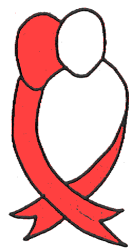


Report on Local Strengthening Visits November 2001 – August 2003



Spiritia Foundation



Acronyms and Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral (drugs)
ASA	Aksi Stop AIDS, program of USAID/FHI
ASO	AIDS Service Organization
Depdiknas	Departemen Pendidikan Nasional (Indonesian Ministry of National Education)
Depkes	Departemen Kesehatan (Indonesian Ministry of Health)
DPRD	Dewan Perwakilan Rakyat Daerah (Provincial/District/Town Parliament)
GIPA	Greater Involvement of People Living with and Affected by HIV/AIDS
HIV	Human Immunodeficiency Virus
IBI	Ikatan Bidan Indonesia (Indonesian Midwives Association)
IDI	Ikatan Dokter Indonesia (Indonesian Medical Association)
IDU	Injecting Drug User
IFPPD	Indonesian Forum of Parliamentarians in Population and Development
IHPCP	Indonesia HIV/AIDS Prevention and Care Project
KPA	Komisi Penanggulangan AIDS (National AIDS Control Commission)
KPAD	Komisi Penanggulangan AIDS Daerah (Provincial/District/Town AIDS Control Commission)
NGO	Non-governmental Organization
NTT	Nusatenggara Timur (East Nusatenggara)
PEP	Post-exposure Prophylaxis
PKBI	Perkumpulan Keluarga Berencana Indonesia (Indonesian Family Planning Association)
PLHA	People Living with HIV/AIDS
PMI	Palang Merah Indonesia (Indonesian Red Cross)
PNO	Pertemuan Nasional Odha (National Meeting of PLHAs)
Pokja	Kelompok Kerja (Working Group)
Puskesmas	Pusat Kesehatan Masyarakat (Community health centre)
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
UPC	Universal Precautions
USAID	United States Agency for International Development
UTD	Unit Transfusi Darah (Blood Transfusion Unit)
VCT	Voluntary Counselling and Testing (for HIV)

Contents

Acronyms and Abbreviations	2
Contents.....	3
Executive Summary	4
1. Background.....	5
2. Objectives of the Visits.....	6
3. Findings	7
3.1. General.....	7
3.2. KPADs.....	7
3.3. Local Parliaments (DPRD).....	8
3.4. NGOs	8
3.5. Medical Services.....	9
3.6. Voluntary Counseling and Testing (VCT).....	10
3.7. Surveillance	11
3.8. Blood Safety	12
3.9. Knowledge/Information.....	12
3.10. PLHAs/GIPA.....	13
3.11. Peer Support Groups.....	14
3.12. Vulnerable Populations.....	15
3.13. Funding	16
3.14. Media	17
4. Follow up.....	18
5. Conclusions	19
Appendix 1: Places Visited	20

Executive Summary

Following a request from Indonesian people with HIV/AIDS (PLHAs) at the second National PLHAs Meeting (PNO) in September 2001, Spiritia commenced a program of regional visits throughout the country. The prime objectives were: to obtain a clearer picture of the situation faced by PLHAs around the country; to provide them with support; to contact decision makers and service providers in the regions; and stimulate the formation of local peer support groups. In the almost two years since the first visit in November 2001, Spiritia teams, always including open PLHAs, have visited 36 places in 20 provinces. The Ford Foundation together the IHPCP and ASA projects funded the visits.

In each place, besides meeting where possible with local PLHAs, the teams attempted to meet with provincial and/or district/town AIDS commissions (KPADs) and other local government representatives, local parliament members, hospitals, doctors, and NGOs. Teams also met with groups of vulnerable people, including sex workers, drug users, and transvestites (*waria*). Reports were prepared and disseminated following each visit.

The general picture which appears following this two-year program of visits is of a rapidly escalating AIDS epidemic in several areas and among several groups, with the response lagging behind, in many places very far behind. In several provinces and districts, very urgent action is required if an African-style epidemic is to be averted.

It is impossible to summarize and draw general conclusions from several hundred meetings in 36 places. However, some common threads stand out, and these are described under 14 headings in the report, together with almost 50 recommendations. It is accepted that this is a very large number, and it may not be reasonable to expect all to receive equal attention. While it is difficult to identify the most pressing of these recommendations, the following probably justify highest priority:

1. KPADs must be empowered to play a much more active role, with name membership, and a full-time secretariat.
2. Strategies must be developed to convince local parliament (DPRD) members of the reality of the threat, and encourage them to play a part in the response.
3. NGOs must be encouraged to play a more active role, especially outside the province capitals.
4. Training of health care workers, particularly on management of antiretroviral therapy, must receive urgent priority, together with action to prevent the spread of infection through medical interventions including by unsafe blood transfusions.
5. Provision of voluntary counselling and testing (VCT) in all areas, particularly including physical testing facilities and friendly test locations, must receive very high priority.
6. Unlinked anonymous surveillance must be extended to more sentinels in more areas, including drug users, prisoners, pregnant women, and *waria*, with VCT subsequently offered to all groups.
7. Information must be made more widely available, covering topics important to the various groups in greater detail. This includes upgrading knowledge of health care professionals and KPAD members.
8. The principle of greater involvement of PLHAs (GIPA) must be better promoted. AIDS service organizations must be discouraged from developing dependence among PLHAs they support.
9. Mapping of donor agencies' coverage must be completed, so that gaps can be identified and other agencies encouraged to fill the gaps. Government must be encouraged to provide much more funding.
10. Much greater cooperation and communication is needed between neighbouring administrations/KPADs to address the highly mobile vulnerable populations.

