry of Health).

The perceived rationale for GIPA among policy makers and programmers in Vietnam was varied and included:

- a reduction in stigma and discrimination associated with HIV/AIDS;
- increased effectiveness of policy and programs;
- and improvements in the lives of PLHA.

2.1.1 Reduction in stigmatization and discrimination of PLHA

There was an overwhelming belief that the involvement of PLHA would bring a human face to the epidemic which would help to erode stigma and discrimination, particularly at the community level. Given the primary mode of transmission is through intravenous drug use, and the National AIDS program is structurally linked to the prevention and control of drug use and prostitution, many people in Vietnam still associate HIV/AIDS with these "social evils" and see sero-positive people as being evil or immoral. Policy makers and programmers believed that the continual visible involvement of PLHA would help people put a name, face and personality to the term "PLHA" which would in turn help to erode their fears, prejudices, and preconceived ideas.

"I think PLHA hide, they must appear in order to receive health services and get counseling. If they continue to hide from everybody, including their family, they can get nothing and it is a problem. They must create a positive living, and understand they have a right to live normally. When PLHA appear on television and in public, it will help the public not to stigmatize and not to discriminate against them and maybe treat them" (Ministry of Health).

"Participation of HIV infected people become more active instead of negative. It makes the society see them with more sympathetic eyes. Instead of seeing these people as social evils, people can see them as patients, be compassionate towards them" (Ministry of Health).

"We must let PLHA to appear many time then people will see that HIV infected people are still normal people. When HIV infected people appear many times people can see that the HIV infected people are normal" (Farmers Union).

However there was an underlying paradox within these discussions. Whilst participation of PLHA was supported in order to increase acceptance of PLHAs and to help instill the idea that everyone is vulnerable to infection, there was also the expectation that PLHA would publicly acknowledge and show remorse for past social evils and work hard to stop others falling prey to similar vices.

The conclusion of these discussions was that PLHA would prove valuable in and had a responsibility for educating others about the dangers of risk behavior and their involvement adds weight to prevention efforts. Therefore, PLHA involvement was perceived as a prevention strategy.

“So the introduction of PLHA is good for the community. I invited a group of volunteers from the city who were infected to perform a program of music and song. Everybody saw them with strange eyes. Maybe this was the first time they had seen HIV infected people. The infected people sang and told the people not to take part in any social evils or things such as they had regretted. They made the community brighter just saying these good sentences” (Farmers Union).

“If the purpose of GIPA is to help people understand more and live out usefully the last period of their life, then I think we should do it” (Ministry of Health).

“What you want PLHA to know is that they must realize their role and responsibility to limit the risk of transmission of HIV from them to other people. It is worth it” (Farmers Union).

In the work of communication about HIV/AIDS prevention, there is no one that could do better than the participation of the HIV/AIDS infected people. If they participate the quality of communication is higher.... In order to advocate for prevention, PLHA can tell their true-life stories, we must encourage them to tell the truth about how they got infected, and this is the best way to communicate with others about it” (Farmers Union).

The involvement of PLHA would also demonstrate their contribution or value to society and in turn generate greater sympathy and support for PLHA. Yet senior officials were also firm in their belief that involvement should enable and encourage PLHA to take greater responsibility for their own lives and enable them to solve their own problems.

2.1.2 Greater program practicality and effectiveness

PLHA participation in programs and the policy making process was thought to make policy and programs more practical, effective and of higher quality. It was believed that PLHA were in the best situation to know their needs and to articulate and provide direction for programs designed for their benefit. There was also a perception that PLHAs were well placed to provide insight and feedback on the actual effect and impact that programs had on their lives and as such, they could play a role in monitoring and evaluation. Policy makers believed that PLHA should provide the evidence on which to base policy and programs thus making the process and outputs far more "scientific".

“Firstly, in order to make PLHA not feel isolated, we should guide them to more activities. The one thing when they take part is that the voice of the infected people and people that are living together with HIV/AIDS are more effective and heavier on the community. It contains elements of education, sympathy and is more persuasive” (Women’s Union).

“It is my idea. The HIV/AIDS infected people could take part in developing legal documents. Yes that is it...And because of that participation, the reliability and effectiveness of the process of implementing this legal document will be better. Because this is the voice of the people speaking out, so it is natural for them. The people developing the document need to be reminded, they need to assess and use this information” (Ministry of Justice).

"I think it (policy with the participation of PLHA) must be effective. Not only policy relating to HIV/AIDS and not only in Vietnam, all countries and systems is built on the base of population. Even you and me we all work from the base. Of course people at the management level have specific observations and have the ability to analyze ideas from the base population, from surveys, interview ideas. They summarize and develop policy and strategies" (Department of Labor Invalids and Social Affairs).

"I think that in order to make it more plentiful and more lively, more scientific, the researchers should invite them to participate. I suggested that this is the best method for researching progress" (Farmers Union).

"They (PLHA) should be allowed to contribute from A to Z, because no one understands themselves as much as they do. Only by that way, can the policy be made accurate and practical" (Ministry of Health).

2.1.3 Improved livelihoods for PLHA

The final reason policy makers and programmers supported GIPA was the perceived benefit it would bring to PLHA. Such benefits include making them happier, confident and feeling valued through their contribution to society. Moreover, any money earned for their participation would enable PLHA to cover some of their living and health costs.

"I believe it (participation) creates confidence in people who are infected by HIV/AIDS. When I meet them I see they have overcome their inferiority complex. they feel still useful for the community. It means that the community helps the infected and the people infected with HIV/AIDS helps the community in preventing HIV/AIDS, they are still useful" (Youth Union).

"Remember the day that we organized the meeting for mothers that have infected children. We also invited some infected women to visit. And they said that they only need to sit together and there were some people who listened to them so they felt releases of the feeling of lost and sharing and the feeling of being isolated" (PLHA).

"If they (PLHA) are participating in the social activities they will have a belief in life and they will feel their lives are useful. They will also positively prevent HIV transmission to other people" (Ministry of Health).

2.2 Current Operationalisation of GIPA In Vietnam

2.2.1 Participation of PLHA at lower levels

Despite strong support for GIPA, it is acknowledged by policy makers and most programmers interviewed that the actual implementation to date of GIPA in Vietnam is limited. Discussions revealed that the first involvement of PLHA in any activities was in 1994, through the Ministry of Education and Training.

This initiative involved using photos of PLHAs to demonstrate the physical effect of HIV/AIDS. PLHA were then utilised as resources for teachers. The perception held by people within the MOET was that during the process PLHA felt very uncomfortable and requested their identities to remain anonymous.

"When they developed AIDS, they let us take photographs in order to make a set of pictures for teaching students to see what the clinical effects of infected with the disease... but at this time they (PLHA) were not very comfortable so we had to hide their faces" (Ministry of Education).

Perhaps the largest GIPA initiative to date has been the development of the Friends-Help-Friends Clubs. These clubs were first established in HCMC in 1996 and are under the support and guidance of the Ho Chi Minh PASB. At the beginning, the club

focused on bringing PLHA together to offer emotional support for one another, and it was then expanded to provide more comprehensive support and services to members of the group and wider community.

"Starting from the year 1995, the group just assisted each other, encouraged each other and shared information and experiences together and worked with the family of the HIV infected people in order to create a harmonious relationships between people infected with HIV/AIDS and their families. This is the starting point. People mainly helped and supported each other. But gradually we improved the good conditions for this group such as giving them the means and opportunity to take part in HIV/AIDS communication and health care education" (HCMC Provincial AIDS Standing Bureau).

"They have to take care of the other infected people, advocate and train, go to meetings and conferences, make report on TV, etc "(PLHA).

According to the PASB, the club has an independent standing and steering committee consisting of PLHA. The clubs also receive financial and technical assistance from the state and both local and international non-government organizations. The Friends-Help-Friends model is being replicated in other urban and rural areas.

"They (PLHA) have their standing on steering committee. There, we (leaders) just guide them about the method only. At present, it (the club) is developing not only in the city but also in each district, even into precincts and communes" (Provincial AIDS Standing Bureau HCMC).

Policy makers and PLHA report that most involvement of PLHA is occurring at the community level with PLHA playing the role of target audience, speakers or implementers. Policy makers and programmers perceive that PLHA have been treated mainly as target audiences whereby they receive information to attend training workshops, primarily about HIV prevention.

