Yayasan Spiritia

Report on Activities 2005/2006

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Contents

Contents ... 2
Acronyms and Abbreviations ... 3
Program Activity Summary ... 4
Rationale/Justification ... 4
Goal and Objectives ... 4
General Objectives ... 4
Specific Objectives ... 4
Results and Success Measures/Achievements ... 4
PLHIV Meetings ... 5
Skills Development Training ... 6
Support for Peer Support Groups ... 7
Information Dissemination ... 8
Human Rights ... 9
'HIV Stops Here' ... 9
Representation in International and National Forums ... 9
Special Funds ... 10
Human Resources/Staff Development ... 11
Annual Evaluation ... 11
Additional Activities Not Covered in Original Plan ... 11
Barriers and Strategic Changes ... 12
General ... 12
Scale Up of Services ... 12
Antiretroviral Therapy Scale Up ... 12
Voluntary Counselling and Testing ... 13
Partnership Fund ... 14
Involvement of PLHIV ... 14
PLHIV Meetings ... 14
Local Strengthening Visits ... 15
Information Dissemination ... 15
Human Rights ... 15
Skills Development Training ... 16
Peer Support ... 16
National Meeting of Peer Support Groups ... 17
Indonesian PLHIV Network ... 17
Drug Use ... 18
Representation in International and National Forums ... 18
Human Resources/Staff Development ... 18
Conclusions ... 19
Recommended Actions for the Future ... 20
Appendix 1: Annual Evaluation 2005-2006 ... 21
Background ... 21
Assessment Questionnaire ... 21
Evaluation Agenda ... 21
Summary and conclusions ... 22
Discussion Sessions ... 22
Lessons Learned ... 22
Appendix 2: Details of Peer Support Groups ... 23
Appendix 3: IEC Material Published 2005/2006 ... 24
Appendix 4: "Cipayung" Statement ... 25
Appendix 5: Photographs of Activities ... 27

Acronyms and Abbreviations

AFAO	Australian Federation of AIDS Organizations
APN+	Asia Pacific Network of People living with HIV/AIDS
ART	Antiretroviral therapy
ARV	Antiretroviral (drugs)
ASA	Aksi Stop AIDS (USAID-funded AIDS project)
AusAID	Australian Agency for International Development
Depkes	Ministry of Health (from Indonesian)
DFID	Department for International Development (UK government)
GFATM	Global Fund to fight AIDS, TB and Malaria
GIPA	Greater Involvement of PLHIV
GNP+	Global Network of People living with HIV/AIDS
ICAAP	International Conference on AIDS in Asia and the Pacific
IEC	Information, Education and Communication
IHPCP	Indonesian HIV/AIDS Prevention and Care Project (funded by AusAID)
KNO	National PLHIV Congress (from Indonesian)
KPA	National AIDS Commissions (from Indonesian)
MSF	Médecins Sans Frontières
NGO	Non-governmental Organization
OI	Opportunistic Infection
OSI	Open Society Institute
PLHIV	People Living with HIV
PMI	Indonesian Red Cross (from Indonesian)
PNO	National PLHIV Meeting (from Indonesian)
POW	Regional PLHIV Meeting (from Indonesian)
RSPI	Infectious Diseases Hospital in Jakarta (from Indonesian)
TAC	Treatment Action Campaign (South Africa)
TAG	Treatment Action Group (New York, USA)
UNAIDS	United Nations Joint Programme on AIDS
UNDP	United Nations Development Programme
UNICEF	United Nations Children's Fund
UNV	United Nations Volunteers
UPC	Universal precautions
USAID	US Agency for International Development
VCT	Voluntary counselling and testing (for HIV)

Program Activity Summary

Rationale/Justification

At the Paris AIDS Summit in Paris in 1994, the governments of 42 countries including Indonesia resolved to support the principle of involvement of people living with HIV (PLHIV), as a "means to stimulate the creation of supportive political, legal and social environments." This principle has become known as GIPA (Greater Involvement of People Living with HIV/AIDS). The Paris Declaration became a formal statement by governments of their intent to involve PLHIV in the response to the epidemic at national, regional and global levels.

The Spiritia work plan is designed to turn this principle into practice in Indonesia. All activities have been developed and implemented with the objective of empowering and encouraging PLHIV to play a more active role in their own lives and health, and then in the response to the epidemic in Indonesia. It has been proved that such involvement is one of the most effective responses, giving a human face and voice to the epidemic, and showing that those affected are not 'them' but 'us'.

Goal and Objectives

General Objectives

- Improve quality of life of PLHIV in Indonesia.
- Encourage involvement of PLHIV at every level of AIDS control from becoming critical recipients of services, up to active participation in planning, implementation and evaluation of programs and policy.

Specific Objectives

- Support and encourage PLHIV to play their role more effectively as vital stakeholders in AIDS programs and policy.
- Support and encourage PLHIV and organizations in the regions of Indonesia to develop their own support programs which are empathetic, identify the complementary dynamics of care and prevention, and facilitate the meaningful role of PLHIV in their activities.
- Represent Indonesian PLHIV at national, regional and global level; advocate at all levels for increased access to treatment for PLHIV, including both antiretroviral therapy, treatment for opportunistic infections (OIs) and palliative care.

Results and Success Measures/Achievements

Even though recent official estimates have doubled to over 200,000 the number of people thought to be living with HIV in Indonesia since 2002, the scale up of numbers of those aware of their infection has not occurred as rapidly as planned. A total of less that 12,000 are reported to have been infected by September 2006 according to government statistics, and although it is probable that twice that number have been diagnosed, it is clear that around 90 per cent are not aware that they are living with HIV. Despite massive efforts and funding from the Global Fund to fight AIDS, TB and Malaria (GFATM), scale up of VCT has been fraught with problems, inappropriate targets and in some cases violation of human rights. VCT services seem unable to attract those who have been at risk, and rarely offer a friendly and attractive environment, even often charging for services. These failings do not currently seem to be being effectively addressed.

Thus the numbers of those seeking treatment has not expanded as rapidly as anticipated in the previous report. However, there has been a significant increase, and this has been reflected in an increase in the demand for peer support, leading to a significant increase to almost 100 of the number of peer support groups around the country.

Sadly, after much discussion, the promised major funding from the Indonesian Partnership Fund did not transpire. However, Spiritia did receive significant additional funding from Ford Foundation over the period. This together with a previous grant from Ford plus significant grants

from the AusAID-funded Indonesia HIV/AIDS Prevention and Care Program (IHPCP) allowed a start to be made in significant scaling up of its activities.

In line with this scale up, Spiritia carried out a formal strategic planning exercise, with assistance from professional management consultants, to develop a road map and appropriate organization chart in line with the increase in staff necessary to manage the revised strategy. This increase in staffing has already started.

This strategy review endorsed Spiritia's previous approach of not expanding directly outside Jakarta, relying on autonomous umbrella groups rather than Spiritia branches. The management consultants were also tasked to assist umbrella groups to carry out strategic planning activities.

As the umbrella group for peer support for people living with and affected by HIV in Indonesia, Spiritia is in contact with more than 2500 PLHIV and a similar number of affected people throughout the country, either directly, or through the expanding network of peer support groups under the Spiritia 'umbrella'. Most agree that their involvement with Spiritia has improved their lives: by proving that they are not alone; and assisting them to take control of their lives and their health.

Spiritia's program includes ten external activities, together with support functions (secretariat, strengthening human resources and annual evaluation). This report provides a brief review of the results and achievements over the period November 2005–October 2006, followed by a summary of the main barriers faced and strategic changes which are occurring. Selected photographs depicting the main activities may be found in Appendix 5.

PLHIV Meetings

It will be recalled that in 2004, Spiritia decided to terminate the annual national PLHIV meeting (PNO), and replace it with two separate meetings. The entry-level need, covering those newly diagnosed and not previously involved, is now addressed with a series of regional meetings (POW), while experienced PLHIV are given the opportunity to attend a biennial National Congress of PLHIV (KNO). The first KNO was held in September 2005, and thus there has been no KNO during this period.

