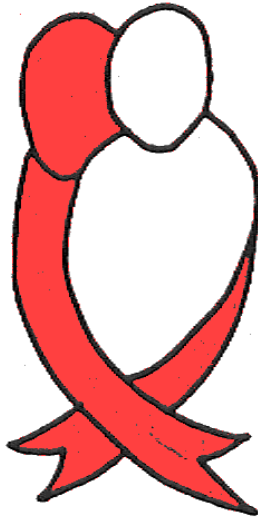


Yayasan Spiritia



Report on Activities 2002/2003

Period of Report: 1 June 2002–31 May 2003

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Acronyms and Abbreviations

AFAO	Australian Federation of AIDS Organizations
APN+	Asia Pacific Network of People living with HIV/AIDS
ASA	Aksi Stop AIDS (USAID-funded AIDS project)
ASO	AIDS Service Organization
AusAID	Australian Agency for International Development
Depkes	Ministry of Health (from Indonesian)
Dinkes	(Provincial or District) Health Service (from Indonesian)
GFATM	Global Fund to fight AIDS, TB and Malaria
GIPA	Greater Involvement of PLHAs
GNP+	Global Network of People living with HIV/AIDS
IEC	Information, Education and Communication
IHPCP	Indonesian HIV/AIDS/STIs Prevention and Care Project (funded by AusAID)
JOY	Jaringan Odha Yogyakarta, the Jogja peer support group for PLHAs
KPA	National AIDS Commissions (from Indonesian)
NGO	Non-governmental Organization
PLHA	People Living with HIV/AIDS
PLKN	National Leprosy Training Center (from Indonesian)
PNO	National PLHAs Meeting (from Indonesian)
STI	Sexually transmitted infection
Stranas	National Strategy on HIV/AIDS (from Indonesian)
UNAIDS	United Nations Joint Programme on AIDS
UNDP	United Nations Development Programme
UNV	United Nations Volunteers
UPC	Universal precautions
USAID	US Agency for International Development
VCT	Voluntary counseling 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/AIDS (PLHAs), 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 PLHAs in the response to the epidemic at national, regional and global levels.

The Spiritia workplan is designed to turn this principle into practice in Indonesia. All activities have been developed and implemented with the objective of empowering and encouraging PLHAs to play a more active role 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 PLHAs in Indonesia.
- Encourage involvement of PLHAs 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 PLHAs to play their role more effectively as vital stakeholders in AIDS programs and policy.
- Support and encourage PLHAs 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 PLHAs in their activities.

Results and Success Measures/Achievements

Only a small minority of PLHAs in Indonesia is aware of their HIV status; some 5,000 out of an estimated 130,000 people infected by HIV. Spiritia’s programs are primarily focused upon those who are willing to identify themselves as HIV-positive, but are also designed to encourage those who have been at risk to come forward for testing, and to ensure that such testing and the follow-up are non-discriminative and friendly.

As secretariat of the Indonesian PLHA network, Spiritia is in contact with more than 100 PLHAs throughout the country. Almost all agree that involvement in the network has improved their lives: by proving that they are not alone; through ongoing peer support; and by providing them with meaning to their lives.

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 June 2002–May 2003, followed by a summary of the main barriers and strategic changes. Selected photographs depicting the main activities may be found in Appendix 2.

There has been a marked improvement in understanding and acceptance of the principle of greater involvement of PLHAs (GIPA), particularly at the central government level, with the National AIDS Commission (KPA) and Ministry of Health (Depkes) leading the way. Examples have been invitations to join in the development of the revised national strategy on HIV/AIDS (Stranas), and of national treatment guidelines. In addition, the number of PLHAs speaking in public in a wide variety of forums has both supported and accelerated this process.

However, the initial objective is to encourage PLHAs to play an active role in their own lives, in their own health. The process of testing for HIV often results in a reduction in self-esteem and a feeling of worthlessness. The process of empowerment of PLHAs must start by proving that they are not alone, and that they have the capability to make a real impact on the epidemic. Skills development is an essential part of this process, and has proved remarkably effective in improving the quality of life of PLHAs.

Although Spiritia coordinates the national network of PLHAs, there is no intention to open branches outside Jakarta. On the contrary, Spiritia's program is designed to encourage and empower PLHAs in the regions to form local peer support groups. There has been significant progress towards this objective over the last year, with the formation of peer support groups in more than ten places around the country.

The GIPA principle also requires that AIDS service organizations (ASOs) involve PLHAs in their planning and program implementation. Although this has been a focus of Spiritia activities, especially during local visits, we have shown less success in achieving this objective.

National PLHAs Meeting

The prime vehicle for encouraging empowerment has been the national PLHAs meeting (PNO). The third national meeting of PLHAs was held in February 2003, attended by 50 people, 80 per cent HIV-positive. This four-day meeting was primarily aimed at those who had had little previous involvement, in many cases little if any contact with their peers. Thus the main objective of the meeting was to provide basic information and to encourage sharing of experience, feelings and information among participants. Based upon final evaluation by participants, and discussions during and after the meeting, these objectives were achieved.