This visit program has been costly in both human resources and funding for Spiritia, but has been of value in improving the lives of PLHAs around the country. However, it is submitted that these visits have much wider value in identifying and describing the AIDS epidemic and responses around the country. Spiritia is soliciting help in extending coverage to provinces and places not yet visited, and in follow-up visits to places already covered. In addition, it is clear that the proposed action requires the active leadership of a variety of parties, most particularly the KPA. It is hoped that this report will stimulate such leadership and urgent action to address the most pressing challenges.

1. Background

One outcome of the second National PLHAs Meeting (PNO) was the request for Spiritia, as secretariat of the newly set up PLHAs network, to visit places throughout the country, with a variety of objectives. Meeting participants wanted to form support groups or networks of PLHA supporters at the local level, but they needed help. They needed Spiritia to open dialogue aimed at increasing the awareness among PLHAs themselves, to promote the GIPA principles to local service providers and policy makers. In addition they wanted Spiritia to provide technical assistance to PLHAs, others affected by HIV/AIDS and to institutions who offer care and support to PLHAs.

On its side, Spiritia needed to see the local situations, and to obtain direct input from PLHAs and other related parties about the problems they face. This has greatly assisted in program planning, to ensure they match the needs of PLHAs. Building relationships with local government and health service providers is useful to extend referral networks, and to open opportunities for advocating the interests of PLHAs.

In the two years since that meeting, Spiritia teams have visited 36 places in 20 provinces (see list in Appendix I), some of them several times. The Ford Foundation, the AusAID-funded Indonesia HIV/AIDS Prevention and Care Project (IHPCP) and the USAID-funded Aksi Stop AIDS Project (ASA) provided funding for these visits. The teams have consisted of up to six members, normally including Spiritia staff and PLHAs from the network who are themselves addressing the same kind of challenges. PLHAs from the places visited are also included where possible. In this way, they will not only bring a wider experience to bear, but will also expand their knowledge and empowerment.

Visits in each place normally covered several days, and provided an opportunity to meet with a variety of stakeholders in the areas, including NGOs, local government, local parliament, service providers and mass media, as well as other PLHAs.

As a result of these visits, Spiritia has what is perhaps a unique view of the overall picture of the response to AIDS around the country. As far as we are aware, no other organization has implemented such a nationwide program, or met so many stakeholders at provincial and district/town levels. Although reports of each visit have been prepared, it seems appropriate that we document some of the main findings and outcomes of these visits, particularly highlighting more general challenges and identifying proposed responses.

2. Objectives of the Visits

- Understand the situation and determine the needs of PLHAs in other parts of the country.
- Provide moral and technical support to PLHAs, those affected by HIV/AIDS and institutions that have supported or plan support programs for PLHAs.
- Build relationships with policy makers and service providers in other locations.
- Increase the skills and experience of PLHAs on the visit teams.
- Encourage the formation of peer support groups for both infected and affected people.

3. Findings

The following represents a synthesis of the impressions and conclusions of team members following the visits. It must be emphasised that each place is different and some generalizations will clearly not apply to every place. However, certain common threads are apparent, and it is these that this report will attempt to identify.

3.1 *General*

As noted, teams invariably included PLHAs, and attempts were always made to include PLHAs from the location visited. Although there was no pressure on them to reveal their status, this was encouraged if they felt comfortable. Apart from one or two meetings with the mass media, there was only one meeting at which not one of the PLHAs present felt willing to reveal: this was the meeting with one provincial KPAD, at a meeting which included two visiting PLHAs and at least two local ones. This reflected the level of discussion at the meeting, at which AIDS was often treated as a joke, and where discussion was dominated by pressure for extension of quarantine regulations to include AIDS. In other cases where PLHAs did introduce themselves as such, there was only one occasion in which they received less than pleasant responses to this. This occurred at a seminar arranged by the Red Cross (PMI) in one city, at which one participant refused to believe that three out of four of the team were HIV-positive, because they looked so healthy. The participant thought we were trying to deceive.

Awareness of the existence of antiretroviral therapy (ART) was extremely rare, even among healthcare workers; most people met continued to refer to AIDS as being untreatable. In many meetings we introduced ART; in most cases teams included at least one PLHA who was receiving ART, and interest in the pills, side effects and other related matters was generally high. We used this as an opportunity to solicit support for provision of ART to indigent people, and to introduce the topic of selection criteria. At least one province has now allocated funds for ART as a result; several others are reported to have decided to do so, or are considering it.

We also took advantage of the opportunities to discuss stigma and discrimination towards PLHAs, in some cases introducing the report of the Spiritia survey. Again, the stories of PLHAs in the teams provided proof that much still needed to be done to eliminate inappropriate treatment of PLHAs, particularly in the health care sector.

Note that the following sections do not include all of the groups/officials met. In particular, meetings with the KPADs also often included contact with the heads of the health services (Dinkes), but often we had separate meetings with these officials. Such meetings usually covered similar topics to those covered with the KPADs. Teams also frequently met with Vice-Governors, but again these tended to address the same topics.

3.2 *KPADs*

At each place, the teams attempted to meet with both province and district/town KPADs as appropriate. This was not always successful, sometimes due to the absence of key people, but more often because the commission did not exist in reality, only on paper. This was rarer among province KPADs, and more common at district/town level. The level of concern also varied widely, with some at both levels being extremely dedicated and well informed. This was more common in provinces supported by donor agencies, which had provided technical support and funding to the KPADs. In provinces not so supported, most KPADs were under-funded, and thus limited in their activities. As noted below, advocacy with the local DPRD (parliament) opened the doors to increased funding from local government budgets.

In many places, we heard that the composition of KPADs resulted in inconsistent representation at each meeting, often with the representative attending having very limited knowledge of HIV/AIDS. This means that it is very difficult to develop effective plans and programs. One can also conclude from this that KPAD members are carrying out very limited AIDS education in their own workplaces.