- Spiritia arranged four POWs during the period, one each in Kalimantan (Pontianak in cooperation with Pontianak Plus Support in January 2006; 18 participants), in Java (Surabaya in cooperation with Surabaya Positive Community in March 2006; 22 participants), in Sumatra (Padang in cooperation with Lantera Minangkabau in April 2006; 19 participants) and in Papua (Jayapura in cooperation with Jayapura Support Group and Cendrawasih Bersatu Merauke in May 2006; 24 participants), also covering West Irian Jaya.
- The Java and Sumatra meetings were the second POWs in these regions.
- These four meetings involved 83 participants, 80 percent of whom were living with HIV. Participants came from a total of 52 districts/municipalities in 20 provinces.
- Spiritia organized each meeting, with assistance from a local organizing committee drawn from support groups in the region. The local committee was responsible for selection of participants, and for providing local speakers where appropriate. With this experience, it should be possible to reduce, and in time eliminate, the involvement of Spiritia in future POWs in these regions.
- Bali Plus, the umbrella group for Bali, also organized a meeting of PLHIV in the province.
- Feedback from participants and local committee members confirms that such local meetings are the most appropriate direction for the future, with the ability to reach a much larger number of newly diagnosed PLHIV. Some specific outcomes:
  - Self esteem of participants increased
  - Participants increased their knowledge of HIV, specifically in regarding the basics of HIV/AIDS and its treatment
  - Encouraged almost all participants to involve themselves in a variety of activities responding to HIV/AIDS in their areas

- Strengthened the communication network and cooperation among participants and their peer support groups, including to become members of group committees
- Peer groups involved as local organization committees provided with opportunities to extend their networks with other groups in selection of participants and with local stakeholders during advocacy nights following the meetings
- Local groups gained experience in organizing meetings
- Strengthened regional and provincial networks, with new representatives in areas that had not previously been reached

Skills Development Training

Regional meetings (POW) provide only a basic introduction to the knowledge and skills required to support effective and meaningful involvement by PLHIV. Thus Spiritia continues to place emphasis on developing suitable skills in a way that also improves self-confidence. There is clearly a wide variety of skills and knowledge that are required, and it is beyond us to address all of these, so we carried out informal assessments to identify priority needs.

With the rapid expansion in the number of peer support groups, it was clear that one of the main needs was for skills in setting up and running such groups. We therefore held two four-day courses covering this. The first was held in Mataram in cooperation with NTB Plus, in June 2006. A second course was held in Balikpapan in cooperation with For Plus in July 2006. These two courses involved a total of 40 participants from 37 districts/municipalities in 28 provinces.

Outcomes of these two courses include:

- Participants from areas without a peer groups have been motivated to start groups; most have since been involved in formation of new groups
- Participants better understand the role of peer groups, and how to address related challenges
- More than half felt a benefit from sharing experiences with other participants, and plan to share further with colleagues in their areas
- Groups involved as local committees obtained valuable experience in organizing meetings
- Participants who are already members of groups plan to hold similar training with colleagues in their groups and with others in their areas
- Course module regenerated

In the previous period, we pioneered the Treatment Education courses, with the aim the each peer group should have at lease one treatment literate member, able to support other group members, answering questions and acting as a go-between or interpreter with doctors and other health care workers. The main objective is to support and encourage adherence to the antiretroviral therapy (ART) that is now being more widely offered. But treatment literacy also supports treatment advocacy and responds quickly to simple questions from members about their infection and its progression. To respond to this need, a further two five-day Treatment Education courses were run, first in Makassar in cooperation with Sari Battangku in June 2006 and the second in Pekanbaru working with Lancang Kuning in September 2006. These two courses involved 34 participants from 33 districts/municipalities in 23 provinces.

In order to encourage sustainability and local dissemination of treatment knowledge, all Treatment Education courses now involve at least three alumni from earlier courses as the main course presenters. These presenters are coached by rehearsing their presentations for a full day before the meeting, with additional coaching as required each evening. This approach strengthens their confidence, increases their skill and experience, and deepens their knowledge. Several have used this experience and knowledge to carry out similar training in their groups or areas.

Outcomes of these two courses include:

- Participants increased the depth and breadth of their knowledge of HIV, opportunistic infections, and ART, its side effects, resistance and the importance of adherence
- This increased knowledge better prepared and empowered participants in their relationship with their doctors

- Most participants shared their knowledge with their group members, and several also held similar courses for their groups
- Six local activists gained experience and knowledge as presenters

Support for Peer Support Groups

Spiritia views peer support as a central element of the response to the epidemic, with the development of local, autonomous peer support groups as the main strategy to encourage infected and affected people to organize and provide mutual support. And since Spiritia cannot provide all of the services required by these groups at the local level, the strategy has also encouraged development of umbrella groups at regional or provincial levels.

Peer support is the essential next step after PLHIV have started to play an active role in their own lives and in their own health. Initially this may be as a member of an existing group, later as a leader of a group, then extending to involvement in formation of new groups. Peer support groups play a vital role in connecting Spiritia with PLHIV at the grass roots, and also in advocacy at their local levels.

Over the period, additional funding from both Ford Foundation and IHPCP has allowed us to offer limited funding, covering communication and transportation costs, as well as provision of small snacks at meetings, photocopying and the like, to a greater number of groups. By the end of the period, Spiritia had funded 64 peer groups including four umbrella groups in 40 places/27 provinces. The minimum funding was Rp 800,000 per month, while one group received over Rp 7 million per month.

Spiritia attempts to visit groups, particularly those receiving funding from Spiritia, on a regular basis. These visits not only provide an opportunity for technical support and assistance in advocacy with local stakeholders, but also allow Spiritia to maintain a closer understanding of the 'grass roots'.

- Currently 90 peer support groups have been formed in 27 provinces (an increase of 35 groups during the period), most actively in contact with Spiritia – see Appendix 2 for details of groups and a location map. Although it is difficult to determine total numbers, these have supported at least 3000 PLHIV and over 1100 affected people, with a total of almost 2000 people still directly involved. Current details of groups may be found on the Spiritia web site
- Problems experienced by the umbrella group in Jogjakarta mean that only four such groups still exist, in Bandung, Bali, Medan, and Pontianak. Groups in eight other towns have shown potential to develop into umbrella groups
- The trend towards the formation of more specialist groups has continued. There are now 16 groups specifically for those with a drug-using background, seven for transsexuals, two for gays, seven for women and four for parents/family members/others directly affected
- The majority of groups now have an E-mail address, although not all regularly access E-mail
- Groups are becoming more 'professional' with a more formal structure and many starting to develop clear vision and mission statements. Most having produced a profile for distribution to stakeholders and clients
- An increasing number of groups are carrying out their own training, often using Spiritia modules. Nineteen groups organized courses on public speaking for PLHIV, while umbrella groups arranged a variety of trainings, including covering income generating and peer education
- Groups extended Spiritia's program of local strengthening visits to their own local areas, covering parts of East Nusatenggara, West Java, North Sumatra, West Kalimantan and the Riau Archipelago. These visits involved local stakeholders, including from local AIDS Commissions, Health Service, hospitals and Global Fund
- Groups are increasingly being involved by local stakeholders, including as staff of AIDS Commissions, case managers, outreach workers, and working with the health and social welfare departments

- More groups are directly accessing funding, including from APN +, FHI/ASA, IHPCP, Oxfam, HIVOS, Global Fund, and the Red Cross
- Groups are playing a more active role in care, support and treatment, developing relationships with local AIDS referral hospitals, and making their voices heard regarding the needs of PLHIV

The Third National Meeting of Peer Support Groups held for five days in Bogor in September 2006, with representatives from 81 groups in 47 districts/municipalities in 26 provinces. This meeting is now held biennially, on alternate years with the National Congress. Each day opened with a plenary session, involving invited speakers, and this was followed by presentations on special topics, and skills-building sessions.

The meeting was opened by Dr Nafsiah Mboi, recently appointed secretary of the re-formed National AIDS Commission, and closed by the Minister of Health, Dr Siti Fadilah Supari.