Skills Development Training

Effective involvement, as experts rather than tokens, requires that PLHAs possess the necessary skills. While many of those who are diagnosed HIV-positive have capability, few have the necessary skills, and many suffer from low self-esteem, often as a result of testing that is not in accordance with the laid-down procedures. Thus one element of Spiritia's program has been to offer skills development training for PLHAs, in a way that also attempts to improve self-esteem. Over the period, more than 30 PLHAs were provided with skills training, in courses on public speaking, and on formation and management of peer support groups. Modules for both of these courses have been developed and tested, and are available for use by other groups. Success of this training can be seen in the number of PLHAs speaking out effectively, and in the development of peer support groups referred to above.

Local Strengthening Visits

As noted, it is difficult to make contact with PLHAs around the country, many of who are unwilling to communicate their status outside a small group of family or care providers. In addition, the challenges faced by PLHAs around the country vary greatly, and it is crucial for Spiritia to understand these differences if PLHAs are to be represented effectively at national and regional levels. Thus one important activity has been local strengthening visits, carried out by teams of around four people, including those who are openly HIV-positive, and members of the network as well as Spiritia staff. Since this activity started, visits have been made to more than 30 towns and cities in 19 provinces.

Apart from meeting local PLHAs and ASOs in the places visited, the teams have also met with doctors and nurses, hospital management, local AIDS commissions (KPAD) and local health service (Dinkes) officials. It became clear early on that these visits offered a unique opportunity for advocacy in support of PLHAs and the more general response to HIV/AIDS in the places concerned. One major reason for this was the impact made by confident and skilled PLHAs on the teams presenting their case persuasively; in many cases those met had never before had contact with an openly HIV-positive person. Invitations were sought to meet with local government (usually vice-governor) and legislatures (usually Komisi E). In many cases, team members also

appeared on local radio and TV talk shows. Feedback following visits indicates significant success in opening doors and starting dialogue between local NGOs and decision/policy makers.

One specific outcome of this advocacy was the agreement by several local administrations to consider providing funds for a number of local PLHAs to access antiretroviral therapy. As a direct or indirect result, at least five provinces have now budgeted funds for over 100 PLHAs to receive this therapy.

In most of the places visited, the teams managed to meet with at least one 'new' local PLHA, thus significantly expanding the network. In many places, at least one local PLHA was deemed to have capability for further empowerment, with follow-up skills development opportunities being offered.

Information Dissemination

One essential of empowerment is provision of information. Spiritia has attempted to address this need by distribution of monthly newsletters and by publishing a number of books and other material for PLHAs in Indonesian language. *Senandika*, a monthly newsletter aimed solely at PLHAs in the network, is primarily a vehicle for strengthening and maintaining the network, offering space for PLHAs to communicate with each other, and to share experience, feelings and information with their peers around the country. Feedback indicates that this has been a much appreciated medium, but that efforts are needed to make it more attractive and readable, criticism which has since been addressed.

During the period, Spiritia commenced publication of a further newsletter, *Sahabat Senandika*, intended as a medium to disseminate information more widely to individuals and organizations supporting PLHAs. Contents include articles on advocacy, developments in treatment and care for PLHAs, and reports of Spiritia activities and other matters of interest. This is now distributed monthly to more than 400 recipients.

Early on, Spiritia identified a need for a set of booklets for PLHAs on the basics of HIV and AIDS for those infected and affected. Three booklets were published: *Living with HIV/AIDS*; *Empowered Patient*; and *Alternative Therapy*. The first two of these were somewhat dated, so *Living with HIV/AIDS* was revised and reprinted in a more easily read format during the period. Feedback on this was very positive, and the second book has now been revised and is in printing in similar format.

In addition, three additional booklets on treatment were produced in draft format, in photocopied form. These cover home care from the viewpoint of family carers, caring for oneself outside the hospital, and information on antiretroviral therapy to assist PLHAs in making a decision to start treatment and understand the benefits and drawbacks. There are plans to print at least two of these over the coming year.

To provide more detailed information on treatment, Spiritia now publishes a series of 71 fact sheets for PLHAs, covering antiretroviral therapy, drugs, side effects, opportunistic infections, and other health-related matters. Although focused towards PLHAs, these have proved very popular among health care workers, since no other source of such information is available in Indonesian.

Development of Treatment Expertise

Empowerment of PLHAs requires that they become knowledgeable about developments in treatment, which take place rapidly and continually. The Spiritia work plan includes an activity to develop treatment expertise among PLHAs, and it was planned that this would take the form of regular meetings in Jakarta to discuss developments, and to train PLHAs to become proficient in accessing information, both from the Internet and from other sources. For a number of reasons, this has yet to commence in the form envisaged, but some of the objectives of this activity have been achieved by dissemination of the fact sheets referred to above, and in discussions and presentations during the local visits. Nevertheless, the need remains for development of treatment educators who can access information themselves from the available sources; challenges related to this will be discussed in the following section.

Human Rights

Spiritia was the key implementer of a project for documentation of violations of human rights of PLHAs, carried out in four Asian countries under the auspices of the Asia Pacific Network of PLHAs (APN+). The main finding of this project, which involved interviews of 42 PLHAs by HIV-positive interviewers, was that many PLHAs around the country had experienced discrimination at the hands of health care providers. Although this was carried out prior to this period, the results were disseminated at a workshop in Jakarta in November 2002. This was attended by more than 100 government officials, health care workers and activists, and facilitated a better understanding of the problems. The meeting was followed up with a comprehensive report in both English and Indonesian, which has been widely circulated around the world. However, the challenges to improvement remain huge, and it is not clear how these can be addressed.