Regional autonomy is having a very significant real or potential impact on the role of KPADs at both levels, but one that is poorly understood or planned. In many districts/towns, officials claimed that the province had no responsibility for implementation, or in some cases, policy. This was particularly true in

Papua, where the local autonomy situation is still quite fluid, and communications to the province level are limited and slow. Given the high mobility of the at-risk populations in the province, coordinated responses between neighbouring administrations are crucial but rare. Similar concerns arise throughout the country, especially between town administrations and the districts that surround the towns.

As noted above, where appropriate we attempted to solicit funding by the local government for ART, at least for a few PLHAs in the location. We used the Bali KPAD as a role model, and in several cases we had some success, although in each case, it was dependent upon allocation of funds by the DPRD.

Recommendations – KPADs

1. Membership of KPADs should be by name, rather than position. KPADs should also include activists and PLHAs, again by name. KPADs should set up a secretariat, including a dedicated office and a full-time staff.
2. KPADs should be encouraged and assisted to produce a strategic plan, based upon the national strategy.
3. A booklet providing basic information on HIV/AIDS and the Indonesian response/policy for KPAD members should be published and distributed to all KPAD members. This might also be made available to members of DPRD Komisi E. The book might also provide details of how local funding can be obtained.
4. Province KPADs should take a more active role in coordination between neighbouring district/town KPADs.
5. KPAD members should be encouraged to disseminate information on AIDS in their own workplaces.

3.3 Local Parliaments (DPRD)

In several places, the teams met with members of the E Commission (responsible for health and welfare) and/or other commissions of the local parliament (DPRD). In general such meetings were very productive. The general level of knowledge among commission members was low or non-existent, and it was clear that it was very rare that any previous advocacy had been carried out, either by NGOs or by local government. Often the members requested follow-up meetings, and planned consultations with invitations for health service or KPAD members.

We usually solicited funding for ART for local PLHAs, often following interest shown by the KPAD or local government. In several places this appeared to have some success, with solid promises from West Java, East Java, and even East Nusatenggara. Even more frequent were promises to significantly raise funding for KPADs, including often by district/town DPRDs.

We tried to include representatives of KPADs and local NGOs in such meetings, partly so that there could be ongoing advocacy. However, there is need for better understanding of advocacy strategies by such participants; on some occasions, the discussions were hijacked by people with private agendas.

Recommendations – DPRD

1. Strategies for advocacy towards DPRDs at both levels by KPADs and NGOs should be developed. All must be encouraged to develop working relationships, and provide information.
2. We should cooperate with the Indonesian Forum of Parliamentarians in Population and Development (IFPPD), who already have plans in place to work with provincial and district/town parliaments.

3.4 NGOs

In many places, there were few local NGOs working in the field of HIV/AIDS. In fact in several places, the local PKBI branch was the only NGO having ongoing programs in any way connected, with these often being more directed towards reproductive health. Several of these branches are already overloaded and underfunded, and have no spare resources to allocate specifically to HIV/AIDS, let alone care and support for PLHAs. This clearly impacts negatively upon HIV/AIDS programs, leaving the crucial community involvement lacking.

The exceptions were naturally in places with donor agency presence, where the reverse was often the case, often with several NGOs competing with each other, with limited coordination and some overlap. Even in such places, it was rare for NGOs to provide effective services for PLHAs. A few NGOs offered such services, but most such treated PLHAs as objects, as recipients of services, and even as assets. The principle of empowerment of PLHAs was rarely respected.

In some cases, we encouraged existing groups to become a contact point and support base for PLHAs we met in the area. In at least one case, in Manokwari, that led to a group with no funding finding itself taking responsibility for a rapidly increasing number of PLHAs, many in terminal state. It is difficult to see how we can avoid this; equally we are at a loss to how we can support such groups at a distance.

It was rare to find NGOs who were carrying out effective advocacy to local government or DPRD. Often there was a view that this was useless, that there was little hope of any real action by these groups. On the other hand, we were often told that NGOs could do little until the KPADs got themselves sorted out. Some of the most effective NGOs are poorly funded, but have a vision and just get on with it.

Given the lack of NGO responses in the province capitals and major centres of population, it must be assumed that the situation in the smaller towns is much worse. In such places, community responses must surely be based upon existing religious structures. However, at best these seem to be involved in limited activities around World AIDS Day and the Candlelight.

Recommendations – NGOs

1. We need to publish and disseminate success stories of activities by NGOs, including in advocacy towards DPRD and KPAD.
2. Greater efforts are needed to encourage and empower religious organizations to play the community role in the response to AIDS where there are no other NGOs working.

3.5 Medical Services

In every place we attempted to visit at least the public hospital. Often meetings took the form of a discussion with a group of doctors and nurses, sometimes also including hospital management. Around half of hospitals had already knowingly admitted patients with HIV/AIDS. Some had decided to provide separate wards for PLHAs, others placed them in isolation rooms, while others (mostly private) transferred them to other hospitals, claiming that they “weren’t ready” or didn’t have the expertise or facilities to care for patients with AIDS.

Most provincial hospitals claimed to have an AIDS working group (Pokja), and in some cases we met with some of the members of this. Few of these groups seemed to have any clear objectives or activities.

Most welcomed the opportunity to meet and discuss with the PLHAs on the teams, especially about ART and its management. The PLHAs often felt proud of the way that they were listened to and treated as experts by doctors, and this helped the empowerment process. We met few cases of intentional discrimination, although lack of interest by hospital management was more common. Many felt that other infectious diseases, such as TB, malaria, etc., deserved greater attention. On the other hand, in almost every place, we met at least one highly dedicated and concerned doctor, often treating PLHAs in ways well beyond the call of duty. Many of these were very interested to learn about ART, and volunteered to be the point contact for ART in their locations.

Knowledge of management of patients with HIV was very rare, and training was almost non-existent. In several cases, we heard that a team from Pokdisus had visited the place recently to talk about ART, but clearly this is only a beginning.