Some outcomes of this meeting:

- Network among peer groups strengthened. Groups from different areas and backgrounds were able to share experience and ideas on how to address the challenges faced. They asked Spiritia to continue this process by developing an E-mail mailing list
- The role and development route of umbrella groups is not clearly understood. Spiritia was asked to publish guidance
- Groups requested more frequent visits by Spiritia to assist in development and advocacy
- An evening debate was held with the subject "'HIV Stops Here' is a Violation of Rights of PLHIV". Speakers included health-rights activist Iskandar Sitorus (for) and Dr. Nurlan Silitonga (IHPCP - against). Although no vote was held, most participants found it valuable in helping them to see both sides
- The meeting produced the 'Cipayung Statement' (attached at Appendix 4). This was prepared in a more interactive way than earlier meeting statements, with daily sessions involving all participants to agree content and develop consensus on the final text. The Statement was presented to the Minister of Health during the closing ceremony.

Information Dissemination

Spiritia continues to consider the availability of accurate and clear information about the disease and its treatment is an essential element in allowing PLHIV to take control over their lives and health. This is addressed in a number of ways. First is the publication of a ten booklets in Indonesian, together with a series of fact sheets and other materials. Spiritia's two newsletters support these, one a communication medium among PLHIV in the network, and the other with wider distribution providing information on care and support of PLHIV.

Spiritia finally launched its web site in July 2006. This is designed for ease of use and fast access resulting from a minimum of graphics, bearing in mind that many in Indonesia can only access the internet through slow and expensive dial-up services. All Spiritia documents are now accessible through this site, together with a wide variety of other information of interest both the PLHIV and to those supporting them. In addition, an English language section provides information on the state of the epidemic and the local response for people overseas. This site is continually updated and added to.

A list of all Spiritia publications may be found at Appendix 3. Copies of any of these may be obtained free-of-charge on request to Spiritia or most peer support groups.

- As at October 2006, total distribution of the newsletter Senandika was 645 copies, while 583 subscribers receive Sahabat Senandika every month
- Almost 4000 sets of the booklets have been distributed, many through peer groups and health care providers. We frequently meet 'new' PLHIV in the areas who have already obtained copies of the books from such sources
- The booklet 'HIV & TB' financed by OSI, was printed and officially launched in April 2006. This has been very well received, and one illustration from it has been appeared in two

international publications. In addition, the MoH has requested Spiritia to produce a version (TB & HIV) for use in community health centres

- Spiritia's series of fact sheets now encompasses 122 topics, of which 7 were released during the period. Fact sheets have been regularly updated, with more then half having been revised in the period
- The website, spiritia.or.id, is attracting increasing attention. Despite the long holiday in October 2006, almost 5000 visitors accessed the site during that month, viewing more than 10,000 pages. A total of almost 40 anonymous questions posted on the site have been answered

Human Rights

As was noted in the last report, a second phase documentation project was started in late 2003, involving 203 PLHIV interviewed by nine peer interviewers. At that time, the final report had not yet been completed; this is now available.

- The report shows that there has been little improvement since the first phase carried out in 2001. Almost one third of respondents continue to report a lack for respect for their rights in HIV testing and in health care services
- Stigma and discrimination resulting from these violations continues to adversely affect the response of others, particularly family, friends and the public
- Despite this, there are signs of improvement. For example the peer group in Merauke, Papua, reports that stigma and discrimination against PLHIV is now very rare in all sections of the community in Merauke town. In addition, groups working with PLHIV incarcerated in the main prison in Bali report that 'discrimination has disappeared' in the prison, including among staff, warders and inmates

'HIV Stops Here'

The topic of prevention of positives continues to attract much attention and discussion. Spiritia continues to promote this through the 'HIV Stop di Sini' initiative. As noted above, this was also the subject of a debate and the last annual meeting of peer support groups, and was also the subject of a plenary session at that meeting. In addition, it is addressed in most Spiritia activities, including with one session on the subject during the Treatment Educator courses.

As noted in the last report, with less than 10 percent of those thought to be infected actually aware of their status, this initiative will not have significant impact on the spread of the epidemic. Yet it does indicate that the infected community cares about this matter, and that they are taking a responsible approach in their lives.

Representation in International and National Forums

Dhayan Dirgantara (now a Spiritia staff member) took over as the Indonesian representative on APN+, and as member of the APN+ steering committee. Spiritia is assisting him in the election an alternate APN+ representative, in a process that will allow network members to nominate candidates, followed by postal voting.

While not directly covered in the work plan, efforts have been made to promote Spiritia's name and credibility in international and national forums. Some highlights from the period:

- The recently issued Presidential Regulation on the National AIDS Commission (No. 75/2006) provides that the chair of the national PLHIV organization should be a member of the NAC. Daniel Marguari, Spiritia Project Coordinator, currently fills this position. In addition, Christine Wahyuni was chosen as a member of the Implementing Team of the NAC.
- Spiritia was chosen from among more than 500 NGOs globally to be among 25 finalists for the Red Ribbon Award. Sadly we were not among the five who received the main award.
- Spiritia continues to provide one community member of the Country Coordinating Mechanism (CCM) of the Global Fund (GFATM), who is also vice chair of CCM technical working group.

- One Spiritia staff member continue to act as consultant to the AusAID-funded Indonesia HIV/AIDS Prevention and Care Project.
- One Spiritia staff member continues to act as consultant to the Indonesian Red Cross (PMI).
- One Spiritia staff member continues to act as member of expert advisory panel for the bi-weekly newsletter 'HIV/AIDS Treatment in Practice', published by the NAM, UK, and as advisor to The AIDS Infonet, publishers of an internationally respected set of AIDS-related fact sheets.
- Two Spiritia staff members currently actively involved as members of the ACATA (Asian Community on AIDS Treatment Advocate) network.
- Mrs. Tony Blair, wife of the Prime Minister of Great Britain, visited Spiritia with the wife of the British Ambassador to Indonesia.
- Spiritia staff participated in the following international and significant national functions:
  - 9th Bangkok Symposium on HIV Medicine, Thailand, as participant, January 2006
  - TAC/i-Base Global Treatment Literacy Meeting, Cape Town, South Africa, as participant, March-April 2006
  - Stakeholder Meeting on HIV/TB/Malaria, New Delhi, India, as participant, April 2006
  - Asian Tsunami Project, International Federation of Red Cross and Red Crescent Societies/APN+, as consultant, May 2006
  - UN Summit on Progress since UNGASS 2001, New York, USA, as member of Indonesian delegation, May 2006
  - Country Consultation Meeting to prepare draft proposal for ASEAN inter-country consultation meeting, two participants, July 2006
  - Six Spiritia staff attended the International AIDS Conference, Toronto, two as speakers, August 2006
  - UNITAID Initiative meeting, New York, USA, as speaker, September 2006
  - ASHM 2006 Conference, Melbourne, Australia, as speaker/participant, October 2006
  - International Civil Society Meeting, Global Fund, Durban, South Africa, as participant, 2006
  - Asia Stakeholders Consultation on Confronting HIV, Tuberculosis and Malaria, New Delhi, India, as participant, April 2006. Two participants, one also speaker.
  - Study tour to three cities in Brazil with national stakeholders to learn about their experience in responding to AIDS, August 2006
  - Spiritia facilitated two meetings between a PLHIV from the network with senior politicians: first with Aburizal Bakrie as Chair of the NAC, at the Scientific Meeting on HIV, May 2005; second with Minister of Health at closing of the Third National Meeting of Peer Support Groups, September 2006

Special Funds

Spiritia operates two special support funds: Positive Fund, to offer emergency loans or grants to PLHIV in difficulty; and ARV Fund, originally formed to pay for antiretroviral treatment for activists who need it. However, with the availability of free ART from the government, including second line regimens, the need for the ARV fund as originally envisaged has almost disappeared. We have been using the fund to pay for CD4 testing for those unable to afford this, but again, it is still promised that such testing will be available free of charge Real Soon Now. We have offered to use the fund to pay for viral detection testing to offer early determination of HIV-infection status of a baby born to an HIV-positive mother, and this is attracting increasing response. We have also been using the fund to buy pillboxes for those on ART, to assist in adherence.

Over the period, the Positive Fund has supported more than 100 people, but often the Fund is only able to contribute towards costs, and must sometimes turn down requests, especially those needing larger sums. We need to be sure that the money offered provides solutions, and is not (for example) used for expensive tests to diagnose conditions for which no affordable treatment is available.

