Amplifying the Voices of People with AIDS in Papua

Report on a Visit to Papua by a Spiritia Team, February-March 2006

Background

HIV/AIDS has affected Papua worse than any other part of Indonesia, with by far the highest reported prevalence: 49 AIDS cases per 100,000 population. Many believe that this significantly understates the actual situation, with HIV prevalence rates probably approaching those of some countries in sub-Saharan Africa. Reported numbers are low because of limited access to health services including HIV testing. In addition, people are discouraged from accessing available services by the deep-rooted stigma surrounding the disease.

These reasons exacerbate the already difficult conditions faced by people living with HIV/AIDS (PLHAs) in Papua, with the result that their voices are rarely heard, either on their own behalf or in the overall province-wide effort to respond effectively and humanely to the presence of HIV and AIDS in the community. This further hampers access to care, support and treatment (CST).

FHI Papua, wishing to find ways to support PLHAs and strengthen their voices, asked Spiritia, as the national umbrella peer support group for PLHAs, to visit Papua in early 2006, to gather and share relevant information.

Objective

To help identify alternatives which make it possible to serve positive people more effectively and support their broader participation in local and provincial responses to the epidemic.

Activities

For this purpose, Spiritia formed a team consisting of three members of Spiritia staff plus one experienced member of the national PLHA network. Two, one a women, were openly HIV-positive, both taking antiretroviral therapy (ART). The visit covered the period 22 February – 10 March 2006, during which visits of around four days each were made to Sorong, Timika, Merauke, and Jayapura. At each location, the team attempted to meet with local stakeholders including district/municipality AIDS commissions (KPAD), health service providers, other NGOs, and PLHAs, both as individuals and groups. An interim report was presented to provincial stakeholders including a representative of the province KPAD on 9th March. This document is a more formal version of that report, and takes account of several comments made during that meeting.

Findings

General

It is difficult to draw valid and defendable conclusions regarding a province as large and diverse as Papua on the basis of brief visits to four towns on the coast. However, we did meet with several health care workers with experience in the interior, and added this to our own earlier experience from a visit to Wamena in 2004. All of this suggests that many of the challenges we report below also pertain to the interior, often with greater levels of concern. There is evidence that AIDS is already a major problem in many parts of Papua's interior, probably even greater than in the coastal towns. Yet the responses are even more muted and less effective. The levels of stigma in rural areas are often greater and more pervasive, particularly if driven by cultural factors.

The recent splitting of the province into two, later perhaps three, provinces, and the splitting of several districts into multiple new districts is also having a negative short term effect on responses to the AIDS epidemic. Experienced staff are being drained to set up new administrations. Yet the institutions of the new administrations are not yet effective or even in place. In particular health services (Dinkes) are

weakened, while under-staffed and under-resourced community health centers (puskesmas) are being forced to take on the role of district hospitals. And if KPADs are weak in existing districts, their effectiveness in the new districts can be imagined.

Note: This is a report on a visit, not of a survey or a study. It is based mainly upon comments made by those we met, and what we heard could not always be independently verified. In addition, we may have misheard or misunderstood some of the comments. Thus it should be considered more as painting a picture of what was seen during a very limited visit, rather than a definitive report.

KPAD

We met with five KPADs: Kota Sorong, Kab. Mimika, Kab. Jayapura, Kota Jayapura, and Kab. Merauke. We were not able to meet with the province KPAD, except nominally when presenting our preliminary visit report. We noted considerable differences in the apparent level of concern among the KPADs we met, and it is difficult to draw general conclusions based upon this. However, it seems that in many cases, the KPADs are very dependent upon the efforts of one or two key members, usually including the head of the local health service (Kadinkes). In addition, the active involvement and leadership of the district/municipality head (Bupati/Walikota) is a crucial element in driving an effective response. This was particularly demonstrated in KPAD Kab. Jayapura, and also in Kota Jayapura. In particular, the support for formation of sub-district (kecamatan) level KPADs in Kab. Jayapura was particularly interesting. On the other hand, the political vacuum in Kab. Mimika clearly has a major negative impact; even though KPAD members as individuals articulated a considerable level of concern, the KPAD itself appeared to have little impact.

In most cases, it did appear that KPADs were making an effort to involve the community, and NGO membership of the KPAD seems to be more common. However, it is not clear in all cases that the NGOs are in fact representing the community or even the views of all AIDS NGOs in the district. We found no cases in which the KPADs saw it as their role to encourage and stimulate the formation of NGOs or community groups to assist in the response.

Although we attempted to include local people living with HIV/AIDS (PLHAs) in our meetings with the KPADs, mostly these people were unwilling to reveal their status, and there was no clear indication that the KPADs were committed to hearing the voices of PLHAs.