Other human rights activities planned include dissemination of information on human rights to network members, and the monitoring of violations, including by media watch. Although this has been started, it has yet to show significant results.

Representation in International and National Forums

As secretariat for the Indonesian network of PLHAs, Spiritia is also responsible for providing representation at the regional level through APN+. The Indonesian representative on APN+ is Frika Iskandar Chia, and she has also been elected as one of the APN+ representatives to the global network, GNP+. Frika also works as a part-time staff member of Spiritia, and Spiritia supports her work, with reports on regional activities being disseminated to the Indonesian network through the newsletters.

Additional regional activities supported by Spiritia over the period have included attendance by two PLHAs at the Muslim Leaders meeting in Malaysia, and participation by two other PLHAs from the network in a regional meeting in Bangkok. Again reports on these meetings have been published in Spiritia newsletters.

One essential element of GIPA is the participation of PLHAs in national forums, and efforts have been made to solicit and accept invitations to such meetings. One highlight was the presentation by a group of more than ten PLHAs from around the country at the opening of the national consultation on HIV/AIDS at the Nam Centre in 2002, a meeting attended by more than 200 KPAD and NGO representatives from around the country. This provided an opportunity to present the hopes for outcomes of the meeting by the positive community; its success was indicated by the fact that the Minister of Health referred to the points raised in his opening speech. It also provided an opportunity for the group of PLHAs to have a brief closed meeting with the Chairman of the KPA and the Minister of Health, at which several concerns were discussed.

Other participation included involvement in development of the revised national strategy, which considerably strengthens the care and support elements of the response; involvement in development of national guidelines on care and treatment for PLHAs to be published in August 2003; participation on other KPA meetings; and attendance as resource people in a variety of workshops and training sessions.

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

- Spiritia was one of five NGOs from around the world to receive a special award from FHI at the Barcelona AIDS Conference
- Five members of the network attended the Barcelona AIDS Conference; one presented an oral paper, and two others presented posters
- Among these Spiritia Barcelona participants, two were chosen to join an MTV youth dialog with many celebrities, including President Bill Clinton
- Among many other distinguished visitors to the Spiritia office, we were honored to receive Dr. Peter Piot, Executive Director of UNAIDS

- One Spiritia staff member and one PLHA from the network were invited to attend the International Roundtable on Increasing Access to HIV Treatment in Resource Poor Settings, held over five days in Canberra, Australia
- An article about Spiritia's activities was included in a special Asia edition of the monthly magazine HIV Australia, published by the Australian Federation of AIDS Organizations
- One Spiritia staff member has been selected as a member of the advisory panel of the bi-monthly HIV & AIDS Treatment in Practice, published by the National AIDS Manual in the UK
- Several articles describing Spiritia activities have appeared in the Jakarta Post and Kompas dailies, and in the weekly Tempo
- One Spiritia staff member was requested to carry out a 45-day survey of the needs of PLHAs and how these are being met, together with operational research on documented responses, as a consultant for the AusAID-financed Indonesia HIV/AIDS & STIs Prevention and Care Project (IHPCP)
- Spiritia has received prime funding for major activities and secretariat/staff from Ford Foundation. Supplementary funding for several activities was received from a number of agencies, including IHPCP, the USAID-funded ASA project, and UNAIDS. This funding has been used to fund attendance of activities by additional participants, and to add additional places to the list of towns visited. Dissemination of the Human Rights report was also supported by these agencies
- AusAID Jakarta granted Spiritia a used vehicle which was surplus to agency requirements, after reviewing proposals from a number of organizations around the country

Special Funds

Most PLHAs in Indonesia come from a low economic level, and few are formally employed. Thus infection with HIV can result in severe economic hardship, often for the lack of relatively small sums of money. In an attempt to assist in addressing this, Spiritia many years back instituted a special support fund, called the Positive Fund, to offer emergency loans or grants to PLHAs in difficulty. These funds are available for such needs as payment of hospital treatment, drugs for treatment of opportunistic infections, purchase of food supplement for those with wasting, and renting accommodation in case of eviction. The Positive Fund can also provide small sums as micro-credit to allow PLHAs to start small businesses. Funds are solicited from Spiritia staff, visitors, and participants at Spiritia activities. Financial reports are included in the monthly newsletter, to assist in promoting the fund, and to assure transparency.

In 2001, following attendance of the second national PLHAs meeting, one female PLHA from Papua became determined to fight for her fellows by speaking out. Within three months she was well known throughout Papua, having been featured in many activities and newspaper reports. Sadly, following this she fell sick and died soon after. This stimulated Spiritia to promise to do all possible to allow such activists to stay healthy and continue to make an impact on the epidemic. Spiritia set up an ARV Fund, to solicit funds from well-wishers in Indonesia and overseas, to pay for antiretroviral treatment for activists in this situation. Since then, three PLHAs, all female, one from Jakarta, one from Malang, East Java, and one from Papua have been fully funded to receive antiretroviral therapy, and two others (both male, one from Bali, one from East Nusatenggara) have been supported to add a third drug to an existing dual combination. About half of the funding has been received from HIV-positive activists in Australia.

To ensure that the fund is effectively used and transparent, Spiritia has developed a set of selection criteria and priorities. These have been circulated throughout Indonesia and worldwide, attracting much interest; it appears that few have so far attempted to develop such guidelines.