- Discussion continues with contributors and members of the network about future of the ARV fund, but so far there is no consensus.

- Balance sheets for the funds over the period are as follows (figures in brackets from the previous period):

	Positive Fund (Rp)	ARV Fund (Rp)
Balance as at 1 Nov 2005	10,855,675 (6,227,675)	80,690,125 (75,086,522)
Contributions Nov 2005 - Oct 2006	9,059,294 (13,885,000)	7,350,000 (49,640,900)
Outgoings Nov 2005 - Oct 2006	6,728,300 (9,257,000)	9,935,075 (44,037,297)
Balance as at 31 Oct 2006	13,186,229 (10,855,675)	78,015,050 (80,690,125)

"Our feelings after receiving assistance from the Positive Fund to carry our a viral load test on our baby, we were really happy especially after we knew that our baby was not infected, so that we both felt really moved and proud that we had not infected our baby. We want to express our thanks to all around us who have helped and supported us and also to Spiritia for helping us through the Positive Fund."

Human Resources/Staff Development

Among the outcomes of the strategic planning process carried out by Spiritia with the help of local management consultants (see below) was a change in the Spiritia's management structure. It is planned that the number of Spiritia staff will rise from 11 to 18 by early January 2007, while retaining a gender balance. In the recruitment process for new staff, professionalism was considered a priority, although concern for HIV remained an important element.

Annual Evaluation

An annual evaluation was carried out in September 2006, in a two-day meeting with participation by 20 members of the Indonesia peer support group network from 16 provinces around the country. Dr Mangku Karmaya, a member of the Bali AIDS Commission, facilitated the meeting. Prior to this meeting, two questionnaires were prepared and distributed: one for individuals that was sent to 430 members of the network, of which 275 were returned; the other for peer support groups sent to 75 groups, of which 48 were returned. Both figures for returns show a significant increase from previous years, when less than 50 percent were returned.

A brief report on the results of this evaluation may be found in Appendix 1. The evaluation provided valuable input and feedback, contributing greatly to this report. In addition, many ideas for detailed improvement of elements of the program were identified. Compared with last year's evaluation, participants were a little less critical, but there was good participation.

Additional Activities Not Covered in Original Plan

Strategic planning

In the framework of a four-fold scaling up of Spiritia activities supported by Ford Foundation for the period 2006-2008, Spiritia sought assistance from PPM Consultants to assist us with strategic planning, including redefinition of Vision and Mission, as well as development of organisational structure, job descriptions and operating procedures. This six-month process actively involved all Spiritia staff. Together with PPM Consultants, Spiritia also assisted four umbrella groups (Bali, Medan, Pontianak and Bandung) to start a similar process.

This process provided particular benefits for all Spiritia staff, but also identified many challenges faced in such major scale up. Among these is the need to change from a family-style organisation to a more professional one, requiring awareness of individual shortcomings and willingness to address these. We determined to carry out the changes flexibly and in stages to avoid this becoming a problem, but rather to encourage enthusiasm for the changes.

Advocacy

Spiritia continued to advocate at the national and local levels together with other PLHIV, both as individuals and groups. Advocacy targets included care, support and treatment, policy, and the like.

When Mrs. Tony Blair visited Spiritia, we invited representatives from peer groups in Jakarta to join the meeting, during which a number of important topics were raised, such as pharmaceutical patent polices, and funding support by DFID.

Among the successes of Spiritia advocacy:

- The GFATM CCM agreed to recruit a second Principal Recipient (PR), to be from civil society
- Provision of a second line ART regimen
- Peer groups were offered seats on the national and many local AIDS Commissions

Barriers and Strategic Changes

General

In the last report, we noted the risk that Spiritia could become more remote from the 'grass roots'. This remains a significant challenge, particularly as we recruit professional staff with little if any background experience with HIV and AIDS. One way to address this is to involve all members of staff in meetings and visits. We also maintain an 'open door' to visitors, and we welcome phone calls, text messages, and E-mails from anywhere, offering to ring back to callers to avoid them incurring charges. However, this contact tends to be dominated by 'activists', and the voice of the 'average' PLHIV is often muted. We must continually look for ways to amplify these voices.

An associated challenge is to assure that peer groups within the network share the vision of empowerment of PLHIV. There was discussion at Spiritia's annual evaluation regarding our response if groups with a different vision or those concerned solely with providing services to PLHIV requested to join the network. As the number of groups continues to increase, this will become an increasingly important discussion.

Scale Up of Services

We are seeing a relatively rapid scale up in the number of people who have become aware of that they are HIV positive. However, in many places, comprehensive programs of prevention, care, support and treatment are not keeping pace with this increase. Peer groups can and should be playing a more active role in advocating for adequate services for PLHIV in their areas, and in working together with care providers. We must therefore intensify efforts to encourage formation of peer groups in every district/municipality, and increase their capacity to advocate for these services. We also need to encourage existing VCT centres in hospitals to consider becoming Day Care Centres similar to those in Thailand, shifting tasks from doctors to nurses and from nurses to properly-trained PLHIV.

Antiretroviral Therapy Scale Up

It is now two years since the Ministry of Health (MoH) announced universal access to antiretroviral therapy (ART) with full subsidy. At that time, a target of 10,000 people on ART by 2005 was set. What has been the progress?

Initially 25 hospitals around the country were designated as AIDS Referral Hospitals, and staff in those hospitals were trained. A further 50 hospitals have now been designated as referral hospitals, and a basic cadre of staff at most of these have been trained. However, statistics are only now becoming available from the first 25 hospitals.

From these it is clear that the rollout is going much slower than planned. The report shows that some 6000 people have started ART in those hospitals, but less than 60% are still on therapy. More than 20% have died, mostly in the first few weeks or months following start of therapy, probably because they were diagnosed very late. More than 750 have dropped out; reasons for this have not yet been determined, although some are known to have switched to traditional therapies.

While the numbers on ART are well below the target, it is probable that the majority of those who are aware of their infection and meet the criteria for starting therapy have in fact done so. According to the latest figures from MoH, less than 12,000 cases of infection with HIV have been

reported nationally, of whom some 7000 had progressed to AIDS, with more than 1600 having already died. Although some estimates put the total number of infections nationally at around half a million (of whom at least 20% must be assumed to have progressed to AIDS), we cannot treat those who are not aware of their infection. It is clear that many people are dying of AIDS undiagnosed, and the drugs that are sitting on the shelves could save many of these.

Efforts have been made over the last year to scale up voluntary counselling and testing (VCT) services; the success of this effort is discussed below. But if all those infected were immediately to become aware of this, other services would not yet be ready to cope with such numbers. Many of the current 75 referral hospitals are extremely short of staff trained to treat HIV infection, and few of those trained have any real depth of experience. Partly as a result of advocacy by Spiritia during the recent national peer groups meeting, the Minister of Health has decided to accelerate the rate of scale up, bringing the number of referral hospitals to 400 in 2007. However, for this to be effective, training must be improved, and mentoring systems put into place to support those with limited experience.

In addition, experience here and in other countries shows that hospitals are not the best solution for long-term chronic support; community health centres (puskesmas) must also play a crucial role, at lease by providing routine support and refilling ART prescriptions once the acute period has passed. Although there is some resistance to this approach in Indonesia, there is a growing consensus that this will be necessary, and indeed a few puskesmas are already starting to take on this role. However, the community health system in Indonesia has been starved of funding and support over the last few years, and adding to the load without a significant policy change will add to the current overload.

Monitoring and reporting by the referral hospitals still leaves much to be desired, nowhere more so than in adherence to ART. We are not aware of any hospitals where the adherence of those collecting monthly prescriptions is formally probed and reported, with extra support offered to those exhibiting problems. Without this, we have no picture of the challenges faced with adherence, and we run the risk of early development of resistance to first line regimens.

Such resistance is already beginning to become apparent with indications of increasing rates of failure of first line regimens. This is increasing demand for a second line therapy, but the status of this is still unclear, and the regimen apparently to be provided is less than ideal. In addition, one of the drugs (Kaletra) from the planned second line has already been distributed to some hospitals, and there have been reports that this has been substituted on a single basis for one apparently failing first line drug. If true, this will contribute to early failure of the second line. A clear policy on second line therapy is thus urgently required.