In general, the KPAD members’ level of knowledge and understanding of the epidemic and the challenges faced appeared quite low. Few seemed aware about the availability of VCT services or CST in their districts. We found little evidence that the local KPADs were receiving technical support or guidance from the province KPAD. On the other hand most were dependent upon funding from outside their district, either from the province or from donors. There appeared to be little effort made to mobilize local funding.

We found little evidence of any attempt to involve the local parliaments (DPRD). It seems that KPADs do not view advocacy to the DPRD as their role, while perhaps DPRD members are unwilling to accept invitations from the government. We found no cases in which local NGOs had attempted any real ongoing advocacy towards DPRDs.

Few KPADs had initiated an effective information, education and communication (IEC) program. In most places the ‘standard’ brochures distributed by the national KPA were all that was available. It is doubtful how effective these are in Papua. Only in one place (Merauke) did we see an effective billboard campaign, and this had been implemented by MSF. However, this appeared very effective and could become a model for other parts of the province.

Community

As noted, we saw no evidence of significant community response to HIV. Few new NGOs have been formed over the last two years; if anything numbers have decreased. We saw no signs that the churches are playing a really active role, although there are indeed several individual religious leaders who are demonstrating a high level of concern. We were informed that seminaries in Papua do not yet discuss HIV/AIDS in their training.

Little if any attention was given to the epidemic in the campaigns for the recent gubernatorial elections. If it had been, it is unlikely that it would have been a vote-winner. The previous vice-governor, whose concern about HIV is well known, did not do well.

Mass Media

We had little opportunity to interact with the mass media, but did meet with editorial staff of one newspaper and with managers of one local radio station. In both cases, we found staff supportive, but very poorly informed. They indicated a willingness to run regular columns/slots on HIV, but admitted that they had insufficient knowledge to support this.

VCT

Access to VCT remains limited, and in many places difficult. VCT is generally offered only in hospitals, which are often somewhat remote and unfriendly to the target populations. The mobile VCT service now operating in Jayapura might be a model for other areas. Although rapid test kits are now becoming more widely available, we saw little evidence of strategies being developed to maximize the benefit from these, such as providing immediate results in mobile test services.

There seemed to be significant discrepancies between VCT statistics as explained to us and those reported to the Global Fund. Although there has been a significant scale up in VCT, it is far from achieving the level needed to make a significant impact on the epidemic, or to direct the required numbers to CST. Indeed, in some cases, we found reluctance to scale up VCT because organizations felt overwhelmed and unable to provide adequate support to people newly identified as HIV-positive. On the other hand, the linkages that have been set up by several NGOs in Jayapura to refer clients to other services impressed us.

Care, Support and Treatment

The improvements in CST services were very apparent, with most of the referral hospitals playing an active and proactive role. Levels of stigma and discrimination in health services appear to have decreased, but it remains difficult for PLHAs to be confident of confidentiality. There is a conflict between promoting AIDS-related services (VCT and CST) and making them more accessible on the one hand, and the concern that people accessing them are likely to be immediately identified as PLHAs on the other.

While efforts to train health care workers have intensified, it is clear that level of knowledge about AIDS treatment are still quite limited, and often non-existent among those not directly involved. We heard few cases of non-medical staff, such as cleaners, caterers or receptionists being given any training on HIV/AIDS. There is apparently no formal systems in place to allow doctors to consult outside their own institutions in case of difficult cases. Few doctors have means or capability to access new or updated information, or to extend their knowledge through formal continuing medical education.

Few hospitals had effective AIDS Working Groups (Pokja) and those groups that did exist had little influence. There was no formal mechanism for involving PLHAs in service provision. However we were impressed by the developments in the Merauke hospital, which might be considered a model for an integrated response, including a one-stop service for PLHAs with TB.

We found few new NGOs working in the field of support. Indeed, while previously there had been indications that some faith-based organizations were interested in playing a more active role, they seem to have made little progress. Few of the non-peer managed groups really understand the concept of empowerment. There tends to be at best a paternalist attitude that ‘we know better what they need’, while some groups still appear to view the PLHA clients as ‘assets’.

There has been slow progress in the development of effective peer support around the province, other than in Merauke. There are many reasons for this: death of previous champions; lack of understanding of the concept; fear of revealing HIV status; low level of education among many PLHAs; language challenges; incompatibility between indigenous and migrant members; and lack of funding. However, the impressive development of Cendrawasih Bersatu Merauke (CBM) demonstrates what can be achieved with a little money and the dedicated commitment of one or two people with vision.

It is becoming increasingly evident that parents/families/partners of PLHAs can play a crucial role in the response, and support groups of such people can have great influence. There are currently no such support groups in Papua. However, we met two parents in Jayapura who appeared interested to set up such a group there, and hopefully they will be supported and encouraged to achieve this.

