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Acronyms

AFAO  Australian Federation of AIDS Organisations
AHAPI  AusAID HIV/AIDS Partnership Initiative
ALAW  Australian Leadership Award Fellowship
APN+  Asia Pacific Network of People living with HIV
ART  Antiretroviral therapy
ARVs  Antiretroviral drugs
AusAID Australian Agency for International Development
CAP+  China Alliance of Positive People
CBO  Community-based organisation
CCM  Country Coordinating Mechanism
CDC  Centre for Disease Control
DFID  Department for International Development (UK)
FHI  Family Health International
FIN+  Fiji Network of People living with HIV
GFATM  Global Fund to Fight HIV/AIDS, TB and Malaria
GIPA  Greater Involvement of People living with HIV/AIDS
GNP+  Global Network of People living with HIV
HAARP  HIV/AIDS Asia Regional Programme
HIV  Human immunodeficiency virus
INGO  International Non-Government Organisation
IPPF  International Planned Parenthood Federation
IPPI  Indonesian Positive Women’s Network
JOTHI  Indonesian National PLHIV Network
KANGO  Kiribati Association of Non-government Organisations
LNP+  Lao PDR Network of People living with HIV
MPG  Myanmar Positive Group
NAC  National AIDS Council/Commission
NACA  National Advisory Committee on AIDS
NAPWA  National Association of People living with HIV/AIDS (Australia)
NGO  Non-government organisation
NSP  National Strategic Plan
PIAF  Pacific Island AIDS Foundation
PICT  Pacific Island Countries and Territories
PLHIV  Person living with HIV
PNG  Papua New Guinea
PRHP  Pacific Regional HIV/AIDS Project
PRSP  Pacific Regional HIV and STI Strategy
SINAC  Solomon Islands National AIDS Council
SPC  Secretariat of the Pacific Community
STI  Sexually transmitted infection
TSF  Technical Support Facility
TSG  Technical and Strategy Group for HIV and AIDS
UNAIDS  Joint United Nations Programme on HIV/AIDS
UNDP  United Nations Development Programme
USAID  US Agency for International Development
VNP+  Vietnam Network of People living with HIV
VWU  Vietnam Women’s Union
WHO  World Health Organization
Executive summary

The greater involvement of people living with HIV and AIDS (GIPA) is now generally accepted as necessary for a successful response to HIV; people living with HIV (PLHIV) bring their unique experience to HIV programs, meeting PLHIV significantly reduces discrimination, and PLHIV are invaluable public health educators and service providers. To date there is limited understanding of how to maximise and integrate the expertise of PLHIV, and of the complex work of developing sustainable PLHIV organisations. Although the roles of PLHIV have increased over the past few years, particularly with the establishment of the Global Fund to Fight HIV/AIDS, TB and Malaria (GFATM), the practical implementation of GIPA often falls short of aspirational policies.

In July-August 2009, AusAID conducted a GIPA scoping exercise in order to maximise its support for the meaningful participation of PLHIV and guide AusAID’s future support and engagement in the implementation of GIPA in the Asia-Pacific region. The countries included were: China, Myanmar, Lao PDR, Indonesia, and Vietnam in Asia; and Fiji, Kiribati, Papua New Guinea, Solomon Islands and Vanuatu in the Pacific. Consultants carried out a desk-based literature review and analysis of national HIV policies, plans and other relevant documents, and conducted over fifty-five interviews with key stakeholders, the majority via telephone. Several aspects of GIPA programming were reviewed:

1. Strengthening PLHIV Networks
2. Involving PLHIV in national planning, coordination and governance
3. Supporting policy and legal environment
4. Involving PLHIV in service design and delivery

The mapping of GIPA programming and GIPA aid modalities.

The mapping of GIPA programming and GIPA aid modalities, shows the following:

PLHIV networks

National PLHIV networks are crucial to GIPA, and national PLHIV and Positive Women’s networks are now established in many of the countries covered by the scoping exercise. Although some of these organisations are well-established, several networks are currently weak, and many lack an understanding of their comparative advantage and role as a peak PLHIV organisation. In some countries such as Myanmar, PLHIV organisations are not able to register as an NGO, which limits their ability to respond effectively.

In some countries (e.g. Indonesia) there is no single cohesive national organisation representing the voices of PLHIV. In some countries (e.g. China) , national PLHIV networks formed in response to the GFATM requirement that civil society is part of the Country Coordinating Mechanism (CCM) for grant applications, but these groups often lack vision and the ability to strategically plan their activities. This results in a fragmented GIPA response.
Involvement in national planning

PLHIV networks are involved to some degree in the planning of the national response in all countries. PLHIV sit on most National AIDS Councils/Commissions (NAC), with the exception of China and Lao PDR, and in PNG, the PLHIV on the NAC is not representative or elected. Engagement in national decision making at NAC and CCM level is particularly challenging and often PLHIV do not easily gain respect. In Indonesia and in some Pacific countries, involvement in national strategy development is well supported by both AusAID and government.

Supportive policies and programs

A supportive policy environment is necessary for GIPA. This requires access to antiretroviral therapy (ART), low levels of stigma and discrimination, and a governance system with broad civil society involvement of PLHIV, including women, men who have sex with men, sex workers and drug users.

GIPA is a guiding principle in several National HIV/AIDS Strategies. Although GIPA as a principle is widely supported in most countries covered by the scoping exercise, there does not seem to be much clarity and consensus on what GIPA means at field level and it appears hard to operationalise GIPA into National HIV/AIDS Operational Plans (and budgets). Only the Myanmar National Operational Plan includes support for establishing self-help groups, and there is a budget code for GIPA in the Lao PDR budget. Some countries (China, Vietnam and PNG) have developed a National AIDS Law (or similar legal frameworks), which include provisions to support the rights of PLHIV. No countries have developed a specific GIPA Policy. Effective bilateral and multilateral policy dialogue can help governments to understand the need for GIPA.

Involvement in service design and delivery

PLHIV groups in most countries are providing crucial peer counselling and support. In some countries (e.g. Fiji), PLHIV are highly engaged in community education but involvement in design of services is not always meaningful. Sometimes donors involve PLHIV because it is part of their mandate to be GIPA compliant.

Mapping of current GIPA support

Capacity building for GIPA policy development and national networks takes place in all reviewed countries. It mainly involves financial, technical and organisational support for positive networks. The main providers are Australian and other international NGOs, UN agencies (especially UNAIDS and UNDP) and in some countries (Indonesia, Fiji) the national AIDS program provides financial or material support.

AusAID programs and financial support promote GIPA in a variety of direct and indirect ways:

- The Asia Pacific Network of People with HIV (APN+) is the peak regional PLHIV network with a mandate to support national networks. APN+ recently received core funding from AusAID. This has enabled APN+ to better support network members and
has led to greater sophistication in PLHIV advocacy.

- The HIV/AIDS Capacity Building Program supports a partnership involving AFAO and APN+ to undertake capacity building of country level PLHIV networks (via the “Consortium”). This has addressed an important gap.
- The International HIV/AIDS Alliance is receiving funding to do capacity building with key populations, and provide technical support to regional organisations.
- UNAIDS Technical Support Facility for South and South East Asia and the Pacific receives funding to provide technical support to civil society organisations that cannot afford it.
- The Pacific Islands HIV and STI Response Fund support capacity building at regional, national and community levels.
- The HIV/AIDS Asia Regional Program is mainly a harm reduction program; it has worked with APN+ on developing regional advocacy strategies.
- In PNG, AusAID provides direct financial support to Igat Hope, the national PLHIV network, for staffing, operational costs and activities. AusAID also supports a GIPA Advocacy Officer in PNG, which has been instrumental to the involvement of provincial networks AusAID also funds Australia’s NAPWA for capacity building of Igat Hope
- In Indonesia, the HIV Cooperation Program for Indonesia provides financial, organisational and technical support to Spiritia Foundation and to JOTHI, both national PLHIV networks.

Other development partners supporting GIPA in the region are primarily GFATM, UNAIDS, UNDP and USAID. In Vietnam, USAID support has been crucial in developing a strong national network, VNP+. Other bilaterals openly support the principle but the review did not find any specific programs promoting GIPA in country. Donor efforts come across as generally uncoordinated.

**GIPA aid modalities**

There are several aid modalities to support GIPA, each with their advantages and challenges. Traditionally, bilateral donors support vertical projects, including funding for specific (PLHIV) organisations, or specific (GIPA) approaches, in line with national needs and donor priorities. Increasingly donor support is harmonised and aligned to national programs and processes, resulting in more country-led responses. These may or may not include GIPA or other donor priorities, so the modality of budget support requires policy dialogue at the time of national planning. Finally, development partners use multilateral organisations and platforms, e.g. UNAIDS PCB and the GFATM Board, to promote GIPA programs and processes.

**The review shows some important gaps in all areas of GIPA programming**

1. **Strengthening PLHIV Networks**
   - Core funding
   - Strategic planning capacity
   - Longer term and sustained support
   - Improved capacity building strategies
• Provincial network strengthening
• Information and support to isolated PLHIV
• Women’s leadership

2. Involving PLHIV in national planning, coordination and governance
• Confidence and capacity to engage on NAC and CCM
• Leadership, including women’s leadership

3. Supporting policy and legal environment
• Advocacy capacity of PLHIV and their organisations
• Policy dialogue with governments as part of bilateral aid planning and on national platforms
• Access to second-line ART and treatment for co-infections

4. Involving PLHIV in service design and delivery
• Capacity of PLHIV to engage in service design
• Employ PLHIV as educators, counsellors, treatments’ advocates
• Research skills development

5. Crosscutting gap
• Need for systematised monitoring and evaluation of GIPA at country level

In conclusion, implementation of the GIPA principle in the Asia-Pacific region ranges from tokenistic to genuine partnership and empowerment. Until sustainable government support is available, PLHIV organisations must rely on international donors. Development partners can play a role in encouraging governments to support core funding of national and provincial PLHIV networks, and support core funding of national networks in the interim, where gaps exist.
1. **Background to scoping exercise**

1.1 **Objectives of the report**

The Australian Government’s new HIV international development strategy “*Intensifying the Response: Halting the spread*” identifies fostering leadership on HIV as a priority, including supporting people living with HIV (PLHIV) to take on leadership roles in global, regional and national forums and supporting regional advocacy groups and networks.

In July-August 2009, AusAID conducted a scoping exercise in order to guide AusAID’s future support and engagement in the implementation of the greater involvement of people living with HIV and AIDS (GIPA) in the Asia-Pacific region.

The objectives of the assignment were to map, review and identify the gaps in current and planned interventions, and to identify opportunities and provide recommendations for AusAID to maximise its support to the meaningful participation of PLHIV in all aspects of HIV responses in the region. The exercise included ten countries: China, Lao PDR, Myanmar, Indonesia, and Vietnam in Asia; and Fiji, Kiribati, Papua New Guinea, Solomon Islands and Vanuatu in the Pacific. Country briefs are provided in Annex 1.

1.2 **Methodology**

Consultants carried out a desk-based literature review and analysis of national HIV policies, strategic and operational plans, and other relevant policy documents (see Annex 2) including:

- National HIV policies
- National HIV strategies
- National HIV operational plans
- National sectoral HIV strategies (health, education, social welfare)
- Most recent joint review of national response
- National GIPA policy/strategy
- Strategic plans of national PLHIV networks
- Most recent evaluation/review of national PLHIV organisations
- Donor/INGO strategic plans for those donors supporting GIPA
- Any research or mapping studies on GIPA/PLHIV/etc
- GFATM proposals and work plans
- UNGASS reports
- Work plans or other documents describing current and planned GIPA activities by agencies.

Over fifty interviews were conducted with key stakeholders (see Annex 3); the majority via telephone; calls were 25 to 95 minutes duration (average 50 mins); interviews in Solomon Islands and with some Asia Pacific Network of People Living with HIV/AIDS (APN+) country contacts were done face-to-face. E-mail responses were received from three respondents. Respondents
include:

- 10 AusAID officers
- 10 PLHIV country representatives
- 10 international non-government organisations
- 7 Government officers
- 5 UNAIDS officers
- 7 other development partners
- 8 PLHIV regional representatives

1.3 Limitations

The desk-based literature review relied heavily on Internet based searches, complemented by occasional reports provided by respondents. Most official documents, scientific articles and INGO/donors strategies are easily accessible on the Internet. However, project progress reports, sectoral strategies and evaluation reports were harder to find. Pacific Island governments have little information on the Internet and some of the information in the tables in Annex 3 was obtained via personal e-mail communications.

This scoping exercise provides a broad overview of the current level of involvement of PLHIV in the response to HIV and AIDS in the ten countries. However the report, based on a limited number of interviews in each country, does not purport to be an exhaustive review of all the capacity development and other technical support that PLHIV organisations have received to date. Additional support has been provided to GIPA by a range of bilaterals, UN agencies and NGOs that is not captured in this report. For a more detailed picture of what is happening in each country, a more in-depth study would be required.
2. Mapping – PLHIV involvement

The review found some generic experiences across countries about what GIPA means to different stakeholders, and how GIPA is operationalised at regional, country, and local level.

2.1 GIPA - Scope and purpose

The need for the involvement of people living with HIV (PLHIV) in the global response to HIV and AIDS was articulated in the Paris AIDS Summit Declaration (1994)\(^1\), which stated that for an effective response, it is necessary to encourage the greater involvement of people living with HIV and AIDS (GIPA) in HIV policy and program design, implementation and evaluation.

GIPA is a critical principle because PLHIV bring the unique perspective of their experience to HIV programs. Meeting PLHIV can significantly reduce stigma and discrimination and improve people’s attitude to HIV and AIDS, and properly trained PLHIV who are open about their HIV status are invaluable public health educators;\(^2\) PLHIV also perform valuable roles as health workers, particularly as counsellors for people newly diagnosed with HIV and for PLHIV going onto antiretroviral drugs (ARVs) in order to increase adherence.

To date there is limited understanding of how to maximise and integrate the expertise of PLHIV, and of the complex work of developing sustainable PLHIV organisations. Continuing challenges to GIPA include: stigma and discrimination; poor access to ARVs and other HIV services; limited counselling; financial survival; lack of capacity; tokenism; and constraints of funding bodies and of governments\(^3\).

The International HIV/AIDS Alliance (“The Alliance”) developed a pyramid of PLHIV involvement, from target audiences to decision makers (see Figure 1 below).

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1 UNAIDS Policy Brief: the Greater Involvement of People living with HIV (GIPA), March 2007
Over the past five years, donors have increasingly required agencies’ commitment to involving PLHIV. The Global Fund to Fight HIV/AIDS, TB and Malaria (GFATM) has increased involvement of PLHIV by requiring civil society representation on each Country Coordinating Mechanism (CCM), which acts as the steering committee for GFATM grant proposals and projects. Although GIPA as a principle is now widely supported, there is a lack of clarity and consensus on how GIPA ought to be operationalised, and what it exactly means at field level. Some respondents emphasized involvement in national level strategy development, others consider anti-discriminatory legislation, or peer support, or access to treatment as more important, or as conditions for the former.
The scoping exercise indicates that for GIPA to be a reality, several aspects need to be in place in each country, i.e.

1. A strong national PLHIV network, including
   - Organisational capacity (planning, management, reporting, etc.)
   - Personal skills of members (advocacy, communication, etc.)
   - Capacity of national organisation to develop a network of local groups
   - Representation of several subgroups (women, men who have sex with men, drug users, various ethnic groups)

2. Local PLHIV organisations accessible to local PLHIV, including
   - Capacity to provide peer support and referral services
   - Organisational capacity

3. Involvement in national planning, coordination and governance
   - Representation of PLHIV in the National AIDS Council/Commission
   - Involvement in the CCM and other steering committees
   - Involvement in technical working groups, developing guidelines, review process
   - Equitable representation of women and men

4. Supportive policy/legal environment for GIPA
   - Anti-discrimination legislation and implementation
   - Policy ensuring access to HIV medical care for all PLHIV (including antiretroviral therapy or ART)
   - Supportive NGO legislation for community organisations

5. Involvement of PLHIV in service design and delivery
   - PLHIV involved in HIV education
   - PLHIV involved in peer counselling, particularly post-test and ART adherence counselling
   - PLHIV involved in guideline development.
   - PLHIV involved in evaluation and audits on service quality.

2.2 PLHIV networks and organisations

National PLHIV networks are crucial to GIPA; these national organisations often start out as peer support groups. In the Asia-Pacific region, the development of peer support organisations ranges from not yet established (Kiribati, Solomon Islands, Vanuatu) to highly-developed (Indonesia, Vietnam). Once support organisations are developed, the next step is to become an efficient and effective advocacy organisation that can speak on behalf of all people living with HIV. In most countries national networks are currently weak, and lack understanding about their comparative advantage and roles, and there are various levels of understanding of what GIPA means and entails within the region.
Quality of PLHIV involvement often depends on the capacity and organisational development of the PLHIV networks and local groups. Networks need support for their secretariat, governance training, building and strengthening systems, to enable them to manage their network. PLHIV also need individual technical support to build their capacity - negotiation skills at national level, advocacy to become powerful and effective.

As more people are diagnosed with HIV and are living longer, new networks of PLHIV have developed throughout the Asia-Pacific region. The level of complexity of how networks are operating is far beyond what it was a decade ago. Network development in the Asia Pacific region is currently very dynamic, and several networks for drug users and for men who have sex with men (many of the members of which are HIV-positive) are in their fledgling stages and require nurturing.