We continue to receive regular reports of stock-outs of first line drugs, particularly efavirenz, resulting at best in inconvenience for those taking the drug, and running the risk of development of resistance if treatment interruptions occur. Spiritia often finds itself in the middle between hospitals and the MoH in responding to these shortages. A formal system to respond to such emergencies, and to investigate the causes, is urgently needed.

Voluntary Counselling and Testing

A significant proportion of the funding from Round 4 of the Global Fund to Fight AIDS, TB and Malaria (GFATM) has been allocated to scaling up VCT. On the evidence it is difficult to conclude that this has achieved significant success. We have yet to see figures, but it seems unlikely that the target of HIV-testing of up to 500,000 people during 2006 will be reached. It was assumed that around 10% of those tested will be found to be infected, but in fact through the third quarter 2006, only a little over 2000 cases were reported. This either suggests that the wrong people were being targeted or that only around 20,000 people have been tested.

Evidence suggests that indeed the targeting may have been less than ideal, with outreach workers ‘contracted’ to achieve targets of numbers of ‘warm bodies’ presenting for testing. In addition, promotion of VCT has been very low key, if indeed implemented. Even in Jakarta, we still frequently receive questions regarding where VCT can be carried out. In addition, many places

report that charges are levied for VCT, sometimes as high as Rp100,000. Few people are willing to overcome these barriers.

Partnership Fund

In the last report, we noted doubts over whether the promised significant additional funding to Spiritia from the Indonesian Partnership Fund (IPF) would in fact be realised. Following further discussions, Spiritia decided in early 2006 that pursuing funding from the IPF was a distraction, and communicated the decision to terminate discussions with the Fund. Since then, the Fund, through UNDP, advertised a Request for Proposal (RFP) for “Accelerating the National Comprehensive HIV/AIDS Response in 100 districts/cities in Indonesia”. On examination of the terms of the RFP, Spiritia decided that this di not justify any change in our decision to withdraw; indeed it was clear that the RFP was not in fact directed to community organizations, but rather to international bodies. This was confirmed by the single award in October 2006 to DKT Indonesia.

Fortunately, Ford Foundation in Indonesia recognised that the many of the ideas originally proposed by Spiritia for funding by the Partnership Fund should be supported. In mid 2006, Ford thus offered significant additional funding to Spiritia to expand existing programs, and this is already starting to allow increased and more effective activities.

Involvement of PLHIV

As numbers of those aware of their infection increases, so an increasing number are becoming involved, and most chose to do so by joining or associating with peer groups, either existing of by forming new groups. As a result, the voices of PLHIV are being more clearly heard, and pressure to involve them meaningfully grows. More local AIDS Commissions and NGOs are now offering opportunities for engagement, although not infrequently this remains tokenistic.

Increasing calls are being heard from PLHIV activists for the formation of a more independent network, or at least for the network of PLHIV to form some form of independent directing body. A steering committed is in process of formation to look into options and aspirations, with the aim of reporting to the next National Congress of PLHIV in mid 2007.

It must however be noted that the vast majority of identified PLHIV in Indonesia have no great desire to become activists. The challenge of tokenistic involvement can only be addressed if those involved are willing to be empowered, and understand the intent of such empowerment. Recent developments have added to the concern expressed in last years report that ‘empowerment’ is becoming a ‘buzzword’, with limited understanding either of its meaning or its history.

The challenge of ‘representation’ is also becoming more apparent. It is often difficult for activists to really identify with and understand the real concerns of the silent majority of PLHIV. Indeed, such activists frequently have their own agenda, and staff in Spiritia inevitably bring their own views and preconceptions to the table. On the other hand, many PLHIV expect or at least hope that Spiritia and/or the network will address all of their needs. It will be increasingly difficult to satisfy all of these conflicting strains as the network becomes increasingly large and diverse.

PLHIV Meetings

The redirection of strategy from single national to multiple regional entry-level meetings of PLHIV has now been completed successfully. However, except in a few local areas, we have not yet reached the stage where such meetings can be organized and implemented by local groups. Problems still arise in identifying participants, particularly in places were peer groups have yet to form. Potential participants are frequently worried about confidentiality. On the other hand, with numbers of those becoming aware of their infection increasing rapidly, selecting participants in some areas can be a challenge.

Clearly PLHIV come from a wide variety of backgrounds, and finding local speakers who are able to communicate effectively with participants from such varied backgrounds can be difficult. However, these meetings have been most effective in providing broader experience to local organizing groups; formal daily and final evaluations with local organizers have proved extremely valuable for this purpose.

There is a risk of raising expectations and needs among participants that cannot be immediately filled, particularly for those coming from places without any peer group. Clearly we hope that such people will be encouraged to form local groups, but they rarely have adequate skills for this at the early stage, and the entry level meetings cannot offer much help in providing these.

Local Strengthening Visits

Spiritia has now visited, and frequently revisited the majority of provincial capitals, and has developed effective communication with stakeholders at this level. The program of local strengthening visits has now been taken on by local groups, particularly umbrella groups, visiting capitals of districts and municipalities, in a similar way to that originally carried out by Spiritia at the province level. Meanwhile, Spiritia continues to achieve many of the original objectives the program by visiting local stakeholders with representatives of peer groups during regular monitoring visits.

It is however sad that despite continued encouragement, there seems to have been no obvious enthusiasm at a national level to expand this process to include a wider range of stakeholders, to provide a national source of information about the state of the response to the epidemic in all parts of the country. We should again press the National AIDS Commission to make similar visits throughout the country, with teams including PLHIV, other activists, the media, perhaps also parliament, and of course appropriate department representatives, and to provide detailed reports of the findings.

Information Dissemination

The current program of information dissemination is maturing, and it is now time to move to a higher level. Spiritia must provide a wider range of publications, and distribute them much more widely. The newsletters must be reformatted to be more attractive, using colour and graphics, and produced and distributed in a more professional manner. New media must be considered, including comics, and single sheet brochures that are not so formidable to those for whom reading is not a normal daily activity. And we must consider greater use of electronic distribution – CD, VCD, CD-ROM, and DVD.

We continue to see Spiritia publications being the main if not the only source of information in Indonesian on care, support and treatment of HIV for health care workers, especially outside the main centres. There remains a huge unfilled need for such information, and without it, health care professionals cannot develop their capacity effectively. We have started to address this need, but must more swiftly.

The Spiritia web site is proving an extremely valuable and respected addition to this program. Again, it is effectively the only comprehensive and up-to-date source of information on care, support and treatment, both for the community but also for the medical professions. We will need to make it more attractive without adversely affecting access. It needs to be extended to provide the daily treatment ‘news’ that is available from a number of English language sites.

Human Rights

Although an interim dissemination of the results of our human rights survey took place in early 2005, the report is only now being finalized. There is no doubt that this delay has resulted in missed opportunities for advocacy to address the rights violations identified. There have been a number of reasons for this delay, but we do need to address the system weaknesses that allowed this to occur.

We now need to determine whether to carry out a phase 3 survey. One challenge for this is that it is clear that significant changes are required to the instrument to eliminate a number of inconsistencies and confusions. But change to this will mean that results can no longer be easily compared with earlier surveys.

While it is valuable to identify sources of stigma and discrimination, we also need to be more active in addressing the causes of these. One is the lack of clarity regarding the rights (and responsibilities) of PLHIV. A booklet on this topic is becoming increasingly urgent.

We also need to be cautious that our efforts do not strengthen the self-stigmatization that is commonly felt by PLHIV, especially in the aftermath of an HIV diagnosis. As noted, there have been significant improvements in regard to community and professional discrimination in certain areas, and this has occurred at least in part as a result of empowered PLHIV providing strong role models.

Skills Development Training

Although topics vary, one common objective of the training carried out by Spiritia is to provide skills as a trainer to participants. We always hope that they will share the skills and knowledge that they have gained during the training with other members of their groups, and clearly this requires specific skills. To achieve this, we have considered running dedicated 'training of trainer' courses, but we neither have the capacity nor the time to do so.