Stigma and Discrimination

As noted, levels of stigma and discrimination in the health services appear to have reduced in significance. On the other hand, there remain very significant problems in the community, although these seem to be being addressed in Merauke. PLHAs are no doubt at risk of discriminatory behavior, in some cases in real physical danger, particularly it seems in Mimika. However, we heard many stories of families and communities uniting to accept and support PLHAs; the status of the majority of members of CBM is known to their families, and all reported acceptance and support. It is difficult not to draw the conclusion that much of the problem arises from self-stigmatization, which can be addressed by real empowerment, together with mutual support.

Voices of PLHAs

We found little evidence that the voices of local PLHAs were being heard in any forums. As noted, KPADs have not involved PLHAs. PLHAs rarely have the opportunity or the readiness to speak in front to congregations. Reporters rarely have the chance to interview PLHAs, few of whom are anyway trained to speak effectively in public. Most service organizations, both health care and community, appeared to view PLHAs solely as recipients of services. Few health service heads or other heads, let alone Bupati/Walilkota, have met with members of peer groups.

Other Challenges

It is clear that poverty, together with its related problems such as corruption, malnutrition, lack of education and unemployment, plays a major role in the explosion of the HIV epidemic in Papua. It is equally clear that we can make few comments on efforts to address these immense challenges. However, the provision of potent and still expensive antiretroviral drugs to people who have little else with which to fill their stomachs must be a questionable strategy.

It is also clear that lack of empowerment of women is a driver of the epidemic. Again there is little that we can suggest to address this, other than increased cooperation and collaboration with groups pressing for women’s empowerment.

Although we were unable to confirm this, we heard of early and regular sexual activities involving multiple partners among the youth in several places. For example, in Sorong, we were told that young girls are expected to engage in sex to show ‘love’ for their partners.

In contrast to most of Indonesia, addiction to alcohol is clearly another significant driver of the epidemic through its impact on risk behavior. Although some districts have attempted to control alcohol use, there are few signs that this is an effective response; indeed history teaches us that prohibition is counter-productive. We saw no evidence of real efforts to address this problem with treatment or approaches such as Alcoholics Anonymous. We were also informed that the province health service (Dinkes) does not view addiction to alcohol as health matter.

On the other hand, while there is considerable evidence of substance abuse, it is said that this does not yet extend to ‘hard’ drugs (heroin) and injecting is rare. While this may (perhaps!) currently be true, we have seen such drug use exploding elsewhere in Indonesia in conditions not greatly different from those that exist in the coastal towns of Papua. We must therefore counsel a high level of vigilance, and readiness to respond rapidly with harm reduction programs should evidence of such drug use appear.

Recommendations

As noted, it is difficult to make definitive recommendations based upon such a limited visit. However, the following may stimulate some ideas.

1. **Revitalize KPADs in all areas, with provision of adequate resources and training.** The province KPAD could be the main motor for this, providing not only funding but technical assistance, pressure for leadership by the Bupati/Walikota and DPRD, and by routine monitoring and evaluation.
2. **Promote more effective IEC programs by KPADs.** Materials should use appropriate language and many pictures. The mass media should be supported with material for regular columns/slots, while people with appropriate knowledge and experience should be encouraged to host talk shows. The availability of antiretroviral therapy should be carefully promoted.
3. **Extend and promote VCT services**. This should include more mobile services, making full use of rapid tests to give while-you-wait results. VCT should be available in all puskesmas, with a higher index of suspicion among people with TB. VCT must be totally free-of-charge, and confidentiality must be guaranteed. Local PLHAs should be trained to provide immediate peer support.
4. **Extend cooperation with religious organizations.** Understand their organization and hierarchy, particularly of the multitude of protestant sects. Arrange meetings with Synods; promote the inclusion of HIV into curriculum of seminaries. Undertake similar exercises with Catholic and Muslim groups, including NU, Muhammadiyah and MUI at provincial level.
5. **Encourage the formation of new NGOs**. Allocate funds and offer technical assistance, so that in every district there is at least one organization reaching out to all risk groups. Encourage the formation of community forums, and strengthen referral networks and systems. Consider encouragement for the formation of provincial umbrella group(s) on the Spiritia model.
6. **Initiate dialog on role of AIDS Service Organizations**. Ensure that such groups are client-centered, needs driven and do not trigger dependence and inappropriate attitudes towards PLHAs.
7. **Encourage the formation of peer support groups for PLHAs in every place.** Identify capable people, provide them with training and try to involve them more widely. Identify all sources of funding and other resources/technical assistance; consider secondment of more experienced staff from peer groups in the national network. Focus on increasing self-esteem, knowledge and skills. Press local governments to provide funding for local groups. Support Spiritia's provincial PLHAs meeting, planned for May/June 2006. Some specific activities:

   General
   - Increase knowledge and skills of PLHAs, particularly regarding 'Positive Development' and public speaking
   - Provide technical assistance together with funding to facilitate group formation

   Jayapura
   - Encourage PLHAs to form local independent groups under the umbrella of the support NGOs

   Merauke
   - Provide skills training in group dynamics, computers and English language
   - Provide technical assistance for advocacy and development of referral system
   - Provide micro credit for fund-raising enterprise

   Timika
   - Encourage PLHAs to meet and develop mutual support, with a view to formation of a group

   Sorong
   - Group refreshing around benefits of working as a group
   - Develop advocacy skills
   - Provide limited funding for training

8. **Recognize that peer support is essential to achieve required ART adherence levels.** Involve peer groups in the system for provision of ART in AIDS clinics; consider formation of dedicated clinic-based groups. Encourage a dialog regarding the role of families in adherence and other support.
9. **Increase involvement of PLHAs.** Each KPAD should reserve a seat for a peer support group. Offer positions to PLHAs in KPAD secretariat and other bodies; provide training to ensure that they are not just tokens.
10. **Accelerate involvement of district hospitals/puskesmas in PCST.** PLHAs who meet the criteria for ART should be able to access it at most within a one-day journey. Consider ART service on a specific day each week, to encourage mutual support among users and families. Set up a Papuan network of doctors in AIDS care, with a hotline, perhaps initially via SMS, but to extend to Internet. This network could also publish a regular newsletter. Encourage access to and use of the Internet, with use of dial up through Telkomsel GPRS.
11. **Address Alcohol Addiction.** Consider support for development of Alcoholics Anonymous groups. Collaborate with other similar efforts, including the national Narcotics Anonymous network. View alcohol addiction as a health problem, rather than solely as a social problem.

Conclusion

There remain many challenges to the meaningful involvement of PLHAs in Papua. Some of these are cultural, resulting in high levels of discrimination, both external and from self-stigmatization. However, there are examples that counter the assertion that real PLHA involvement is currently impossible in Papua. If these examples are used as role models, there is no doubt that the voices of PLHAs will be heard more clearly. It has also been demonstrated that this has a positive impact both on the quality of life of other PLHAs and also in reducing the impact of the epidemic.

This report has identified one of these role models, and has attempted to describe how it could be cloned. It has also suggested a number of actions by other stakeholders that, if implemented, could put in place an environment more conducive to the development of these responses.

The report has not attempted to determine who should take the actions described; as outsiders it would be inappropriate of us to do so. However, as noted, Spiritia and members of the Indonesian peer support network could play a crucial role in the development of more effective support groups around the province; we are ready to assist.

Appendix: Detailed Comments from Each Town

Sorong 22 – 25 February

Current situation

- KPAD Kota Sorong exists, but dependent upon ASA for funding
  - KaDinkes is main driver with KaDisnaker; apparently Walikota takes little interest
  - No real advocacy apparent to DPR
  - Most parties are said to be concerned, but not concerned enough to attend meetings
  - KPAD Kab. Sorong said to be even less involved
  - 'Many political problems'
  - Doesn't function as it should (no effective secretariat...)
- Number of NGOs in AIDS field, but limited funding
  - No funding from KPAD Kota
  - Tendency to blame other parties (KPAD, DPR) but little or no follow-up of potential opportunities
  - Work alone (forum not working)
  - Limited knowledge
  - Don't have strong human resources, funding, ASA funding not consistent
- Lokalisasi continues to operate
  - Latest surveillance shows 17% HIV prevalence among sex workers there
- NGOs report high level of risky sex in campuses
  - Many female students become 'ayam kampus' to support their studies
  - Sex before marriage is considered mandatory to show 'love'
- RS Sele Be Solu (RS Kota) becoming very active as referral hospital
  - VCT running since June 2004, becoming more effective
  - Staff understand their limitations
  - Increasing number of PLHAs accessing ART (currently 29)
  - Dr Ferhat respected by all
  - Support from hospital management?
  - ASA funding effective
  - VCT room perhaps not felt suitable for PLHAs not yet open
- RSUD (Kabupaten) a disaster area
  - Little clear direction
  - Tendency to refer all cases to RS Sele Be Solu
  - VCT apparently not offered, since PMI have been forbidden to offer VCT
  - Perhaps upset that RS Sele Be Solu became referral hospital
- Yay. Sosial Agustinus complementing RS Sele Be Solu
  - 'One stop shop'
  - Outreach
  - VCT offered
  - Support to PLHAs
  - Interested in Alcoholics Anonymous concept
  - Providing some nutritional support, but limited; sorely needed
- Concern over HIV levels in prison
  - YSA offering VCT but overwhelmed
    - 137/237 inmates request VCT, 58 so far tested, three positive (5%)
  - Probable risk factor sex, thought to be not primarily in prison
  - Most held for alcohol-related offenses
  - No current discharge planning
  - Little sign of drug use
- Increasing number of asymptomatic people seeking VCT
  - Referrals from STI clinics, TB?
- Mass media (print, radio) concerned
  - But lacking in knowledge and sources of information/news
    - No news releases or updates from KPAD
  - Willing to consider greater involvement
- Army becoming concerned at increasing number of cases
  - Reported 20 cases in Sorong area (covers most of West Irian Jaya)
  - Asking for guidance and support
  - Level of knowledge quite low
- Cultural issues
  - "Who brought the virus to Papua?"
  - Alcohol, sex
  - Language problems, said to be not major in Sorong
  - Culture appears stronger than religion
  - Competition among protestant sects
  - Poverty, low levels of education
  - High mobility
- Existence of Sorong Sehati, status
  - Rather weak lately
  - Around 15 PLHAs from RS Sele Be Solu and YSA appear to want to see regeneration
  - Several apparently willing to speak openly
  - Potential problem with 'old' management
- Donor agencies
  - Only ASA