Table 1: National/Regional PLHIV Organisations

<table>
<thead>
<tr>
<th>Country</th>
<th>Organisation</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regional</td>
<td>APN+</td>
<td>Asia Pacific – established 1994</td>
</tr>
<tr>
<td></td>
<td>PIAF</td>
<td>Pacific only; based in Cook Islands</td>
</tr>
<tr>
<td>China</td>
<td>CAP+</td>
<td>Not registered</td>
</tr>
<tr>
<td></td>
<td>Positive Women’s Network</td>
<td>Informal, started recently</td>
</tr>
<tr>
<td>Indonesia</td>
<td>JOTHI</td>
<td>Since 2008</td>
</tr>
<tr>
<td></td>
<td>Spiritia</td>
<td>Supports many local self help groups; CCM member; not PLHIV-only</td>
</tr>
<tr>
<td></td>
<td>IPPI</td>
<td>Positive Women - struggling</td>
</tr>
<tr>
<td>Lao PDR</td>
<td>LNP+</td>
<td>Not yet legal status</td>
</tr>
<tr>
<td>Vietnam</td>
<td>VNP+</td>
<td>Not yet legal status</td>
</tr>
<tr>
<td>Myanmar</td>
<td>MPG</td>
<td>Cannot get registered</td>
</tr>
<tr>
<td>PNG</td>
<td>Igat Hope</td>
<td>Also 4+ provincial groups</td>
</tr>
<tr>
<td></td>
<td>WABHA PNG</td>
<td>Positive Women - struggling</td>
</tr>
<tr>
<td>Fiji</td>
<td>FJN+</td>
<td>Registered as an NGO</td>
</tr>
<tr>
<td>Kiribati</td>
<td>None</td>
<td>One man, emerging group</td>
</tr>
<tr>
<td>Solomon Islands</td>
<td>None</td>
<td>Two people active in community education</td>
</tr>
<tr>
<td>Vanuatu</td>
<td>IZA Foundation</td>
<td>Essentially one person</td>
</tr>
</tbody>
</table>

In several countries covered in the assessment young positive leaders are emerging, testing the waters, finding their feet. In the Asia-Pacific region, culture promotes respect to seniority, but PLHIV are often young, so they do not gain respect easily. Similarly, men who have sex with men are poorly represented in most countries and this is a big weakness and leads to information gaps - for example, most Asian men would have no knowledge about risks of anal cancer.

In some countries there is no single cohesive national organisation representing the voices of PLHIV and advocating on behalf of all PLHIV; this results in a fragmented GIPA response. However, in China and Indonesia most respondents said that it is too early to have one organisation that is capable of speaking on behalf of all PLHIV in the country and several organisations should be encouraged to coexist and develop their niches. Where national PLHIV
networks have formed in response to the GFATM requirement that civil society is part of the CCM (e.g. China), sometimes these networks lack vision and the ability to strategically plan their activities, and they need basic organisational development.

The Vietnam Network of People Living with HIV (VNP+) is perhaps the most successful national network model in the region. VNP+ developed slowly and steadily with strong support from within Vietnam – from the Social Affairs Commission, which is part of the National Assembly and from the Vietnamese Women’s Union. PLHIV also got sustained funding support over several years from USAID. Furthermore an experienced ex-pat PLHIV worked closely with PLHIV in the country to help develop the network, and APN+ provided various skills development. VNP+ is now in a strong position to reach out to all the provincial support groups and include them in the national voice.

VNP+ understands the networking process and that is reflected in PLHIV commitment and organisational capacity. PLHIV worked well to build its platform as a network before it started doing advocacy.

Slowly and steadily VNP+ has built up from a strong base in developing partnerships. VNP+ is now in its final stage of registration. PLHIV have no official role yet in government decision making although they are invited to participate in meetings and they are working with various offices of government and trying to develop their involvement.

The PLHIV response has taken a long time to develop the process but this has made them aware that they are representing all PLHIV. VNP+ is comprised of 70 out of a total of 120 self-help groups in Vietnam, so they cannot yet speak on behalf of all the groups; they are hoping to actively include all of them soon.

In Lao PDR and Myanmar, where PLHIV organisations are not able to register, support for capacity building of the national networks is vital at this point. In Kiribati and Solomon Islands, the PLHIV who are open need support to develop a PLHIV support network and to design programs and do more outreach.

Often there are underlying tensions within positive people's organisations between service delivery and advocacy and representation. For example, Igat Hope, PNG, had long debates until it articulated its role as an advocacy organisation. In Indonesia, Spiritia has proven competency in advocacy and service delivery, including peer support and now JOTHI wants to become the nationally representative voice of PLHIV and advocate on behalf of all PLHIV. PLHIV need to ensure that there is no overlap and replication of roles.

PLHIV working at a professional level have no systematised support to debrief or share experiences with peers. Very little counselling is available to positive leaders. There is a need to build up a support system.

**2.3 Involvement in national planning, coordination and governance**

PLHIV and their networks are involved in the planning and review of the national response in all
countries of this review. PLHIV sit on most National AIDS Councils/Commissions (NAC), with the exception of China and Lao PDR (although in Laos this will change if a new decree is approved by the Prime Minister). PNG is the only country where the PLHIV on the NAC is not representative or elected. The GFATM requirement that PLHIV are represented on the CCM is now in place in most countries.

In Indonesia and in some countries in the Pacific (e.g. Solomon Islands), involvement in national strategy development is strongly supported by AusAID, other bilaterals, UNAIDS and the government. This is a unique situation that provides optimal opportunities for PLHIV to develop sophistication in their response. Co-location of the national PLHIV network and NAC was described as a powerful symbol of partnership in Indonesia. It is one thing to see PLHIV in meetings and know them. It is rather different working with them over a long process - in workshops or side-by-side in an office.

Indonesian national government leadership on GIPA is strong - particularly from the Secretary of the National AIDS Commission. Government is committed to supporting PLHIV to run their organisations effectively. There are Provincial AIDS Commissions and PLHIV sit on them to a greater or lesser extent, down to local level. Government also has various harm reduction working groups that involve drug users.

The review indicates that membership of the NAC or CCM is necessary, but in itself this is not sufficient for meaningful involvement. PLHIV mentioned several challenges to actually influencing decision making at these boards. Challenges to PLHIV involvement include slow professionalisation of the community sector and ensuring there is accountable representation - who turns up to the table, whether they report back, how confident are people that PLHIV speak on behalf of the community. In some countries, governments select PLHIV whom they know will be friendly to their agenda and will not “rock the boat”.

Often PLHIV who become involved in the HIV response have low capacity or experience to negotiate on high-level decision-making bodies and engage with educated and experienced public health professionals, government leaders and international donors. PLHIV who take on a role to represent their peers in high-level decision-making forums often lack confidence to speak out, so their voices are not heard.

PLHIV who sit on the CCM (or the NAC) have the most challenging role. The CCM provides an overwhelming amount of material (usually in English). Great detail is required in putting GFATM proposals together and prioritising issues at national level. It is challenging for any PLHIV group to be engaged at that level of dialogue. The issues are complex and it is hugely demanding to keep up with the process at every stage, including public-sector budgeting, but that is where the decisions are made. Individuals from national PLHIV networks who are involved in CCMs need strong support and mentoring to understand all the material and be in a position to make a valuable contribution.

Often decisions are made on the CCM at the last minute - components are dropped. If PLHIV are
not there at that moment and able to speak out, they might miss out, whether or not they are involved at the provincial level may have no bearing on the final decision. A real challenge in this region is language. Most documents are in English which is often people’s second or third language.

PLHIV who are willing to speak out in public and become advocates for their peers often come from populations that are highly stigmatised (widows, men who have sex with men, drug users). For PLHIV to negotiate effectively at national level, they need to speak the language and know what is working and why. Often PLHIV are not properly prepared when they speak out and have not strategically thought through what they need to say.

“Going into ICAAP, UNAIDS are flat out preparing briefing notes, but there is nobody available for leaders of civil society to prepare speeches, arrange appointments, etcetera; PLHIV are not as strategically prepared and their issues are not as thoroughly researched and thought through.”

(UNAIDS officer)

Another challenge is equitable representation within positive networks. Men inevitably represent national and provincial networks in Asia. The politics of national organisations are such that they tend to keep putting men up for representative positions. It is very difficult to have women in these roles and the culture generally dictates that more men get elected. Positive women’s issues (such as forced sterilisation, abortion, contraceptive and pregnancy choices, cervical cancer and pap smears, etc) are generally not on the agenda at national level. In the Pacific most PLHIV speaking out are women and they are strong individuals but they are not advocating on positive women’s issues. Many positive women are not aware of issues specific to women such as reproductive and sexual health and rights and they are not being discussed.

Table 2: Representation of PLHIV on national boards

<table>
<thead>
<tr>
<th>Country</th>
<th>PLHIV in NAC</th>
<th>PLHIV in CCM</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>China</td>
<td>No</td>
<td>Yes</td>
<td>PLHIV sits on the CCM but many decisions are made before meetings, person has limited decision making power</td>
</tr>
<tr>
<td>Indonesia</td>
<td>Yes</td>
<td>No</td>
<td>Spiritia represents affected communities on CCM; JOTHI and IPPI represent PLHIV on national governing body of Indonesian Partnership Fund</td>
</tr>
<tr>
<td>Lao PDR</td>
<td>No</td>
<td>Yes</td>
<td>NSP outcome is to ensure GIPA in NAC and CCM</td>
</tr>
<tr>
<td>Vietnam</td>
<td>Yes</td>
<td>Yes</td>
<td>PLHIV input is currently tokenistic; GFATM has resulted in increased PLHIV involvement PLHIV on UNGASS delegation</td>
</tr>
<tr>
<td>Myanmar</td>
<td>No</td>
<td>Yes</td>
<td>The PLHIV on CCM has limited effect because they lack both experience and support No PLHIV sits on the Three Diseases Fund Board</td>
</tr>
<tr>
<td>PNG</td>
<td>Yes</td>
<td>Yes</td>
<td>PLHIV do not feel confident to speak out at CCM level; PLHIV on NAC does not represent Igat Hope</td>
</tr>
<tr>
<td>Fiji</td>
<td>Yes</td>
<td>Yes</td>
<td>CSOs on NAC make environment friendly; PLHIV needs to advocate effectively; FJN+ also on research centre committee; PIAF sits on regional CCM on behalf of PLHIV</td>
</tr>
</tbody>
</table>
2.4 GIPA in national policies, strategies and action frameworks

The review assessed the extent to which governments support GIPA in national and sectoral HIV/AIDS strategies and operational plans, and if national HIV legal frameworks or GIPA policies address the rights of PLHIV.

Most reviewed countries mention GIPA as one of the guiding principles in their National HIV/AIDS Strategy (NSP). All national strategies include objectives related to increasing access to treatment, care and support for PLHIV (including peer counselling and self help groups), but few have national objectives related to addressing stigma and discrimination, or indeed involving PLHIV in the response. Some NSPs address GIPA under the implementation arrangements (e.g. PNG), or in the monitoring and evaluation section (e.g. Myanmar: total PLHIV in self help groups). However, it appears hard to operationalise GIPA into National HIV/AIDS Operational Plans (and budgets), besides treatment, care and support for PLHIV. This may be partly due to limited willingness of national AIDS programs to engage PLHIV (and the marginalised communities they come from), a lack of appreciation of how powerful PLHIV can be in the response, and also a lack of experience and ability to conceptualise GIPA activities. Only the Myanmar National Operational Plan includes support for establishing self-help groups, and there is a budget code for GIPA in the Lao PDR budget (although the review could not establish the planned activities).

Some countries have developed a National AIDS Law (or similar legal frameworks), which typically include provisions to support the rights of PLHIV. For example, the China Regulation on AIDS Prevention and Treatment, and the Vietnam Law on HIV/AIDS both set out the rights (and responsibilities) of PLHIV. The PNG HIV/AIDS Management and Prevention Act deals with discrimination, stigmatisation and mandatory screening. Indonesia does not have an AIDS Law, but the Presidential Regulation about the NAC specifies that one NAC board member should be a PLHIV. Although these policies per se do not change the status quo, they act as an advocacy tool and open doors for PLHIV to develop their capacity to participate more effectively.

None of the reviewed countries have developed a specific GIPA Policy. The closest may be the “Vietnam call to action for GIPA”, issued jointly by the government, the Communist Party, PLHIV groups and development partners in 2007, and providing clear principles and action points for GIPA. This document is a powerful advocacy tool, and the UNAIDS Second Independent Evaluation found evidence that PLHIV involvement has increased due to high-level government support, and increased financial and technical support from donors. The review found no evidence that GIPA is included in sectoral HIV/AIDS strategies, e.g. health sector or education sector HIV strategies and action plans.
### Table 3: GIPA in national policies, strategies and action frameworks

<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>China</td>
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<td>No</td>
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<td>Indonesia</td>
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<td>No</td>
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<td>Vietnam</td>
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<td>Yes</td>
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<tr>
<td>Myanmar</td>
<td>Yes</td>
<td>Yes</td>
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</tr>
<tr>
<td>PNG</td>
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<tr>
<td>Fiji</td>
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<td>n/a</td>
<td>n/a</td>
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</tbody>
</table>

n/a = document does not exist, unknown = relevant documents not accessed

The review indicates that often policies are in place, but implementation of the GIPA principle ranges from tokenistic involvement to genuine partnership and empowerment. Very few partners really integrate GIPA. Several respondents suggested AusAID can promote dialogue at government level and influence government health departments and ministries to understand the need to implement GIPA. The International Code of Conduct for NGOs, developed by the Red Cross, addresses discrimination against and involvement of PLHIV, and could be promoted widely.

A supportive environment for GIPA involves several conditions, for example a pluralistic governance system with broad civil society involvement; low levels of stigma and discrimination of PLHIV, involvement of women and people most at risk of HIV infection; and access to HIV management and ART, so PLHIV are well enough to involve themselves. All countries in the scoping exercise are able to provide free ARVs to PLHIV who can get access to an HIV service centre. Not all countries are able to register NGOs.

#### 2.5 Involvement in service design and delivery

Involvement of PLHIV in HIV program design and implementation is increasing, and this certainly contributes to making prevention, counselling, support and treatment more effective and relevant to the needs of PLHIV.

PLHIV involvement in design of services, particularly in developing service guidelines and quality assurance is not always meaningful. Sometimes donors involve PLHIV because they have to - it is part of their mandate. Some INGOs involve the PLHIV community because they

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<sup>4</sup> Presidential regulation about the NAC specifies one member to be PLHIV, no national AIDS law

<sup>5</sup> The “call to action” is not legally formalized.


<sup>7</sup> Only reducing stigma, not greater involvement
get pressure from the system to be GIPA compliant – it provides legitimacy.

In some countries PLHIV are highly engaged in community education (e.g., Fiji). Some PLHIV are speaking out about their rights to treatment access, and they need help to advocate effectively for increased coverage and quality of treatment services. PLHIV organisations and self help groups in most countries are providing crucial counselling after diagnosis, and support treatment adherence. There is scope for much deeper and more meaningful engagement of PLHIV in design, implementation and evaluation of service delivery, e.g. developing mechanisms of feedback to service providers.

Aidscare, a PLHIV-led organisation in south-west China, is helping to improve the quality of treatments in China, and is one of the most effective PLHIV models in the region. Aidscare has very good relations with the government and has engaged effectively in providing feedback on issues like quality of treatments or lack of confidentiality by health care professionals.

Aidscare provides direct services to the community where it is needed. The organisation is reaching 13,000 people on treatment in 39 project sites, more than 25% of all PLHIV on treatments in the country. PLHIV actively connect with newly diagnosed PLHIV in hospital settings. Support groups have officers inside the HIV clinics and PLHIV from the networks are paid to work in the clinics and provide peer support. This is a very positive, innovative GIPA model.

Aidscare provides counselling on ART clinical management and administration. They make appointments for clients and set up client procedures; this benefits both the doctor and the PLHIV and makes the system more efficient. Aidscare has developed IEC material, an SMS platform and a telephone hotline. Aidscare started income generation with 60 families, nutrition and education support for 300 children affected by HIV, and now runs four children homes for orphans living with HIV - caters for over 30 children.

Aidscare also helps to define the gaps in treatment and policy issues and report back to the government. In one province they found that only 40% of the money allocated for ARVs was being used and the rest was in the bank so they asked the National Centre to investigate. They have managed to increase the supply of 3TC and they are now pushing for accessibility of Efavirenz.

The quality of generic ARVs in China is problematic. Aidscare noticed that Chinese PLHIV were developing resistance more quickly than expected. They found there was good adherence but still resistance developed within 2 to 4 years. They discovered that some people were taking capsules that were empty. They linked resistance to the empty capsules and under dosing - the active ingredient is not enough but is mixed with other powders. They are now collecting samples and will send them to the labs to do some tests because they are confident that there is a problem.

Aidscare has demonstrated efficiency of community participation and now government understands the value and need for PLHIV-driven services. Some government officials realise that community participation is important.
2.6 Capacity building needs for GIPA

PLHIV need a range of support modalities to enable them to manage their networks and develop effective partnerships with decision-makers. In each of the reviewed countries, PLHIV capacity building needs are numerous and significant. In many countries, PLHIV have not developed their internal capacity to manage their organisation and strategically plan their activities. Many organisations lack organisational capacity. Organisational capacity needs include negotiation, leadership, data collection, advocacy, message development, analytical skills, monitoring and evaluation, tool development, program design, strategic planning. PLHIV need to know how to develop the arguments and how to present their case effectively.

Past and current efforts to support individuals and organisations are not able to keep up with support needs. Typical capacity building needs evolve around:

1. For individuals:
   a. Advocacy and negotiation skills
   b. Public speaking
   c. Networking skills
   d. Technical knowledge in prevention and treatment
   e. Ability to influence decision making at NAC, CCM, etc.
   f. Ability to write funding proposals

2. For PLHIV organisations and networks
   a. Management systems and capacity
   b. Human resources
   c. Governance
   d. Sustainable funding and fundraising capacity
   e. Networking and collaboration
   f. Communication with gatekeepers and decision makers

Several respondents mentioned challenges with the capacity building they receive. Many spoke of the inadequacy of one-off workshops, and of project funding that does not develop the PLHIV organisation. UNAIDS support is usually one-off, for conferences or small workshops, rather than ongoing. Long term support is preferable. One-off training without ongoing support is insufficient to instil the skills and confidence PLHIV need to become strong leaders. Some respondents said PLHIV would benefit from an experienced PLHIV working with them for several months – mentoring them on how to write policy papers, and develop strategic and operational plans.