To address this, we have taken two approaches. The first is to include basic sessions on adult education in other courses where time allows – the Treatment Educator course includes two such sessions. The second is to involve alumni from earlier courses as trainers in later trainings, and provide these speakers with coaching prior to the start of the formal course. This is also done during the Treatment Education courses, as described above. We need to extend either or preferably both of these approaches to other trainings.

Although require that participants meet determined criteria, it is difficult to insist on this. The result is that there are frequently one or two participants on each course who are out of their depth. While they may gain something, they can also hold back other participants. Perhaps we need to consider same form of pre-attendance evaluation to attempt to avoid this waste of resources and disturbance of others.

Spiritia usually tries to involve local stakeholders as speakers where appropriate, for example to introduce the role of the AIDS commissions during the Treatment Education training. Unfortunately these speakers sometimes lack both knowledge of the topic and communication skills, so that the result is disappointing. Whether the advocacy benefit exceeds these drawbacks is sometimes questionable.

Although we hold pre- and post-tests, plus daily and final evaluations, it is difficult to determine the extent to which the skills and knowledge provided are actually used by participants. We should consider some form of assessment (say) three months following the courses, to attempt to get a better feel for this.

With an increasing number of people aware of their infection, and a growing number of peer groups, demand for training is far outpacing our ability to provide it. We plan to expand to one course per month over the coming year, but even this will make only a relatively small impact. One consequence of this is that selection of participants is becoming increasingly difficult, and fraught with disappointment or charges of preferential treatment. We have relied on peer groups to assist in this process, but the groups are not always able to take an objective approach, especially where there are several groups in one place.

Peer Support

Although 35 new peer support groups were formed over the period, this is not a significant increase over the previous period. Yet with the large jump in the number of people aware that they are infected, plus the scale up of ART, the need continues to accelerate. While it may be too early to say that each district/municipality (440 throughout the country) needs at least one group, multiple cases of infection have officially been reported from 110 districts/municipalities, whereas there are now groups in less than 50. It is clear that we need to keep up the effort of identifying potential group founders, and support and encourage them to organize.

On the other hand, it is encouraging to see a growing number of more specialised groups forming, particularly those for women (now seven). There has however been little progress in forming parent/family groups (still only four). In addition, there must be a growing need for groups

specifically for mother of young infected children, and later groups specifically for those children as they grow older.

Progress in development of umbrella groups has also been discouraging, with one (JOY, one of the original role models) actually disbanding during the period, and no real progress made in the two places where umbrella groups are most urgently needed: Jakarta and Surabaya. There are several groups demonstrating potential to take on the role of umbrella groups, but discussion at the annual evaluation indicated that there is need for more guidance on the roles and activities of such groups. We need to respond to this quickly.

As the number of groups increases, we will be faced with the challenge of ensuring a common vision. This was also brought up at the evaluation: Do we accept groups that are primarily concerned with providing services to PLHIV? How do we respond to groups who may only be developing dependency among members? These matters will need to be considered quite soon.

A related concern raised at the evaluation was the splitting of groups because of differences of vision or approach, with unsatisfied members leaving to form breakaway groups. While it is hoped that this can occur without recriminations, such situations will occur.

One consequence of the wider availability of ART is that PLHIV are beginning to look forward to a ‘normal’ life, with a future, a family, a house, even a pension. We can no longer expect them to work as unpaid volunteers in peer groups; we must offer them prospects, even a career path. Groups are already losing some of their best people to other jobs (including positions with the Global Fund or with AIDS commissions). We should be glad of this, but we also need to be able to compete, and attract/retain capable people with vision within the peer support network. Thus ‘limited funding’ of peer groups, covering only the cost of activities, is no longer a satisfactory solution; we must also offer funding to provide staff with a salary. This will offer a new challenge: how to assist groups to select those to receive salaries from among their current volunteers, recognizing that only a small number can be funded.

National Meeting of Peer Support Groups

A growing challenge with such large meetings is that Spiritia becomes increasingly busy with organizing the meeting, leaving Spiritia staff little time for interaction and discussion with participants outside sessions. The result is that we lose a major opportunity, as well as sometimes appearing to be aloof. We need to make more use of event organizers, and separate organizing committees, to allow this important objective of such meetings to be achieved.

Spiritia staff and representatives of peer groups presented most of the sessions, with the objective of increasing their capacity. However, it appeared that participants would have preferred a wider range of materials related to HIV/AIDS, with greater involvement of outside speakers.

Active drug use or relapse by more than a dozen participants represented a major challenge. As a result, several participants missed a number of sessions, and their behaviour also adversely affected other participants.

Indonesian PLHIV Network

During the year, the topic of developing a more formal national network of PLHIV with an independent structure was raised again. Spiritia welcomes this discussion, and has facilitated initial steps to form an independent steering team to develop proposals regarding function, role, form, structure, membership, etc. of the network. It is hoped that the steering team, which is currently being chosen by existing network members, will report to the next National PLHIV Congress in mid-2007, at which time will be provided to discuss the proposals and make a decision regarding action.

At the same time that this process was being developed by Spiritia, four PLHIV from Indonesia developed an initiative to regenerate the network with support by the Asia Pacific Network of PLHIV and parties. However, this initiative differed from that being implemented by Spiritia, and resulted in the appearance of conflict, with charges of bias being made. Several parties including Spiritia are attempting to find a compromise. Spiritia is willing to transfer its current process to

anyone from the network that is willing to take responsibility for it, but unfortunately so far none has come forward.

Since women are clearly more vulnerable to HIV infection, and once infected they are more likely to experience discrimination, several HIV-infected women took the initiative to form a national network of women with HIV. This network, supported by Spiritia, was selected to hold a national congress of women living with and affected by HIV prior to the upcoming national AIDS meeting.

Drug Use

We have previously noted the challenges resulting from the fact that the majority of members of the network have a background of injecting drug use. Indeed, it is crucial that we reach out to drug users and ensure that active users can access peer support, i.e. groups that are primarily formed from those currently using drugs. Yet this raises the question of how we involve them in general activities. One active user can provide the stimulus for those in recovery to relapse. For example, at the recent meeting of peer groups, at least ten participants were reported to relapse. We cannot take responsibility for this, but there are possible legal consequences if we turn a blind eye. In addition, the (mis-)behaviour of a small number of active users at meetings can seriously disturb other participants.

We have attempted to identify solutions used by other organizations either local or overseas, but while some specifically drug-user focussed organizations have suggested ideas, these would be difficult to implement in activities involving people from other backgrounds. For example, one proposed solution is to hold meetings in remote locations where access to drugs is difficult, as was done during the recent Jangkar jamboree. But few other network members would relish the idea of meetings held in tents in the middle of the forest!

We also need to involve peer groups in identifying approaches to this challenge, including greater attention to this in selecting candidates to attend meetings. However, we cannot ignore the needs of active or relapsing users with HIV, and need to identify other approaches to ensuring their effective involvement.

Representation in International and National Forums

As in the past, Spiritia has been bombarded with invitations to attend both local and regional/international meetings as participants or speakers, as well as to join committees and panels, often requiring significant investment in time. The local requests frequently arrive with very limited notice. While this reflects a growing willingness to accept the GIPA principle, it is often difficult for us to respond. Where possible we offer opportunities to groups within the network, but with the limited notice, it is often difficult to arrange transparent selection, and often the deciding factor is knowledge of English and the possession of a valid passport.

We need to develop the skills, both language and knowledge, of members of the network, and especially of those chosen for task such as membership of APN+ board, to assure that those selected can participate fully, and not just as tokens.

Human Resources/Staff Development

As Spiritia scales up to respond to the increasing challenges and in line with a significant expanding work plan, we will be almost doubling the number of staff. Candidates will be selected primarily for their experience and capability, rather than because they are infected or affected by HIV. Spiritia has up to now been akin to a family organization, and although great strides have been made in professionalism over the last few years, we still have some way to go. Integrating so many new staff without the ‘soul’ of AIDS over next few months will be a major challenge, and no doubt some mistakes will be made. However, a new structure is in place, developed with the help of the management consultants, and there is a determination by existing staff to make this work.