"Since 1993, during our program for assisting HIV infected people ... we attracted active and enthusiastic people who created peer support groups. This is the first group in the whole country of the infected people that took part in the work of preventing HIV/AIDS" (PASB HCMC).

"He (PLHA) said and he did. This time he was a hospital orderly helping the more severely infected patients, at another time, he was a nurse helping to do injection in the hospital because there were so many patients.

Then when a patient died so he would become like the person in the church to comfort ... he said he is very willing" (Male PM).

Most policy makers and programmers were also familiar with the concept of PLHA as implementers within health or HIV/AIDS projects. Such roles included peer educators, IEC officers for the general community or workplace, cultural performers or carers for other people living with or affected by HIV/AIDS. PLHA also educate groups about high risk behaviors and about how to minimize the risk and harm associated with these behaviors. Within such projects, policy makers and programmers did not think PLHA were involved in the design or in any decision-making. This perception was verified by PLHA.

"Yes some of our centres have invited the HIV/AIDS people to take part in peer education activities. So, people that are infected with HIV/AIDS are involved in communication activities" (Fatherland Front).

"In fact they only take part in education activities when we invite them. One example is December 1st last year; they took part in what we called an exchange or relations and

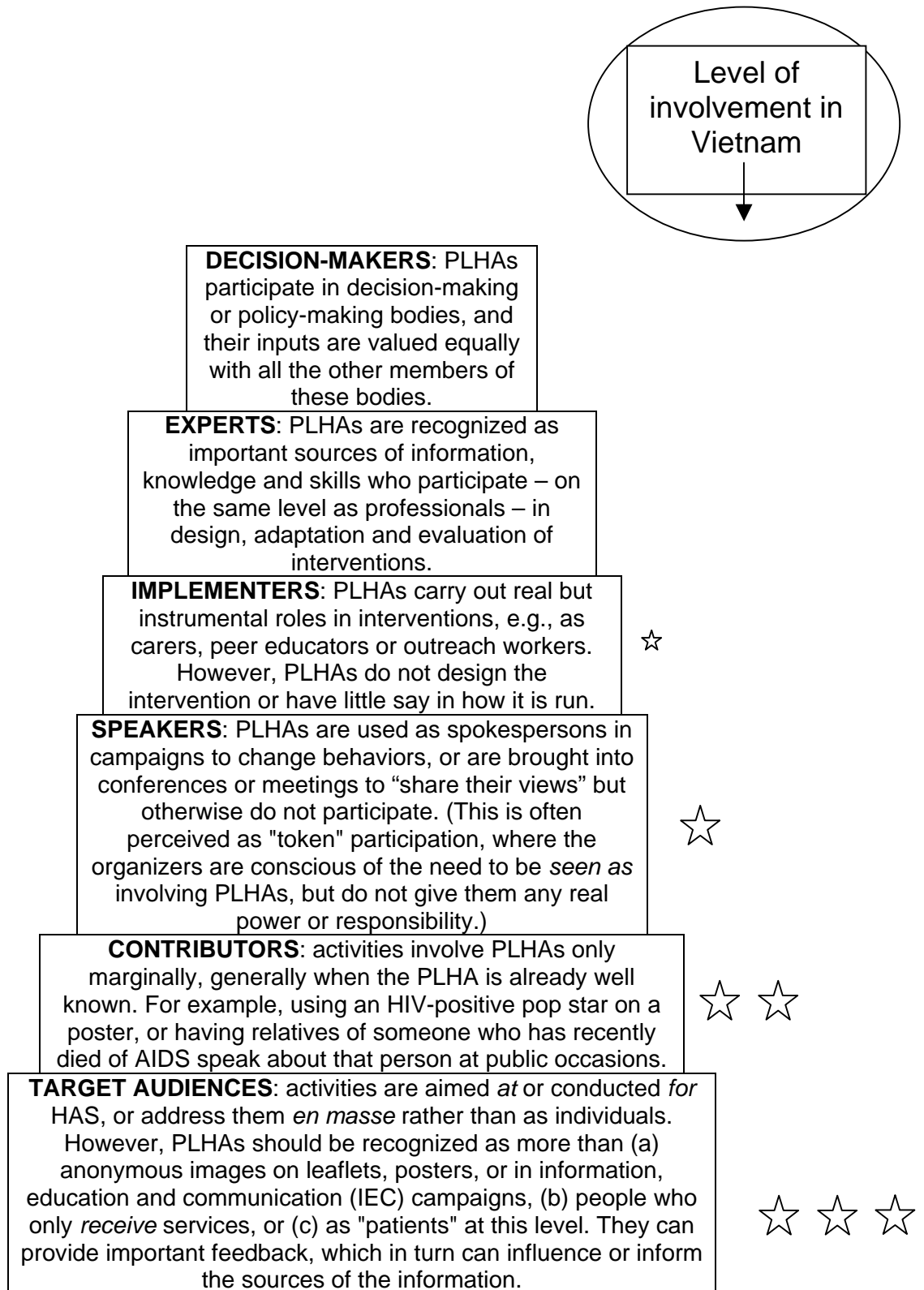
experiences day, not a meeting on the day for preventing and resisting HIV/AIDS. We had five advocacy teams who performed brief plays” (Youth Union).

“They contribute to restrain "social evil" in Vietnam. Their achievement exceeds far beyond the target of HIV/AIDS program. A man working for PASB in Ho Chi Minh City is an example. He joined in training program for the group of IDU. He also share his experience in undergoing detoxification and how to overcome stages of detoxification in order to return to his life” (Ministry of Labor Invalids and Social Affairs).

Participation and involvement of PLHA outside the health and HIV/AIDS sphere was far more limited. Policy makers and programmers believe PLHA find it hard to influence employment, education and even health care options. Work as ‘motorbike washers’ was the only known income generating initiative mentioned.

The conclusion that can be drawn then in terms of ranking PLHA involvement (according to the UNAIDS pyramid of PLHA involvement), is that they are primarily ‘target audiences’, and occasionally ‘contributors’ and ‘speakers’.

A pyramid of possible involvement by PLHAs.⁷



⁷ UNAIDS: From Principle to Practice, op.cit., p.3.

2.2.2 PLHA involvement in policy and decision-making

PLHA participation at levels whereby they are considered either experts or decision-makers was considered very scarce. Whilst policy makers and programmers see a value and need to involve PLHA in the policy making process, little has been achieved on this front other than appearances of PLHA at conferences. The perceived and actual role of PLHA at such forums is to share their views on issues or to encourage others to refrain from engaging in risky behavior.

PLHAs verified that it was very hard for them to participate in policy-making. This was attributed partly due to PLHAs being focused on earning a living and partly because the state does not really facilitate such participation. Only one senior programmer was aware of the room created for a PLHA on the Global Fund Country Coordinating Committee.

"In the work of defining policy, in fact in our state it is very hard for PLHA to take part. They try and live well and do useful things. We will demonstrate this usefulness to the state officers and then they may change their way of looking... but for our country it is hard for them" (Ministry of Education and Training).

"The difficulty is that PLHA are afraid to participate in policy. We are the PLHA representatives at the friends-help-friends club so we collect the ideas of the HIV infected people and then bring them to the annual plan and already it changes (local policy)" (PLHA).

2.2.3 Rewards or supports for PLHA to participate

Many PLHA were considered "volunteers" although some PLHA were provided with payments for their participation. There was no uniformity in the payments, so whilst most received reimbursement for travel expenses, some received a small amount of money for time allocated to the activity. No policy makers, programmers or PLHA reported any capacity building activities to prepare or support PLHA participation.

"In fact we have not learned much about participation, formerly everyone has their own field and lives. We usually participate or work when it is urgent or immediate therefore we normally have to train ourselves. Working and going to any training depends on the project. Sometimes we work continuously for a month and maybe we will be off for a whole week or month. Such participation is due in one part to our low capacity another part is due to the finances. Our expenses for activities are very low, normally they provide travel support and we really do not have any salary" (female PLHA).

"Of course we paid for all, you know, For example some people from X province they came to a meeting, we pay, we cover their transportation and accommodation costs.... The problem is that we can't cover their (PLHA) money, all expenses and in the program they work as volunteers" (Ministry of Health).