Donor funding is often based on quantity - how many training workshops are provided rather than seeking out the needs of PLHIV to create leadership. Developing PLHIV leadership needs long-term vision and a long-term program developed by PLHIV. People need opportunities to make mistakes, the chance to work in an office environment, at provincial or national level. Mentoring is very labour intensive but it helps people to know and understand how to do things for themselves. PLHIV organisations need mentoring to integrate what they have learnt into what
they do. Mentors preferably should be people who speak the local language.

Some mentoring is happening but people need to be able to communicate effectively through e-mail and Skype, and this creates challenges in terms of the need for IT skills and equipment. In some countries, PLHIV do not access their e-mails, either because of slow connectivity or because the language is too difficult and complex. For GIPA to work, PLHIV also need IT technical assistance.

In terms of capacity building approaches, the review established several lessons in terms of effectiveness and sustainability.

- Capacity building needs to be a sustained process; one-off initiatives are not so helpful.
- Mentoring is an important methodology. The way the AusAID Consortium is working through long term, twinning, developing partnerships and empowering PLHIV is a model that could be expanded, enabling more development of networks at the national, provincial and local levels.
- It is important that Asians and Pacific Islanders lead, and that Australians provide technical assistance and guidance. Expatriate consultants can be useful, but only if they develop long term, mentoring relationships, rather than fly in and out.
- Focus on individual leaders is important, as they are often key change agents. There needs to be a system of peer counselling for leaders across the region.
- Quality of capacity building should not be measured in terms of numbers of people trained and supported. For example, a three-month mentorship program of a country rep to the APN+ office might have more impact than a one-off workshop for 20 people or more, and may cost far less money.
- Women PLHIV (and representatives from specific groups) must be targeted, as women are very powerful advocates.
- Support for a Treatment Advocacy Officer in APN+ would be very helpful to increase in-country capacity to improve ART adherence.
3. Mapping – Current support modalities

3.1 Current AusAID support for GIPA

AusAID supports GIPA as a component of several regional and country support programs, as indicated below:

*The Asia Pacific Network of People with HIV (APN+)* is the peak regional PLHIV network with a mandate to support national networks. APN+ recently received core funding from AusAID via UNAIDS. This has provided enormous support to APN+. Previously APN+ had to constantly chase and rely on project money. They could not work outside projects, and project funds were often dictated by donors. Core funding has enabled APN+ to better communicate with and support network members so they have increased capacity and can negotiate with other agencies - this has lead to greater sophistication in PLHIV advocacy. APN+ appears to be a well-respected network that promotes PLHIV empowerment; it has good contacts in the region, has flexibility in the way it can respond to PLHIV needs, quickly, directly and proactively, and has the capacity to train PLHIV in all countries. APN+ is seen by most respondents as an effective support mechanism to respond to the needs of national networks as it has a clear strategy with a particular focus on strengthening PLHIV capacity in country.

*The HIV Consortium for Partnerships in Asia and the Pacific (2008-2011)* links a Consortium of Australian HIV/AIDS organisations with partner organisations in the regions and at country level in order to build capacity. NAPWA is no longer a member of the Consortium, although they supported PLHIV groups in PNG and East Timor in the earlier AusAID HIV/AIDS Partnership Initiative (AHAPI)*. The Consortium’s 2009 progress report discusses GIPA, as a key principle for the Consortium’s work. The Consortium has established and supported a “GIPA and Affected Communities Working Group” to review work plans and to make recommendations to the Consortium Group and Program Coordination Committee. In the first year, 21 of 28 program components included the direct involvement of people living with HIV and affected communities as part of their development or implementation. Many of the remaining seven projects plan to do so in subsequent years. Examples of GIPA achievements include 1) PLHIV participating in training programs; 2) PLHIV presenting sessions during training courses; 3) Partner organisations collaborating with local PLHIV groups; and 4) PLHIV groups included on project steering groups. In 2009, the Consortium agreed to support a further partnership involving AFAO and APN+ to undertake capacity building of itself and country level networks on a range of projects.

The APN+ component of the AusAID Consortium Capacity Development Initiative has the ability to support projects that may not easily be funded by local government or other donors (e.g. in Myanmar or Laos). It has also supported projects for groups that do not have the capacity to write their own funding proposals. Examples so far include: providing financial support for strategic planning of the Vietnamese Positive Women’s Network, under VNP+; liaison between

8 Greater Mekong Sub Region, Indonesia, the Pacific and East Timor
Lao PDR and Thai national PLHIV networks (LNP+ and TNP+) about skills exchange over the next year; commitment to provide English training to the lead advocate in Solomon Islands. This has addressed an important gap in the program in terms of partnerships to address capacity building of PLHIV organisations in the region, particularly networks that do not yet have the skills to apply for capacity building funding from other sources.

*The Pacific Islands HIV and STI “Response Fund”* (2009–2013) is a multi-donor funding mechanism to finance implementation of national and regional HIV strategic plans. The Response Fund contributes to the Pacific Regional HIV and STI Strategy (PRSIP) goal, to reduce the spread and impact of HIV and other sexually transmitted infections (STIs) while embracing people infected and affected by HIV in Pacific communities. The Response Fund finances capacity building at regional, national and community levels. The support is provided by the Secretariat of the Pacific Community (SPC), WHO and UNAIDS, UN Technical Support Facility, as well as the Consortium. The Fund is managed by the SPC. A rapid 2008 GIPA review identified that The Pacific Regional HIV Project (PRHP – the precursor of the Response Fund) supported FJN+, and other PRHP grants supported involvement of two other positive people in the Pacific (Vanuatu and Kiribati) as HIV/AIDS Ambassadors; current AusAID funding has continued to support PLHIV groups and networks. This support for PLHIV in the Pacific has been crucial to their development. PIAF receives AusAID support; recently PIAF received a grant for research around stigma and discrimination of PLHIV in the Pacific.

*The HIV/AIDS Asia Regional Programme* (HAARP 2007-2015), is mainly a harm reduction program, but worked with APN+ on developing regional advocacy strategies, and supported national PLHIV networks to apply for innovation funds in Country Flexible Programs.

*The International HIV/AIDS Alliance* is receiving money that is very flexible to do capacity building with key populations, and provide technical support to regional organisations - mentoring local people over a long term, so that organisations are not constantly having to buy international support and fly consultants in and out all the time. For example, the Alliance supports the APN+ MSM group - developing strategic thinking, and looking at what to do with recent treatments research findings.

*UNAIDS Technical Support Facility for South and South East Asia and the Pacific* (TSF) has a fund to provide technical support to civil society organisations that cannot afford it, and build the capacity and organisational management skills of national PLHIV networks.

UNAIDS TSF provided 18-month training and mentoring program for PLHIV in professional development. They expected a 40% drop-off but only one person dropped out. Different PLHIV communities were represented. They looked at how to develop a consultancy, write ToRs, work plans, reports and CVs. PLHIV worked in pairs on assignments with mentors. Now TSF use them in consultancy assignments. Many of the people who were involved in this training now work as consultants. There are efforts being made to bring in academic experts to provide mentoring.
A rapid mapping on AusAID support for GIPA in 2008 assessed AusAID’s country level activities. In PNG, AusAID provides direct financial support to Igat Hope for staffing, operational costs and activities, including positive speaking and a national workshop for positive people to build a network. AusAID now supports a GIPA Advocacy Officer; this position has been instrumental to the involvement of provincial networks in the response, although the person in the position is overstretched, and provincial networks are not receiving any core or project funding. The Australian National Association of People living with AIDS (NAPWA) undertakes capacity building of the national PLHIV group in PNG, Igat Hope. AusAID provides ongoing support to NAPWA for this work. If NAPWA wants to be involved in capacity building beyond PNG, several respondents said this could best be achieved by stronger engagement with APN+. NAPWA could provide resources that APN+ could draw on.

In Indonesia, the HIV Cooperation Program for Indonesia (HCPI) provides financial, organisational and technical support to Spiritia Foundation and JOTHI, through capacity building and a National PLHIV conference and regional PLHIV support. Respondents considered AusAID support in Indonesia as appropriate, adequate and effective.

In Myanmar, AusAID provided $1.9 million to the Burnet Institute (2007-2012) to build capacity of local NGOs to deliver HIV projects, including quality HIV prevention, care and support programs. There is no specific GIPA component.

3.2 Other development partner support for GIPA

Other development partners support in a range of ways GIPA. In Vietnam, USAID support has been crucial in developing the strong national network, VNP+. Of the multilateral donors, GFATM and UNAIDS are particularly important. Most bilateral donors have GIPA as a guiding principle for their support for HIV/AIDS programs; however, the review did not find specific programs in support of GIPA. Review respondents mentioned that donors need to coordinate their efforts, instead of each donor following their own priorities. Implementation of GIPA requires commitment to partnership and collaboration; this cannot happen in isolation.

Within the UN division of labour, the UNAIDS Secretariat is responsible for dialogue on GIPA. Most UN agencies mainstream GIPA in their HIV/AIDS work. The UNAIDS Secretariat in Geneva developed an influential Policy Brief on GIPA for donors, governments and NGOs in 2007. UNAIDS country offices support GIPA through 1) ensuring representation of PLHIV on CCM and NAC; 2) organisational/technical support for PLHIV leaders and organisations; 3) research on barriers to GIPA and policy reviews; and/or 4) policy dialogue on stigma and discrimination. At a regional level, UNAIDS has collaborated a great deal with APN+, for example, having very prominent APN+ involvement in the Commission on AIDS in Asia. The UNDP regional office has developed programs on GIPA in several countries (including Vietnam and Indonesia) recruiting PLHIV as UNV volunteers to work with a variety of NGOs and government institutions, and entrepreneurial training for PLHIV (Indonesia). In the region, UNAIDS and UNIFEM have collaborated closely to support networks of women living with HIV. Currently a great deal of capacity building of civil society is ongoing in relation to the monitoring and evaluating of programs in preparation for the next UNGASS.
GFATM has been instrumental for GIPA through demanding PLHIV representation on CCMs, and their involvement in proposal development and supervision of grant implementation. With support from Policy Project, GNP+ developed (draft) guidelines for GIPA in CCMs, and a handbook for PLHIV on how to get involved in CCMs.  

ASEAN has developed a GIPA Framework, the Vientiane Declaration. The ASEAN Task Force will hold a regional meeting in 2010 to assist Member Countries to follow up on the Vientiane Declaration.

DFID’s updated strategy on HIV/AIDS (2008) mentions GIPA as one of the core principles. A specific objective is “responding to the needs and protecting the rights of those most affected” and deals with supporting PLHIV networks and supportive public policies.

USAID undertook a review of GIPA in 2004 and found a high level of awareness and commitment to GIPA in USAID Country Offices, implementing agencies (IAs) and NGO partners in five Asian countries. Several IAs and NGOs implement a variety of strategies to reduce barriers and address challenges to GIPA, including: 1) recruitment of HIV-positive staff and providing care for those staff; 2) strengthening of PLHIV organizations; 3) research on barriers to involving PLHIV; 4) involving PLHIV in advocacy; 5) capacity and skills development; and 6) fostering GIPA in project decision making.

The European Commission 2007-2011 HIV/AIDS strategy mentions GIPA as an issue for bilateral policy dialogue with host countries. However the 2009 progress report did not mention specific strategies or actions in countries, and only 35% of EC Delegations in Sub-Saharan Africa took part in CCMs. In Asia-Pacific this percentage is probably lower.

The World Bank supports national HIV/AIDS programs through governments. Although the World Bank is committed to GIPA and human rights based approaches and advocates civil society responses, the supported programs are essentially dependent on government priorities and the ability and willingness of National AIDS Programs to support and operationalise GIPA. Bank-supported programs include NGO-led targeted prevention interventions, but there is no evidence of technical or financial support to PLHIV organisations.

The Clinton Foundation has been instrumental in supporting PLHIV-run support in ART centres in China via Aidscare (see Section 3.5).

### 3.3 Aid modalities for GIPA support

AusAID uses several aid modalities to support GIPA in the region, all of which have their merits and limitations. Clearly much depends on the context, and what works in one country may be inappropriate in another, so generalisations should be made with caution.

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In the last decade, the Paris declaration on aid effectiveness has dominated the debate on aid modalities, in general and for HIV/AIDS in particular. UNAIDS calls for development partners to harmonize and align aid for national HIV/AIDS responses. Donors are encouraged to align their support to the national HIV/AIDS strategy and workplan, and to harmonize financial support and reporting requirements with other donors in line with the national planning and budgeting systems. Specific to GIPA, UNAIDS calls for donors to harmonize, simplify and create more flexibility in donor procedures to facilitate access to technical and financial resources for organisations and networks.\(^\text{11}\)

In several countries, community-based organisations find it increasingly difficult to get access to support for their work, if these are not endorsed by the government and the National Strategy, such as rights-based interventions with drug users, men who have sex with men, and sex workers, or activism around GIPA or treatment access (e.g. Vietnam, Myanmar, and China).

The Paris Declaration also calls for governments to strengthen governance and development performance. GIPA and supportive policies for civil society, PLHIV and vulnerable groups could be part of the policy dialogue between governments and development partners. Often GIPA is mentioned as a donor requirement, but during implementation of the national strategy it is not prioritised. An alternative strategy to ensure emphasis on specific issues is to earmark specific funds for capacity development interventions for PLHIV. No bilateral donor has earmarked specific funds for PLHIV capacity building.

There is also scope for specific initiatives through country programs, especially in countries like China and Vietnam, via aid modalities that are currently in place such as HAARP, but to date, little support has been given to GIPA within this program. This review indicates that the UN system, especially UNAIDS country offices, and the GFATM are AusAID’s partners in supporting GIPA. Other than AusAID, most bilateral donors and development partners, such as World Bank, DFID, USAID, NZAID\(^\text{12}\) and the EU, support GIPA, but do not provide specific aid to PLHIV organisations.

Many development partners and INGOs support generic NGO capacity building for HIV programming, and in some cases PLHIV organisations benefit indirectly from this. In general, it appears that programs that encourage national governments to support PLHIV organisations as part of public-private partnerships are less efficient than INGO programs that directly support PLHIV organisations. INGOs are better able to complement financial support with technical and organisational support, and NGO staffs are less likely to experience personal hesitations to work with PLHIV, sex workers, drug users and men who have sex with men.

\(^{11}\) UNAIDS, 2007, Policy Brief: Greater Involvement of People Living with HIV (GIPA)

\(^{12}\) NZAID, 2009, “Factsheet: Responding to HIV and AIDS - an NZAID priority”
4. Gaps

The scoping found several areas where GIPA can be supported more effectively. PLHIV need a range of support modalities to enable them to manage their networks and develop effective partnerships with decision-makers. In each of the reviewed countries, PLHIV capacity building needs are numerous and significant. Efforts to support PLHIV and their organisations are insufficient. This chapter presents gaps in GIPA support for each of the main components of GIPA programming, in order of priority.

4.1 Gaps in capacity of PLHIV organisations

1. More focus on individual leader

Individuals are often key change agents. There needs to be a system of peer counselling for leaders across the region. Developing PLHIV leadership needs long-term vision and a long-term program developed by PLHIV. People need opportunities to make mistakes, the chance to work in an office environment, at provincial or national level.

2. Women’s leadership

In several countries women have taken on prominent roles in their organisations but issues of particular relevance to women (e.g. forced abortion or sterilisation; women’s access to services), are rarely raised as issues of concern because the women’s networks are struggling – this is particularly the case in PNG and Indonesia. Women need support to foster and develop their leadership capacity.

3. Strategic planning

Networks in big countries with little history of civil society engagement in decision-making processes, but with the opportunity of attracting large amounts of funding (e.g. CAP+, JOTHI) need to develop their vision and strategically plan their work. They need help to develop as accountable, sustainable civil society organisations, and they need to be clear on their purpose, and be able to develop, carry out and evaluate their strategic plans.

4. Core funding

Sustainable core funding for PLHIV organisations is a major challenge. Without it, positive groups cannot function properly, and PLHIV organisations remain short-staffed and unprofessional. Core funding is vital for networks to be effective. Many networks struggle to find core funding and most rely on project funds, which can sometimes detract from core business or strategic plans. Some networks receive superior support from AusAID in-country, e.g. Indonesia; other groups that are deserving of core funding (e.g. in Vietnam) have not yet managed to secure it. The future funding of LNP+ and FJN+ is uncertain.
Ultimately PLHIV will have to find core money, and national and provincial governments should provide it. However, many government leaders have not yet been convinced of the value of including PLHIV in the response to HIV and AIDS. If donors are serious about GIPA they have to be serious about helping to develop sustainable networks. Until government support is available, PLHIV organisations must rely on international donors, for the most part. Set-up funds could help organisations to prove that they are able to function effectively, manage their organisations and produce good programs.

5. Provincial network strengthening

Some countries such as Vietnam and PNG have developed strong national bodies and are now at the point where the provincial networks could play a crucial role in the response. They need to strengthen provincial networks so that PLHIV in the provinces can be trained as counsellors, community educators, treatments’ advocates, and be engaged more directly in the response.

6. Information and support to isolated PLHIV

In countries such as Kiribati, Vanuatu and Solomon Islands it is important to ensure that PLHIV who are active in the response have access to the information necessary to ensure they are best equipped to make the most effective contribution, for example, information about grants, access to further education – e.g. in English or IT; scholarships.

7. Appropriate and needs-based capacity building methodologies

Several respondents mentioned challenges with the capacity building they receive. Many spoke of the inadequacy of one-off workshops, and of project funding that does not develop the PLHIV organisation. In terms of capacity building approaches, the review established several lessons in terms of effectiveness and sustainability.