Human Resources/Staff Development

Spiritia's Executive Director, Suzana Murni, passed away on 6 July 2002. It has been the unanimous decision of Spiritia staff that her position should be filled by an HIV-positive person, but a suitable candidate has yet to appear. In the meantime, strategic direction has been determined

collectively in staff discussions led by Daniel Marguari, Project Coordinator. All other positions provided for in the workplan have been filled, with a total of nine full-time staff plus one additional part-timer, five of whom are female, and five also openly HIV-positive.

Priority for staff development has been placed on English language training, to allow more effective participation in international meetings. Courses are arranged in-house at two levels, each twice weekly. In addition, on-the-job training has been provided in computer skills.

Annual Evaluation

An annual evaluation was carried out in May 2003, with participation by 24 members of the Indonesia PLHA network. 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.

The full day allocated for this turned out to be insufficient to cover all elements of the Spiritia program; in future two days should probably be considered.

Additional Activities Not Covered in Original Plan

Spiritia was asked to coordinate the photographing of a number of PLHAs around the country by a renowned photographer, Rio Helmi. These photographs, of 16 infected people and 20 people affected by HIV, were used in an exhibition in the lobby of the national parliament building, a first. A week of activities, including a seminar, talk show, and dialog with members of parliament, supported this exhibition. The response by members of parliament was universally supportive, with many indicating greater interest in pressing for a more effective response by government. Media coverage was generally positive, and no PLHAs suffered unduly unpleasant results. A national team made up of those photographed has been set up to develop follow-up activities, and Spiritia stands ready to support this.

Spiritia has been a major player in advocating for improved access to antiretroviral therapy, and it is probable that more than 100 additional PLHAs will receive such therapy at least partly due to Spiritia activities. Besides advocacy to local government and legislature, this has also included development of fact sheets and guidelines to assist decision/policy makers to understand the issues.

Spiritia has played a major role in encouraging and promoting training for healthcare workers, and has worked through Depkes to develop the national leprosy training centre (PLKN) in Makassar as a centre for training healthcare workers in management of HIV infection, at least for the eastern part of Indonesia. This approach, originally proposed by Spiritia in early 2002, is now finally bearing fruit, with modules in final stages of development, and training scheduled to start by early 2004.

As more PLHAs have become open and trained in public speaking, Spiritia has looked for opportunities for PLHAs to appear in public. This has been particularly effective in TV talk shows.

Barriers and Strategic Changes

Involvement of PLHAs

As noted earlier, one of the greatest impediments to involvement is the fact that so few PLHAs are aware of their status; clearly there is little that can be done to improve quality of life or empower infected people who are unaware of their infection. This will be addressed later in discussion on voluntary counseling and testing (VCT).

Other barriers to involvement include lack of education and skills, and lack of self-esteem. Spiritia's strategy is to address these through skills training, but this will require working together with other peer support organizations to provide such training at local levels.

Peer Support

Spiritia's vision is for the formation of 'umbrella' peer support organizations at provincial or regional levels around the country. Such groups would provide services to PLHAs and small peer support groups in their areas, in a similar way to that provided by Spiritia at a national level. These services would include training, advocacy, and representation. They would also assist small peer support groups by offering space and resource people for meetings. There are groups in Jakarta (Pelita Plus) and Bali (Bali Plus) that show potential for playing this role, although much assistance and development is needed.

Local peer support groups are often small (involving perhaps only 4-6 PLHAs) and unstructured. Their main objective is to meet regularly (perhaps twice a month) to share feelings, experience and information, and to provide mutual support. They often welcome outside speakers at such meetings, although other meetings may be closed. They may extend activities to some form of buyers' club, or develop referral lists of doctors and other service providers who are 'friendly' to PLHAs. Few, particularly in the early stages, have a vision of scaling up, engaging in fund raising, or becoming legal organizations. In several cases, many of the members are active or recovering drug users, and this clearly presents a risk to continuity.

Such groups generally have limited need for funds, primarily to pay for transport for members to attend meetings, provide snacks for meetings, and for communications—the total may be less than Rp 1 million a month. On the other hand, they often have limited ability to take responsibility for any funds provided, with no accounting organization, and as non-legal organizations, may not be eligible to receive funds from donors. And donors frequently are unwilling to disburse such small sums of money, and tend to put pressure on these groups to scale up more rapidly than they feel comfortable.

Clearly this can be simply addressed if larger ASOs support such groups, although this may increase the problems of dependence. Cases have been reported of ASOs expecting relatively large additional funding from donors to provide this administrative support, institutionalizing PLHAs as 'assets'.

Spiritia has sought sources of more independent funding for such groups. One success has been the funding of Jaringan Odha Yogyakarta (JOY, the Jogja peer support group) by AFAO, following introduction by Spiritia. However, such sources are limited. Spiritia accepts that it must play a role in addressing this challenge of limited funding for peer support groups. It is probable that funds can be identified for this purpose; the biggest challenge is the responsibility for disbursement of and accounting for such funds in dozens of groups from one end of Indonesia to the other. At some stage, we must grasp that nettle.

There is a number of ASOs around the country providing services to PLHAs. Some of these have supported the formation of semi-autonomous PLHA groups under their auspices. Unfortunately many such organizations view PLHAs as objects, as recipients of services, even as assets ('our PLHAs'). This often results in a culture of dependence among PLHAs, and hinders any attempt at empowerment. PLHAs are rarely involved in planning and program implementation in such organizations. Eventually this often results in the PLHA groups breaking away, engendering hard feelings and accusations that they have only taken advantage of the host organization.