2. 3. Barriers To Operationalising Gipa In Vietnam

The results show that stated support for GIPA has not yet been translated into action. Some of the key barriers to operationalising GIPA include:

- lack of capacity among PLHA and service providers;
- high levels of stigma and discrimination especially related to IDUs;
- insufficient funds;
- lack of a legal framework for civil society groups; and
- high levels of poverty among most PLHA.

2. 3.1 Perceived poor capacity of PLHA

Most of the policy makers and programmers interviewed perceived PLHA to have low levels of education, poor public speaking skills, low levels of confidence and pessimistic attitudes. Given these characteristics, senior leaders think that participation in highly specialized tasks such as policy making is beyond most PLHA. Sero-positive IDUs (reformed or active) were considered to have the lowest capacity amongst PLHA. They were considered to have the lowest knowledge and skill level due to the fact that had allowed themselves to become infected with HIV/AIDS.

"If they work at the top policy level, they need high education level. Because they have low education level they can't understand anything, even when you speak about their rights, they don't know, they don't discuss with other people about what they should do or what others like ... If there is a policy and we ask about their agreement, they all agree, never comments, never discuss... they don't have the capacity" (Ministry of Health).

"If we let them (PLHA) propose, it is hard isn't it? Because if we want to propose a policy, at least, we need to have some certain knowledge. So now, if we let them make policy, it is quite putting too much hope on them... In reality, the policy needs people that are specialized in this matter but not mean that every body could make policy. That means they (PLHA) could tell more than others could about what things they know" (Fatherland Front).

"About the matter of building policy, it still relates to many matters... if they take part in this they may contribute to some certain parts and not all of them could take part because in Vietnam their education levels are often not high and their knowledge is low they are HIV/AOIDS infected people but they could tell all the things that policy makes need to collect. So policy makers should base policy on them, watch them and through their activities draw up regulations" (Farmers Union).

Whilst some PLHA 'admitted' their low capacity, some PLHA expressed the view that programmers and policy makers do not know how to attract skilled PLHA nor to provide training and support to increase the existing capacity of PLHA.

"They explained that infected persons do not have the ability to. I think this is wrong; it's only just that they do not know how to attract skilled people, or people with the ability to improve attend training. If they don't use these people how would they know of their capacity?" (PLHA).

The issue of illness and death amongst PLHA in Vietnam was considered a crucial PLHA capacity issue by many interviewees. Anecdotal evidence suggests that given the lack of treatment options combined with low utilization of public health services, PLHA experience high levels of illness and a short life expectancy. This will undermine the involvement of PLHA both now and in the future.

"I always think about the handicap association and what they did, they established a handicap association by themselves. What I really want is to establish our own association, but it requires much time and effort and we are limited by time. Besides the sickness, at the moment we have no medicine, almost 100% of us have no medicine- so we change to the AIDS period quickly at any time"

"Some PLHA students and others with good education levels can manage the program. But of course some of them die of HIV/AIDS, we need to train and train them very much, need to put them in management boards, but in fact most of them work on delivering support for PLHAs". (Ministry of Health).

2.3.2 Poverty and PLHA

PLHA and programmers reported that high levels of poverty among PLHA in Vietnam means that many PLHA focus on obtaining employment and some degree of financial security for their families. Thus they do not have the time or energy to participate in any advocacy initiatives. Moreover, it has been documented that high levels of poverty reduce PLHAs capacity to access care and support services,⁸ which further increases the likelihood of illness and incapacitation.

“The second barrier for participation is the economic condition. .. A person infected with HIV/AIDS - their ability to work and earn income is reduced and then they must spend money for treatment. Their economic condition is weakened. Most of them are like that. There are not many rich PLHA families” (Ministry of Justice).

“Because their economic situation is difficult they just think about supporting their expenses...but whatever you say the matter of living for PLHA is very important. They could participate but there is no mechanisms for them to take part and then the living condition of their wives and children is not guaranteed” (Women’s Union).

“Generally there are many problems for PLHA but mainly how we can increase our knowledge and have a stable income. Stable income is very important because in Vietnam people look at income and highly value the income. A man will be much disregarded and disrespected if he does not go to work and stays at home - no matter how much his family loves him he will be disregarded. If he is disregarded he won’t have self-confidence to do other work” (Male PLHA).

2.3.3 Lack of knowledge and skill amongst policy makers and programmers to apply GIPA

A smaller number of respondents among the policy makers and programmers also acknowledged a lack of knowledge and capacity on their part to meaningfully involve PLHA. This was set against a background whereby many non-health ministries and agencies interviewed expressed an overall need for more guidance, and technical and financial resources to implement the rather "vague" or "general" policies and circulars that are disseminated about HIV/AIDS. There was also a request from senior decision makers within the Ministry of Health to obtain models and lessons learned from other countries implementing GIPA.

“We organized meetings and discussions about HIV/AIDS. But at present there are not much documents about HIV/AIDS and not many officers are that good at talking about HIV/AIDS in the community. And our offices of the Fatherland Front do not have much knowledge about HIV/AIDS so they cannot talk well with the community so, as everyone knows. So we are lacking good advocacy workers that have deep knowledge and good ways to talk with residents, we lack documentation, methods to approach HIV/AIDS people to make them feel confident so that can talk freely and open-minded” (Fatherland Front).

International experience demonstrates that the most important factor for success in the battle against HIV/AIDS is the commitment and involvement of national leaders. Results from this study show that some leaders, especially local leaders, are not aware of the potential benefits of GIPA.

“At the break of the workshop, when people were drinking water, there was only me sitting with the HIV infected people, all our leaders sat to one side (Dept of Labor Invalids and Social Affairs).

⁸ CARE Vietnam, Regional PLHA CARE & Support Study, 2003.

"I organized a conference "finding the solution for supporting PLHA. I invited all local branches and leaders across many sectors to attend. I told them the restaurant will serve food and when they saw the PLHA having lunch the officers ran away" (PLHA).

"Generally speaking our policy makers are not really aware of the seriousness of HIV/AIDS. A lot of them do not show a proper concern about the matter... The Prime Minister, Deputy Minister or the Ministry of Health on their own are aware that if SARS couldn't be stopped, it will spread among community. And HIV/AIDS is even much more hazardous and complicated because of its invisible contagiousness. HIV/AIDS occurs in "underground world" and so smoothly that policy makers, who are committed to many things, are not really aware of HIV/AIDS dangers" (Youth Union).

2.3.4 Stigma & discrimination

A reoccurring theme for both policy makers and PLHA was the reluctance of positive people to participate in any part of the response because of the fear of stigma and discrimination associated with being identified as positive. Given the high degree of stigma that is associated with the primary transmission behaviours in Vietnam, both policy makers and PLHA believed that PLHA did not to publicly participate because others would automatically assume they were IDUs or sexworkers. As such they feared they would face negative repercussions across many spheres of their lives.

"The picture in Vietnam is very hard to transform. Because in Vietnam 80% of people infected with HIV/AIDS are drug addicts so if they see PLHA in the community, they immediately know that the workers of officer is related to drugs or social evils such as commercial sex. It is this view that leads people to think that all HIV infected people are social evils.... This makes PLHA discriminated against" (Women's Union).

In an attempt to maximize their limited resources, many sectors outside of health combine HIV/AIDS work with programs related to the abolition of drug use and sex work. Such a strategy reinforces the link between HIV/AIDS and social evils and perpetuates stigma and discrimination.

"At the central level, people established a committee whose name makes people think that HIV/AIDS is evil. Then on the ground you can see the association between HIV/AIDS and social evil because we write, "Keep away from drugs, prostitution and AIDS" so how can people be compassionate with people with HIV/AIDS? Even at our centre, we put the name of the centre as preventing social evils and HIV/AIDS. People often say we are the centre of social evils. It is very frightening that they never separate these" (Farmers Union).

"Of course we have met many difficulties because of our resources in the field of HIV/AIDS is very thin. So we must combine our HIV/AIDS communication with other communication about prevention of crime, drug use and prostitution" (Fatherland Front).