- **Long-term, sustained capacity building**: Capacity building needs to be a sustained process; one-off initiatives are not so helpful. The way the AusAID Consortium is working through long term, twinning, developing partnerships and empowering PLHIV is a model that could be expanded, enabling more development of networks at the national, provincial and local levels. UNAIDS support is usually one-off, for conferences or small workshops, rather than ongoing. Long term support is preferable. One-off training without ongoing support is insufficient to instil the skills and confidence PLHIV need to become strong leaders.

- **Mentoring for leadership**: Mentoring is an important methodology. Some respondents said PLHIV would benefit from an experienced PLHIV working with them for several months – mentoring them on how to write policy papers, and develop strategic and operational plans. Mentoring is very labour intensive but it helps people to know and understand how to do things for themselves. PLHIV organisations need mentoring to integrate what they have learnt into what they do. Mentors preferably should be people who speak the local language.
• **It is important that Asians and Pacific Islanders lead:** Australians may provide technical assistance and guidance. Expatriate consultants can be useful, but only if they develop long term, mentoring relationships, rather than fly in and out.

• **Better M&E of capacity building:** Quality of capacity building should not be measured in terms of numbers of people trained and supported. Donor funding is often based on quantity - how many training workshops are provided rather than having a dialogue with PLHIV organisations and seeking out the needs of PLHIV to create leadership.

• **PLHIV also need IT technical assistance.** For mentoring to be successful people need to be able to communicate effectively through e-mail and Skype, and this creates challenges in terms of the need for IT skills and equipment. In some countries, PLHIV do not access their e-mails, either because of slow connectivity or because the language is too difficult and complex.

### 4.2 Gaps in involvement in national strategic planning

1. **Confidence to engage in national forums**

Most PLHIV who participate in CCMs or NACs lack confidence to speak out and express views on issues relevant to their community. PLHIV need mentoring to help to guide them through the depth and breadth of material covered in such meetings. This is only happening in Indonesia, and in some Pacific countries. UNAIDS could play an important role in helping to mentor PLHIV on decision-making committees. In Indonesia, AusAID has been remarkably successful at bringing together the voices of all PLHIV and affected communities and ensuring everybody is heard at the decision-making table.

2. **Advocacy needs**

Some networks are still weak in terms of their ability to advocate on their own behalf. MPG, in Myanmar, and FJN+ in Fiji could benefit from capacity building in this way.

3. **Support more women representatives**

Women PLHIV (and representatives from specific groups) must be targeted, as women are very powerful advocates.

### 4.3 Gaps in supportive policies and programs

1. **Access to second-line ART and treatment for co-infections**

Poor access to medical treatment and ART, and mortality of PLHIV community leaders and advocates remains a major challenge to GIPA. Access to sustainable supplies of high quality
ARVs is essential for GIPA. There has to be greater investment made in creating good modelling to show the long-term economic returns from sustainable treatment. Models that show the costs of treating and not treating PLHIV - impact in relation to healthy PLHIV able to work productively, contribute to GDP, pay taxes, versus costs of lost productivity, health care, etc. Models need to show that ART provision is a commercially viable return on investments - a sound commercial proposition.

2. Increase in-country capacity to improve ART adherence

Research carried out by APN+ in 2008-2009 indicates gaps in treatment literacy throughout the region. Support for a Treatment Advocacy Officer in APN+ would be very helpful to assist in-country treatments’ trainings.

4.4 Gaps in involvement service design and delivery

1. Employ more PLHIV as educators, counsellors

Relatively few PLHIV are actively engaged and employed in the HIV response in most countries. Provided they are appropriately trained and resourced, PLHIV can play invaluable roles as community educators and as counsellors – particularly peer counselling after HIV diagnosis or around treatments decisions and pregnancy options.

2. Mentor PLHIV to engage in service delivery planning

There is scope for much deeper and more meaningful engagement of PLHIV in design, implementation and evaluation of service delivery, e.g. developing mechanisms of feedback to service providers.

3. Research skills development

There is great scope to engage PLHIV in research project design and implementation in order to provide PLHIV with the tools and the confidence to respond to community needs most appropriately. Training PLHIV to document HIV-related discrimination and access to HIV services can be particularly empowering for the data collectors.

4.5 Cross cutting gaps

The range of capacity development needs is vast; however capacity development alone will not fulfil the demand for meaningful involvement. The following are crosscutting needs that emerge from the mapping and are conditional to capacity building.

1. Need for systematised monitoring and evaluation of GIPA at country level

This review indicates a dearth of evaluations of GIPA activities in terms of impact, or even
outcomes and outputs. The Country Progress Reports developed for UNGASS monitoring in 2008 discuss to some extent the status quo of supportive policies, access to treatment and care, and involvement of positive people and organisations. The next and final round of UNGASS reports is due in 2010. Similarly, the (ongoing) Second Independent Evaluation of UNAIDS explored evidence for GIPA, as this is one of the intended outcomes of the UN response to HIV/AIDS, in Vietnam, Indonesia and the Pacific Islands, which were case study countries.

In general, quantitative indicators (e.g. the number of PLHIV participating in meetings or trained in public speaking) are less useful to measure GIPA than qualitative indicators, and need to be complemented with narrative information. Indicators of the National Composite Policy Index, part of the UNGASS report, are relevant to measure GIPA and include qualitative indicators for human rights and civil society engagement. On the other hand, GIPA reviews need to include data from monitoring coverage and quality of treatment and care services, which are already part of most national monitoring and evaluation frameworks. The Minimal Standards for Civil Society Participation in Universal Access Initiative can be used to assess progress in universal access to ARVs over time.

4.6 Country-specific gaps

China

PLHIV involvement in the response to HIV in China is limited but increasing. Capacity of PLHIV is low and they lack organisational management skills. PLHIV need opportunities for intensive capacity development. Different groups need different help. Aidscare needs organisational development; the China Alliance of People Living with HIV, CAP+, needs help on how to involve many PLHIV and how to work with different groups, develop a common vision and make joint decisions; the Positive Women’s Network has just started so they need all types of training.

There is no strong PLHIV leadership in China - INGOs encouraged the formation of CAP+, but it formed from the top down rather than from the bottom up. Since large amounts of money started coming in (GFATM, Gates) several groups are vying to be the national voice for PLHIV. Chinese PLHIV are from very mixed backgrounds so it is difficult to get consensus.

Civil society is young in China and the concept of GIPA is not always understood in a meaningful way. It is difficult to get registered as an NGO so it is hard for civil society to organise. The government wants to work with civil society but has not found the modalities with which to engage. PLHIV are perceived by government to be people who need care and help, rather than a valuable resource to contribute to the response. With the help of PLHIV organisations such as

13 Some of the initial findings are reflected in the review, but the evaluation has not (yet) commented on approaches to measure outcomes or impact of GIPA
Aidscare, some government officials are recognising the need for PLHIV involvement in order to improve national HIV programs:

- Follow-up after HIV diagnosis is poor.
- China has an estimated 220,000 PLHIV but only about one in four are on ART.
- PLHIV need outreach to increase treatment adherence.
- Treatment for opportunistic infections is not free.
- Second-line ARVs are unavailable - only 500 people are on pilot studies in the country.
- Counselling is very weak.

**Indonesia**

Neither JOTHI, the newly formed national PLHIV network, nor IPPI, the national network for women living with HIV yet have the level of capacity as Spiritia which was formed over sixteen years and has been the main NGO responding to PLHIV support needs. There are many differing opinions about these newly formed networks. Some organisations are unwilling to recognise JOTHI as the voice for Indonesian PLHIV and have accused it of not being participatory or consultative. JOTHI currently needs to strengthen its strategic planning and precisely define its role in order to take optimum advantage of its position as a peak organisation for PLHIV. IPPI has held two national congresses, and they are trying to become a legal entity but they are struggling. IPPI needs institutional strengthening.

It is hard for the community sector to develop without broader civil society support and high level advocacy to government is necessary. Civil society is underdeveloped in Indonesia and is still learning. Needs of various PLHIV are at different levels. Some need basic health care and basic incomes; others want to do advocacy. PLHIV can be empowered to work at different levels – already the government works with local AIDS commissions at district level. PLHIV need to communicate so everybody is working collaboratively to avoid overlap.

According to AusAID, higher-order representation is generally working well; problems arise at the provincial and district level, HIV-positive people involved in the response are often unpaid whereas other people involved are employed by various organisations, agencies and government departments. Relatively few PLHIV are employed professionally in public health promotion or service delivery. The voluntary nature of PLHIV involvement creates challenges in positive people's ability to be most effective.

**Laos PDR**

PLHIV in Lao PDR do not yet have the necessary confidence, skills and experience to develop their own funding proposals, implement projects and evaluate their work. LNP+ need ongoing capacity building and could benefit from mentoring by PLHIV. GFATM helped LNP+ to submit their independent proposal to the Global Fund, not via government.

LNP+ has no guaranteed core funding. Once they become a registered community-based organisation they will lose funding from the Red Cross so they need to strategically plan how to
raise funds in the future.

**Myanmar**

The biggest issue for PLHIV in Myanmar is access to ART; 12,500 people are on treatment but it is estimated that around 70,000 people need treatment. Getting on ART is difficult. People have to live in the town where they are registered and be assessed as being adherent. Government treatment facilities are only available in major cities and there are few services outside Yangon or Mandalay.

MPG has to build skills of key people so that they can push donors on resource mobilisation. PLHIV only get funding to meet together. The top priority for most PLHIV is not treatment but work and money, particularly for people who have lost their partner; it is harder for women to get jobs than it is for men. Income generation is very important. PLHIV need good advocacy about why income generation is important for people to survive – e.g. to pay for travel to their service provider every month. Increasing public speaking skills of PLHIV in the country would be helpful.

The Burnet Institute program in Myanmar has a component to build capacity of a diverse range of civil society organisations to respond to HIV in their communities; it is about to have the mid-point review of local partners they are currently strengthening and this can be an opportunity for MPG to get support.

**Vietnam**

PLHIV input on the CCM is requested at the end of a process to provide a “rubber stamp” but they are not involved in planning. It is very difficult to be outspoken on the CCM as the PLHIV is only one of the 25 members at any meeting. There will be a strong role for PLHIV in the future. PLHIV will be essential in sustaining ART; only one in three people who need it are currently on ART.

A lot of work is needed with the national positive women’s network, provincial PLHIV networks and other self-help groups to help them to understand how to interact with government officials and how best to represent their voices.

**Fiji**

The voices of PL HIV are not heard at government level and PLHIV in Fiji are not confident to participate actively in decision making, so they are not able to be effective players on the national platform. They need to be able to understand technical information as well as the process of advocacy, so they are comfortable to respond at the level needed; they need to be guided through the processes, which can be overwhelming.

FJN+ has few members outside Suva and there is little encouragement of new leaders. Most PLHIV who have come out as HIV-positive have precarious income-earning capacity and HIV
has not helped that. They need to look at ART access and financial needs, not only community education.

FJN+ needs sustainability so it can provide better support services to its members. Currently it is unknown whether AusAID will continue to fund FJN+.

**Kiribati**

The PLHIV advocate is trying to connect with other PLHIV and encourage more people to come out but he needs more support. He needs money to conduct meetings and travel to the outer islands to carry out public education on HIV prevention. He does this work but the program only focuses on Tarawa because of the cost of going too far. Even though he is a member of the Kiribati HIV/AIDS Task Force, he is unsure of what funds are available and how to apply to the Response Fund. There are opportunities to get funding; and assistance is available from SPC to put proposals together but his capacity to find out this information is limited. The active PLHIV is unable to go to the next level of strategically planning his work. After 2009, the Community Development Organisation in Kiribati it will be the Family Health Association so the PLHIV advocate will have to negotiate ongoing support through them.

**Papua New Guinea**

Respondents said that most PLHIV involved in Igat Hope do not understand their role and responsibilities in the HIV response and the level of knowledge and understanding of issues by board members is low, so they have little confidence to engage in policy and project design and there is no mentoring of their work.

PLHIV groups in the provinces are unsure of what they are doing, have received no funding in the past and have no individuals to guide them. There is a need to articulate how GIPA helps to support prevention messages. PLHIV are not involved in prevention and public education at the level they want to and should be. Provincial PLHIV groups have an essential role to play in delivering clinical services, conducting community outreach, providing a continuum of care, delivering treatments’ advocacy and education; unfortunately most groups are struggling to survive.

Most PLHIV groups have not been able to get access to funding to date and volunteers walk long distances to provide home-based care and do hospital visits out of their own pockets. They are showing great initiative but have not received financial or technical support. They are frustrated not being able to carry out their work. PLHIV in PNG are ready to move forward but do not receive adequate support or resources to do so; in 2009, Tru Warriors in Western Highlands and the Marobe Network of People Living with HIV received no funding for their activities - their proposals sat with the NAC’s Small Grants Program committee and because NAC was not functioning, the proposals went nowhere. New changes within NAC (see country overview) give hope for real engagement of PLHIV in the provinces.

Igat Hope should be able to support groups in the provinces but they do not have technical
capacity to do so. Igat Hope needs to become more professional and build communication systems. It needs to strengthen its capacity to coordinate and network at a national level. At the moment PLHIV groups are working in isolation from each other.

There is no formal avenue for women to have their voices heard - within Igat Hope; women’s issues are not a priority. The new national women's network, WAHBA, is trying to meet every week in the National Capital District, but they have no funding. They need to develop their objectives and a strategic plan.

**Solomon Islands**

Sometimes people undermine the PLHIV advocate because she is female and does not have higher education. She would like to go do more public education, especially in Western District, and there are funds available to do so, but there is resistance to allowing her to go out into the field, so she spends most of her time in the capital.

**Vanuatu**

IZA is not sustainable and is not able to create its own agenda, according to its founder. She says she does not receive adequate support to develop her technical capacity on how to manage an organisation. She rarely uses e-mail because her internet connection is too slow. By now her capacity for office management should have increased but it has not. Some respondents believe that establishing IZA as an independent organisation would be a duplication of resources, but various PLHIV believe there needs to be one organisation in each country focused solely on HIV. “She is the one that everyone wants but no one wants to give her the freedom to be.” Her position in Save the Children comes to an end at the end of 2009.
Annex 1 – Country summaries

China

Overview

The most active NGO movements in China currently are PLHIV and gay groups. PLHIV do not have input into government decision making but GFATM offers huge opportunities for PLHIV and civil society to have their voices heard. In principle, PLHIV are on the CCM, but that is not where the decisions are made so their influence is limited and their presence somewhat tokenistic. GFATM advisory and working groups involve PLHIV and they are involved in developing the proposal for the Round 3 Rolling Continuation Channel. The CCM signs off on the final proposal but shaping the proposal is a more involved process beyond the CCM.

At provincial level, implementation of HIV policies generally is weak. The local policy makers deal with people's daily needs so it depends how willing they are to work with NGOs and take their issues on board. Small NGOs do not know where to start and it is very difficult to channel funds to grassroots organisations in China, but this is one area that can make a real difference.

<table>
<thead>
<tr>
<th>Inclusion in national response</th>
<th>NCAIDS: National Centre for AIDS/STD Prevention and Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. GIPA/ non-discrimination included in the national HIV policy?</td>
<td>• The Regulation on AIDS Prevention and Treatment (Decree No. 457) was issued by the State Council in early 2006. This provides a legal framework for AIDS initiatives, and sets out the rights and responsibilities of PLHIV.</td>
</tr>
<tr>
<td></td>
<td>• Stigma and discrimination against PLHIV remain widespread in some communities, work places, and among health-care workers. Involvement of PLHIV in the design and implementation of IEC messages remains weak.</td>
</tr>
<tr>
<td>3. GIPA activities in the National HIV Operational Plan?</td>
<td>• 2008 Country Progress report mentions increasing involvement of civil society organizations and community-based groups in implementation of HIV interventions at various levels. The number of CBOs including PLHIV support groups, women’s groups and other intervention</td>
</tr>
</tbody>
</table>

16 2008, UNGASS country progress report China
17 2008, UNGASS country progress report China
18 2008, UNGASS country progress report China
| 4. GIPA in sectoral HIV Strategies/policies? (education, health, etc) | • Difficulties in obtaining registration and legal status limit the number of CBOs and constrain organizational development.  
|---|---|
|   | • Ministries of Civil Affairs, Justice, Railways; General Administration of Quality Supervision, Inspection & Quarantine; General Administration of Traditional Chinese Medicine, All China Trade Union, Red Cross Society of China and other sectors have AIDS action or strategic plans.  
| National GIPA strategy |  
| 5. National GIPA policy/strategy/action plan? | No  
| Representation |  
| 6. PLHIV representation at National AIDS Commission/CCM/other? | • A PLHIV represents the affected communities on the CCM.  
|   | • No mention of PLHIV on the NCAIDS or SCAWCO  
| 7. How is representation dealt with of different positive people/women? | Not as yet – National Positive Women’s Network recently formed.  
| National PLHIV Networks |  
| 8. Main national PLHIV network(s)/organisation(s)? | CAP+  
| 9. Main strategies/activities | CAP+ is developing its agenda; Aidscare provides considerable HIV service support in south-west China; Positive Talks is a successful public education project supported by Marie Stopes; there are considerable numbers of peer support groups throughout the country.  
| 10. How is the National Network(s) involved in the national response? | Sits on CCM  
| Support for GIPA/Networks |  
| 11. Current AusAID support | The China Australia Health and HIV/AIDS Facility (CAHHF 2007-2012, A$25 million) aims to improve China’s capacity to strengthen its health systems, protect its population against emerging infectious diseases, and prevent and care for HIV infection. CAHHF provides grants to Chinese organisations working collaboratively with their Australian partners. Objectives for HIV are: 1) to support activities that promote leadership and coordination of China’s response to HIV and AIDS; 2) prevention-based activities (including harm reduction) that address the needs of populations most likely to be exposed to HIV, and 3) strengthen policy related to community based VCT and care, treatment and support. CAHHF provides grants to  