It will be crucial to immerse the new staff members in the AIDS world as swiftly as possible, by involving them in activities with the network. On the other hand, it will be necessary to train/retrain existing staff members to carry out their new, more narrowly defined tasks, and improve their

professionalism. And all this must be achieved without losing contact with the grass roots, and retaining the flexibility and 'can-do' attitude that has characterized Spiritia's approach up to now.

Conclusions

Spiritia's strategy of concentrating on development of peer support groups, and encouraging selected groups to become 'umbrellas' is now beginning to mature and bear fruit. By this means, and increasing number of individuals infected and affected by HIV are being reached and supported. Although this strategy raises the risk that Spiritia will become remote from the grass roots, this risk is being reduced by regular visits and meetings, and continued direct communications.

However, we cannot yet claim success. Less than 100 groups clearly cannot support effectively a population of 250 million, especially when compared with 490 groups in Cambodia and more than 900 in Thailand, each with much smaller populations, although it must be noted that many of these groups have been formed as a result of government action, rather than as a result of grass-roots action as is the case in Indonesia. To ensure that this bottom-up approach develops more rapidly, groups need adequate funding to provide a competitive wage and a future for at least the main staff. Other PLHIV involved as 'volunteers' must be provided with the means to survive, and preferably offer a future. This means real involvement, not just as tokens or members of committees, but in a way that makes use of their real expertise and experience.

Spiritia is now in the early stages of a significant scaling up process, as a result of a four-fold increase in funding. Such rapid expansion would offer challenges for any organization, and is not without risks. The formal strategic planning process carried out with the help of professional consultants will reduce the risks, and help to assure that Spiritia continues to develop into a more professional organization, providing efficient and effective services in response to the epidemic.

However, despite the scale up, it will be essential for Spiritia to remain focussed on its main objectives. In responding to the inevitable criticisms, Spiritia will need to remain humble, yet determined, and not be swayed by unreasonable demands or complaints. Spiritia will also need to be nimble, rapidly responding to changes in the epidemic and the responses of others, particularly if the anticipated major scale up of VCT ever occurs. And all this must be done without loss of contact and understanding with the grass roots, not only those who have no interest in activism, but also those people with HIV who are not yet aware of their infection.

Recommended Actions for the Future

Last year, we noted that the peer response required significant additional funding to address the rapidly growing needs for peer support for people living with and affected by HIV in Indonesia. In the event, the discussions with the Partnership Fund did not bear fruit, but happily Ford Foundation offered to fill much of the funding gap. This additional funding started flowing in August 2006, and will continue through January 2008.

1. The main focus of this funding has been to scale up support to peer support groups:
   - Currently there a peer support groups in 27 provinces; this must be extended to at least 33 provinces, with West Sulawesi following soon after.
   - In addition to the current four umbrella groups, which must be further strengthened, there needs to be umbrella groups in at least a further nine provinces, and groups elsewhere must be encouraged to develop in this direction.
   - Massive scale-up of peer support activities must continue to be a priority, with the objective that at least 150 groups would be in operation around the country by the end of 2007, supported by the 13 umbrella groups.
   - It will be necessary for Spiritia to provide limited funding to at least two-thirds of these groups, including grants to many of these groups to allow them to employ staff.
   - Umbrella groups must be encouraged to become self-sufficient, able to raise funds from other sources and provide technical support to groups under their umbrella.
   - To support this process, it will be necessary to strengthen and develop programs and support systems for fund raising and income generation, including rolling credit and technical support to assure success.
2. Up to now, Spiritia has invited participation and input into its annual evaluation by PLHIV, those affected and peer groups from around the country. In the future, Spiritia should also involve other stakeholders, such as NAC, implementing agencies, government departments and the community.
3. Spiritia’s training efforts must be more formalised, with more forward planning, development of new and more professional modules (including advanced treatment educator, strengthening peer groups, and advocacy), training of facilitators, as well as improved selection and evaluation of participants. Spiritia must also develop a database of PLHIV who have attended any form of training, not only that offered by Spiritia.
4. The recently issued Presidential Decree No. 75/2006 on the NAC offers the opportunity to press for peer groups to be offered seats on local AIDS Commissions, and this must be followed up.
5. Spiritia must continue to advocate for extension of the free treatment program, to assure availability of appropriate second line regimens, access to CD4, viral load and resistance testing, as well as sustainability and scale up as more PLHIV start treatment.
6. Spiritia should set up an independent process to monitor reach, extent and quality of CST-related programs, including standards of VCT, availability of drugs, and cost at point of care. This should also include development of a referral database, listing CST-related sites, organizations and individuals.
7. Spiritia should build upon the early success of its web site, to ensure that it becomes a prime source of information for health care providers as well as PLHIV and peer groups. Further, Spiritia must more widely distribution its printed booklets to reach a wider public.
8. The ‘HIV Stops Here’ initiative must be developed to become a more concrete program, better understood by peer groups, and extended its reach to the medical profession, and promoted to the community.
9. Time must be found to provide skills development training for Spiritia staff, particularly in management and supervision.
10. Ways must be found to respond to the nutritional needs of indigent PLHIV, in cooperation with all parties concerned. This is particularly crucial for Papua.

Appendix 1: Annual Evaluation 2005-2006

Background

Spiritia held its annual evaluation for the period 1 November 2005–30 September 2006 on 29–30 September 2006. Besides all Spiritia staff, 20 members of the national PLHIV network from 13 provinces attended representing the clients of Spiritia's programs. Dr. Mangku Karmaya, KPAD Bali, facilitated the two-day meeting at the Hotel Acacia in Jakarta.

Assessment Questionnaire

Note: In this report, figures in parentheses are for previous report.

Prior to the meeting, all members of the PLHIV network had been asked to complete a questionnaire of 15 questions, which had been sent to 430 (325) members of the network, both infected and affected, in 40 (45) towns in 25 (26) provinces. A total of 275 (101) questionnaires were returned completed, more than double the number from the previous year, with 64 (59) per cent by members who had been involved in the network for less than two years. This relatively high number is not significantly different from the previous year, continuing to reflect the rapid scale-up in membership over that last several years. Almost 60 per cent had become aware of Spiritia through friends.

The most significant results were:

- 92% (96%) felt that involvement with Spiritia was beneficial in finding friends
- 94% (98%) agreed that they had received valuable information support from Spiritia
- 91% (99%) felt empowered, with 89% (89%) of these acknowledging that Spiritia had played a role in this empowerment
- 74% (90%) have become involved in AIDS programs in their areas, with 87% (91%) of these reporting Spiritia had played a role in this involvement

A separate questionnaire with ten questions was sent to 75 (52) peer support groups, of which 48 (19) were returned, 66 (50) per cent of which stated that their groups had been involved with the network for less than two years.

The most significant results were:

- 80% (98%) stated that Spiritia had been instrumental in the formation of their group, of which 21% noted that the most important role provided was that of limited funding
- 58% (100%) agreed that their groups had benefited from the moral and information support provided by Spiritia
- 94% (94%) stated that technical support from Spiritia, and their involvement with the various activities organized by Spiritia, had been beneficial in empowering and strengthening their groups

As before, the questionnaires provided space for respondents to indicate the needs that they hoped could be met by Spiritia or the network. A wide variety of responses were received; some are beyond our means, but others will provide ideas for future development.

Evaluation Agenda

- Results of questionnaire
- Description of Spiritia program
- Goals and main objectives
- Skills development training
- PLHIV meetings
- Information dissemination
- Peer support group development
- Other programs
- Lessons learned

Summary and conclusions

For each of the main topics, the Spiritia staff member responsible first described the program. This was followed by a brainstorming session, and finally the discussion points were classified for later inclusion into the lessons learned.

Discussion Sessions

A wide range of matters was raised in the brainstorming sessions. An effort was made to ensure the comments were balanced, and in general some constructive criticism was aired, and participants suggested some useful and stimulating ideas for future programs.

Lessons Learned

A separate report has been prepared detailing the input provided by the participants. There were no overriding themes raised requiring major attention; rather there were a large number of detail points, complementing those from the questionnaires, which will be used to guide future programs.