Doctors are not clear about recommendations/policies for testing patients who may be unable to give informed consent. Patients are being tested without informed consent, because they are deemed not ready or too ill to talk about the possibility that they are infected with HIV. When results come back positive, this only makes the matter more difficult and urgent. In fact, in discussion, almost all such doctors agree that knowing the patient is HIV-positive has had no impact on the management of their infection, except that potentially ART can be offered; however this can only be done once patients have been informed of their status.

In several places, we made contact with clinics or puskesmas with large TB caseloads. Rarely were staff at such clinics aware of the high rate of HIV infection accompanying TB infection. In no place did we find effective cooperation between such clinics and organizations offering VCT.

Universal precautions (UPC) and infection control were almost universally bad. Generally UPC was applied only to patients known to be HIV infected. There was frequent evidence of reuse of syringes, sometimes with needles being changed, often not. Facilities for hand washing were generally very poor; in at least one case, water was in short supply. There are many reasons for these failures, some obvious, some more obscure; it is not just a matter of training or funding.

Occurrences of occupational exposure by health care workers are increasing. Few hospitals appear to be aware of the options for post exposure prophylaxis (PEP), and fewer still have procedures in place to respond to workplace accidents, let alone offer PEP.

In many places, it was the midwives who were most concerned, even afraid. According to standards for UPC, midwives should always use full protection, from goggles to boots. Needless to say, such protection is rarely available, particularly outside large hospitals.

Recommendations – Medical Services

1. A clear set of criteria to be achieved by hospitals in accepting patients with AIDS must be developed, with time scales for achievement mandated, to avoid the excuse of ‘not being ready.’ Depkes must play a more proactive role, together with the national hospital association.
2. Training of healthcare workers in HIV at all levels, but particularly hospital management, doctors and nurses, must receive much greater priority.
3. Doctors should be given clear guidance on testing without informed consent.
4. Efforts must be made to encourage doctors and nurses working with high TB caseloads to suspect co-infection with HIV, and to connect TB clinics to VCT centres.
5. Very urgent attention must be given to implementation of universal precautions and infection control measures. We may be facing major epidemics of HIV and viral hepatitis spread by medical interventions, especially in Papua. We must avoid facile assumptions as to causes, and study the problem in detail.
6. We must work with the Indonesian Midwives Association (IBI) to find feasible solutions to universal precautions during delivery.

3.6 Voluntary Counseling and Testing (VCT)

VCT is crucial as the entry point to care and support for PLHAs. Currently less than 2.5% of the estimated number of HIV-infected people in Indonesia are aware of their infection. Yet it has to be said that VCT doesn’t work in Indonesia.

Few places we visited offered even basic VCT services. Although great efforts have been made to train counsellors in several places, only a very few of these seem actually to be practicing. Partly this may be because the physical facilities for testing are so poor. We also heard of several cases where counsellors felt they were unable to communicate positive results.

Although most province capitals have a health laboratory with ELISA equipment, there is still a widespread belief that confirmation by Western Blot is needed, a misconception that is still promoted by the experts in Jakarta. On the other hand, medical services in other towns are dependent upon a variety of rapid tests, several of which have yet to be validated and approved in Indonesia. Requirements for confirmation of such tests are often unclear, and unfeasible. Where testing is possible, it is often expensive, and requires the person to visit a hospital or lab. Counselling in such environments is often poor or non-existent.

In the rare cases in which VCT is effectively carried out in places friendly to the target groups, it is rarely well-promoted, and even in Jakarta it has proved difficult to obtain details of where VCT is offered and

when. In addition, outreach workers are ill informed of the benefits to their target groups of knowing their HIV status, and many are still unaware that antiretroviral therapy is now available.

Cost of testing can be an impediment. Some provincial laboratories did not have a clear pricing strategy, requiring patients to pay for each confirmation test. This has a number of downsides: besides resulting in extra costs for patients, it also requires that patients becoming aware of positive results in initial screening, and often not obtaining confirmation.

Although there has been an effort by ASA to address some of these challenges, later visits to some of the places where the ASA program was carried out show little obvious progress.

Recommendations – VCT

1. Huge efforts must be made to provide effective, trustworthy and fully confirmed test facilities in all towns. Where logistics allow, this may involve sending samples to provincial labs; in other cases, a full set of rapid test facilities should be made available. Procedures for testing must be clarified.
2. Huge efforts must be made to train and retain counsellors and outreach workers, including provision of support for these.
3. NGOs and clinics must be encouraged to offer VCT in locations friendly to their target groups. Authorities must clarify policies on how samples can be taken and procedures for sending samples to labs, and returning results to counsellors.
4. NGOs and KPADs should be encouraged to work closely with provincial and other laboratories to negotiate special prices for testing. In several places, such laboratories indicated a willingness to subsidize testing, using the social safety net funds, or funds left over from surveillance activities. Laboratories should also set up a pricing strategy that provides an all-in price including confirmation where screening gives a positive result.

3.7 Surveillance

All provinces report carrying out serosurveillance in sentinel groups. Mostly this is of sex workers; some now also include prisons, and a very few injecting drug users (IDUs). Transvestites (*waria*) are almost never included, even though there is evidence that prevalence among *waria* is very high. Apart from places that still have *lokalisasi*, identifying sentinels of sex workers and drug users is difficult or almost impossible.

The objective of serosurveillance is rarely clearly understood. Adherence to the principles of ‘unlinked-anonymous’ is the exception rather than the rule, and where health service officials strictly adhere, they are criticized for not identifying the cases to other officials, for example in prisons. Where health service officials are aware of the identity of those found to be positive, some do attempt to maintain a policy of confidentiality, but this can be difficult if (for example) the Governor asks for details.

VCT is rarely offered to sentinels even if they are made aware of prevalence rates; this is partly because VCT is anyway so poorly provided.