In many countries, anti-discrimination laws have been key to protecting the rights of PLHA and moving GIPA. However in Vietnam there is a perceived gap between laws and policies and the implementation thereof. Whilst the ordinance stipulates that PLHA are protected against stigma and discrimination, in reality stigma and discrimination against PLHA is still common, not only in the community but also amongst leaders and health providers⁹.

"The policy is not to discriminate. But is that correct? Is there any regulation that defines if the company does not accept the HIV/AIDS infected people should be penalized? No. It is clearly no. The director fires the workers that are infected with

⁹ CARE Vietnam PLHA CARE & support study, op.cit.

HIV. Does the State law regulate that if he intended to fire this person, what is the penalty that he should bear? Hence, they still do that. In the field of medical examination and treatment, the law regulated that the hospital should not refuse, but they still refuse. So, is there any law you have to penalize or criticize the refusing people? No you do not have" (PLHA).

This situation is further compounded by the lack of human rights legislation and knowledge amongst PLHA about how to assert their citizen's or human rights.

"There is a clause like this. The 18th clause of the HIV/AIDS law stipulates that only those who are authorized and responsible can inform the relatives of infected people and the 5th clause stipulates clearly that "only those who are of the district and higher level of official can inform'. The stipulation is so clear, but in fact at lower level the heads of small medical stations inform people and have the right to do this thing and that thing. When I asked them they said they think they are specialized people of the area. Thus I gave up. The second thing is that, the laws and other things have been made but no one implemented them. We do not know who are implementing them. There is no one to help us either, so that when something goes wrong we do not know what organization or agency to go for help to claim back the equality" (PLHA).

2.3.5 Self-stigma

Policy makers and programs perceived self-stigma amongst PLHA to be high which prevented many PLHA from becoming involved. PLHA interviewed did not self-stigmatize but focused on their capacity building needs that, if fulfilled, would facilitate their participation.

I think that the infected people themselves know that are infected and it will lead them to hopelessness and negative attitudes. They feel inferior because they are infected with this disease and are being discriminated against by the society and the community. So they do not want to be open-minded they want to shrink into themselves. And adding to the hopeless mood, with the shame and regret, and so they do not want to be contacted" (Women's Union).

The lack of a critical mass of sero-positive people was considered by PLHA interviewed to be a deterrent to involvement, as it is hard to build up a strong sense of community unity and solidarity amongst a relatively small number of PLHA located in diverse locations throughout Vietnam. Therefore PLHA believed that the establishment of a network would facilitate greater involvement by creating unity and motivation. However it was also recognized that currently in Vietnam there was no legal framework for the development and operation of such a network, which severely hampers the GIPA movement.

"I mean they (the Government) should issue a decision to establish our group, and they should have responsibility to us so we can work more actively, at present we work voluntarily by ourselves in small groups.... The main job is for people like us to go and mobilize all the PLHA throughout Vietnam, thus it is our words, our work that together will have more value and thus our work will be better" (PLHA).

"I think it is good for the PLHA should become closer because they are together at the point like when they are patients infected with the disease. If their lives could become nearer they could help encourage one another in their life so organization or society can see that they are useful for the society... whether they establish an association we must consider whether the association are in accordance with the standards... it must follow the regulations of the state". (Farmers Union)

"If the purpose or aims of a network is to help these people understand more and live their latter years usefully, then I think it is the thing to do. But if we establish a

network that does not act and follow the regulations of society then it must be reconsider" (Ministry of Health)

Moreover, given that so many PLHAs are IDUs, they often detained and placed in the rehabilitation camps. This reduces the number of PLHA available to participate in any response or the wider civic, political or social spheres of life.

"The stage of trying to attract PLHA is the most difficult. Because in the city now if there is any HIV positive person related to drug using, so people in the city catch them".

2.3.6 Insufficient funds

Insufficient funds to mobilize and sustain the involvement of PLHA was also considered a deterrent to the movement. Most policy makers and programmers acknowledged that PLHA were volunteers or received minimal compensation for their contributions. PLHA reported receiving small amounts of money to cover travel requirements. The minimal nature of these contributions was attributed to an overall lack of investment in HIV/AIDS at the central and provincial level. This lack of support combined with high levels of poverty dissuades PLHA from participating.

"Last year, we intend to organize this thing, we have a plan ready to organize and discuss about managing and taking care for HIV/AIDS infected people at the centre, In this schedule and plan we intended to invite PLHA to participate. We wanted them to speak about what they need. But then due to the problem of no money we could not organize" (Department of Labor Invalids and Social Affairs).

"In the district, the fund that they gave us is too small, not enough. If I have a bike then I need to buy petrol but with only 250,000/month this is not enough for the petrol not to mention my daily living expenses" (PLHA).

"For example when I lived in X, an organization implemented some programs or some projects in so many years, then at that time we operated very well. But when the project expired almost all our activities stopped immediately. When we asked about continuing our work they said there was nothing they could do.... In general the budget ran out... there is no other source of funding" (PLHA).

PLHA also reported that did not received adequate training time to equip them to meet the high expectations placed on PLHA - only short training that lasted a few days. This was not considered long enough for them to actually increase their skills and have the capacity required to undertake such activities as peer education. Moreover, they did not have any resources or materials to give to or attract other PLHA that would encourage their participation.

"When I did the training, there were many organizations, many experts, but the training only lasted 2 days so we could not get much knowledge. I received support for traveling but it was not a salary just for petrol and transport" (PLHA).

"...my experience is learning from friends, not from professors or from experts in raining, and from reading guide books and finding out from actual experience" (PLHA).

"The greatest difficulty is when we come to talk with PLHA, we just only talk but we do not have anything for them. We talk for a long time so they get bored.... We should have something that would encourage them even something as small as food" (PLHA).

2.4 Supporting Factors

2.4.1 Improved Governance in Vietnam

Whilst barriers to implementing GIPA clearly exist, policy makers and programmers believed that a more enabling environment is emerging in Vietnam. One of the frequently mentioned positive factors was the growth of a more democratic and transparent policy making process. Interviewees believed that the Government of Vietnam was creating a more open and participatory system for policy and strategy development that would benefit the HIV/AIDS program and PLHA.

"It means everyday policy making is becoming more public and the process improving. This is one of the most favorable conditions for GIPA" (Ministry of Justice).

"General speaking, Vietnam's legal framework is quite remarkable. It can be said that the spirit of policy is quite opened. It has not too much restriction or limitation in any target group in participating in the prevention against HIV/AIDS"(Ministry of Justice).

"In the law, I think that we give the HIV/AIDS infected people many rights...About the rights of taking part in building policy I still do not see. I only know the right as a normal citizen." (PLHA).

"In general, the policy of Vietnam to the HIV/AIDS infected people is very fair. It promotes the liability and duty of the HIV/AIDS infected people that take part in. But in fact, the implementation of this policy at every where anytime is still very limited" (Women's Union).

Experience from countries such as Thailand has demonstrated that the commitment of national leaders is the most important factor for the success in the struggle against HIV/AIDS. Although HIV/AIDS only emerged in Vietnam in the early 1990's, the Government responded very quickly by establishing the National AIDS Council and program. Officials interviewed believed that this strong leadership in relation to HIV/AIDS, combined with the support for GIPA by National assembly members, would facilitate its application. Policy makers and programmers interviewed suggested that the current Ordinance Review should include PLHA as a positive and proactive force rather than as social evils and or victims. Interviewees anticipated that such demonstration of their commitment would be important to generate faith and trust between government and PLHA, which in turn would encourage and motivate other PLHA to become involved.

"I feel fully sympathetic about the role of the HIV infected people. And we will have more proposals in order to amend the Ordinance to emphasize the role of HIV infected people as a member, a positive force in the work of preventing HIV/AIDS not only as a subject to care and cure for" (Ministry of Health).

"I think it is good if the Government or ministries could attract PLHA into works such as defining policy for HIV prevention. And when the government and ministries do this, I believe that HIV/AIDS patients will have more faith and trust and see now the government and the state care so much about the work of prevention of this epidemic and they will then take part actively" (Fatherland Front).

2.4.2 Well-defined systems and structures

Many programmers and policy makers professed that having an organized political and social system and structure that extends from the central to the grass roots level would facilitate the involvement of PLHA. Mass organizations interviewed believed that their 'systems' and organisations could be used to mobilize PLHA, as it had been to successfully achieve reductions in fertility and other health targets. However, from the PLHA perspective the system was deemed heavy and worked against them.