Comments/thoughts/potential actions

- VCT scale up crucial
  - Promotion essential
- Malnutrition
  - Develop local guidelines
  - Education
- Stigma may not be as bad as it is sometimes reported
  - Level of self stigmatization high
  - Several PLHAs report family/community support
  - Fince (leader of Sorang Sehati) is great role model, others possible
  - RS Sele Be Solu and YSA providing excellent service
    - Could GF support them?
    - Advocacy to hospital management
    - Increase knowledge of staff/provide information
- Support regeneration of Sorong Sehati
  - Limited Spiritia funding
  - Meeting with Walikota
  - Meeting with DPR?
  - Promotion in mass media
  - Short term secondment of more experienced group manager
- Support mass media
  - Regular mailings/ready-to-use news items
  - Column: Dr Ferhat with support?
- Technical assistance
  - Urgently needed
- Promote Alcoholics Anonymous
  - Support people from Papua to join national congress April in Bali

Timika 25 February – 1 March

Current situation

- Kabupaten Mimika is in a chaotic state politically
  - Bupati is ineffective
  - DPR has yet to be approved and to meet
  - Funding continues only at previous levels
  - Total population: 135,000, kota 40,000
  - Current dispute with Freeport over support to 7 tribes exacerbating problem
  - Alcohol big problem
- AIDS cases exploding
  - 861 cases reported to Dec 2005
    - vs. 2005 total estimate of 890
  - 95% heterosexual transmission
  - One in four cases among housewives
  - No funding provided by local govt for AIDS programs
  - Many cases among migrants
  - Lokalisasi (surveillance?)
  - Mobility high
  - Little opportunity for recreation
    - Mainly alcohol (officially banned) and sex
- Freeport major employer, and has major influence over all policies/activities
  - 14,000 formal workers in Mimika, 80% male, 60% of those bachelor status
  - 500 government employees
- KPAD Kabupaten Mimika exists, but has no funding
  - Formed April 2005, but ‘not yet functioning’
  - There is a strategic plan, but again not yet implemented
    - Only UP training and media campaign
      - Media campaign very apparent
  - No operational funding, but received Rp50 million from province
    - Used to rent a KPAD office
  - KaDinkes is very concerned
  - KPAD meets rarely, if at all
  - Membership includes NGO
    - 3 members from WAARTSING, no one seemed to know who or what this is
      - Apparently they have no activities
  - Meeting well attended, representatives from all major govt. depts
    - Several community/religious groups also attended
  - Bappeda rep promised to arrange meeting with Kepala Bappeda within one week
- No effective NGO response
  - Yapeda (Pastor Bert)/Pila focus on youth
    - ‘Single fighter’, only one other member
    - Reported to have built a shelter for PLHAs
  - LPMAK (Freeport fund distributor) no real response to AIDS
    - John also ‘single fighter’
  - Topemala exists but no effective program
  - Catholic church concerned, but no program
  - WAARTSING?
  - NGOs receive no funding
  - Donor only GF
- Main hospital RSMM
  - Private hospital, provides free services only to members of 7 tribes
    - Others (migrants) must pay full (and expensive) charges
    - Long way from town, expensive and difficult to get there
  - ART and DOTS support from government
    - 15 people on ART
  - VCT support from GF
    - But reported only one test
      - Non-7-tribes must pay for counseling and confirmation test (Rp100,000?)
  - Many TB cases
    - Report local puskesmas don’t offer DOTS
    - Migrants must pay for sputum test, etc.
  - No initiative to arrange meeting of PLHAs
  - Not willing to consider cross-subsidy for migrants/non-7-trribes
- Government hospital under construction
  - 80% complete, to open ‘Real Soon Now’
  - Staff? Apparently there is a doctor (Singgih?) waiting to become director
  - In meantime, Puskesmas (PKM) Timika carrying some of the load
    - Some staff have been trained to administer ART
    - But BKTIA designated as AIDS Referral Hospital
- Balai Kesehatan Ibu dan Anak (BKTIA) offer VCT
  - Funded by GF
  - Unclear how many people VCT’d and results
  - Say they don’t offer VCT to pregnant women (?)
  - Also designated AIDS referral hospital by Depkes
    - Already have stock of ARVs
    - But no staff trained, and no wish to do AIDS work