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19 2008, UNGASS country progress report China  
20 2008, UNGASS country progress report China  
21 [http://www.theglobalfund.org/programs/ccm/?CountryId=CHN&lang=en](http://www.theglobalfund.org/programs/ccm/?CountryId=CHN&lang=en)
<table>
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<tr>
<th>12. Are development partners/INGOs financially supporting GIPA and/or national networks?</th>
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</thead>
<tbody>
<tr>
<td><strong>Chinese and/or Australian organisations.</strong></td>
</tr>
<tr>
<td>• AusAID co-funded with DFID the China HIV/AIDS Roadmap Tactical Support Project (CHARTS) which aims to strengthen national and provincial level capacity in planning and response to HIV/AIDS.</td>
</tr>
<tr>
<td>• AusAID works in two provinces with government (Yunnan and Guangxi), doing harm reduction interventions. There is no direct support to GIPA, however about 30% of injecting drug users in these provinces are HIV-positive.</td>
</tr>
<tr>
<td>• AusAID funded Clinton Foundation Xinjiang HIV/AIDS Project (2007-2009) works directly to support treatment for PLHIV.</td>
</tr>
<tr>
<td><strong>13. Any technical support for GIPA/Networks</strong></td>
</tr>
<tr>
<td>• UNAIDS supports GIPA and PLHIV participation in meetings and conferences of local, national and international importance and assisting in the creation of a national network of organizations of PLHIV.</td>
</tr>
<tr>
<td>• Clinton Global Initiative supports ACC with US$450,000 to establish a pilot clinic in Yunnan province that offers affordable medical services for people living with HIV/AIDS in rural areas, to be replicated across China.</td>
</tr>
<tr>
<td>• GFATM support in 21 provinces includes CSO capacity building and anti-discrimination activities, besides comprehensive treatment, care and targeted interventions.</td>
</tr>
<tr>
<td>• DFID’s joint HIV and AIDS project with the Chinese government and the GFATM is China’s largest HIV and AIDS project (£30.5 million). The project provides support at national level and in seven high prevalence provinces. This project runs till 2011 and also supports the UN Joint Programme on AIDS in China. The project builds on the successes of two previous projects: the China-UK HIV and AIDS Prevention and Care project and the China HIV and AIDS Roadmap Tactical Support project.</td>
</tr>
<tr>
<td>• US CDC Global AIDS Program is strengthening surveillance and laboratory systems and the integration of VCT and surveillance (but USG also supports Alliance for NGO support work).</td>
</tr>
<tr>
<td>• AusAID/DFID co-funded China HIV/AIDS Roadmap Tactical Support Project (CHARTS) includes $3.9m, AusAID contribution for Phase I (completed) and $2.5m for Phase II.</td>
</tr>
<tr>
<td><strong>12. Are development partners/INGOs financially supporting GIPA and/or national networks?</strong></td>
</tr>
<tr>
<td>• HAARP works in Yunnan and Guangxi on harm reduction through engaging ex drug users (some of whom are PLHIV) as outreach workers and service providers.</td>
</tr>
<tr>
<td>• The Alliance works in several sites in Sichuan, Yunnan and Guangxi to help communities affected by HIV (including people living with HIV) to respond to the epidemic (with support from USAID and various foundations). Alliance</td>
</tr>
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</table>
supported PLHIV groups to find answers to stigma and discrimination, resulting in the Face and Let Face document of lessons learnt\(^23\).
- FHI/China supports NGOs with support from AusAID, DFID and USAID\(^24\).
- RTI International’s Health Policy Initiative/Greater Mekong Region and China, a consortium supported by USAID, works nationally, and in Yunnan and Guangxi provinces (2007-2010), including exploring models of mobilizing community advocates that can work within the context of China\(^25\).
- APN+, via the AusAID Consortium is supporting the empowerment of local PLHIV leaders involved in Aidscare in Yunnan and Guangxi provinces.

<table>
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<tr>
<th>14. Is government funding GIPA and/or national networks?</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Strategic information and research</strong></td>
<td></td>
</tr>
<tr>
<td>15. Research findings on the needs of PLHIV, situational analysis legal/social context?</td>
<td>APN+, 2009, “A long walk – Challenges to women’s access to HIV services in Asia. Participatory action research”.</td>
</tr>
<tr>
<td>16. Any evaluations of GIPA responses?</td>
<td>No</td>
</tr>
</tbody>
</table>

\(^{23}\) [http://www.alliancechina.org/Alliance_China_Office/Alliance_China_Publications.html](http://www.alliancechina.org/Alliance_China_Office/Alliance_China_Publications.html)


Indonesia

Overview

PLHIV are represented on a range of government decision-making bodies in Indonesia. Spiritia was the first organisation established in Indonesia for people infected and affected by HIV. Spiritia has set up provincial support groups, has been a catalyst for the establishment of local support groups throughout the country, and provides most of the HIV services in the provinces. JOTHI, the national PLHIV network, and IPPI, the national positive women’s network, formed over the past couple of years. They both have secretariat offices based in the NAC.

The government, AusAID and UNAIDS are all openly supportive of JOTHI, IPPI and Spiritia. Everybody was invited to be part of the consultative process on the Program Coordinating Committee (PCC) of the Australia-Indonesia Partnership for HIV. There was agreement that JOTHI will represent PLHIV at national and provincial level; individual support groups supported through Spiritia will be the voice at local and district level. AusAID has supported meetings with Spiritia and JOTHI.

AusAID has demonstrated commitment for GIPA by supporting the National Congress for PLHIV, peer support at provincial level, capacity building at national level, and providing funds to both Spiritia and JOTHI. AusAID consults with JOTHI before meetings, particularly the PCC meetings, and talks through issues, making it easier for PLHIV to contribute. USAID and AusAID try and coordinate their planning so they each have a clear picture of what the other is doing.

Both the government and AusAID contribute to core funding to JOTHI. Government contribution is very appropriate and indicates in principle support. UNAIDS provided core institutional funding from the Gates Foundation to IPPI for two years; their grant has now finished.

### Inclusion in national response

<table>
<thead>
<tr>
<th>Inclusion in national response</th>
<th>KPA (NAC): National AIDS Commission - Secretariat</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. GIPA/ non-discrimination included in the national HIV policy?</td>
<td>• No national AIDS Law; Presidential Regulation No. 75/2006 (about the NAC) specifies the chairperson of the PLHIV association is member of the NAC. That is new since 2006.</td>
</tr>
</tbody>
</table>
| 2. GIPA included in the National HIV Strategy? | • 2007-2010 National Strategic Plan recognises stigma and discrimination as a challenge and proposes support for PLHIV organisations and anti-discrimination activities.  
• “PLHIV have the right to participate at all levels of the response and prevention effort, from the policy-making stage to the evaluation and monitoring stages. To play their roles effectively, PLHIV will need to improve their knowledge and capabilities. In tandem with their rights, PLHIV also have the obligation to not spread HIV to their partners and other |

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26 2006, GOI, Presidential Regulation No. 75/2006  
27 2007-2010 National HIV/AIDS Strategy Indonesia
3. GIPA activities in the National HIV Operational Plan?  
- The National Action Plan 2007-2010 mentions no specific activities on GIPA, supporting PLHIV organisations or stigma and discrimination reduction.

4. GIPA in sectoral HIV Strategies/policies?  
- No information.

### National GIPA strategy

5. National GIPA policy/strategy/action plan?  
- No GIPA policy, but GIPA guidelines

### Representation

6. PLHIV representation at National AIDS Commission/CCM/other?  
- Chairperson of PLHIV association is member of the NAC.
- PLHIV are represented in the NAC at national and provincial levels; JOTHI and IPPI represent PLHIV on the Steering Committee and the Management Committee of the Indonesia Partnership Fund.
- PLHIV part of the Indonesia UNGASS forum and participate in production of the shadow report and the NCPI report.
- PLHIV not directly represented on the CCM; Spiritia holds the civil society position on the NAC and CCM. The Support Group and Spiritia meet every quarter to share information.
- Improvements have been made at the organizational level, where PLHIV are involved in many NGOs, bilateral agencies, UN agencies, and other international organizations in a more meaningful way.

7. How is representation dealt with of different positive people/women?  
- Spiritia recognizes the challenge of ‘representation’ in the 2005/6 annual report. “It is often difficult for activists to really identify with and understand the real concerns of the silent majority of PLHIV. Indeed, such activists frequently have their own agenda, and staff in Spiritia inevitably brings their own views and preconceptions to the table. On the other hand, many PLHIV expect or at least hope that Spiritia and/or the network will address all of their needs. It will be increasingly difficult to satisfy all of these conflicting strains as the network becomes increasingly large and diverse.”
- IPPI mentions that “participation of women and young girls, especially those who are living with HIV, needs to be improved at every level. Often, people living with HIV only take part in AIDS response as testimonial speakers or are invited to meetings without knowing what they can contribute to those meetings.”

### National PLHIV Networks

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28 2007-2010 National HIV and AIDS Action Plan in Indonesia  
29 2006, GOI, Presidential Regulation No. 75/2006  
31 2008 CSO Shadow report Country Progress Report UNGASS  
33 2008 CSO Shadow report Country Progress Report UNGASS
8. Main national PLHIV network(s)/organisation(s)

- Spiritia.
- JOTHI, National umbrella of PLHIV, since 2008.
- IPPi, National Positive Women Network.
- PITA, support group for parents of HIV-positive people, used to be based at UNAIDS.
- As of 2008 there were 115 support groups that help 5000 PLHIV in 71 municipalities, as well as a growing number of community organizations that help reducing stigma and discrimination against PLHIV\(^{34}\).

9. Main strategies/activities

- (As of 2004\(^{35}\)) Spiritia is an umbrella for several support groups. There are an executive director and three program directors. At first, PLHIV or people who had lost siblings or partners to AIDS, held each of the program director positions. They mentored PLHIV so that they can take on these positions. Spiritia carries out ‘strengthening visits’ (members visit out-patient departments, STI clinics and testing centres to make direct contact with positive people) stimulating new peer support groups and expanding the network throughout the country. Spiritia also developed a strong skills-building component: people were trained as trainers in public speaking.

10. How is the National Network(s) involved in the national response?

- Spiritia noted\(^{36}\) that “the vast majority of identified PLHIV have no desire to become activists. The challenge of tokenistic involvement can only be addressed if those involved are willing to be empowered, and understand the intent of such empowerment. ‘Empowerment’ is becoming a ‘buzzword’, with limited understanding either of its meaning or its history.”

Support for GIPA/Networks

11. Current AusAID support

- Mainly support to Gov of Indonesia but large NGO support component through Australia-Indonesia Partnership for HIV and HCPI. HCPI supported JOTHI by establishment of National Secretariat and support to provincial affiliate networks; HCPI funds Spiritia in capacity development to strengthen peer support and PLHIV advocacy for policy development and information dissemination.

12. Are development partners/INGOs financially supporting GIPA and/or national networks?

- HCPI financial - mainly technical support to Spiritia; also capacity development through Leadership component.
- PITA received material support (office space and equipment from UNAIDS) until 2008.
- UNAIDS and HIVOS (Netherlands) supported IPPi in past.
- Burnet Institute carried out an HIV project in Aceh that consciously sought genuine partnership with PLHIV. The project came about following the APN+ scoping exercise into the impact of the tsunami on PLHIV. Staff came from

\(^{34}\) 2008 Country Progress Report UNGASS

\(^{35}\) 2004, APN+, Position Paper 2 GIPA

Medan+ and recruited local volunteers. PLHIV now run the program and Burnet provides managerial support and technical guidance. Aceh is the most conservative province in Indonesia yet the project helped to develop specific HIV legislation, set up eight VCT sites (where there was nothing in 2006), get people on ARVs, and develop a buddy system. The project employs openly HIV-positive people and has positive advocates who work directly at community level.

### 13. Any technical support for GIPA/Networks

- UNAIDS has formally and informally supported PLHIV to organise and get involved in policy development.\(^{37}\)
- AusAID-funded IHPCP project (2002-2007) supported PLHIV organisations financially and technically.\(^{38}\) Current HCPI provides considerable support.
- UNDP supports entrepreneurial training for several PLHIV.

### 14. Is government funding GIPA and/or national networks?

- The NAC provides space for the PLHIV networks (and other community groups) at the NAC Secretariat.

### Strategic information and research

#### 15. Research findings on the needs of PLHIV, situational analysis legal/social context?

- Civil society involvement is challenged because few members of civil society are familiar with commitments such as UNGASS-related the Declaration of Commitment on HIV/AIDS and are not aware of the requirements and opportunities to participate in related processes.\(^{39}\)
- The “Cipayung Statement”\(^{40}\) of the Third National Meeting of Peer Support Groups in September 2006 (81 peer support groups from 47 districts/municipalities) included a call for:
  - Peer groups to facilitate needs of other groups in the area
  - National/local AIDS Commissions to be more proactive in advocacy, become data centres, facilitate program funding support for community
  - The NAC to involve PLHIV in all working groups, the secretariat, and all other activities in accordance with the capability of the PLHIV/affected people.
  - PLHIV and civil society leaders to increase public awareness of the dangers of HIV/AIDS and to reduce stigma and discrimination.

#### 16. Any evaluations of GIPA responses?

- The UNAIDS evaluation of GIPA found that “PLHIV perceive that they are engaged in the national response as equals, although it is difficult to attribute positive changes in national laws and policies to their participation.”\(^{41}\)

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\(^{39}\) 2008 Country Progress Report UNGASS


Lao PDR

Overview

Establishing NGOs is new territory for the government, and they have naturally been cautious. The national PLHIV network, LNP+, has been developing Articles of Association so it can form an organisation. UNAIDS and UNICEF are working together with the government to assist LNP+ to develop its proposal to provide them with legal status as an NGO in Lao PDR. LNP+ will be one of the “first cabs off the rank”; they and the Women's Union have pushed the agenda of the government to make this happen.

The National Committee for the Control of AIDS (NCCA) recently agreed to add a PLHIV representative onto the committee.

ARVs and drugs for opportunistic illnesses are provided free by the government via funding from GFATM; funding also covers transport for PLHIV to collect ARVs, attend monthly meetings and to employ some PLHIV as peer counsellors. NCCA has created a Task Force on Treatment Care and Support to facilitate support for PLHIV in Lao PDR.

LNP+ is connected to support groups in the 11 provinces. They receive funding via Lao Red Cross mainly from Danish Red Cross and some from Australian Red Cross. LNP+ provides some financial support to some of the provincial support groups.

| Inclusion in national response | NCCA: National Committee for the Control of AIDS  
| NCCAB: NCCA Bureau |
|---|---|
| 1. GIPA/ non-discrimination included in the national HIV policy? | • The Lao PDR does not have specific HIV legislation that protect PLHIV against discrimination, but it has a national policy on non-discrimination which specifies protection for vulnerable groups.  
| 42 UNGASS country progress report 2008 |
| 2. GIPA included in the National HIV Strategy? | • GIPA is included in the NSP, but not as a guiding principle.  
| | • Support for PLHIV networks is a strategy under care and treatment.  
| | • NSP outcome is “PLHIV are actively participating and have advisory roles in all HIV/AIDS decision making bodies, including NCCA and CCM”.  
| | • Strategy 1) Strengthen the ability of PLHIV to organize themselves, and to effectively voice issues that are of concern to them by: strengthening the National Network of PLHIV, carrying out other programs for GIPA and providing PLHIV with adequate capacity to contribute to HIV related organisations.  
| | • Strategy 2) Ensure full involvement of PLHIV in the decision-making process at all levels of policy and program |
3. GIPA activities in the National HIV Operational Plan?

- GIPA has activity code in operational plan (but no operational plan is available).
- Training activities for PLHIV were conducted to enable them to work as resource persons in training & advocacy workshops. PLHIV are members of all coordinating bodies, both at national and provincial level⁴³.

4. GIPA in sectoral HIV Strategies/policies?

- Min. of Public Security, Min. of Labour and Social Welfare, Ministry of Defence, Ministry of Education, Min. of Transport) and have developed sectoral plans, or implemented activities (UNGASS report 2008).

**National GIPA strategy**

5. National GIPA policy/strategy/action plan?

- No

**Representation**

6. PLHIV representation at National AIDS Commission/CCM/other?

- PLHIV are included on CCM.

7. How is representation dealt with of different positive people/women?

- No policy

**National PLHIV Networks**

8. Main national PLHIV network(s)/organisation(s)?

- Lao Network of Positive People (LNP+) as well as six functional PLHIV self help groups⁴⁴.

9. Main strategies/activities

- Monthly meetings; placement in hospitals that provide HIV-services

10. How is the National Network(s) involved in the national response?

- No involvement other than as support services providers

**Support for GIPA/Networks**

11. Current AusAID support

- Through the APN+ Capacity Development Initiative (part of the Consortium), and with added support from the Alliance, over the next 12 months Thai PLHIV will go into Lao PDR and provide technical support and mentoring; then key PLHIV from LNP+ will spend time in Thailand learning from the Thai network. This exchange will be facilitated because the two groups know each other's culture and language.