"Many people within the system disclose the status of many people and it flows through the system. Hence it is difficult to think this helps and how the system are of benefit" (PLHA).

"In terms of advantages (to implement GIPA), in the first place Vietnam's legal system is quite remarkable. The legal framework consists of many previous years' circulars and we have strategic organizations and guidelines, which are considerably transparent. Secondly our leaderships is very systematic and we have a system effective enough to implement anything. We do work effectively enough to deploy any program to the community level, which was highlighted in the SARS experience". (Youth Union).

"There are many opinions saying the a favorable factor in Vietnam is the system from central to local level. But I think it is not favorable because a bulky system is certainly not a good system.... (PLHA).

2.4.3 Increased access to information

Both PLHA and officials recognize that having greater access to the Internet and other internal and external sources of information will enable PLHA and officials to understand and collaborate with other GIPA movements and practices taking place globally. Officials were also cognizant that an increased knowledge of the law and human rights among PLHA would legitimize and encourage their participation.

"Compared with other countries in the region, HIV was latecomer to Vietnam. Accordingly, "Vietnam has drawn a lot experience from other countries in HIV/AIDS prevention, which is very important". What is said, is that their disadvantages will turn out to be our advantages "(Ministry of Health).

"For instance, we have the same border with Thailand, in which HIV/AIDS has become contagious and to which a lot of our colleagues have been sent. We do have opportunity to derive their lessons from HIV/AIDS prevention. We make use of their difficulties and we are likely to have other advantage" (Youth Union).

"There are some well-educated PLHA that connect to the Internet, so every week the friend-help-friends club answers the emails. You can also connect to the Internet and there is someone that answers your questions online. PLHA cooperate in this manner and share and work together" (Ministry of Health).

The Vietnamese tradition of altruism was also believed by policy makers and programmers to provide a strong base from which to launch GIPA. This notion of putting others first and helping others was considered a lever to help facilitate GIPA.

"What's more, personally, Vietnam has a tradition of helping each other in difficult situations. It is our tradition... in Vietnam it goes without saying that peoples help each other in difficult situations. Our responsibility of loving and caring for one another is undeniable and an advantage" (Youth Union).

"Vietnam also has another advantage. It is our tradition. Vietnamese have a tradition of "La lanh dum la rach". It means "people help each other in difficult situation". In terms of advantage, the Vietnamese's sentiment of loving and caring for each other is undeniable. For example, people can get on well with an infected person if he or she innocently acquired with HIV, if he or she is not drug users or sex workers or exercise as prostitution (Farmers Union).

"When I visited the Hai Phong Cement Company, I asked them where the HIV infected person is. They answered me that he is working at the part of OTK- checking

the quality of finished product. They are in sympathy with him and they said:” he is innocent, he has a very honest and healthy way of living. But he went to the hospital for injecting, and there he was unlucky to acquire HIV”. That means a man (PLHA) that can get on with and work with them (uninfected people) if they learn that he has a serious life and he lives with conduct” (Fatherland Front).

2.4 Study Participants Recommendations for Implementing GIPA

Due to the association with social evils, PLHA are vilified and experience high levels of stigma and discrimination. This prevents PLHA from participating and integrating into society, which prevents personalization of the risk for non-infected people, and which hampers prevention, care and support efforts. Policy makers, programmers and PLHA interviewed believed that the key to the implementation of GIPA was the erosion of HIV/AIDS related stigma and discrimination.

“We must create agreement and approval at all levels about not considering HIV/AIDS as a social evil and we must reduce and avoid discrimination and stereotyping of PLHA. In general in Vietnam, this comprehension is gradually improving and thus the expression and participation of HIV/AIDS infected people in the activity and community and work is becoming more clear” (Ministry of Health).

Many respondents believed that this could be started with the wide promotion of PLHA as positive, valuable members of society. Employment of PLHA was considered key to demonstrating this contribution and value to society.

“As you know, according to us, we most value being able to work and earn a living. This is what we need to consider and the Government of Vietnam must create work for PLHA to be able to work and earn money to live” (Ministry of Health).

“We need to know what conditions PLHA need to continue to live and work. We need to show that they are useful to society as well as to the community. I think if we could do that it would be good” (Fatherland Front).

Some officials believed it would be best to ignite GIPA through the use of PLHA who were not IDUs, a strategy employed early on by the “friends-help-friends” club to generate community acceptance. Others believed that there should be no distinction based on transmission modes and all PLHA should be encouraged and able to participate equally.

“But at first we had tried to do the good thing that the community is comfortable with and accepts. For example, we use the active and good (not IDU) infected people and get them to write reports for the newspaper demonstrating the good man and the good work.... Because we created something that the community accepted, our office was able to stay in the city” (PLHA).

In X, there are some people that were unintentionally infected with HIV. For example they got married and then after that they found out that they have been infected with HIV. These people could participate very actively” (Ministry of Health).

“Each PLHA participation is worthy and equal. We should not discriminate who is higher” (PLHA).

Officials and PLHA believed that empowerment and capacity building of PLHA was a crucial element of GIPA in Vietnam. PLHA with a low level of education need skills building in the areas of public speaking, human rights awareness, negotiation skills and confidence building. Whilst capacity was being built, it was thought best for such

PLHA to continue working at the community level as implementers of HIV/AIDS or on other community development projects

“First of all, with those special subjects, I personally believe that the most important things is that we need to create confidence in the people who are infected by HIV/AIDS” (Youth Union).

“The centre of our PLHA programs should be the elimination of illiteracy, increase education levels and increase knowledge of the law” (Ministry of Labor Invalids and Social Affairs).

Programmers and policy makers supported the idea of the more educated PLHA being groomed for and used as contributors to policy. It was thought that their role could increase in parallel with the promotion of good governance across Vietnam.

“We should invite them to participate, maybe some people who are educated, good education they should participate at top level and they can give their ideas about difficulties faced” (Ministry of Health).

The establishment of self-help groups was thought to be a good start to GIPA in Vietnam. The groups could begin by members sharing experiences and providing support, then expanding to include concrete activities that would be of benefit to and which would sustain the group. It was thought that networks would then organically emerge.

“Firstly, we should have PLHA register to take part in establishing groups. We create suitable conditions for the groups to work. This is the first condition” (Youth Union).

“Our purpose is to attract PLHA. They will only come here if you can have some benefits...the human life and needs are very multiple and we have to try and diversify the activity in order to meet the requirements of the PLHA coming from all provinces” (PLHA).

However, many officials interviewed were cautious about the formalization of a network. Some voiced the opinion that it should purely be a loose connection not a formal association due to the absence of a legal framework. There was a clear and recurrent message that any PLHA group or network had to follow the law of Vietnam.

“We have to come to an agreement that the HIV/AIDS infected people could not establish a close network from the centre to the grass roots level.....such an association like the Red Cross or Women’s Union could not happen. .. so the association of HIV infected people is just loose connections between HIV infected people at different regions and different target groups. But they are coming together in order to exchange and share their experience they could assist and support one another. These are the principles for establishing this group. But whom will the group work with? There are many HIV infected people that come from the class of free labor. They are the low class in the society; their education level, their knowledge and other abilities are very low. This is the fact. It differs from other international experience. These people could not organize and manage their work. They also do not have good enough condition to organize and develop their organization. Moreover, these organizations are tattered so they would sink into society and they could not live. Together with the structure of the regime in Vietnam, it is impossible to let these organizations establish improperly in the society. Who will manage them? So in Vietnam due to our characteristics, we should have our own methods that are not like other countries” (Ministry of Health).

To this end there was strong support for PLHA groups to connect with mass organizations and/or other members of civil society (such as local research organizations for example). In addition to the legality of such a strategy, using existing organizations could also help support and stabilize the groups economically and socially. Furthermore, officials believed that the mass or local organizations could also be a bridge between PLHA and the community, and help build social cohesion.

“Promoting the role of HIV infected people must be a long-term process not a short term process. But we should start. ... Will the state admits social organizations to do this work? For example the Women’s Union, the Red Cross will these associations with official names stand for gathering a group of HIV infected people under their banner? They would guarantee the political and social sides of the HIV infected group and they also guarantee about the budget for feeding these PLHA. They could not do it themselves” (Ministry of Health).