Recommendations – Surveillance

1. Sentinel sites should be extended to include more IDUs, prisons, *waria*, and pregnant women, at least in Papua. However, this should only be done if unlinked-anonymous status can be guaranteed.
2. The objective of surveillance must be much better communicated, including to groups who feel they are responsible (Social Dept, Prisons, local government).
3. In some areas where prevalence is high, consideration should be given to surveillance among groups that may include sex worker clients, including government employees. This may go some way to addressing the moral stigma attached to HIV.
4. VCT, once established, should be offered to all sentinels at the time that results of serosurveillance are communicated.

3.8 Blood Safety

In many places, we called upon the blood transfusion units (UTD), usually at the general hospital. Some of these are operated by the Red Cross (PMI); others, in the smaller, more remote areas are operated by the hospitals.

In general screening at UTUs run by PMI appear to follow correct procedures, although in at least one case, no screening was being carried out, reportedly due to lack of funds to purchase test kits. There also seems to be confusion over the need for confirmation of positive results. In many cases, screening for HIV is by dipsticks, and not all of these are validated/approved for Indonesia—there is concern that some never show an HIV-positive result even in areas known to be of high prevalence. Given the low positive predictive value of most of these dipsticks, we should be cautious of using the screening data to do more than identify trends, at least in very low prevalence areas.

Screening in hospitals not supported by PMI gives cause for significant concern. Whereas in one hospital, the lab maintained that all donors were screened, the number of tests they had carried out was far below the number of donors reported by the emergency room and operating theatre. In addition, there was significant doubt over the quality of the dipstick used for screening.

At some hospitals, screening for HIV had only relatively recently started, but had shown a significant number of positive cases from the start. In addition, pre-screening by questionnaire to eliminate those in the window period was often poorly implemented in many cases, particularly where donors are family members recruited specifically to provide blood in emergencies.

In places where there are no other facilities for HIV testing, the UTD is often under pressure to carry out this task, or at least to inform donors who are found to be HIV-positive of their status. In addition, where donors are family members, it is difficult to discard blood found to be infected without providing reasons to the person concerned. This puts transfusion units under considerable pressure.

Although we did not look into screening for other blood-borne conditions, it seems that screening for hepatitis C at least is not carried out in a number of places.

On this evidence, we can assume that there is at least some transmission of HIV from transfused blood, particularly in several areas of Papua.

Recommendations – Blood Safety

1. Much greater efforts must be made to safeguard the blood supplies, particularly in remoter areas. This should include provision of approved test kits in adequate quantity, and implementation of an appropriate questionnaire.
2. Blood transfusion units should not be allowed to provide normal testing.
3. PMI should provide simple brochures in local languages to be offered to donors. Donors should also be informed of prevalence of HIV and other infections among local donors, to encourage donors to consider VCT.

3.9 Knowledge/Information

In many places visited, we found very limited knowledge about HIV and AIDS outside the activist community. Even in hospitals, the questions raised were often very basic. But most concerning was the very low level of understanding among decision and policy makers in KPADs and DPRDs. Hopefully our visits made some impact on this, not only from the discussions, but also by providing them with the Spiritia booklets. However, we are pessimistic that this has made a major impact, and in addition, there are still more than 400 district/town KPADs and DPRDs that we have not met, and have probably had not equivalent contact with other sources of information.

Provision of information to KPADs and DPRDs is not among the objectives of this Spiritia program, although it is clearly an important side product. In only one province did we find a program being implemented to upgrade the knowledge of district/town KPADs. On the other hand, in several places, KPAD members did not even know what the abbreviation ‘KPAD’ stands for.

Some efforts have been made to upgrade the knowledge of medical professionals, but there is as yet no effective, nation-wide program to address this. We found little evidence of any action by the Indonesian Medical Association (IDI) to address this. We are aware of many cases of doctors prescribing monotherapy, often without concern for indications. Many doctors and nurses have huge knowledge gaps, including at basic levels like how HIV is—and is not—transmitted. It is rare that other potentially affected groups of workers in healthcare environments, such as hospital caterers and cleaners, are provided with education on HIV.

Recommendations – Knowledge/Information

1. The KPA must play a more active role in educating KPAD members on the basics of HIV. One approach may be for national KPAD meetings to include sessions offering such education. Provincial KPADs must also take responsibility for educating district/town KPADs. KPA/KPAD members should also take responsibility for educating staff in their departments.
2. We should work with IFPPD to provide materials and facilities to educate DPRD members about HIV.
3. A system must be put into place to upgrade the knowledge of professionals and others working in the health service. If IDI are unwilling to accept this responsibility, pressure must be put on Depkes and Depdiknas to achieve this.

3.10 PLHAs/GIPA

The prime original objective of the visits was to make contact with PLHAs, and understand the challenges they face. We therefore tried hard in each place to meet with PLHAs. However, this was sometimes not successful. In many places, VCT is not available, so most cases of HIV are discovered through surveillance, and at least in theory, cannot be identified. Other cases are identified as a result of AIDS symptoms, and the patients often die soon after. We were also hampered by our determination that we should not be introduced to patients without their informed consent in advance, and in several cases, this was not possible during the period of our visit. However, we did manage to meet with a significant number of PLHAs, both previously known to us and also new friends.

One major objective of the visits was to promote the GIPA (greater involvement of PLHAs) principle, and to demonstrate its benefits with the active involvement of open PLHAs in the teams. In general, this objective was achieved, with many comments indicating that participants in our meetings had been influenced very positively. This was particularly true in meetings with medical professionals, who in many cases had not previously considered the role of patients in the response to the disease. In return, as noted above, many HIV-positive team members gained self-esteem from the reception they received from such professionals, who often admitted that they had learned much from the discussions with PLHAs.