- Freeport hospital in Tembagapura for employees/families only
  - Increasing number of cases of AIDS among these (90?)
    - Several cases of pediatric infection
  - Offers VCT, but for ART must go to RSMM
- A complex of 3 buildings has been built near BKTIA as a quarantine centre for PLHAs
  - Agree that this is not appropriate
  - Buildings currently not used
  - Suggest to use as KPAD office, to save rent cost
  - Also could be used as a hospice/shelter and drop in centre for support group
- Existence of Timika Support Group
  - Group formed several years back
  - Supported by nurse (Sister Nona) from RSMM
    - Will become more difficult if more than one referral hospital
  - No real activities since Eta ceased involvement then died
  - No local funding available
  - Met with 7 PLHAs
    - They wish to see regeneration, but not clear who would be leader
      - Limited education, literacy
    - Remain very dependent upon Sister Nona
    - Communication difficult
      - Only one (migrant) has telephone access
    - None willing to be open

Comments/thoughts/potential actions

- Difficult to see solutions until political situation clarified
- Services generally limited to members of 7 tribes
  - Services for migrants (non-Freeport employees) awaiting opening of govt. hospital
- In meantime, PKM Timika could administer ART
  - Have trained staff, ARVs could be transferred from BKTIA
- Propose one day for ART at hospital
- RS Tembagapura could become satellite of RSMM
- Local print media (Timika Pos) appears supportive
  - Local media campaign appears reasonably effective
  - Encourage PLHAs to use this medium anonymously?
  - Provide regular mailings for articles/columns
- A few local PLHAs have potential
  - But one with greatest potential is a migrant
  - Challenge to support people from all tribes/migrants
- Stigma (including self stigma) a major barrier
  - Religious organizations must play greater role
- Prevention material must be appropriate
- Encourage formation of peer support group in Tembagapura
- Support funding and technical assistance for community in Timika

Merauke 2 – 5 March

Current situation

- Kab. Merauke is still in process of splitting into five districts
  - Government staff are being drained to set up offices in new districts
  - Total population of Merauke as split: 100,000, around 60,000 in Merauke town
  - We were unable to meet with any of the top bureaucrats (Bupati/Wakil/Health Service)
  - Health service office did not give good first impression, files of statistics could not be found
  - MSF are in final process of pulling out after more than three years
- AIDS cases continue to be reported
  - Difficult to detect trends, since splitting of district makes comparison difficult
  - Also not clear what surveillance has been carried out recently
    - Not done since 2003 among sex workers
    - Screen of all Army members (800+): 1 positive, 2 indeterminate
    - But 19 Army/police VCT'd in 2005, 5 positive
  - Reported cases show modest increase in 2005
    - 803 positive of which 419 AIDS
      - 14% housewives, 19% sex workers
    - But numbers VCT'd have gone down
  - In Merauke town, 2 lokalisasi, with 225 SW
    - 11 bar, 4 massage parlors
    - Have a 100% CUP bylaw
      - Condom use reported around 80%, but falling
  - Puskesmas Asgon (now in Kab. Mappi), reported 39 cases
  - Alcohol plays a major role in behavior
  - Level of discrimination among public has reduced
- KPAD exists, with secretariat under Dinkes
  - All members are current/retired government employees
  - Main activities seem to be those of the Pusat Kesehatan Reproduksi (PKR) under Dinkes
    - MSF had an effective publicity campaign
      - Billboards in 10 places very striking
- Several NGOs working in prevention
  - Yasanto: PSK
  - Yamikari: Only worked for 3 years on HIV, with community (7 villages), also to religious leaders
  - Yapepa: School children, reproductive health and STIs
    - Have produced an excellent training module with teachers work book
  - AESCULAP: program HIV 2002-2005 funded by ASA, farmers, leaders of 5 religions
  - Yamapan: Muslim community and undergraduates at Islamic college
  - Appears to be limited funding for NGOs
    - GF funding apparently short term (3 months)
- Main hospital well set up, model one stop, TB and lab separate
  - Previously assisted/supported by MSF
  - Pokja set up in 2001, became active in 2003
    - Funded by hospital, Dinkes and GF
  - Drugs and reagents received from variety of sources
    - MSF, GF, Province, MoH
    - Excess stock ARV, 100 bottle efavirenz borrowed by Depkes
  - VCT offered both in PKR and in Pokja
    - Numbers tested dropped from 2024 in 2004 to 1726 in 2005
  - 303 patients recorded since beginning
    - 90 active controlled
    - 51 currently on ART
      - from 77 total (2 decided to stop, 19 dead, 5 lost)
    - Around 30% on efavirenz, 12% d4T
    - 3 children on ART, 2 years up
      - AZT and nevirapine syrup available
  - CD4 testing available since 2004, Dynabead method
    - Reagents originally from MSF to June 2006, will be by GF
  - Challenge: no transport for home visits; families not aware; PLHAs unemployed