However, PLHA groups that currently exist express a desire to have greater independence, as they believed this would be more cost effective and they would be in control of decision, their work plans and programs.

“AIDS activity is now being done a lot by PLHA. But the activity is being undertaken through other departments. This is a major obstacle. If they let us do activities directly, it will reduce costs for them. Because say the health department does some of the work when we go to the ward to work they say that PLHA program is one in 25 programs and they are very busy. If they let us do it, it will reduce costs and bad attitudes” (PLHA).

Another key factor in Vietnam is the need to mobilize resources - human and financial - to support PLHA and organizations or sectors promoting GIPA. All officials and PLHA interviewed expressed a need for more financial resources from the central and provincial level to pay PLHA for their participation and build the capacity of PLHA and state employed staff to implement GIPA.

In order to attract the people we should have suitable economic policies... because we should not invite them to participate without proper reward and without expression or assessment of their contribution to the field” (Women’s Union).

If we want to work with PLHA, we could not only talk about it but we need the conditions and budget for it. So however we need to have resources for investing in these activities. We are very weak at the resources” (Ministry of Health).

We need to have leaders that have knowledge. The important factor is to mobilize leaders that have knowledge. But in Vietnam this is low- people are scared and afraid to participate” (Farmers Union).

Moreover many organizations and ministries outside of the health sector requested GIPA be included in national policy and strategy dialogue, and that concrete examples and financial guidelines be provided to provinces on ways to promote and financially support GIPA.

“Expenditure must be expanded. Secondly there should be a GIPA policy encouraging infected people involvement and budget and support for them. I think we should ‘forgive them’ and treat them openly. Thirdly HIV/AIDS prevention is not put in the right place. It should not only be within the Ministry of Health” (Ministry of Agriculture and Rural Development).

PLHA backed up calls for more resources to be invested in promoting GIPA, and requested that they receive capacity building to facilitate their effective involvement and adequate remuneration.

“One part of our difficulty is knowledge and another part is due to finance. Our payment for expenses are very low, normally they called it support for traveling only and we do not have but need salary or other income” (PLHA).

It was also thought advantageous to provide support to and involve family members of sero-positive people in the GIPA movement in Vietnam. This was considered important in light of the high numbers of IDUs among PLHA and the exhaustion of family resources to combat drug addiction or to provide care and support for positive family members. Given rates of illness and death, involvement of family members could also help sustain achievements and efforts of PLHA.

The greatest difficulty is the economics. Most of the infected people are drug addicts. More than 60% of HIV infected people are drug addicts. It means now the condition of the family is very exhausted. Now if we invite the families to participate in the activities that contain economic benefit it would attract them immediately... we could support them and combine with the mobilization of PLHA so they will take part” (Women’s Union).

There was recognition among policy makers and PLHA that there was great deal of diversity within the PLHA community. Such diversity needed to be respected and embraced. As such the roles PLHA play should be based on their personalities, desire and capacity. Moreover people aiming to involve PLHA should be open minded, flexible and compassionate.

“In order to do this work it is not easy. This must be a process of investigation about characters, their psychology and then encourage and promote their participation. And this process must be done with an open-minded contact with an honest attitude to attract them”.

2.5 Summary of findings

- **Reluctance of HIV positive people to participate and join PLHA groups because of fear of stigma and discrimination**
- **Insufficient capacity for PLHA individuals and groups to function and to advocate effectively at various levels – this is particularly a problem with un-educated and highly marginalized groups, and also for women for whom going out to join groups and becoming openly involved in the public sphere may be very alien**
- **Lack of access to treatment which provides little incentive for PLHA to participate, and which also limits PLHAs physical capacity to participate over a long time period**
- **Lack of knowledge and skill among senior programmers and policy makers (especially non-health sector personnel) on how to meaningfully involve PLHA**
- **Limited knowledge amongst health workers about how to deal physically and psychologically with PLHAs**
- **Lack of Government budgetary guidelines supporting GIPA related expenditure**
- **Lack of attention to poverty alleviation strategies (i.e. employment & income generation) for PLHA**
- **Lack of a legal framework for the establishment of independent PLHA groups in Vietnam**
- **Lack of anti-discrimination laws and little enforcement of existing statements and laws prohibiting stigmatization and discrimination of PLHA**
- **Lack of knowledge among PLHA about rights and lack of process to facilitate fulfillment**
- **Insufficient referral mechanisms to build up a sufficient critical mass of members to enable initiatives to become effective and cost-effective**
- **Better coordination is required of activities between donors in their support of PLHA groups**
- **HIV – focused agencies are beginning to move beyond “GIPA tokenism”**

SECTION 3: DISCUSSION & STUDY RECOMMENDATIONS

This study has highlighted that in Vietnam, political will and commitment to GIPA exists among both PLHA and senior policy makers and administrators. The primary means by which the GIPA principle is being operationalized so far is through local level involvement of PLHA and other marginalized groups in specific projects, in ways that enhance their visibility.

However, in order to move beyond this point, consideration must be given to a range of reinforcing strategies that place GIPA within the wider picture of people's participation. This needs to be done in the context of a socialist-turned-market oriented economy and the changes such transition brings. As such the following recommendations are made to progress GIPA in Vietnam.

3.1 Creation of an enabling environment

GIPA cannot be widely accepted and promoted without addressing wider societal and structural issues that obstruct PLHA participation. In Vietnam the following sub-strategies are suggested:

3.1.1 *Reduce stigma and discrimination through the promotion of positive and productive images of PLHA*

Stigma associated with PLHA is extremely high in Vietnam mainly because prevalence is high among sex workers and drug users who are considered to be “social evils” by most people in Vietnam. Such widespread negative attitudes have been perpetuated through shared social discourse produced and encouraged by the media. Most publicity campaigns throughout Vietnam have emphasized the dangers of HIV and the inevitability of death, which perpetrates fear and anxiety rather than normalization. Campaigns have also focused on the vilification of “core transmitters” such as intravenous drug users (IDU) or sex workers (SW), creating and reinforcing division between “guilty” and “innocent” PLHA. Moreover such associations have been reinforced structurally through the establishment of the “National Committee for the Elimination of HIV/AIDS, Drug use, Prostitution and Gambling”, and programmatically through the combination of HIV/AIDS communication and social evil campaigns. This has in part been due to a lack of resources for separate campaigns at a field level.

This strong association with social evils has magnified the level of stigma and discrimination PLHA face. Subsequently PLHA are afraid to participate in the response due to negative repercussions, whilst community members are reluctant to engage with PLHA due to preconceived judgments about the morality and character of PLHA.

This situation is further compounded due to the high numbers of IDU who are sero-positive, which projects the notion that most PLHA are incapacitated and unable to contribute constructively to society – and to contribute is a key and necessary personal feature, highly valued in Marxist and Vietnamese ideology. ***Thus de-linking PLHA from social evils, through the creation of positive images that highlights the value of PLHA work, is essential to the operationalisation of GIPA in Vietnam.*** Such campaigns should be gradual and strategic, starting with PLHA who were infected through “non-social evil” related paths. This would also reinforce the message that everyone is vulnerable to HIV/AIDS, facilitating greater perception of risk among the general community.

3.1.2 Increase access to treatment for PLHA

There is very limited access to treatment in Vietnam and as such there is little incentive for PLHA to join groups without at least this concrete benefit. Moreover without such access key national PLHA leaders will die representing a vital loss of capacity. There is a vicious circle here – without access to treatment, capacity building efforts are unsustainable – yet at the same time, capacity building is needed to enable PLHA to effectively advocate for better access to treatment. Thus any GIPA work needs to advocate for or provide treatment, or provide resources for PLHA to afford treatment. Information about the existing and potential treatment options also needs to be developed and shared with PLHA. This could potentially be done using the Peer Treatments Officer model.

3.1.3 Development of GIPA Policy, budget and guidelines for all sectors

Many senior programmers were supportive of the involvement of PLHA, however they reported having no instructions or guidelines from the central level to work on this issue. The **development and dissemination of a GIPA policy** would allow and help facilitate implementation of GIPA activities. To increase understanding and encourage application of the policy, guidelines and education materials - similar to those produced to facilitate implementation of the grass roots democracy decree - should be produced. This would be particularly useful at the provincial, district and community levels and could be used by PLHA and professionals across all sectors.