It is sad that it was among several NGOs, especially those ‘supporting’ PLHAs, that that GIPA principle was least understood and implemented. In several cases, such NGOs are treating PLHAs as objects, as recipients of services, even as assets. They are intentionally creating an environment of dependency, so that PLHAs will feel themselves bound to the NGO and feel ‘ungrateful’ if they leave. PLHAs are rarely involved in decision and policy making; indeed they are rarely involved except to provide testimony at meetings. We found several cases where PLHAs had been denied the opportunity to meet in closed sessions without the presence of NGO staff. In some cases, we managed to facilitate such meetings. In the words of one visit report, “after the meeting, everybody looked so happy and laughing.”

Many PLHAs are young and have limited education, with the result that they have never been employed, at least in the formal sector. We met many PLHAs for whom the greatest challenges were food, clothing and shelter. Such people are very vulnerable to becoming dependent upon charity or NGOs. It is rare that they are offered opportunities to develop life skills, or to generate income to counter this dependency.

Even though HIV-positive people are an essential link in the chain of infection, few are being targeted by prevention activities. There are of course many challenges in such an approach, not least to ensure that the rights of PLHAs are not violated. But the demonstration that PLHAs wish to take a responsible approach can also impact on stigma and discrimination.

Recommendations – PLHAs/GIPA

1. Greater efforts are needed to promote the GIPA principle, particularly to NGOs and community groups. This should include preparation of an attractive brochure describing GIPA, and explaining the benefits of the involvement of patients in their health.
2. NGOs, government and the private sector must be encouraged to employ PLHAs, particularly where their expertise as positive people can assist in prevention programs.
3. Greater efforts are needed to offer life-skills training, to develop income-generating activities, and to offer micro credit for PLHAs.
4. Spiritia should develop a program ‘HIV Stops Here!’ with PLHAs to identify ways in which the HIV transmission chain can be broken. However, this can only make a real impact on incidence if many more PLHAs become aware of their status through VCT.

3.11 Peer Support Groups

Partly as a result of the disempowerment of PLHAs, early in the program we decided to include an additional objective, not considered when the program was initially designed: to stimulate the formation of new peer support groups. Although our hope had been that peer support groups would be formed within larger AIDS service organizations (ASOs), as noted our experience quickly demonstrated that this is rarely appropriate. We therefore encouraged PLHAs to get into contact for mutual support, in hope that this would result in the formation of peer support groups. Note: we consider two PLHAs providing mutual support as an embryo peer support group, although we always hope that some of these will develop further. Once such embryo groups form, they can offer themselves as referral to organizations providing VCT or doctors who may encounter cases in their hospitals or practices. In such ways, the groups will expand and play an increasingly important role.

The challenge is that such groups are often totally lacking in funds, and members have no money to communicate and meet. It may take some time before they feel ready to become more formal groups, let alone legal organizations that can solicit funding. Particularly where membership is dominated by drug users (active or in recovery), it may take time for them to build up trust in potential leaders. Clearly one solution is for them to form as subgroups of existing ASOs; however, as noted this has not often been successful. The alternative of nominating an existing ASO as ‘foster parent’ may be no better, or even worse.

To date, some 15 formal peer support groups (having a name and a structure) have been formed around the country. This is clearly a drop in the ocean of need, but they do provide role models that stimulate the formation of new groups. In contrast to what we hear from other countries in the region, these groups see significant benefit in membership of a national network. However, as the number of groups increases, it becomes more difficult for activities to be implemented on a national basis. Spiritia’s strategy is to encourage the development of appropriate local groups to become regional or provincial ‘umbrella groups’. Such groups would offer services (training, meetings, advocacy, etc.) to local groups in a similar way to that which Spiritia is currently doing nationally. Indeed, such a movement is already starting to develop in Bali, where BaliPlus last year held a Bali PLHAs meeting. Spiritia hopes to stimulate two three more similar groups to develop, covering at least Greater Jakarta, Sumatra and East Indonesia, over the next year.

As groups develop, members often find they have little in common, particularly if they come from very different backgrounds. Often this results in groups splintering, with those from a similar background (e.g. *waria*, drug users, gays, women) forming their own groups. Similarly, PLHAs may be unwilling to travel long distances for meetings, and groups of PLHAs living close to each other may form. Such developments should be encouraged, but hopefully ‘umbrella groups’ can in time support such groups.

Several groups have carried out needs assessments among their members. Although this is a valuable approach, care must be taken to ensure that the results do not reflect ‘wants’, rather than ‘needs’. ‘New’ PLHAs often do not have a clear understanding about how their disease may progress, and are thus unaware of what they will need at a more advanced stage of infection. Questionnaires may not be the best

method for identifying needs. Alternatives such as focus group discussions may be more appropriate, offering the opportunity to simultaneously provide education.

Recommendations – Peer Support Groups

1. Spiritia should implement a program to stimulate the formation of additional peer support groups around the country, and to encourage existing groups to develop, including becoming ‘umbrella groups’. This program should include provision of limited funds to support activities in a way that avoids development of dependency.
2. Development of peer support groups should not be forced. Members need time to become comfortable with each other, and develop a mutual trust. This is even more important in groups including active or former drug users. Focus should be on providing useful services to members (e.g. referral networks, information, advocacy), rather than on having frequent meetings of members.
3. Funders should ensure that their objectives in regard to support of PLHAs do not drive further dependency, or further encourage ASOs to view PLHAs as assets.
4. Needs assessments among PLHAs must be carried out with care.
5. Spiritia should urgently work with UNAIDS to finalize the Indonesian version of the GNP+/UNAIDS publication “Positive Development”.

3.12 Vulnerable Populations

During our visits, we tried to meet with groups of people vulnerable to HIV (sex workers, *waria*, prisoners, drug users). For many, this was their first contact with openly HIV-positive people, and often generated much discussion. Certain common threads appeared: lack of knowledge about HIV (particularly among *waria*), lack of access to condoms and syringes, high mobility of sex workers. In most places (but not all), there was a least one NGO reaching out to sex workers. However, it was rare to find NGOs reaching out to drug users and particularly *waria*. In all *waria* groups, we heard stories of members dying for unidentified reasons, but with symptoms suggesting AIDS. Few *waria* seemed to be aware of their vulnerability, and even where there were NGOs targeting *waria*, they seemed unable to provide support for members falling sick.