- Puskesmas Asgon relatively well set up
  - 3 days by boat from Merauke
  - 39 HIV cases identified, 12 AIDS all died
    - Main symptoms: wasting, diarrhea, TB, Candidiasis
    - Locals do not consider themselves sick if they can still work
    - 2/3 cases migrants
    - For locals, AIDS is a curse and a 'dirty disease'
      - Increasing stigma
- Two NGOs supporting PLHAs
  - Yamikari supported 26, of whom 10 remain alive
    - 20 referred to VCT, all positive
    - Stopped referring target groups to VCT because afraid overwhelmed with cases
    - Also support families of PLHAs
    - Provide limited food to take home
  - Yasanto support 21 PLHAs
    - 2005 74 VCT, 31 +ve, 2006 68, 1 +ve
    - 5 currently on ARV
      - 2 others unable to tolerate, died
    - Provide shelter, current 3 occupants
    - Close meeting of PLHAs supported, weekly meetings for support
      - Provide limited food to take home
    - Home visits to those who need 4x/week
    - Focus on families to encourage support
- Met with a number of religious/community leaders
  - All protestant, but from different sects
  - HIV/AIDS not on curriculum of Sekolah Tinggi Teologi
  - There are more than 12 protestant sects in Papua
    - Each has a Synod in different towns
    - Suggested we should try to call a meeting of all Synods to discuss HIV
  - Provide a chance for members of CBM to meet with religious leaders
- Support Group CBM (Cendrawasih Bersatu Merauke)
  - Originally set up as support for adherence in hospital
    - Supported/funded originally by MSF
      - Now Spiritia providing limited funding
  - Relatively strong management
    - Supported by Pastor Stevie
    - Need computer
    - Produced good profile, well distributed
  - 16 members, most open and supported by families
    - 14 on ART
  - Activities: close meetings, discussion groups, hospital visits, producing souvenirs
  - Looking for support for income generating
    - Microcredit – Spiritia may be able to help
  - Want to do training
    - Computer, English
  - Good example of effective support group
    - Role model for Papua and for RS
    - Knowledge level high

Comments/thoughts/potential actions

- Increasing concern over situation in the interior
  - Puskesmas have little capability to address
- Yamikari seem to have potential to influence protestant leaders throughout Papua
  - Need support for all Papua pastoral counseling training
- CBM needs more support, particularly for income generation
  - But could also provide model - or more - for other places
- Drug procurement must be better organized
- PLHAs tend to be in organizational pigeon holes
- Role of KPAD must be reoptimized
  - CBM should be a member of the KPAD

Jayapura 1, 5 – 10 March

Current situation

Kabupaten

- Population 107,000, including migrants from outside Papua and within
- KPAD quite strong, 1 full time civil servant as staff
  - Bupati and vice-bupati concerned and involved
  - DPRD also supports
  - No professional staff or working groups
- No AIDS NGOs
- No district hospital, currently under construction, due completion June 2006
- Have set up KPADs a sub-district (kecamatan) level, involving community and puskesmas
- Have bylaw 20/2003 on HIV/AIDS
- Surveillance among plantation laborers showed 3% prevalence
- 3 Puskesmas will become VCT and ART referral centers this year
  - There are 12 puskesmas in the district
- Donor ASA and UNICEF, GF not yet
- 1 baby HIV-infected from blood transfusion, given nutritional support by KPAD

Kota

- 2005 budget Rp200 million for AIDS, will rise to perhaps Rp 600 million in 2006
- Bylaw on AIDS will be issued this year
- 204 cases up to December 2005
  - More housewives than sex workers
  - There are indications that IDU has started around Jayapura
- Family welfare cared (Gakin) easy to obtain
- Lokalisasi at Tanjung Elmo
- New coalition 'Jakofa Jaya' involves 7 NGOs, 8 bars and 39 hotel
  - Formed Feb 2006
  - Main activities condom promotion and distribution