Policy articulation should be coupled with **provision of a budget line item for GIPA** so as provincial and district state organizations working on HIV/AIDS can legitimately spend money on GIPA related activities.

3.1.4 Financial support for PLHA participation.

The socio-economic status of PLHAs is often extremely low, and many positive IDUs have also already exhausted a great deal of their family's wealth. There is therefore a great opportunity cost for PLHAs to be involved in non remunerated activities. Policy makers supported the strong PLHA call for the provision of salary payments for PLHA participation, in line with MPI regulations.

3.1.5 Training and support for people working with PLHA

As the research demonstrates, many health care providers are fearful of infection from PLHAS. It is very necessary that all staff working with or for PLHA are provided with orientation and training about transmission and about the rationale and mechanisms to involve PLHA. Individuals should be aware of and able to apply universal precautions for HIV prevention and organizations should be informed of the benefits, risks and risk minimization strategies of involving PLHA.

It is also important that people and organizations in Vietnam recognize the ethical dimensions of involving PLHA, which given the lack of attention to ethics in any medical training could best be addressed **through training on human rights and HIV/AIDS for health and social service providers.**

3.2 Building capacity and supporting PLHA to be involved in the response

The results of the study reveal that some PLHA are participating at the community level but require greater support and capacity building to increase the magnitude and effectiveness of their involvement. Strategies to strengthen capacity and generate motivation for PLHA to be involved include:

3.2.1 Creating self-help groups linked to civil society

Many people infected and affected by HIV/AIDS feel that support groups can reduce some of the pressures associated with living with HIV/AIDS. Working together and sharing ideas and solutions to problems can help provide PLHA in Vietnam with

emotional and practical support. Given the high levels of poverty among PLHA in Vietnam, it is also necessary for self-help groups to have concrete functions and activities such as income generation so as to attract new members and sustain activities.

It is thought that building cooperation and connections between PLHA groups and forming an independent social movement that is able to influence and bring about change is unrealistic at the present time. One reason is the lack of a legal framework for the regulation of civil society. Recent signs indicate the Government is investigating and proposing options for the development of civil society. Given this and the experience of other movements such as the handicap forum, it is recommended that PLHA groups and networks stay loose and less formalized than PLHA networks and associations in other countries. However there is still a need for any PLHA groups to act within the law and as such they require some form of registration and legalization. Options for doing this include:

- Creation of formal linkages with local or international organizations who could provide mentoring and guidance for the PLHA groups, as they are less bureaucratic and 'heavy' than some of the mass organizations;
- PLHA groups and community members could be organized around the co-operative law; or
- Formal linkages with mass organizations or associations could be formed.

3.2.2 Skills building

The study revealed that both programmers and PLHA lack knowledge and skills in a number of areas, which was a key factor inhibiting involvement. The two identified areas of need where training and capacity building is required were in relation to:

- the development and implementation of networks and self-help groups; and
- the ability to speak out and lobby for the rights and needs of PLHA.

Specific capacity building programs could include organizational planning and development, resource mobilization, effective communication and negotiation as well as human rights training for PLHA.

3.2.3 Disclosure options

It is clear from the research that the implementation of GIPA is strongly equated with increased visibility (due to the obvious need to promote positive images of and attitudes towards PLHA). However, given not every PLHA wants to publicly disclose their status or join a group that associates them with other PLHA, mechanisms for participation that do not require public disclosure need to be considered. Moreover, given the potential negative consequences for PLHA of being involved, GIPA initiatives should also include options and space for the participation of those closely affected by HIV/AIDS.

3.2.4 Co-opt and target well-educated PLHA to participate

Key to the effective participation of PLHA in higher -level activities such as program design or policy development, is the need to identify and support potential leaders. In the longer-term, this can be achieved through capacity building efforts described above. However, given education is valued so highly in Vietnam, targeted efforts to attract well-educated PLHA would help facilitate high-level involvement in the near future.

3.3 Mobilising support

3.3.1 Network creation

PLHA believed that the establishment of a network would facilitate greater involvement by creating unity and motivation. However it was also recognized that currently in Vietnam there was no legal framework for the development and operation of such a network, which hampers the GIPA movement. Policy makers and programmers interviewed suggested that the current Ordinance Review should include PLHA as a positive and proactive force rather than social evils and or victims. There was a clear and recurrent message that any PLHA group or network had to follow the law of Vietnam.

3.3.2 Clarification of government position

Support the creation of concrete guidance to clarify the rather "vague" or "general" policies and circulars that are disseminated about HIV/AIDS, and mobilise technical and financial resources to implement and disseminate these guidelines.

3.3.3 Documentation of GIPA Projects in Vietnam

In order to support the Ministry of Health to assist other sectors in applying GIPA, documentation of existing experiences is important. This will help other actors and organizations understand some of the key elements and benefits of GIPA, in addition to providing concrete examples of how GIPA can be implemented within the Vietnamese context. Documentation of other participatory movements such as the disability forum would also assist the application of GIPA in Vietnam. Given GIPA is in its infancy in Vietnam, setting up a case study project that could help organizations monitor, record and link their experiences would be very proactive and efficient. There was also a request from senior decision makers within the Ministry of Health to obtain models and lessons learned from other countries implementing GIPA.

3.3.4 Mobilize donors to support and provide funding for GIPA

There is an urgent need to increase technical and financial support for GIPA. Encouraging the government to create space for GIPA within state budgets is one option, yet given the competing demands on these scarce and finite public resources, it is also necessary to encourage donors and international agencies to support and fund GIPA initiatives.

3.3.5 Demonstrate value-added of GIPA

Programmers and policy makers interviewed were supportive of GIPA, but also expressed a need for evidence demonstrating GIPA's contribution to containing the epidemic. Empirical evidence needs to be collected across both government and non-government programs highlighting the number of PLHA participating and corresponding changes in risk behaviors stigmatization or prevalence data. Additionally, given one of the underlying premises of GIPA is the benefits of involvement for PLHA themselves, process indicators should also be developed and data collected against these indicators. Such information could then be utilized by the Government of Vietnam to report against international commitments such as UNGASS or the right to health contained within International Covenant on Economic, Social and Cultural Rights (United Nations 1966).

Appendix ONE

Policy Maker Interview Guide

Interview Guide- National AIDS Program Managers and policy makers (decision makers)

Name:

Title and position:

Date of interview:

SECTION 1- DESCRIPTION OF HOW PLWHA HAVE BEEN INVOLVED

Warm up: Describe your related to HIV

- What they do
- What their HIV activities are etc.

Are you aware of the information about the Greater involvement of people with HIV/AIDS?

If so, what do you think it **means** / what is your **understanding**

Do you think it **is important to involve PLWHA**? Why or why not?

Describe how have you involved people with HIV/AIDS in your area/ department?

Does your department/ ministry have a AIDS strategy/ plan or policy?

If yes How was it developed?

- Why was responsible for developing it
- Who participated in process / who was consulted

Were people with HIV/AIDS involved in the development of the policy / strategy/ plan

If yes

- How did PLWHA **become involved**?
- Who Which PLWHA were they involved(organizations or individuals)
- **How often were they involved**, for example only once to comment on the draft or throughout the process to give suggestions and input?
- Describe their involvement:/ describe what they did in process
- Were PLWHA **give support to be involved**?
- EG: training, payment for involvement

Do you know who is **responsible for the national AIDS program** in Vietnam?

Do you know if any **PLWHA represented in this organization**?

If yes do you know how are they chosen?

Do you know **if PLWHA are involved in the national program?** If so how?

What kind of support do they receive to take part in the program?

Does Vietnam have **HIV/AIDS legislation?**

Do you know if PLWHA are involved in the development of legislation

It yes, how were they involved / how did they participate?

SECTION 2- BENEFITS

If organization has involved PLWHA: **what were the benefits of involving them?**

If they have not involved: What do you think **the benefits would** be of involving PLWHA in your work?

What are the benefits for PLWHA if they participate?

What are the benefits for the national program / policy if PLWHA participate?

In what areas do you think it is important role for PLWHA to participate?