Prevention among sex workers is often hindered by their very high mobility; many *lokalisasi* workers move to another town every three months, which makes sustained outreach challenging. This challenge is increased by the lack of communication and cooperation between neighbouring administrations. Administrations also need to be more aware of the risks resulting from return of sex workers from other provinces, for example Manadonese bar workers returning home from Papua, or West Java sex workers returning from Batam. It appears that most migrants in Batam who are diagnosed with HIV tend to return to their villages in Java, but there is no system of referral for such people on return.

In connection with this, care must be taken in assessing possible caseloads in such places. Since HIV-prevalence in the Riau islands is found to be high in sentinel surveillance, the assumption is that treatment requirements, including uptake of antiretroviral therapy, will be high. In fact, there are indications that most migrants return to their place of origin when they are sick, so the caseload is in fact transferred elsewhere, often to rural locations.

While talking of the Riau islands, it must be noted that apparently there is effectively no cooperation or communication with authorities or groups in Singapore, from where most of the sex-worker clients come, and where some sex workers (particularly *waria*) go to work. Spiritia attempted to stimulate some communication with an NGO in Singapore, but this did not bear fruit.

In regard to drug use, this is now found throughout the archipelago. While the 2001 rapid assessment found very limited injecting drug use in Manado, now it’s exploding there. Even more concerning, there is now evidence of probable injecting drug use in Papua. We would be foolish to assume that Papua is not vulnerable to this epidemic, but it will make the challenges there even more difficult to address.

We visited a number of prisons. Many are filled to more than twice capacity as a result of the policy of incarcerating drug users. While some prison staff have a good understanding of HIV, knowledge was

generally low. In several cases, surveillance has already identified a number of cases of HIV infection among prisoners, and this is stimulating a search for solutions by staff. At least there is now an acceptance at a national level and in many provinces that this is a problem, but solutions are few. Only in a couple of cases is there any contact with local NGOs, although experience in Bali has shown that this is helpful. There is still no consensus on VCT in prisons; most are not ready to offer it, and in any case, it is not clear who will pay. None of the prisons we visited provided condoms; in one the need for them was questioned by staff, who noted that there was no contact between male and female prisoners!

The prison doctors we met appeared to be very concerned about the health of their charges, but are generally overloaded, with abysmally low budgets. None had any real knowledge of antiretrovirals. Even though it may be unreasonable to hope that ART will be offered to prisoners, there may be cases in which PLHAs already on treatment are incarcerated, and they will probably wish to continue treatment.

Recommendations – Vulnerable Populations

1. KPADs must be aware of the possibility of migrant sex workers from their provinces/districts/towns returning with HIV infection, and develop appropriate strategies, including referrals, to address this.
2. There is great concern over the vulnerability of *waria* to HIV infection. Outreach to this group is limited in most areas, and peer support for those who become sick is lacking. *Waria* must be empowered to accept HIV-positive peers, and to offer support to those who become sick.
3. While 100% condom-use programs are an important element of the response, we must always remember that we currently reach few of the informal sex workers. Much greater efforts are needed to improve access to condoms in a way that is user friendly.
4. We all know what we need to do in regard to drug users. Now all we have to do is just do it! (No more difficult than saying ‘no’.)
5. Surveillance sentinels of drug users must be set up throughout the country. This should probably include surveillance in prisons if it can be guaranteed to be unlinked-anonymous.
6. Prison authorities in general admit they need help. We must find ways to support them. Among possible solutions, publishing a newsletter similar to the HIV Education Prison Project (HEPP) bulletin published by Brown University in the US may be helpful.
7. We need to press for a policy regarding continued use of ARVs by incarcerated PLHAs who are already on treatment, and extension of this policy to allow provision of ART to prisoners who fulfil starting criteria.

3.13 Funding

After lack of human resources, the biggest challenge to the community response in most places visited was lack of funding. Even in provinces where bilateral donors have a presence, there are many places that are as yet untouched by the funder programs. NGOs often ask to whom they can apply for funding, but currently there is no clear mapping of donor involvement—or the gaps.

Where local governments have made funds available, they often have limited ability to select recipients. In one place, we heard that Rp 50 million had been allocated for community responses to drugs, but this had resulted in proposals from more than 50 NGOs. The solution was to give each Rp 1 million, a sum that is totally inadequate for any real response.

Yet often local NGOs and KPADs are lacking in capability to advocate for additional funding by local governments. In several cases, significant additional funding was allocated to the response to AIDS following meetings between Spiritia teams and local government and parliament. No doubt it remains easier for visitors from Jakarta to open such doors, but in many cases local NGOs were not even aware of the role of the E Commission of the DPRD.

Recommendations – Funding

1. The mapping of donor responses by UNAIDS becomes increasingly urgent, so that significant gaps can be identified, and funders encouraged to fill the gaps. Among these gaps, it does appear that urgent consideration must be given to support for Lampung and DIY.
2. KPADs must partner with communities to request appropriate funding from local government budgets, particularly with advocacy to DPRDs.
3. Much greater efforts must be made to encourage the private sector to play a part in provision of funding, to allow a sustainable response. NGOs and KPADs require guidance on how to approach companies, and identify to them the benefits of involvement.

3.14 Media

In many places, the Spiritia team appeared on talk shows on radio and TV. It is sad that almost uniformly TVRI requested a considerable fee for such appearances, and we had no funding for this. It is difficult to assess the value of such appearances, but PLHAs speaking openly invariably results in a number of calls, many of which are looking for information. In some cases, local AIDS NGOs are already partnering with local radio stations with regular slots, and these were most grateful for the stimulation provided by PLHAs talking. In every case we experienced a warm response at radio stations and among listeners.