Appendix 2: Details of Peer Support Groups

Map showing locations of Peer Support Groups

Appendix 3: IEC Material Published 2005/2006

Spiritia published the following books and other information materials over the period. Copies of these are available on request:

- Hidup dengan HIV/AIDS (Living with HIV/AIDS) – reprint
- Pasien Berdaya (The Empowered Patient) – reprint
- Terapi Alternatif (Alternative Therapy) – reprint
- Pengobatan untuk AIDS: Ingin Mulai? (AIDS Therapy: Want to Start?) – reprint
- HIV dan TB (HIV and TB) – first printing with support from OSI, reprinted
- Lembaran Informasi tentang HIV/AIDS untuk Orang yang Hidup dengan HIV/AIDS (Odha) (122 Fact Sheets on HIV/AIDS for PLHIV) – photocopies, many sheets updated
- Self Empowerment to Face HIV/AIDS in Indonesia – Spiritia Profile – revised and printed
- "Cipayung" Statement (Declaration by participants of 3rd National Peer support Groups Meeting) – photocopy version in English and Indonesian
- Report on Activities 2004/2005 – photocopy version in English and Indonesian
- Newsletter Senandika – every month
- Newsletter Sahabat Senandika – every month

Other IEC materials not revised:

- Hepatitis Virus dan HIV (Viral Hepatitis and HIV) – photocopy version
- HIV, Kehamilan dan Kesehatan Perempuan (HIV, Pregnancy and Women's Health) – photocopy version
- Pemberdayaan Positif (Positive Development) –support from AIDSFonds
- Dari Prinsip ke Praktek – Keterlibatan Lebih Besar Orang yang Hidup dengan HIV/AIDS (From Principle to Practice – Greater Involvement of People Living with or Affected by HIV/AIDS – GIPA) – photocopy version
- Merawat Odha di Rumah (Home Care of PLHIV) – photocopy version
- Perawatan AIDS di Luar Rumah Sakit (AIDS Care outside the Hospital) – photocopy version
- Mengangkat Beban Kerahasiaan: Pedoman Berbicara di Depan Umum untuk Odha (Manual on Public Speaking for PLHIV) – photocopy version
- Mengangkat Beban Kerahasiaan: Modul Pelatihan untuk Pembicara HIV-Positif (Training module for above manual) – photocopy version
- Berdayakan Diri Menghadapi AIDS (Self Empowerment to Face HIV/AIDS – Spiritia Profile) –photocopy version
- Ketika Temanku AIDS (If My Friend has AIDS) – printed card
- Kepatuhan? Huh? (Adherence? Whazzat?) – draft four page photocopied brochure

Appendix 4: “Cipayung” Statement

Declared by Participants of the Third National Meeting of Peer Support Groups for People Living with and Affected by HIV – 2006

This “Cipayung’ Statement represents one output of the Third National Meeting of Peer Support Groups in September 2006, which was attended by representatives of 81 peer support groups (including four provincial umbrella groups) from 47 districts/municipalities in 26 provinces. Through these peer groups we have supported around 3000 people living with HIV (PLHIV) and more than 3000 people affected by HIV.

We declare that we are serious in our wish to play an important role in the response to HIV/AIDS, and in advocacy efforts directed towards all stakeholders at national and local levels. We therefore state a number of important matters as follows:

- We fully support the Cikopo, Tretes, Bali and Lembang Statements. Here we reassert outputs that may not have been optimally declared in those statements. In the Cipayung Meeting, we also announce a number of important points that were not accommodated in the previous statements for immediate implementation.
- There are now four provincial umbrella groups and 86 peer groups for PLHIV/affected people in at least 50 districts/municipalities in 26 provinces, including specific groups such as for transsexuals, gays, methadone users, injecting drug users, women, parents, partners, nurses and carers.
- We need the full support from all parties, particularly central and local government, as well as donor agencies, to help us to encourage and facilitate the formation and development of peer groups in every district/municipality. This must be done with due concern for the principles of autonomy, confidentiality, friendship, equality and mutual benefit.
- We appreciate the full support of the government in providing first and second line antiretroviral (ARV) drugs with full subsidy. These ARVs have allowed us to remain healthy so that we can work and engage in the HIV/AIDS response. We hope that this policy of providing first and second line ARVs will continue to be fully supported and extended to include pediatric treatment, CD4 tests and treatment for opportunistic infections everywhere that they are needed, as well as viral load and resistance testing which can be easily accessed in many places.
- Harm reduction, in particular methadone substitution and distribution of needles and syringes, must be implemented as national programs in every district/municipality. Injecting drug users who are detained by police for drug use should be offered rehabilitation.
- Comprehensive programs providing voluntary counseling and testing (VCT), antiretroviral therapy (ART), prevention of transmission of HIV from mother-to-child (PMTCT, provision of condoms and methadone maintenance as well as needles/syringes should be available in community health centers. All of these services must address availability, distribution processes, access to services, as well as monitoring and evaluation.
- Universal precautions are not well implemented, and must be enforced more seriously at all levels of the health service. Availability of hospital wards and comprehensive laboratory facilities must also be addressed. In connection with this, it is necessary urgently to increase the number and quality of general practitioners, specialists and dentists, nurses, midwives and laboratory staff, as well as counselors for VCT and ongoing counseling.
- We support eh acceleration program for 100 districts/municipalities, but there are many other districts/municipalities that are potentially high risk and must be given the same consideration in the response to HIV/AIDS, which can explode at any time.
- Peer groups play an important role in supporting, empowering and encouraging involvement of PLHIV/affected people in the response to HIV/AIDS, particularly in breaking the chain of transmission through moral support, information, skills and addressing the needs of PLHIV.
- Peer groups are ready to fully assist HIV/AIDS control programs at national and local levels. Thus all stakeholders, in particular national and local government, donor agencies, and provincial and district/municipal AIDS Commissions, as well as the National Narcotics Board

must actively involve peer groups as equal working partners in all HIV/AIDS activities at national and local levels.

- PLHIV/affected people require the same treatment in social life, education, employment, services, treatment and support for all aspects of their lives.
- VCT services are now available in a number of hospitals in several areas. But the reality is that the public is still reluctant to access VCT in hospitals, so there is a need for NGOs to provide voluntary and independent counseling services that are friendly in every district/municipality. The quality of the voluntary counseling services must be assured, not just aimed at achieving targets.
- We agree to build and enhance cooperation and networking among peer groups throughout Indonesia. Peer groups with the capability should become umbrella groups, facilitating the needs of other groups in their areas in an equitable and independent manner, at district/municipality, province and national levels.
- National and local AIDS Commissions in accordance with their function, must be more proactive in advocacy, become data centers, encourage the formation of NGOs, facilitate program funding support for the community, and carry out monitoring and evaluation of the response to HIV/AIDS. The National AIDS Commission must involve PLHIV/affected people in all working groups, the secretariat, and all other activities in accordance with the capability of the PLHIV/affected people.
- To increase public awareness of the dangers of HIV/AIDS and to reduce stigma and discrimination, PLHIV/affected people, religious and community leaders, the private sector and community organizations have no choice but to become immediately involved in a concrete significant and equitable manner.
- The national and local government must allocate and facilitate funding budgets for the HIV/AIDS response in every government sector.

We make this statement as an effort to encourage concern and responsibility that is never easy.

HIV/AIS clearly needs everyone’s concern.

Let us strengthen our aim; hand in hand we will walk together with the warm breath of endeavor.

We love our country!

Appendix 5: Photographs of Activities

The 3rd National Meeting of Peer Support Groups, Puncak – September 2006

Regional PLHIV Meeting, Padang – April 2006

Treatment Educator Training, Jogjakarta – December 2006

Peer Support Group Training, Mataram – July 2006

Monitoring Visit, Salatiga – November 2006

FHI Consultancy, Sorong, Papua – February 2006

Book Launching, "Dua Sisi Dari Satu Sosok", Suzana Murni – May 2006

Strategic Planning with Umbrella Group, Medan – November 2006

Annual Evaluation, Jakarta – September 2006

Visit to Spiritia by Mrs. Tony Blair – March 2006

Spiritia Open House in New Office – August 2006

Spiritia Staff Members – December 2006