Spiritia's vision is that peer support groups should preferably be headed by open PLHAs, but including, where appropriate, affected people. Host organizations must respect this, and must be willing, even proud, to see peer support groups spin off to become independent.

It is discouraging that, while many government organizations and KPADs have accepted and supported the GIPA principle, the greatest impediment to its implementation comes from the NGO sector.

National PLHAs Meeting

The objective of these meetings to date has been to stimulate empowerment of PLHAs who have yet to be reached in this way. Numbers of such people have been increasing, but there is a limit

to how many can be accommodated at such meetings—the planned participation for 60 people in the next meeting is probably close to the limit. On the other hand, alumni of previous meetings feel neglected. The strategic direction must be for the objectives of the current meetings to be achieved through regional or provincial meetings, organized by peer support groups in those areas, initially with support from Spiritia. Meanwhile, the national meetings should probably be replaced by a form of congress, directed towards more experienced PLHAs, with larger attendance and more focused programs.

One challenge experienced in such residential meetings, including training meetings, has been the involvement of drug users. At one meeting, participants at the start included one active drug user plus three users in recovery. At the end of the three-day meeting, there were four active users! It is clearly impossible for Spiritia to accept responsibility for this, but it does have a very negative impact on the value of the meetings, and tends to give us a bad reputation, at least among parents of those affected.

Skills Development Training

Again, with three or four courses per year, with a maximum planned attendance at each of 16 people, such courses can only reach a small proportion of PLHAs. The strategic direction must be to encourage and support regional training meetings. With this in mind, Spiritia is developing modules from the courses to assist others to implement them.

As the network not only for those infected with HIV, but also those affected, there is need for skills development training for carers (families, support NGOs, etc.). It is planned that one course in the coming period should be allocated for this, probably focusing on home care.

One request from the evaluation was to consider providing leadership training. While it would probably be inappropriate for this to be organized by Spiritia, it may be possible to arrange special courses to be held by an organization specializing in such training, or for Spiritia to fund places on more general courses offered by such providers.

Local Strengthening Visits

As Spiritia has developed more experience with such visits, the objectives have also developed, to include much greater emphasis on advocacy. This requires effective follow-up. It is hoped that this can be taken on by local NGOs, but frequently there is doubt over their capacity to accept this responsibility. Thus follow-up visits to many places will be crucial if progress is to be sustained.

Having already visited more than 30 towns in 19 provinces, Spiritia has obtained an unparalleled picture of the status of the epidemic around the country. Although reports are produced on all visits, these have somewhat limited distribution, and are probably poorly read. Spiritia is now planning to invite national stakeholders to a meeting at which an overview of the findings of the visits will be presented, followed by discussion on action needed to address the problems identified.

Information Dissemination

A huge barrier to provision of information is that there is no culture of reading in Indonesia. This is a special challenge in reaching PLHAs, many of whom have limited educational background. Spiritia can provide newsletters, books and fact sheets, but if these are not read, they are a wasted effort. Currently we have no clear strategies for addressing this challenge.

On the other hand, Spiritia hopes that every PLHA and carer will have access at least to the basic information provided in the booklet 'Living with HIV/AIDS'. But ensuring this around this huge country is difficult. One approach to this is to encourage stocking and dissemination by programs and NGOs around the country, but this may require much larger print runs. Another approach being considered is to distribute the books commercially through bookshops; this will be further considered over the coming period.

Another challenge is that the field of AIDS treatment is one that develops very rapidly. Thus books may be out-of-date soon after they are printed. For fact sheets, this is addressed by producing them in photocopied format, with updates regularly published, and this approach may continue to be appropriate at least for the booklet on antiretroviral treatment. However, there remains to challenge of ensuring that 'subscribers' receive and access the latest version.

As more PLHAs, doctors, and decision makers start to access the Internet, it will become more important for Spiritia to disseminate more information through this medium. Currently the fact sheets and some Spiritia booklets are available on the WartaAIDS website, and treatment news is disseminated through the WartaAIDS mail list, but a more dedicated site must now be considered.

Development of Treatment Expertise

As noted earlier, this element of the workplan has not developed as hoped. This is due to a number of challenges: lack of suitable candidates to be trained as treatment educators; poor capability in English language; and the conception that this is beyond the capacity of PLHAs. As an alternative, Spiritia has been proposing to support groups to nominate one member as a treatment educator, and make use of existing Spiritia materials (fact sheets and booklets) for self-education. However, this has also not yet borne fruit.

One result of this failure is that PLHAs in general are unempowered with information about their treatment, being dependant upon often-inexperienced doctors. A consequence of this is that many PLHAs are not offered prophylaxis for opportunistic infections in a timely manner, and thus fall sick and suffer unnecessarily.

Human Rights

As noted earlier, many violations of human rights originate in the health care sector. Many occur as a result of lack of understanding or knowledge, often resulting in fear of infection. This has been discussed with the Minister of Health, and he is concerned, but is not able to promise swift responses. Efforts to improve training of healthcare workers in HIV/AIDS are clearly a major element in the response, but it will be many years before this has a significant impact. Spiritia has found that PLHAs meeting with healthcare workers and recounting their experience can result in significant improvement, but again this is a long process.