- Policy making
- Program design
- Program implementation
- Program evaluation

SECTION 3 BARRIERS TO INVOLVING PLWHA

What do you think are the major barriers to involving people with HIV/AIDS in policy making or program design and delivery?

Program

- Community attitudes towards people with HIV/AIDS
- Institutional resistance from within the National AIDS program or other government agencies
- Lack of capacity on the part of people with HIV/AIDS
- Lack of time
- Other factors that constrain involvement

Do you think all PLWHA should be involved regardless of how they got infected ?
(why/ why not)

How could you improve / increase the involvement of PLWHA

What resources do you need to increase the involvement of PLWHA

Appendix Two

Study PARTICIPANTS

Organization	Position	Person	Date of interview
NASB	Chairman of NASB Vice chairman of NASB	Prof. Chung A Chu Quoc An, MA	Not undertaken
MOH	Head of Preventive Medicine Division	Mr. Kinh	4 July 2003
	Head of Legislation Division	Ms. Trinh Le Tram	25 June 2003
MOLISA	PO of Social Evil Preventive Department	Mr. Le Van Khanh	19 June 2003
Ministry of Police	PO of Health Division	Mr. Nguyen Thanh Lam	23 June 2003
National Assembly	Head of Social Affair Division	Nguyen Van Tien, Ph.D.	Not undertaken
Fatherland Front	Chairwoman Head of IEC Department	Ms. Ha Thi Lien	20 June 2003
		Mr. Ha Van Nui	20 June 2003
Ministry of Agriculture and Rural Development	Director of Labor Health Center	Mr. Luong Hong Tuong	26 June 2003
MPI	Head of Department of Literacy and Labor	Ms. Tran Kim Nguyen	Not undertaken
Ministry of Justice	PO of Criminal, Administrative and Legal Division	Mr. Dang Thanh Son	24 June 2003
Ministry of Education & Training	PO of Physical Education Department	Mr. Mai Huy Bong	20 June 2003
Youth Union	Director of Population Health & Environment Center	Ms. Dang Thi Khao Trang	23 June 2003
Women's Union	Head of Family Life Board	Ms. Tran Thi Hoa Binh	20 June 2003
	PO of Family Life board	Ms. Nguyen Thi Nhan	20 June 2003
Farmer Union	Head of Farmer Union	Ms. Hoang Dieu Tuyet	9 July 2003
League Labor Federation	Vice Director of Center for HIV/AIDS and Social Evil Prevention	Mr. Dang Hoa Ai	24 June 2003
STUDY PARTICIPANTS IN HO CHI MINH CITY			
HCMC ASB	Head of AIDS Division	Dr. Le Truong Giang	30 June 2003
	PO of AIDS Division	Dr. Tran Thinh	30 June 2003
Women's Union	Head of Women's Union	Ms. Le Thi Thu Hien	1 July 2003
	PO Of Women's Union	Ms. Plham Thi Dan Linh	1 July 2003
DOLISA	Vice Director of Health Center	Mr. Le Van Nhan	2 July 2003
Hospital	Vice Director of Hospital	Dr. Nguyen Tran Chinh	3 July 2003
	Head of HIV/AIDS Department	Dr. Nguyen Huu Chi	3 July 2003
'Friend help friend Club	Manager of Club	Dr. Nguyen Huu Luyen	4 July 2003

Appendix Three PLHA Interview Guide

Name:

Title and position:

Date of Interview:

SECTION 1- DESCRIPTION OF HOW PLHA HAVE BEEN INVOLVED

Warm up: Describe your work related to HIV

- what they do
- what their HIV activities are etc

Are you **aware** of the information about the Greater involvement of People with HIV/AIDS?

If so, what do you think it **means** / what is your **understanding**

Have you been involved in any HIV/AIDS activity?

If yes

- How did you **become involved**?
- How **often were you involved**, for example only once to comment on the draft or throughout the process to give suggestions and input?
- Describe their involvement :/ describe what they did in process
- Were you **given support to be involved**?
- EG: training, payment for involvement

Do you know who is **responsible for AIDS program** in your area?

Have you had any **contact** with them?

Do you know if there is a national HIV/AIDS strategy?

What do you think about it?

Does Vietnam have **HIV/AIDS legislation**?

What do you think about it?

SECTION 2- BENEFITS

If you have been involved- **what were the good things about it?**

- for you
- for others: community members, family, leaders etc

If they have not been involved:

Why have you not been involved?

Would you like to in the future?

How would you like to be involved / what would you like to do?

- HIV educators
- participate in program delivery
- work with service provider / policy makers
- work with other PLHA
- Others

SECTION 3: BARRIERS TO INVOLVING PLHA

What do you think are the major barriers / difficulties for PLHA to be involved/ participate?

Prompts:

- community stigma / discrimination towards people with HIV/AIDS
- lack of capacity on the part of people with HIV/AIDS
- lack of time
- Health department / policy makers do not listen to us / want us to be involved
- too sick / unwell
- Others

Do you think all PLHA should be involved regardless of how they got infected? (Why / why not)

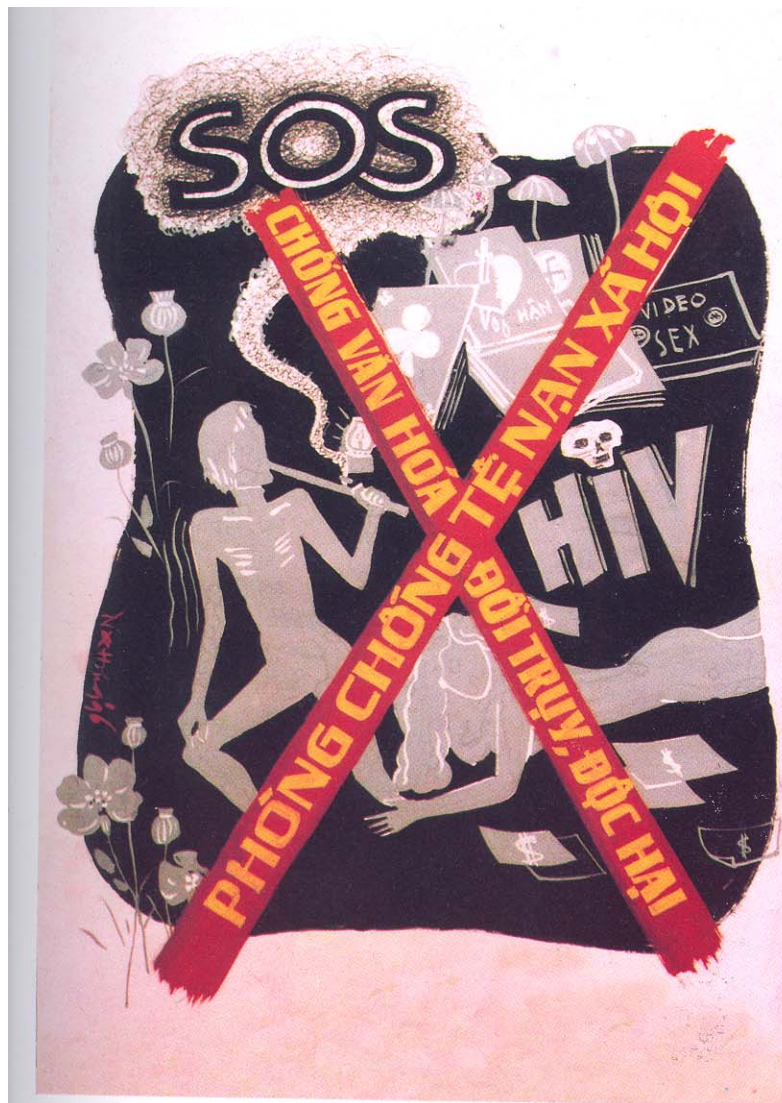
How do you think we could have greater participation of PLHA?

What resources do you need to increase the involvement of PLHA?

- money
- Training / capacity building – what areas?
- more time
- more opportunity

Basically there are three main questions we need answered

- How would they like to participate
- difficulties / barriers for them to participate
- what do they need to help them participate



359. NGÔ QUỐC HÙNG (1955)
PHÒNG CHỐNG TỆ NẠN XÃ HỘI - 1996