Local print media also covered a number of our meetings, and usually reporting was reasonably balanced, even if it was clear that reporters frequently had little knowledge of HIV and AIDS. Only in one case were photos published without permission, and in this case, a follow-up phone call to the editor resulted in an apology.

However, in several cases we heard of local press violating the norms of empathetic journalism. In one case that occurred during the team visit, we managed to stimulate a national response, which may have a longer-term effect. Surabaya particularly is well known for sensational reporting of AIDS stories, including identifying PLHAs, which have resulted in loss of employment and other problems. Because of this, PLHAs in Surabaya remain very closeted.

Recommendations – Media

1. NGOs and PLHAs must take advantage of opportunities to take part in talk shows on local radio. Spiritia should include appropriate skills in training on public speaking.
2. Local AIDS NGOs must be encouraged to take much more critical, urgent and coordinated action in cases of violations of the norms of empathic journalism by local media. KPADs should also take action based upon the national strategy.

4. Follow up

Although this program has been invaluable to Spiritia and the Indonesian PLHA network, it entails considerable utilization of resources, both human and financial. Yet we have only managed to visit two thirds of the Indonesian provinces, and in general only the province capital cities—only in Papua and Riau have we had the opportunity to visit a number of other places. From the limited information we obtained, it is clear that many other places have unique characteristics; we should hesitate to draw conclusions about the situation in the Flores region of East Nusatenggara (NTT), for example, based on relatively brief visits to Kupang and Soe. Even in Papua, where we visited ten places including Wamena in the interior, we recognise that the situation in the rural parts of the interior have special challenges that we cannot visualize.

Yet it is also clear from information gleaned from a number of sources that the epidemic is not limited to the urban areas. Indeed, gut feel (at least) suggests that the situation in many of the remoter parts of Indonesia may be no better than that found in several parts of Papua, where HIV prevalence of 5 percent or more are not beyond the bounds of probability. Certainly there is evidence that parts of NTT and Maluku may have levels of risk behaviour approaching that of Papua.

The challenge is not only to visit a larger proportion of the archipelago. As noted, we have made return visits to a few of the places covered in initial itineraries. As expected, we found that doors opened during the initial visit had already begun to close, as a result of limited follow-up by local groups. In addition, we cannot expect that peer support groups set up as a result of one visit will immediately become self-sustaining—regular nurturing is required.

While Spiritia plans to continue this program—and donors continue to be willing to fund it—there are limits to what is feasible. Further, as was noted during our third visit to Sorong, it is now time for local KPADs and NGOs who value the visits to invite us, contributing to the costs, rather than passively accepting our visits. But human resources remain the greatest challenge: visits planned over the next six months will require more than six weeks of management time away from Jakarta, plus the time spent setting up the itineraries and schedules. While this is an important element of the Spiritia project, it is impacting adversely on other equally important programs.

If these visits are producing valuable outcomes for the response to AIDS in Indonesia in addition to the benefits to Spiritia's project, additional partners are needed. The rather informal approach, in which we are dependant upon friendly NGOs to act as visit hosts, should be replaced by a more formal approach, with the KPA and local KPADs playing a more active role. Funding must also be diversified, again with KPA and KPADs contributing.

Some of the recommendations require action by Spiritia. Others will directly benefit the PLHA network, and therefore justify investment by Spiritia. But many require a much broader response, involving government, donor agencies, UNAIDS, and NGOs. While Spiritia is willing to play a part such responses, it is unreasonable to expect us to take a leadership role. Again, we would like to see the KPA and KPADs take this lead. The question therefore is: How can we work together to stimulate this response?

5. Conclusions

This report has identified a large number of challenges, many of which apply generally throughout the country. Because of this, we have generally avoided identifying the sources of the examples; it is not the intent of this report to fault any parties or places. It is clearly difficult if not impossible to summarize and draw general conclusions on the outcomes of several hundred meetings in 36 places—for those who wish, individual visit reports are available covering each itinerary.

It has also been difficult to avoid ending up with a very large number of recommendations. We have attempted to identify those we feel are the most pressing in the executive summary, but all are important and most are urgent.

This report covers visits starting in November 2001, with the last in August 2003. This two-year period had been one of significant developments in the AIDS epidemic in Indonesia, with the scope of the IDU threat becoming starkly apparent, and with the very worrying extent of the epidemic in Papua becoming clearer. On the other hand, we have seen very heartening developments in several areas impacting on the lives of PLHAs, including the institutionalizing of the GIPA principle in the revised national strategy, much improved access to antiretroviral therapy, and a growing number of PLHAs willing to speak out in public. Nonetheless, this report identifies many shortcomings in the public and community response, many of which will adversely impact on the spread of the epidemic if not addressed promptly. It is hoped that partnerships can be formed to ensure that the required action is taken.

Appendix 1: Places Visited

North Sumatra: Medan

Riau: Pekanbaru, Batam, Tanjung Pinang, Tanjung Balai Karimun

West Sumatra: Padang

Bengkulu: Bengkulu

Lampung: Bandar Lampung

DKI: Jakarta

West Java: Bandung, Bogor

Central Java: Semarang

DIY: Jogjakarta

East Java: Surabaya, Malang

South Kalimantan: Banjarmasin

East Kalimantan: Balikpapan, Samarinda

West Kalimantan: Pontianak

Bali: Denpasar

West Nusatenggara: Mataram

East Nusatenggara: Kupang, Soe

South Sulawesi: Makassar

Central Sulawesi: Palu

North Sulawesi: Manado

Papua: Jayapura, Merauke, Wamena, Nabire, Biak, Manokwari, Fakfak, Kaimana, Timika, Sorong