It should not be assumed that all healthcare workers are discriminative; indeed in our travels, we are frequently amazed at the number of doctors and nurses who are offering exemplary services to PLHAs, families and communities. Perhaps we need to do a better job of publicizing such people.

A more intractable problem surrounds the surveillance carried out among vulnerable groups: sex workers, injecting drug users, and prisoners. Frequently the identity of those found to be positive is known to the officials, even though the surveillance is supposed to be unlinked-anonymous. Often this is felt to be essential 'to protect the community'. Again, all we can do is to explain why confidentiality is essential, and provide examples of what happens when this is not respected.

Many hospitals, particularly private ones, mandate HIV testing for drug users on admission. Often this is done without counseling, on the basis that the result will only be known by hospital staff. The reasons for the policy are never clearly thought out; reasons given usually refer to the need for universal precautions for HIV-positive patients, even though they usually admit that universal precautions 'should' be used for all patients.

There are still many examples of inappropriate and discriminative reporting of HIV/AIDS cases in the mass media. Although Spiritia has tried to set up a reporting mechanism for such cases using groups throughout the country, this has not yet been successful. In addition, it is beyond Spiritia's capacity to respond to local cases; this must be done by local activists, but for some reason this seems to be a major challenge. In some extreme cases, the press training centers in Jakarta and Yogyakarta have taken up the cases with some success, but there is still far to go.

Representation in International and National Forums

With the increased understanding and appreciation of the GIPA principle, the requests for PLHAs to attend a wide variety of functions has escalated, and it has sometimes been difficult to respond. Spiritia has involved PLHAs from the network, both to spread the load and to broaden experience, and where possible has also taken advantage of visits by PLHAs from the provinces to Jakarta for training.

We face the challenge of how we ensure that those selected are and can be seen to be representative. This is clearly an impossible task, given that Spiritia is only in contact with a small proportion of those identified as HIV-positive, let alone the estimated 130,000 people who are thought to be infected in Indonesia. Our strategy for addressing this challenge is to ensure that we consult with PLHAs around the country to the extent possible, and report back on the results of meetings and decisions that may affect PLHAs in the country.

Human Resources/Staff Development

As noted, it has been Spiritia's intent to prioritize employment of PLHAs as staff. Apart from support for the GIPA principle, this also provides opportunity to PLHAs to receive income and thus become more independent. However, Spiritia activities and the GIPA principle would not be furthered by the employment of unqualified people, solely as tokens. Given the small number of people who are aware of their status, and the generally low level of education of these, recruitment of staff has been a challenge. In addition, more highly qualified people frequently already have more challenging and higher-paid employment, and are often unwilling to take the chance that their employers might become aware of their status should they take part-time employment with Spiritia.

A further challenge results from the explosion of HIV infection among injecting drug users. The principle of involvement would mandate that the response encourages full participation from all groups affected by the epidemic, and we clearly need to understand the special challenges faced by HIV-infected drug users. Spiritia has attempted to attract such drug users as staff, but the employment of active users, with the risk that they 'shoot up' on the premises, has proved a step too far. Even employment of users in recovery is not without challenges, since such people are prone to relapse, and are often unwilling to be involved in outreach to active users for fear of such relapse. There is urgent need for guidelines for involvement of HIV-positive drug users in the response; guidelines are available for outreach workers in needle exchange programs, but their challenges are rather different.

Voluntary Counseling and Testing (VCT)

Although outside the original workplan, Spiritia has been forced to advocate for major improvements to the facilities for voluntary counseling and testing (VCT). In most parts of the country, it is effectively impossible to access VCT, let alone in a user-friendly environment. In addition, there is doubt over the accuracy of testing methods used.

Universal Precautions

The concept of universal precautions (UPC) is poorly understood, and worse implemented, in almost all medical facilities around Indonesia. It has been difficult to determine the significant impediments. Clearly lack of knowledge is a major contributor; but lack of funds is often identified as the major constraint. On the other hand, misuse of and poor control over materials and equipment for universal precautions also exacerbate the problem. It is clear that incorrect implementation of universal precautions contributes to stigma and discrimination experienced by PLHAs. Need for selective application of universal precautions is often quoted as a reason for mandatory testing of certain groups of patients prior to admission. HIV-positive patients often bear additional charges for gloves and masks. Other patients seeing nurses using precautions for certain patients may cause them to suspect that the patients are HIV-positive.

Midwives always raise concerns at discussions on UPC. The guidelines require that midwives assisting in births should always wear full protective clothing, from goggles and masks, to aprons

and rubber boots. This is clearly unrealistic in the current environment, but the lack of ability to protect themselves bears heavily on midwives.

In addition, as HIV prevalence in the general population increases, especially in such places as Papua, the risks of a parallel epidemic spread in medical environments becomes much greater. Frequent re-use of syringes and lancets, together with inadequately screened blood supplies, may have already contributed significantly to the HIV epidemic in Papua.

Spiritia has attempted to promote the correct use of universal precautions during visits to healthcare establishments. But not only is this only scratching the surface, it is also not getting to the bottom of the problem. Spiritia has long proposed a series of workshops to identify the impediments to correct implementation of universal precautions, and to develop responses.

Access to Antiretroviral Therapy

One element of Spiritia's advocacy program has been to promote wider access to antiretroviral therapy (ART). This is to support the WHO objective that 50 per cent of those who need it should have access to ART by 2005. It is estimated that this should cover 10,000 PLHAs in Indonesia by 2005.