- KPAD playing a relatively clear role
  - Vice walikota involved, high level of concern
  - Member of local parliament also involved
  - Plan to hold a monthly coffee morning
  - Action plan to be released this month
- Number of AIDS NGOs
  - But limited funding
  - Funding from ASA and IHPCP
  - Refer to services so that their programs are comprehensive
    - But limited cooperation among NGOs
  - YHI and YPKAM outreach to students, street-based SWs, motorcycle taxi drivers, but different areas
- Health services
  - 3 hospitals already providing VCT. 2 ART
  - Dok II Hospital
    - Hoping for stronger links with NGOs
    - All services for PLHAs free-of-charge
    - VCT has been running for 3 years
      - Average 70 tests/month, 8-10 +ve
      - 982 tested since 2004, 129 +ve
      - 99% come under own initiative (not referred by NGOs)
      - 70% are in-patients
      - Have a mobile VCT clinic, funded by GF
    - 6 babies born from HIV +ve mothers
    - 27 receive ARV, PMTCT 3, 16 live in Jayapura
    - Have trained almost all kabupaten hospitals, including army and navy
    - Dok II has become a teaching hospital working with the medical faculty of the Cendrawasih Univ
      - Will become a research hospital
- RS Dian Harapan (RSDH)
  - VCT started in 2004
    - Cooperation with YHI
    - Over last 2 months 48 tested, 5 +ve
    - Also have a mobile VCT clinic
  - Have no AIDS working group
  - Admit AIDS patients
    - For ART, patients transferred to Dok II
- RS Abepura
    - VCT 2005 139 tested (50 inpatients), 18 +ve
    - Reminder mostly came themselves, as result of media reports or word of mouth
    - Jan 2005, 14 tested, 6 +ve
  - ART 3, 2 died
  - Problem with human resources to make reports
  - AIDS patients free-of-charge
  - Not yet ready for PMTCT
  - Have AIDS working group but not yet functioning
  - Inadequate UP supplies, so not effective
    - 1 pair of gloves per day
  - Support from hospital management lacking

- Several NGOS provide support to PLHAs
  - JSG ever supported 215, 72 PLHAs remain, have 10 buddies
    - At least two of those supported under 17 years old
    - 11 ART, 1 d/o
    - Half of families are aware
      - At least 2 families involved with JSG
    - Occasionally obtain funding from local govt.
    - Various services including shelter, food, nutrition counseling
  - YHI support 17 HIV from 100 VCT'd, counseling at YHI, tested at RSDH
    - Collaborate with RSDH, this year also with RS Abe
    - Generally families are aware
    - PLHAs support group formed with 10 members
      - One open
      - Activities only prayer meetings, funded by ASA
  - YPKM ever supported 7 in their shelter, 3 remain
    - Level of understanding of their status appears to be limited
    - Last 3 months VCT for 20, 3 +ve
    - 13 Service Posts in Kota/Kab
    - Trained 25 priests as pastoral counselors (GKI and Baptist)
      - Monthly meeting, 15 attend on average
      - Suggest a meeting facilitated by PGPWT (Persekutuan Gereja Papua Wilayah Timur)
    - 'Communication between NGOs doesn't happen, we must be more open'
- Narcotics prison under construction
  - To cover all of Papua
  - Staff already available, knowledge of HIV low, but want to know
  - Interested in AA/NA
  - None are detained for drunkenness, only for the results
- Kesdam (Army Command)
  - Don't know what they should do
  - 48 positive in Papua, retained in Papua, 20 died, +3 in 2006
  - 1 needs and is ready for ART
  - Most don't know status
    - Those who know their status are posted/moved
  - VCT mandatory before marriage
  - Red Cross required to report names of positive blood donors from the military
  - Lacking in counselors
  - Level of HIV among TB patients high
  - One came of own accord for VCT
  - Want to provide better support for PLHAs
    - But many barriers
  - Level of knowledge among health care professionals mostly limited
    - "Before this meeting, I did not believe that ARV could be effective"

Comments/thoughts/potential actions

- JSG could become a model for buddy-type support
- Hospital service improved
- Discrimination generally started to reduce
  - But still several PLHAs have extreme level of fear
    - One solution may be a parents support group
    - Also improve referral system
- PLHAs knowledge of HIV generally lacking
  - Support organizations need to sharpen their teaching
- Encourage support organizations to help formation of support groups in each area (e.g. Jayapura, Abepura, Sentani, etc.)
- Need more serious effort to follow up surveillance done in Lereh
- KPAD, NGOs and other institutions must become more aware of the threat of IDU
- Need a network of hospitals to provide ART to people who move around