12. Are development partners/INGOs financially supporting GIPA and/or


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⁴³ UNGASS country progress report 2008
⁴⁴ Response Review quoted in the 2006-2010 NSP
<table>
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<th>Question</th>
<th>Answer</th>
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</table>
| national networks?                                                      | organizations and government together for a meaningful involvement of PLHIV**[45].  
  - Lao Red Cross Society HIV Programme 2008-2010 includes a strategy to help develop PLHIV community support groups and networks (as means to reducing HIV stigma and discrimination). In the LRC past supported LNP+**[46].  
  - USG and GFATM support the national response, but not GIPA (USAID: prevention and surveillance; GFATM: treatment). |                                                                                                                                                                                                       |
| 13. Any technical support for GIPA/Networks                              | Red Cross Society; APN+ (also grant support)  
  - AusAID supports Joint UN Workplan on AIDS - Commits co-sponsors to advocate and provide technical assistance**[47]. |                                                                                                                                                                                                       |
| 14. Is government funding GIPA and/or national networks?                | 99% of the national response is financed by development partners. Lao PDR government is not generally supportive of NGOs, but national government accepts LNP+. |                                                                                                                                                                                                       |
| **Strategic information and research**                                   | Yes  
| 15. Research findings on the needs of PLHIV, situational analysis       | No                                                                                                                                                                                                     |
|   legal/social context?                                                  |                                                                                                                                                                                                       |
| 16. Any evaluations of GIPA responses?                                  | No                                                                                                                                                                                                     |

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[47] Prue Borthwick mentioned this**
**Myanmar**

Myanmar is an extremely resource-poor country and support for HIV is not based on epidemiology. The social safety net provided by donors is much smaller than in other countries, even though the country has one of the highest epidemics.

The national network of PLHIV, Myanmar Positive Group (MPG) cannot get registered so it does not have a recognised voice and no role in influencing the government. PLHIV need to be clear to government that they are providing support and counselling and helping with prevention, not trying to create a movement to oppose government in any way.

| Inclusion in national response | • **The National Coordinating Body for AIDS, Tuberculosis and Malaria** (like CCM, chair Minister Health)  
• **NAC**: National AIDS Committee (chair Minister Health)  
• **NAP**: National AIDS Program, Ministry of Health  
• **TSG**: Technical and Strategy Group for HIV and AIDS (draws on technical expertise of UNAIDS cosponsors, undertakes planning, monitoring, and coordination). |
<table>
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</thead>
<tbody>
<tr>
<td>1. GIPA/ non-discrimination included in the national HIV policy?</td>
<td>No evidence of HIV policy.</td>
</tr>
<tr>
<td>2. GIPA included in the National HIV Strategy?</td>
<td>No evidence.</td>
</tr>
</tbody>
</table>
| 3. GIPA activities in the National HIV Operational Plan? | • No; no operationalisation of relevant principles and issues.  
• One of the key issues of the 2006-2009 Operational Plan is “Community-based activities will be directed to reduce stigma and discrimination towards PLHIV and those whose behaviours is perceived as being associated with infection”\(^{48}\).  
• In operational plan and budget allocation for 1) treatment and care for PLHIV (11,000 on ART by 2009), and 2) establishment of PLHIV self-help groups, reaching 10,000 PLHIV by 2009\(^{49}\). |
| 4. GIPA in sectoral HIV Strategies/policies? | • Mention of several sectoral strategies in the NCPI report – not clear if GIPA addressed |
| **National GIPA strategy** | |
| 5. National GIPA policy/strategy/action plan? | No |
| **Representation** | |
| 6. PLHIV representation at National AIDS | • No PLHIV on the NAC, NAP or other national body.  
• PLHIV was on the CCM (in 2006 GF application) |

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\(^{48}\) 2006-2009 Operational Plan  
\(^{49}\) 2006-2009 Operational Plan
• No PLHIV representation on board of Three Diseases Fund.
• PLHIV representative on the TSG for HIV/AIDS “to ensure input based on understanding of living with the virus within communities affected by the epidemic”. During the period 2006-9 PLHIV networks were developed so that PLHIV can move from an advisory to a representative status\textsuperscript{50}.
• NAP guidelines about membership in township/ district AIDS committees do not include PLHIV.
• A PLHIV representative was key note speaker at the Colombo ICAAP satellite on Myanmar.

7. How is representation dealt with of different positive people/women?

• The 2006 WHO review found that the PLHIV rep on the CCM lacked knowledge, support and the appropriate structures and mechanisms to represent existing PLHIV support groups in the country\textsuperscript{51}.
• The NSP mentions that representation needs to be strengthened by supporting the link between MNP+ and self-help groups.

8. Main national PLHIV network(s)/organisation(s)?

• MPG (Myanmar Positive Group) is a network of PLHIV, with the objective 1) to reduce stigma and discrimination through advocacy work with faith-based organisations; 2) to have representation at the national, regional and international levels for PLHIV; and 3) to build the capacity of people living with HIV\textsuperscript{52}.
• A growing number of self-help groups of PLHIV are emerging across the country. Around 3,000 members of self help groups in 2006, more than 30 groups, (10 with >100 persons)\textsuperscript{53,54}.

9. Main strategies/activities

• MPG has 10 board members (PLHIV) from support groups and a secretariat in the Alliance office\textsuperscript{55}.
• Monthly meetings to promote GIPA involving people from different support groups.
• Positive prevention training for PLHIV.

10. How is the National Network(s) involved in the national response?

See representation

Support for GIPA/Networks

11. Current AusAID support

1. In 2007 the Three Diseases Fund was launched by the UK, the European Commission, Sweden, Australia, the

\textsuperscript{50} 2006-2010 National HIV/AIDS Strategy Myanmar
\textsuperscript{51} 2006, WHO, Review of the National HIV Programme Myanmar
\textsuperscript{52} http://www.ngosupport.net/sw53197.asp, accessed 10 July 2009
\textsuperscript{53} 2008 UNAIDS Country Situation, Myanmar
\textsuperscript{54} 2006, WHO, Review of the National HIV Programme Myanmar
\textsuperscript{55} 2006, WHO, Review of the National HIV Programme Myanmar
2. Major AusAID grant provided for harm reduction by UNODC.

12. Are development partners/INGOs financially supporting GIPA and/or national networks?

- The HIV funding situation is precarious: no Global Fund, no PEPFAR funding, no Asian Development Bank, and no World Bank funding. UNAIDS and International AIDS Alliance provide considerable PLHIV support.

13. Any technical support for GIPA/Networks

- Alliance and UNDP supported the GIPA Project Initiative Group (in early 2005), resulting in the establishment of Myanmar Positive Group (MPG). AFAO also funded this group in 2005-6 (from private funds, not AHAPI).
- MPG members were supported to attend the ICAAP in 2005, and training at APN+.

14. Is government funding GIPA and/or national networks?

No

15. Research findings on the needs of PLHIV, situational analysis legal/social context?

- The 2006 Programme Review looked at GIPA and found that involvement was poor but increasing, mainly via self-help groups, convened by NGOs or HIV/SID teams. Access to ART helps PLHIV to get involved, but stigma and discrimination prevents them from being active members (some group members are not out to family).

16. Any evaluations of GIPA responses?

- In 2005, the GIPA initiative group formed an Advisory Committee to initiate a project to promote GIPA. Nine PLHIV were nominated to form a Committee to develop and manage the project. Training was provided to PLHIV in understanding GIPA, project design and proposal writing, and team building. Formation of two committees and developing clear roles for each was important in establishing a structure to undertake activities. Fostering a sense of community among PLHIV to work jointly towards their interests and rights was important.

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56 2008 UNAIDS Country Situation, Myanmar  
57 2008 UNAIDS Country Situation, Myanmar  
59 2006, WHO, Review of the National HIV Programme Myanmar  
60 2006, WHO, Review of the National HIV Programme Myanmar  
Viet Nam

Overview

Most funding for the HIV response in Vietnam comes from the Global Fund but issues are decided by the Ministry of Health and there is no formal mechanism to have input into the decision-making process. The Vietnam Administration for HIV/AIDS Control is now developing a Memorandum of Understanding on how to work with civil society. The Government does not yet formally recognise VNP+, the newly formed national network of PLHIV, because it does not have legal status. At provincial level there is more PLHIV involvement. A GIPA project has been ongoing for over three years – supported by the Women’s Union, UNDP and UNAIDS in four provinces, to instil GIPA into the Women’s Union and the broader community. Partnerships Now PLHIV are leading the way and there is close collaboration between civil society and government. UNDP also has a project with the Communist Party about community mobilisation and creating an enabling environment and increasing involvement of PLHIV; it was in three provinces and they now want to scale up. The joint UN team on HIV has a work plan which is based on the national strategy and it has a strong component on supporting civil society involvement. UNAIDS supports institutional development, including training on advocacy for the steering committee of the networks and helping them to develop their strategic plan and providing support for four face-to-face meetings of VNP+.

In GFATM Round 9 Vietnam agreed to dual track financing. PLHIV are involved in the civil society track and are developing proposals. UNAIDS and PACT did workshops on how to write expressions of interest and provided opportunities for self-help groups to link up with NGOs and jointly develop proposals. Several self-help groups are now sub-recipients. There is good coordination, collaboration and good working relationships among various organisations working in harm reduction - UNAIDS knows what everybody is up to.

| Inclusion in national response | VAAC: Viet Nam Administration for HIV/AIDS Control  
NAC: National Committee for HIV/AIDS, Drugs and Prostitution Prevention and Control |
|-----------------------------|---------------------------------------------------------------------------------|
| 1. GIPA/ non-discrimination included in the national HIV policy? | • Law on HIV/AIDS (June 29, 2006) protects the rights of PLHIV against stigma and discrimination and stipulates the responsibilities in the national response to HIV.  
• Decree 108/2007 ND-CP (June 2007) provides detailed instructions for the implementation.  
• Decision 29/2007/QD-TTg on Management, Care and Support, Treatment and Counselling for PLHIV in closed settings (including educational, rehabilitation centres, detentions, prisons and social care centres).  
• Decision 60/2007/QD-TTg; Decision 96/2007/QD-TTg; Decision 67/2007/QD-TTg on support for people and children living with HIV.  
• There is a concern that the following issues are not |

| 2. GIPA included in the National HIV Strategy? | • National Strategy on HIV/AIDS Prevention and Control in Viet Nam until 2010 (Developed in 2004) contains as guiding principle:  
  - Fighting stigma and discrimination against PLHIV;  
  - Increasing the responsibilities of families and the society towards PLHIV and the responsibilities of PLHIV towards their families and the society.  
  
| 3. GIPA activities in the National HIV Operational Plan? | • There are nine Programs of Action on technical strategies; none on GIPA.  
  • 2007 “Viet Nam Call to Action for GIPA” 2007, joint initiative between the Party, the Government, PLHIV and International partners, provides all the GIPA principles and action points. No evidence of follow up other than as an advocacy tool.  
  
| 4. GIPA in sectoral HIV Strategies/policies? | No information – probably not  
  
| National GIPA strategy |  
| 5. National GIPA policy/strategy/action plan? | No  
  
| Representation |  
| 6. PLHIV representation at National AIDS Commission/CCM/other? | • Previously self-selected PLHIV on the CCM; now position to be held by VNP+.  
  • VNP+ has elected representatives on the Inter-ministerial Committee for HIV and on various Ministry of Health committees.  
  • In most leadership events, PLHIV are invited to participate and address audiences.  
  • Chair of the Southern network of PLHIV was on UNGASS report meeting  
  
| 7. How is representation dealt with of different positive people/women? | • There is a self-selection process by PLHIV for electing a steering committee for VNP+. However, one third of PLHIV organisations are not members of VNP+, often for reasons of fear of being co-opted by the government. This raises questions about the representativeness of VNP+. Since 2008 there has been a self-selection process for  

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63. 2008 Country Progress Report Vietnam  
64. 2004, MoH, National Strategy on HIV/AIDS Prevention and Control in Viet Nam until 2010 with a vision to 2020  
65. 2008 Country Progress Report Vietnam  
66. 2007, Viet Nam Call to Action for the Greater Involvement of People Living With HIV/AIDS  
<table>
<thead>
<tr>
<th>National PLHIV Networks</th>
<th>PLHIV representative and alternate for the CCM (to replace government appointed PLHIV)(^{68})</th>
</tr>
</thead>
</table>
| 8. Main national PLHIV network(s)/organisation(s)? | • VNP+ established in 2008.  
• Over 130 self-help groups.  
• Self-help groups have organized themselves in informal networks, members are involved in policy development processes; raising awareness of updated legislation; supporting ART services and referral; and in fighting against stigma and discrimination\(^{69}\). |
| 9. Main strategies/activities | Strengthening and coordinating provincial networks; focus of the response is very much on access to ART. |
| 10. How is the National Network(s) involved in the national response? | • Meaningful PLHIV participation in policy development and in planning and review of program implementation is limited. Yet, PLHIV have been involved in several policy and programmatic activities, including the development of the National AIDS Strategy 2004, the drafting of the HIV Law 2006 and subsequent directives and decrees, the Programs of Action on Monitoring and Evaluation and Harm Reduction, the development of the country report for the UN High Level Meeting and attendance at the HLM, as well as participation on the CCM and the sub-CCM of the Global Fund. PLHIV participation increased since 2006, due to high level government support, increased financial and technical support from donors, and improved HIV response in Vietnam\(^{70}\). |
| Support for GIPA/Networks | |
| 11. Current AusAID support | • AusAID provides $1 million for harm reduction via Vietnam Administration for AIDS Control; no GIPA component.  
• The Innovations Fund provides up to $250,000 per year for greater civil society participation in HAARP, including at provincial level; there is $80,000-$100,000 for technical assistance that could be used to increase civil society participation and long-term sustainability.  
• AusAID and UNAIDS jointly fund work with the National Committee (national policy and decision making body re HIV) to create a Partnership Forum and ensure everybody working on HIV is included in regular meetings. |
| 12. Are development partners/INGOs financially supporting GIPA and/or | • AusAID supported Sunflower group with US$10,000\(^{71}\), and the UNV GIPA project (US$25,000)\(^{72}\)  
• Other donors for HIV response: |

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\(^{69}\) 2008 Country Progress Report Vietnam  
\(^{71}\) AusAID supported HIV/AIDS projects until 2006  
\(^{72}\) 2006-2010 UNV GIPA Project Document
### National networks?

- USAID, CDC/PEPFAR, DFID, NORAD, AusAID, GTZ/KfW, France; CIDA, SIDA, Denmark, Japan
- WB, ADB, GFATM.
- The INGO Technical Working Group for HIV/AIDS, allows individuals and organizations to share information and conduct joint advocacy work. This TWG has a GIPA subgroup that meets bi-monthly.
- Support for GIPA activities as of 2004:
  - ARC: PLHIV support groups
  - CARE/COHED/ARC/FHI: Train PLHIV as researchers
  - CARE/Policy: training journalists, research legislative reform; PLHIV self-help groups
  - CARE: Capacity building of PLHIV; counselling and support
  - CDC: Treatment related training; Access to treatment and services for PLHIV
  - FHI: Access to treatment and services for PLHIV
  - MCNV: Support group for Women living with HIV
  - Policy: Capacity building of PLHIV; briefing paper
  - UNDP New Delhi/CARE: Capacity building of PLHIV.

### Any technical support for GIPA/Networks

- UN (especially UNAIDS secretariat) supported establishment of VNP+. Ongoing UN support includes for legal registration, organisational development guidelines and Action Plan 2008-2010, including skills building for leaders and the steering committee. VNP+ and other PLHIV organizations require considerable investment in capacity building, particularly communication skills.
- Viet Nam Women’s Union (VWU) supports the establishment of Empathy Clubs, and implements the UNV GIPA project (2005-8), to enhance involvement and participation of PLHIV. Five components: training and support for PLHIV; help them to get access to treatment and other services; reducing stigma and discrimination; promoting understanding and support of GIPA, and provide opportunities for participation of PLHIV in HIV activities. US$667,000 from BMZ (Germany), UNV’s Special Voluntary Fund, PEPFAR and AusAID.
- The Fatherland Front launched a campaign to promote positive living which is named “cultured family and community”. Families and communities will be certified if

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73 2006-2010 UNV GIPA Project Document
74 2006-2010 UNV GIPA Project Document
76 2008 Country Progress Report Vietnam
<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
</tr>
</thead>
</table>
| 14. Is government funding GIPA and/or national networks?               | • VWU and Fatherland Front are para-statal organisations. (see above)  
• Government supports VNP+ to represent PLHIV                                                                                           |
| **Strategic information and research**                                  | • Undated, Centre for Community Health and Development, Positive Perspective: a qualitative research on the greater involvement of PLWHA in HIV/AIDS prevention and care in Hanoi, Hai Phong, Khanh Hoa, Ho Chi Minh City and Can Tho.  
• APN+, 2009, “A long walk – Challenges to women’s access to HIV services in Asia. Participatory action research”.                                                                                               |
| 15. Research findings on the needs of PLHIV, situational analysis legal/social context? | • Providing services in closed settings remains a challenge. Closed settings include education centres, re-education centres, detention centres, prisons or other social sponsored centres.  
• More efforts to promote civil society organisations as equal partners in the national response and to encourage their involvement in all steps of design and implementation of HIV activities.  
• UNAIDS evaluation found as achievements: 1) support for the creation of VNP+ and a self-selection process for leadership; 2) development of an Action Plan to 2018 and capacity building; 3) institution of a CCM self-selection procedure; 4) PLHIV involvement in developing the National Strategy, HIV Law drafting, UNGASS reporting, CCM participation; and 5) Government endorsement of the Call for Action.  
• Vietnam Women’s Union (July 2008). Evaluation of the ‘Promoting the Greater Involvement of People Living with HIV (GIPA) Project in Vietnam’. By Jack Wallace, Australian Research Centre in Sex, Health and Society and Tran Minh Gioi, Centre for Community Health Promotion. |

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78 2008 Country Progress Report Vietnam
79 2008 Country Progress Report Vietnam
80 2008 Country Progress Report Vietnam
Fiji

Overview

The Fiji Network of People living with HIV, FJN+, has the support of the Council of Chiefs, and receives technical assistance from the Ministry of Health - they also provide premises free. FJN+ has developed a drop-in centre which needs refurbishment.

FJN+ is very adept at community education, but they need organisational strengthening and networking skills, and they need training on how to advocate to government and contribute to issues that affect them.