Clearly one major element is to solicit funding for ART, including from government, the Global Fund to fight AIDS, Tuberculosis and Malaria (GFATM), private sector, and private individuals and the community. Some success has been achieved in this area.

One challenge will be to ensure continuity. ART must be continued for life. It is clearly impossible to expect such long-term commitments from government or donors, and Spiritia has focused on guaranteeing therapy for 12 months. The rationale for this is that extending life for this period, and perhaps allowing parents to see their children become one year older, is certainly better than nothing, while during that period, efforts can be made to assure extension. But special efforts will be essential to persuade government agencies to provide funds for this in future annual budgets. One way to assure this is for recipients of such support to report regularly to government and legislature, to demonstrate the benefits, both to the PLHAs concerned, but also to the general community in terms of prevention activities. Spiritia is attempting to encourage such advocacy.

Empowerment

During the program for photographing PLHAs, one matter that received much attention was to prepare a form of informed consent that empowered and protected those being photographed, but also gave some freedom for action to the organizers. Although few similar projects have gone to this trouble, there were a number of criticisms after the event, with some people (mainly non-infected or affected) maintaining that, by its very nature it was impossible for the rights of PLHAs to be properly respected. This was mainly based on the assumption that most of the PLHAs were incapable of understanding the risks involved, an assumption that in itself could be considered unempowering. While changes have been made to the approach for future programs of this nature, it once more draws attention to the challenges of ensuring informed consent.

Spiritia has been working with UN Volunteers (UNV) to prepare a proposal to enhance GIPA in Indonesia. If approved, this two-year program will involve three foreign PLHAs as UNVs, working with nine local volunteers, the majority of whom will be HIV-positive. Activities will be focused initially on three provinces: Jakarta, Papua and one other to be determined. Funding for this will primarily come from Japan, with additional funding from the UN Development Programme (UNDP). It is hoped that this program will commence in late 2003.

Conclusions

Spiritia's program is founded upon the principle of greater involvement of PLHAs (GIPA), and aims to encourage PLHAs (including those affected by HIV/AIDS) first to become involved in their own life and health, and to develop improved self-esteem. Following this, PLHAs are encouraged to meet with other positive people in their areas, to provide peer support. With provision of skills, the next step of real involvement in the response: as active participants; through

speaking out; and through taking part in the planning and implementation of programs at organizational level can take place.

The greatest challenge to this process in Indonesia is that so few infected people are aware of their status, and those who become aware often do so at a very late AIDS stage, often dying soon after. We must therefore encourage those who have been at risk to come forward for testing. This not only requires a huge expansion of friendly test facilities, but also much wider promotion of the advantages of knowing one's HIV status, to counter the disadvantages that are all too clear: stigma and discrimination. PLHAs are best placed to demonstrate the advantages by speaking out, and by talking about the benefits of antiretroviral therapy; we can no longer say that AIDS cannot be treated.

Recommended Actions for the Future

In general, feedback and the annual evaluation indicate that the Spiritia workplan 2002-2004 remains appropriate, and it will be implemented without significant changes to the planned activities. However, the following additional actions and focuses are planned as a result of the evaluation and experience gained in the first year of the plan:

- Additional strengthening visits, both to new locations and return visits to places already visited.
- Invite national stakeholders (KPA, Depkes, donor agencies, etc.) to a meeting to disseminate the findings from strengthening visits, and to solicit responses.
- Current national PLHA meetings to be replaced by regional meetings, starting 2005; organize regular PLHA congresses with wider participation, particularly among those already empowered.
- Develop capacity within Spiritia and the network for PLHAs to be employed as consultants, and to receive fees for public speaking.
- Develop systems and raise funds to allow minimal funding of embryo peer support groups, including to allow them to scale up if they wish.
- Work with more mature peer support groups to develop the concept of 'umbrella groups', providing services to a number of smaller groups in their areas.
- Increase number and scope of skills training, including offering leadership training. Take advantage of courses offered by other organizations to cover topics not specific to PLHAs, such as advocacy.
- Continue advocacy for major improvements in access to voluntary counseling and testing and for action to address shortcomings in implementation of universal precautions.
- Cooperate in development of guidelines for care and treatment of PLHAs, together with training for health care workers on their content, including making PLHAs available as trial patients.
- Develop a program to address prevention of HIV transmission from those who know themselves to be infected: 'HIV Stops Here!' Work with experts and condom suppliers to identify possible activities.
- Develop the ARV Fund to offer antiretroviral therapy to a larger number of network members, and ensure that activists are not hindered in their work by poor health as a result of lack of treatment.

Appendix 1: Annual Evaluation 2002-2003

Background

Spiritia held its annual evaluation for the year 1 June 2002–31 May 2003 on 28th May 2003. Besides all Spiritia staff, 24 members of the national PLHA network attended representing the clients of Spiritia's programs. The full-day meeting at the Hotel Cemara in Jakarta was facilitated by Tryas Prasetyo from INSIST in Jogjakarta.

Assessment Questionnaire

Prior to the meeting, all members of the PLHA network had been asked to complete a questionnaire of 15 questions, which had been enclosed with the Senandika newsletter. A total of 30 questionnaires have been returned completed. The most significant results were:

- 90% found the newsletter Senandika interesting or very interesting
- 20% were confused about Spiritia's role as secretariat of the network
- Almost all felt that they had benefited from their involvement with Spiritia
- 90% felt empowered, with all acknowledging that Spiritia had played a role in this empowerment
- 90% have become involved in AIDS programs in their areas, with 85% of these reporting Spiritia had played a role in this involvement
- All who had attended Spiritia activities felt that they benefited from this participation

The questionnaire also 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 the means of both Spiritia and the network, but others will provide ideas for future development.

Evaluation Agenda

- Description of Spiritia program
- Goals and main objectives
- National PLHAs meeting
- Local strengthening visits
- Skills Development Training
- 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. Although there was an attempt to ensure the comments were balanced, inevitably attention focused mainly on perceived weaknesses. However, in general criticism was positive and provided useful lessons.

Significant Concerns

1. The process used by Spiritia for selecting participants in meetings, training sessions and visits is unclear. Participants asked Spiritia to implement a more transparent process.
2. Spiritia has recruited, or attempted to recruit, key members of other peer support groups.
3. Spiritia has yet to reach out to PLHAs in most of Indonesia; only a very limited number of mainly urban areas have been visited, and it is very difficult to meet PLHAs in many of these areas.
4. There is inadequate follow-up on visits. Local people often do not have the capability to carry out the necessary follow-up.
5. Three days appeared to be too short for skills building training. Either material should be reduced or (preferably) time should be extended.

Main Lessons Learned

The following were the main lessons learned from the evaluation. Some will be immediately implemented or incorporated into Spiritia's program. Others will require additional funding, and will be the subject of supplemental proposals. Efforts will be made to address all points in the coming year.

1. Local strengthening visits are very valuable, particularly to assist local PLHAs to become open. Visits should be better planned, and there should be participation from more members of the network. Greater priority should be placed on meeting with organizations concerned with policy making.
2. Problems identified in the regions should be followed up at the national level, to ensure that they receive attention. Local groups should also follow up.
3. National PLHA meetings in the future should give higher priority to network members who have already attended previous activities. There was general agreement with the strategy to hold 'entry level' meetings regionally, and to turn the national meeting into a 'congress' with participation from experienced PLHAs.
4. Development of peer support groups at the local level must receive much higher priority. This must include both funding and institutional development.
5. Skills development training is a very effective method for empowering PLHAs and those affected to play a greater role in the response to HIV/AIDS, and must be extended. Leadership training should be offered.
6. Spiritia newsletters are valued, but they could be more attractive and readable. Attention needs to be paid to simplifying language.
7. Spiritia should promote its vision, mission and program more widely at local, national and international levels.
8. More time should be allocated to the annual evaluation. The materials should be distributed to participants in advance, and should better represent all elements of groups participating in the activities.

Appendix 2: Photographs of Activities

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3rd National PLHAs Meeting, February 2003

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Skills Development Training, November 2002 — Jakarta: Public Speaking

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Skills Development Training, April 2003 — Jogjakarta: Peer Support Groups

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Local Strengthening Visit, July 2002 — Jayapura, Papua: Meeting with PLHAs and Families

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Local Strengthening Visit, July 2002 — Jayapura, Papua: Meeting with KPAD

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Local Strengthening Visit, May 2003 — Semarang: Meeting with Doctors in the Kariadi General Hospital

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Local Strengthening Visit, May 2003 — Semarang: Radio Talk Show

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Workshop to Disseminate Results of Human Rights Survey, October 2002

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Spiritia Staff Retreat at Ancol, August 2002

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New Spiritia Staff Members, December 2002 — Strengthening Visit to Kutai, East Kalimantan

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Annual Evaluation, May 2003

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Presentation of FHI Award, Barcelona, July 2002

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Exhibition of Photographs of Indonesian PLHAs, Parliament Building, February 2003

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Visit of Peter Piot, Executive Director UNAIDS to Spiritia, May 2003

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Oral Presentation on Human Rights Survey by Siradj Okta, Barcelona, July 2002

Appendix 3: IEC Material Published 2002-2003

Spiritia published the following books and other information materials over the period. Copies of each are attached:

- Hidup dengan HIV/AIDS (Living with HIV/AIDS) — new edition
- Merawat Odha di Rumah (Home Care of PLHAs) — photocopy version
- Perawatan AIDS di Luar Rumah Sakit (AIDS Treatment Outside the Hospital) — photocopy version
- Pengobatan untuk AIDS: Ingin Mulai? (AIDS Therapy: Want to Start?) — photocopy version
- Berdayakan Diri Menghadapi AIDS (Self Empowerment to Face HIV/AIDS – Spiritia Profile) — photocopy version
- Self Empowerment to Face HIV/AIDS in Indonesia – Spiritia Profile — photocopy version
- Lembaran Informasi tentang HIV/AIDS untuk Orang yang Hidup dengan HIV/AIDS (Odha) (71 Fact Sheets on HIV/AIDS for PLHAs) — photocopy version
- Dokumentasi tentang Pelanggaran Hak Asasi Manusia terhadap Orang dengan HIV/AIDS di Indonesia (Documentation of Human Rights Violations against PLHAs in Indonesia) — photocopy version
- Documentation of Human Rights Violations against People Living with HIV/AIDS in Indonesia — photocopy version
- Pernyataan Cikopo (Declaration by participants of 3rd National PLHAs Meeting) — photocopy version
- Positive Fund – Flier in Indonesian and English
- Newsletter Senandika – 12 issues
- Newsletter Sahabat Senandika – six issues