<table>
<thead>
<tr>
<th>Inclusion in national response</th>
<th>NACA: National Advisory Committee on AIDS Secretariat (Public Health Division, Ministry Of Health)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. GIPA/ non-discrimination included in the national HIV policy?</td>
<td>• There is no current HIV and AIDS-specific legislation, nor a cohesive single national policy. ‘HIV and AIDS Prevention’ promulgation has been drafted and is awaiting Cabinet approval.</td>
</tr>
<tr>
<td>3. GIPA activities in the National HIV Operational Plan?</td>
<td>• No national work plan.</td>
</tr>
<tr>
<td>4. GIPA in sectoral HIV Strategies/policies?</td>
<td>• No evidence.</td>
</tr>
</tbody>
</table>

National GIPA strategy

| 5. National GIPA policy/strategy/action plan?                                                  | • No                                                                                         |

Representation

| 6. PLHIV representation at National AIDS Commission/CCM/other?                               | • NGOs in the 2008 progress report: “While some MARP have been represented in the NSP, this has been tokenistic at best. In addition, there is minimal gender and HIV and AIDS coverage in the NSP.”
|                                                                                               | • Presently FJN+ is a member of the Fiji CCM, and the Pacific Islands AIDS Foundation represents PLHIV on the regional CCM. Six NGOs who are significant stakeholders were excluded from the CCM during the GFATM Round 7 process in 2007, for challenging governance practices.
|                                                                                               | • Four NGOs are represented at the NACA; FJN+ has a seat on NACA. CSO representatives on NACA are currently government appointees and therefore not true representation of civil society in general.
|                                                                                               | • PLHIV did not contribute to the UNGASS progress report                                      |

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82 2008 UNGASS Country Progress Report
83 2008 UNGASS Country Progress Report
84 http://www.theglobalfund.org/programs/ccm/?CountryId=FJI&lang=en, accessed 15/7/09
85 2008 UNGASS Country Progress Report
86 2008 UNGASS Country Progress Report
<table>
<thead>
<tr>
<th>7. How is representation dealt with of different positive people/women?</th>
<th>• FJN+ does not represent ethnic diversity and diversity of modes of infection.</th>
</tr>
</thead>
<tbody>
<tr>
<td>National PLHIV Networks</td>
<td>2008 (other NGOs did – see quotes).</td>
</tr>
<tr>
<td>8. Main national PLHIV network(s)/organisation(s)?</td>
<td>Fiji Network of People Living with AIDS (FJN+), established 2004.</td>
</tr>
<tr>
<td>9. Main strategies/activities</td>
<td>Peer support; community education; focus on stigma</td>
</tr>
<tr>
<td>10. How is the National Network(s) involved in the national response?</td>
<td>On NACA, but it has not met under current government.</td>
</tr>
<tr>
<td>Support for GIPA/Networks</td>
<td></td>
</tr>
<tr>
<td>11. Current AusAID support</td>
<td>Core funding and project funding, via Response Fund.</td>
</tr>
<tr>
<td>12. Are development partners/INGOs financially supporting GIPA and/or national networks?</td>
<td>• HIV/AIDS development partners are SPC, UNAIDS, WHO, UNFPA, UNICEF, ILO, &amp; AusAID.</td>
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<td></td>
<td>• UNDP funded a GIPA pilot project with US$110,000 from 2004 onwards, strengthening FJN+ with 1) Organisational development 2) Care and support and 3) Advocacy.</td>
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<tr>
<td></td>
<td>• UNAIDS/Fiji provided funding for business and IT training, advocacy and income generation activities, ToT for 15 people on HIV awareness raising, positive leaders to attend International AIDS Conferences.</td>
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<tr>
<td></td>
<td>• UNAIDS/UNDP supported a Pan-Pacific Gathering for PLHIV in New Zealand in 2008.</td>
</tr>
<tr>
<td>13. Any technical support for GIPA/Networks</td>
<td>• Available through Response Fund.</td>
</tr>
<tr>
<td>14. Is government funding GIPA and/or national networks?</td>
<td>• FJN+ was established with financial support from the MoH under the previous government.</td>
</tr>
<tr>
<td>Strategic information and research</td>
<td></td>
</tr>
<tr>
<td>15. Research findings on the needs of PLHIV, situational analysis legal/social context?</td>
<td>• Inadequate resources and capacity for the Fiji Legal Aid Commission and Fiji Human Rights Commission have resulted in weak provision of legal services for PLHIV, and members of vulnerable and marginalised groups. There is no channel of redress for PLHIV regarding HIV issues; PIAF, 2009, Report on people living with HIV in the Pacific: A qualitative study of HIV and AIDS-related stigma and discrimination.</td>
</tr>
<tr>
<td>16. Any evaluations of GIPA responses?</td>
<td>• Questions exist about whether HIV-positive people have true representation, which makes it hard to gauge the</td>
</tr>
</tbody>
</table>

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87 2009, Summary report Pacific for Second Independent Evaluation UNAIDS
89 2008 UNGASS Country Progress Report
effectiveness of their participation, although the general consensus was that the quality of PLHIV networks is improving.\(^{90}\)

- A review of the Pacific Regional Strategy on HIV/AIDS (2004–2008) in 2006 noted that there has been some positive movement in strengthening leadership. For example, CSOs, in particular those involving PLHIV, have become increasingly engaged in supportive roles.\(^{91}\)

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\(^{90}\) 2009, Summary report Pacific for Second Independent Evaluation UNAIDS

\(^{91}\) 2009-2013 PRSIP draft version
Kiribati

Overview

One man and one woman of the 57 people diagnosed as HIV-positive to date in Kiribati are open about their HIV status. The male is a community educator and has been involved in meetings at national level – the National HIV Task Force, Ministry of Health meetings, and with NGOs. He does a lot of public education and offers peer support. Often he goes out in a tag team with somebody from the Ministry of Health or with another woman. There is potential for an emerging PLHIV group, but many PLHIV do not want to access services.

<table>
<thead>
<tr>
<th>Inclusion in national response</th>
<th>Khatbtf: Kiribati HIV &amp; AIDS, TB Task Force</th>
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</thead>
<tbody>
<tr>
<td>1. GIPA/ non-discrimination included in the national HIV policy?</td>
<td>Mentioned as a guiding principle in National HIV Strategy.</td>
</tr>
<tr>
<td>2. GIPA included in the National HIV Strategy?</td>
<td>Yes</td>
</tr>
<tr>
<td>3. GIPA activities in the National HIV Operational Plan?</td>
<td></td>
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<tr>
<td>4. GIPA in sectoral HIV Strategies/policies?</td>
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<tr>
<th>National GIPA strategy</th>
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<tr>
<td>5. Specific national GIPA policy/strategy/action plan?</td>
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<tr>
<th>Representation</th>
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<tr>
<td>6. PLHIV representation at National AIDS Commission/CCM/other?</td>
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<tr>
<td>7. How is representation dealt with of different positive people/women?</td>
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<tr>
<th>National PLHIV Networks</th>
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<tr>
<td>8. Main national PLHIV network(s)/organisation(s)?</td>
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<tr>
<td>9. Main strategies/activities</td>
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<tr>
<td>10. How is the National Network(s) involved in national response?</td>
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<table>
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<tr>
<th>Support for GIPA/Networks</th>
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<tbody>
<tr>
<td>11. Current AusAid support</td>
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<tr>
<td>12. Are development partners/INGOs financially supporting GIPA?</td>
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<tr>
<td>13. Any technical support for GIPA/Networks</td>
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<tr>
<td>14. Is government funding GIPA and/or national</td>
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<tr>
<td>networks?</td>
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<tr>
<td><strong>Strategic information and research</strong></td>
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<tr>
<td>15. Research findings on the needs of PLHIV, legal/social context, etc.?</td>
</tr>
<tr>
<td>16. Any evaluations of GIPA responses?</td>
</tr>
</tbody>
</table>
Papua New Guinea

Overview

The national PLHIV network in PNG, Igat Hope, has input into government decision making via the National Strategic Plan Steering Committee, a sub-committee of the NAC that provides strategic input to matters of policy and project implementation; Igat Hope also has a place on the CCM. PLHIV are not involved in developing treatment guidelines or policies.

Igat Hope has recently undergone significant changes. Two previous board members have been employed as program officers - one on treatments and the other on stigma and discrimination. Another PLHIV has been engaged as an administrative officer and a fourth as the Network Liaison Officer. This may have a big impact on PLHIV capacity.

A GIPA Advocacy officer in AusAID started working on the ground with PLHIV groups in the Western Highlands and in Morobe and this has made a huge change; by providing them with support, they can effectively advocate to the government for inclusion; change is coming from provincial level because PLHIV are starting to see the importance of their role in the HIV response.

Tingem Laip 2 has included a GIPA position as part of the technical resources of the project; this is an opportunity to develop stronger mechanisms to connect with, train, incorporate, and utilise PLHIV in community education as well as counselling – post-test and/or pre-ARV – especially where sites are linked to testing centres.

The NAC has recently taken a strategic shift in its response towards a more direct engagement at provincial level. This requires direct involvement all stakeholders including PLHIV groups, where they exist, in the planning process and in service delivery. PLHIV groups are now able to identify gaps in the response, set priorities and implement activities directly.

| Inclusion in national response | NAC: National AIDS Council  
|-------------------------------|--------------------------|
| NACS: National AIDS Council Secretariat  
- Prohibition on discrimination and stigmatization of people with or suspected of having HIV, or their families; 
- Obligations of confidentiality regarding HIV status are imposed92. |
| 1. **GIPA/ non-discrimination included in the national HIV policy?** | The NSP 2006-201093 Implementation Arrangements section specifically refers to the active participation of |
| 2. **GIPA included in the National HIV Strategy?** | |

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92 From 2008 UNGASS country progress report  
93 NSP not available on Internet
### PLHIV only in the treatment, counselling, and care and support sections (p61).
- While the family and community support section includes an objective to empower PLHIV as advocates in community education programs (p76), PLHIV are not mentioned in relation to education and prevention, leadership, partnership or coordination.
- Oxfam GIPA review noted that PLHIV were represented on the project steering committee and on five of seven working committees; still the document’s references to PLHIV engagement are surprisingly few in number.  

<table>
<thead>
<tr>
<th>3. GIPA activities in the National HIV Operational Plan?</th>
<th>N/A</th>
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<tbody>
<tr>
<td>4. GIPA in sectoral HIV Strategies/policies?</td>
<td>N/A</td>
</tr>
<tr>
<td><strong>National GIPA strategy</strong></td>
<td></td>
</tr>
<tr>
<td>5. National GIPA policy/strategy/action plan?</td>
<td>No</td>
</tr>
<tr>
<td><strong>Representation</strong></td>
<td></td>
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</tbody>
</table>
| 6. PLHIV representation at National AIDS Commission/CCM/other? | • Igat Hope has a representative and an alternate on the CCM. However, PLHIV do not feel comfortable to speak out. New PLHIV joining the CCM need support to participate effectively.  
  • There is a PLHIV on the NAC since 2007 with full voting rights, but he does not represent the national network. A new council will be set up soon; Igat Hope board will nominate a member to represent positive people.  
  • There are seven focus areas in the NSP; only one area, Research Advisory Committee has a PLHIV as a member. The other six areas do not have PLHIV representation.  
  • The NSP Steering Committee started off with three PLHIV representatives. Since completion no more involvement of PLHIV in the NSP steering committee.  
  • GIPA is central to an effective response, yet HIV positive people’s involvement at all levels of the national response is weak. Too often, the representation of positive people and their organization is tokenistic or non existent. |
| 7. How is representation dealt with of different positive people/women? | • WABHA PNG was formed in 2007 as the national network of women living with HIV in PNG. It was a result of women coming together to express their concerns over issues affecting their lives and the lives of other positive women in PNG. They have an organizational structure and a plan to work around issues of PMTCT, gender violence, stigma and discrimination, OVC and human rights. |

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94 2006, Oxfam Australia, the involvement of PLHIV in PNG’s response  
95 From 2008 UNGASS country progress report  
96 2006, Oxfam Australia, the involvement of PLHIV in PNG’s response
WABHA PNG plans to employ a coordinator and strengthen their core working group before expanding further to other provinces. Work in five provinces will be a pilot program to see what can be done in other provinces. To date, WABHA has not received funding or technical support other than ToT provided by APN+ in 2007.

### National PLHIV Networks

8. Main national PLHIV network(s)/organisation(s)?
   - Igat Hope
   - WABHA PNG (women);
   - Several provincial PLHIV groups

9. Main strategies/activities
   - Since 2006 Igat Hope set up its organizational structure and annual work plan. It is the national network of PLHIV in PNG.
   - Igat Hope wants to play a proactive role by expressing views and getting involved in the activities and the coordinating committees at all levels of the national response to HIV.
   - Activities 2008 and beyond: 1) Public Speakers Bureau (facilitated by NAPWA – Australia); 2) treatment advocacy and printing IEC material 3) expand to other provinces
   - Support groups are located in several provinces: Alotau, Goroka, Mt Hagen, Madang, and Lae. All still need mentoring and support. Igat Hope organized a 2008 national conference to identify areas of support needed for the planned initiatives.

10. How is the National Network(s) involved in the national response?
    - PLHIV inputs in policy, guidelines and strategic development on HIV in PNG is a challenge. Leadership of positive people in the HIV response is also not very active. Need to build Igat Hopes’ capacity in these areas.

### Support for GIPA/Networks

11. Current AusAID support
    - AusAID is by far the biggest funder for the response (US$26/43m for year 2008)
    - AusAID is a supporter of the NSP and NACDS. AusAID will support programs and activities under the NACS’ National Leadership Strategy.
    - Papua New Guinea – Australia Law and Justice Program, is a joint governments’ development initiative, managed by Cardno Acil Pty Ltd. Australia is providing around $200 million from 2003 to 2009 to increase the responsiveness of the justice system and the national, provincial and community levels
    - Oxfam Australia has supported a GIPA review.
    - AusAID provides Igat Hope with ongoing core funding and funding for annual activities (A$300,000).

12. Are development
    - Igat Hope received financial and technical support from

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97 From 2008 UNGASS country progress report
98 From 2008 UNGASS country progress report
<table>
<thead>
<tr>
<th>partners/INGOs financially supporting GIPA and/or national networks?</th>
<th>UNDP, FHI, NACS and NHASP (Care and Counselling Unit), GFATM.</th>
</tr>
</thead>
</table>
| 13. Any technical support for GIPA/Networks | • NAPWA supports Igat Hope capacity development - support for secretariat, governance training and assistance in organisational development.  
• StopAIDS trains and employs HIV-positive advocates since 2000.  
• WHO employs PLHIV as Expert Patient Trainers to train health workers, which is considered successful.  
• FHI/PNG works with the PLHIV support groups and focuses on reducing stigma and discrimination through education for PLHIV and families, engagement, capacity building, interaction and involvement of PLHIV in service delivery serving as a member of the HIV clinic case management team, adherence counsellors and providing care and support at the community level; and member of the Continuum of Prevention to Care and Treatment Coordination Committee. |
| 14. Is government funding GIPA and/or national networks? | Igat Hope "benefits from important support from the government and the development agencies". |
| Strategic information and research | Challenges faced by Igat Hope Inc.:  
1. Treatments, including treatment guidelines and treatments rollout, is an area where Igat Hope members are not consulted or involved.  
2. Prevention is one of the biggest gaps faced by Igat Hope members; not much is done in terms of broadening positive people’s understanding on prevention methods and strategies available.  
3. PLHIV work as volunteers in the Home Based Care and VCT programs. They are expected to work beyond what they are funded to do, and fair compensation needs to be addressed.  
4. Members of Igat Hope do not participate in advocacy much as no training has been provided. |

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100 From 2008 UNGASS country progress report  
101 From 2008 UNGASS country progress report
Solomon Islands

Overview

There is strong support for GIPA both from government and NGOs. Training for Stepping Stones is just happening in the country. HIV is under Reproductive Health Services in the provinces, and testing of all pregnant women on their first antenatal visit is now in place at Honiara Public Hospital; two women have been diagnosed via antenatal testing. Seven of 12 people diagnosed with HIV to date are currently alive. WHO estimate that over 350 people living with HIV in the country but there is very little reliable data. In 2008 less than 500 people came forward for voluntary counselling and testing. Lack of privacy is a significant factor in the low numbers of people testing. There have been cases of ARV drug stock outs. There is no CD-4 counting machine in the country. Solomon Islands has one HIV-positive community advocate. She gets encouragement to speak out and is very involved in public awareness and education. She does talks to youth groups, nurses training courses via Save the Children, Oxfam and various other programs, mostly in Honiara.

<table>
<thead>
<tr>
<th>Inclusion in national response</th>
<th>SINAC: Solomon Islands National AIDS Council</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. GIPA/ non-discrimination included in the national HIV policy?</td>
<td>• National HIV Policy and Multi-sectoral Strategic Plan 2005-2010 (NHPMSP)</td>
</tr>
<tr>
<td>2. GIPA included in the National HIV Strategy?</td>
<td>• National HIV Policy and Multi-sectoral Strategic Plan 2005-2010 (NHPMSP) does not mention GIPA, but reducing stigma and discrimination of PLHIV is an objective.</td>
</tr>
<tr>
<td>3. GIPA activities in the National HIV Operational Plan?</td>
<td>• GFATM Round 8 proposal is through SPC (regional) with sub recipients MoH, SCA, Oxfam and national NGOs. Focus is on prevention and care services (crosscutting is stigma reduction).</td>
</tr>
<tr>
<td>4. GIPA in sectoral HIV Strategies/policies?</td>
<td>No</td>
</tr>
</tbody>
</table>

National GIPA strategy

5. National GIPA policy/strategy/action plan?

Representation

6. PLHIV representation at National AIDS Commission/CCM/other? | • PLHIV on the SINAC
• PLHIV on the CCM for Round 8; no input as yet.
• PLHIV on HIV Task Force developing new legislation. |
7. How is representation dealt with? | There are only two women and one man who are open about their status to any degree. |

National PLHIV Networks

8. Main national PLHIV | • No national network as yet. |

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102 Round 8 Proposal GFATM
103 Round 8 Proposal GFATM
<table>
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<tr>
<th>network(s)/organisation(s)?</th>
<th>Pacific Islands AIDS Foundation, PIAF</th>
</tr>
</thead>
<tbody>
<tr>
<td>9. Main strategies/activities</td>
<td>N/A</td>
</tr>
<tr>
<td>10. How is the National Network(s) involved in the national response?</td>
<td>N/A</td>
</tr>
</tbody>
</table>

**Support for GIPA/Networks**

<table>
<thead>
<tr>
<th>11. Current AusAID support</th>
<th>AusAID provides matched funding to government of $100,000 per year towards the HIV response; one PLHIV is employed by Ministry of Health.</th>
</tr>
</thead>
<tbody>
<tr>
<td>12. Are development partners/INGOs financially supporting GIPA and/or national networks?</td>
<td>GFATM Round 8 and Round 9 proposal not successful.</td>
</tr>
<tr>
<td>13. Any technical support for GIPA/Networks</td>
<td>Oxfam Australia supported the Pacific Regional HIV Project(^{104}) targeting women's and young people's vulnerability to HIV and legislative and policy change(^{105}). Media training in 2009, and support to MoH for national M&amp;E on HIV programme(^{106}). SC Australia supports NGOs for HIV prevention and care(^{107}). SCA plans to support establishment of PLHIV organisation through GFATM Round 8 programme(^{108}).</td>
</tr>
<tr>
<td>14. Is government funding GIPA?</td>
<td>No</td>
</tr>
</tbody>
</table>

**Strategic information and research**

<table>
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<tr>
<th>15. Research findings on the needs of PLHIV?</th>
<th>See regional needs assessment PIAF</th>
</tr>
</thead>
<tbody>
<tr>
<td>16. Any evaluations of GIPA responses?</td>
<td>N/A</td>
</tr>
</tbody>
</table>

\(^{104}\) See Pacific regional AusAID programme  
\(^{105}\) http://www.oxfam.org.au/world/pacific/solomons/, accessed 16/7/09  
\(^{106}\) Round 8 Proposal GFATM  
\(^{107}\) Round 8 Proposal GFATM  
\(^{108}\) Round 8 Proposal GFATM
Vanuatu

Overview

Vanuatu has a sound policy environment. There is only one PLHIV actively involved in the response in the country. The government and key aid agencies consult with her and invite her to all the key meetings. She has been involved in the national strategic planning process.

As a community educator and advocate she has had tremendous influence. She does a lot of outreach and public awareness and education, training workshops. She helps in developing curricula in secondary schools. In remote areas she faces some stigma, and people often ask very personal questions.

<table>
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<tr>
<th>Inclusion in national response</th>
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</thead>
<tbody>
<tr>
<td>1. GIPA/ non-discrimination included in the national HIV policy?</td>
<td>No evidence of national policy</td>
</tr>
<tr>
<td>2. GIPA included in the National HIV Strategy?</td>
<td>No evidence of national strategy</td>
</tr>
<tr>
<td>3. GIPA activities in the National HIV Operational Plan?</td>
<td>No evidence</td>
</tr>
<tr>
<td>4. GIPA in sectoral HIV Strategies/policies?</td>
<td>No sectoral plans</td>
</tr>
</tbody>
</table>

National GIPA strategy

| 5. National GIPA policy/strategy/action plan? | No |

Representation

| 6. PLHIV representation at National AIDS Commission/CCM/other? | PLHIV is consulted for her views on all relevant policies and programs |
| 7. How is representation dealt with of different positive people/women? | • The first and only PLHIV who is publicly out is a woman. |

National PLHIV Networks

| 8. Main national PLHIV network(s)/organisation(s)? | • IZA Foundation, set up in 2004 by HIV-positive woman, a PIAF-appointed AIDS Ambassador since 2003.  
• Pacific Islands AIDS Foundation, PIAF. |
| 9. Main strategies/activities | Public education |
| 10. How is the National Network(s) involved in the national response? | N/A |

Support for GIPA/Networks

| 11. Current AusAID support | Through the PRSIP 2009-2013, see regional. |

12. Are development partners/INGOs financially supporting GIPA and/or national networks?
   • The SPC HIV and STI Section supports the government of Vanuatu with capacity building (not specific PLHIV organisations)\(^\text{110}\).
   • VSO volunteers work with MoH and NAC members to implement a nationwide HIV and AIDS strategy and to increase access to VCT services\(^\text{111}\).
   • Oxfam Australia works on HIV and youth, but not on GIPA\(^\text{112}\).

13. Any technical support for GIPA/Networks
   Save the Children acted as a buddy management organisation to IZA Foundation to ensure financial systems were in place and strengthen organisational management skills. PIAF supports the “out” PLHIV\(^\text{113}\).

14. Is the government funding GIPA and/or national networks?
   There is a lack of support from government and other organisations and a lot of discrimination within the community\(^\text{114}\).

### Strategic Information and Research

15. Research findings on the needs of PLHIV, situational analysis legal/social context?
   No

16. Any evaluations of GIPA responses?
   No

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\(^{110}\) Activities of the SPC HIV and STI section in Vanuatu
\(^{111}\) http://www.vsointernational.org/where-we-work/vanuatu.asp, accessed 17/7/09
\(^{112}\) http://www.oxfam.org.au/world/pacific/vanuatu/, accessed 17/7/09
\(^{114}\) 2004, Minutes APN+ / PIAF Pacific Islands Positive Network Meeting
Annex 2 – References

1. DFID, 2008, “Achieving Universal Access – the UK’s strategy for halting and reversing the spread of HIV in the developing world”
5. NZAID, 2009, “Factsheet: Responding to HIV and AIDS - an NZAID priority”

Regional
1. 2006, Mid Term review of Pacific Regional HIV/STI Strategy
3. AHAPI completion report AFAO/APCASO
5. 2004-2008 Pacific Regional Strategy on HIV/AIDS
7. 2006, Mid term review of the Pacific Regional Strategy on HIV/AIDS

Lao PDR
1. National Strategy and Operational Plan 2006-2010 (but no workplan included)
2. 2008 UNGASS country progress report
5. 2009 (March) GFATM, Grant Performance Report – Round 6
6. 2007 GFATM Grant Proposal – Round 6

China
1. 2008, UNGASS country progress report China
Vietnam
1. 2008 Country Progress Report Vietnam
2. 2004, MoH, National Strategy on HIV/AIDS Prevention and Control in Viet Nam until 2010 with a vision to 2020
6. 2007, Viet Nam Call to Action for the Greater Involvement of People Living With HIV/AIDS
7. 2006-2010 UNV GIPA project document
8. Vietnam Women’s Union (July 2008). Evaluation of the ‘Promoting the Greater Involvement of People Living with HIV (GIPA) Project in Vietnam’. By Jack Wallace, Australian Research Centre in Sex, Health and Society and Tran Minh Gioi, Centre for Community Health Promotion (excerpt only).

Myanmar
3. 2006, WHO, Review of the National HIV Programme Myanmar
4. 2008 UNAIDS Country Situation, Myanmar
5. 2008, UNAIDS/WHO, Epidemiological Country Profile on HIV and AIDS

Indonesia
2. 2008 CSO Shadow report Country Progress Report UNGASS
4. 2007-2010 National HIV and AIDS Action Plan in Indonesia
5. 2006, GOI, Presidential Regulation No. 75/2006
7. 2004, APN+, Position Paper 2 GIPA
9. undated (2006) NAC, PLHIV and Health Service Access: A Participatory Research

PNG
2. 2008 , UNGASS Country Progress report

Fiji
1. 2008 UNGASS Country Progress Report
4. 2009-2013 PRSIP draft version

Vanuatu
3. 2004, Minutes APN+ / PIAF Pacific Islands Positive Network Meeting

Solomon Islands
1. 2008, Round 8 Proposal GFATM
Annex 3 – Key Stakeholder Respondents

Regional
1. Shiba Phurailatpam, Director, Asia Pacific Network of People Living with HIV (APN+), Thailand
2. Frika Iskander, Women’s Coordinator, APN+, Thailand
3. Jane Wilson, Gender, GIPA and Human Rights Officer, UNAIDS, Thailand
5. Gail Steckley, FHI, Thailand
6. Maire Bopp, Chief Executive Officer, Pacific Islands AIDS Foundation (PIAF), Cook Islands
7. Jerry Cole, Coordinator, Pacific Regional Strategy Implementation Plan, SPC, Fiji
8. Robert Verbesaaga, Program Development Officer, SPC, Fiji
9. Saala Tupou Tamani, Program Development Officer, SPC, Fiji
10. Noel Quintos, APN+ Advisor, Philippines
11. Robert Baldwin, APN+ Advisor, Australia
12. John Rock, APN+ Advisor, Australia
13. John Rule, Deputy Director, NAPWA, Australia
14. Suzanne Lau Gooey, former APN+ alternate country rep, Australia
15. Burnet Institute staff X 6, various countries, Australian Office

China
16. Linna Cai, Senior Policy Officer (Health). AusAID, China
17. Wei Chen, Program Officer. AusAID, China
18. Thomas Cai, APN+ Country rep, Aidscare, China
19. Dr Peter Lunding, Senior HIV Adviser, UNAIDS, China
20. Nana Kuo, UNAIDS Country Officer, China
21. Eve Lee, Country Program Officer, Ford Foundation, China
22. Lily Lui, Director, Marie Stopes, China

Indonesia
23. Dr Nafsia Mboi, Secretary, National AIDS Commission, Indonesia
24. Lynette Collins, HIV Adviser, AusAID, Indonesia
25. Tim McKay, Australia Indonesia HIV Partnership Program, Indonesia
26. Denovan, President, JOTHI, Indonesia
27. Nancy Fee, UNAIDS Country Officer, Indonesia

Lao PDR
28. Dr Chansy Phimphachanh, Director, Centre for HIV/AIDS/STI, Lao PDR
29. Dulce Carandang-Simmanivong, Senior Program Manager (Rural Development), AusAID, Lao PDR
30. Kinoi, President, Laos National Network of People living with HIV, Lao PDR
**Myanmar**
31. Bernard Pearce, Humanitarian Assistance Coordinator, AusAID, Myanmar
32. Thiha Kyaing, APN+ Country rep, Myanmar

**Vietnam**
33. Amber Cernovs, Country Officer, AusAID, Vietnam
34. Do Dang Dong, Co-chair, Viet Nam National Network of PLHIV
35. Huynh Nhu Thanh Huyen, Co-chair, Viet Nam National Network of PLHIV
36. Ludo Bok, Partnership Adviser, UNAIDS, Vietnam
37. David Stephens, Nossal Institute, University of Melbourne (ex-Policy Project Vietnam Office)

**Fiji**
38. Dr Josaia Samuela, Deputy Secretary for Public Health, Fiji
39. Tim Wilcox, Second Secretary (Development Cooperation), Australian High Commission, plus four AusAID staff, Fiji
40. Ermosi Vukialau, President, Fiji Network of People Living with HIV (FJN+)
41. Tuberi Mudnavosa, Founder, FJN+, Fiji
42. Temo Sasau, Positive Community Program Coordinator, PIAF, Fiji
43. Tamara Kwarteng, Country Officer, Burnet Institute, Fiji

**Kiribati**
44. Dr Tebuka Toatu, Director of Laboratory Services, Ministry of Health, Kiribati
45. Meria Russell, Country Officer, AusAID, Kiribati
46. Buraua, HIV Outreach Worker, Kiribati Association of NGOs

**PNG**
47. Dame Carol Kidu, Minister for Community Development, PNG
48. Anne Malcolm, Country Officer, AusAID, PNG
49. Maura Mea, GIPA Advocacy Officer, AusAID, PNG
50. Helen Samilo, past-President, now Program Officer, Igat Hope, PNG
51. Nick Evera, Outreach Worker, Poro Sapot Program, Save the Children, PNG

**Solomon Islands**
52. Dr Nemia, Head of HIV Unit, Ministry of Health, Solomon Islands
53. Justin Baguley, Senior Health Development Program Specialist, AusAID, Solomon Is.
54. Joe Gela, Solomon Islands National AIDS Council, Solomon Islands
55. Alice Buko, Community HIV Support Advocate, Solomon Islands
56. Julia Fationo, HIV and AIDS Program Officer, Oxfam, Solomon Islands

**Vanuatu**
57. Irene Malachi, Project Manager, IZA Foundation, Save the Children, Vanuatu
58. Moses Matovu, Ministry of Health, Government of Vanuatu
Annex 4 – Current and Recent Regional AusAID Programs

1. Regional Capacity Building Program 2007-2011

The overall Program Goal: Strengthened role of organisations and individuals in the Asia–Pacific region to contribute to effective responses to HIV.

Purpose: To foster strategic partnerships and linkages between Australian and the Asia-Pacific region to increase the capacity of partners to contribute to effective HIV responses.

Project area: Asia-Pacific

The HIV Consortium for Partnerships in Asia and the Pacific comprises:

- Albion Street Centre (ASC)
- Australasian Society for HIV Medicine (ASHM)
- Australian Federation of AIDS Organisations (AFAO)
- Australian Injecting and Illicit Drug Users League (AIVL)
- Australian Research Centre in Sex, Health and Society (ARCSHS)
- National Serology Reference Laboratory (NRL)
- National Centre in HIV Epidemiology and Clinical Research (NCHECR)
- Scarlet Alliance (Australian Sex Workers Association)
- School of Public Health and Community Medicine (SCPCM)

2. AusAID HIV/AIDS Partnership Initiative (AHAPI) - COMPLETED

Aim: to strengthen the capacity of HIV/AIDS organisations in the Asia-Pacific region to respond to HIV/AIDS. The Initiative works through partnerships between these organisations and Australian organisations that have specialist HIV/AIDS expertise.

Project area: Asia-Pacific

Round I AHAPI Projects (December 2004 – 2007)

- National Serology Reference Laboratory, Australia (NRL)
- Albion Street Centre
- Australasian Society for HIV Medicine (ASHM)

Round II AHAPI Projects (March 2005 – 2008)

- NAPWA - Strengthening the People Living With HIV/AIDS Response – HIV Peer Support and Capacity Building. Igat Hope Inc (Papua New Guinea); Timor Aid (East Timor); APN+: Asia-Pacific Network of People Living With HIV (Thailand). Objective: To build the capacity and visibility of PLWHA organisations to develop and sustain PLHIV involvement within their country’s HIV/AIDS response.
- Albion Street Centre (Australia) and Thai Red Cross AIDS Research Centre, Institute of Nutrition, Mahidol University - The Australia – Thailand HIV/AIDS Nutrition Care,
Treatment and Support Partnership Project to promote, develop, implement and evaluate nutritional strategies for PLWHA in Thailand.

- AFAO/ APCASO Leadership and Advocacy Collaboration Project - To strengthen the advocacy and leadership capacity and skills of vulnerable communities through HIV CBOs in selected countries, in the APCASO and selected members.
- Scarlet Alliance (Australia) and Save the Children PNG. To increase the capacity of Papua New Guinea sex workers to develop and implement an effective community response to HIV/AIDS.
- Strengthening HIV-related social research capacity in PNG: National Centre in HIV Social Research (Australia) and PNG IMR.

3. **HAARP 2007-2015**

HIV/AIDS Regional Program goal is to reduce the spread of HIV associated with drug use among men and women in South East Asia and China. Purpose: To strengthen the capacity and will of governments and communities in South East Asia and China to reduce HIV-related harm associated with drug use among men and women.

AusAID, total funding is AUD$59m over an eight year period. The Netherlands Government contributes 4 m Euros extra over 4 years for the Vietnam Country Flexible Program115.

Project area: Asia


Multi-donor (Australia, NZ, and France) pooled funding mechanism that supports implementation of national and regional HIV strategic plans. The Response Fund aims to contribute to the Pacific Regional HIV and STI Strategy (PRSIP) goal, to reduce the spread and impact of HIV and other sexually transmitted infections (STIs) while embracing people infected and affected by HIV in Pacific communities.

Project area: Pacific

The Response Fund builds on the PRHP, which was implemented by IDSS Ltd and the Burnet Institute in conjunction with the Secretariat of the Pacific Community (SPC). Under PRHP, SPC developed the PRSIP.

The Response Fund supports capacity building at regional, national (both government and civil society) and community levels, including training, technical support and organisational systems strengthening as well as financial resources. Capacity-building is provided by SPC, WHO and UNAIDS, UN Technical Support Facility, and AusAID supported Consortium. The Response Fund will be overseen by a Fund Committee.

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116 2009, SPC, Fact Sheet Response Fund
SPC will manage the Response Fund and provide a secretariat to the Fund Committee.

This program complements other AusAID support for HIV: the Asia Pacific Leadership Forum, the Pacific IPPF sexual and reproductive health capacity building program, the AusAID regional HIV/AIDS capacity building program 2007–2011 and HIV/AIDS research program.


Aimed to strengthen the capacity of PICT governments, NGOs and communities to develop an effective and sustainable multi-sectoral response to HIV.

Project area: Pacific

Franco/Australian initiative, managed by the Secretariat of the Pacific Community (SPC): regional surveillance, behaviour change communication and development of a Pacific Regional HIV/AIDS Strategy and Regional Strategy Implementation Plan (PRSIP).

Components two and three focused on improving national HIV responses in 14 independent Pacific Island countries through building capacity for situational analysis and review, planning, management and monitoring of HIV/AIDS strategies; and building the community response to HIV/AIDS through a Grants Scheme, Implemented through Burnett Institute and IDSS (5 million A$).

References:
1. 2006, Mid Term review of Pacific Regional HIV/STI Strategy
3. AHAPI completion report AFAO/APCASO
5. 2004-2008 Pacific Regional Strategy on HIV/AIDS
7. 2006, Mid term review of the Pacific Regional Strategy on HIV/AIDS