

The Involvement of People with HIV in PNG's HIV Response

**A Review of the Implementation of the Greater
Involvement of People Living With or Affected By
HIV/AIDS (GIPA) Principle in PNG**

**Final Report to Oxfam Australia
December 2006**

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EXECUTIVE SUMMARY

- The true test of GIPA (Greater Involvement of People Living with HIV/AIDS) is not involvement of people living with HIV/AIDS (PLHA), but *meaningful* involvement of PLHA. Performance in implementing GIPA cannot be assessed merely by the numbers of PLHA reached by a program, although this is important. It should be assessed by considering how these people are involved and at what level.
- Agencies in PNG are conducting a range of HIV programs that involve PLHA in different ways. Overall, most PLHA engagement in HIV programs and activities tends to be at the lower levels.
- There is significant agreement amongst service providers and PLHA as to what barriers prevent greater implementation of the GIPA principle. The barriers to implementation of GIPA include stigma and discrimination, expectations relating to disclosure, limited PLHA capacity, limited willingness on the part of agencies to seek 'higher level' inputs, barriers preventing access to training, 'charity models' of working with PLHA, job insecurity and irregular employment for PLHA, poor remuneration, lack of organisational support, poor role models, burnout, disorganisation within agencies, nepotism and favouritism, poor dissemination of learnings, unreasonable demands on PLHA employees, past instances of poor financial management by Igat Hope, unhelpful competition for PLHA amongst agencies and conflicts of interest for PLHA.
- A number of factors appear to facilitate implementation of GIPA in PNG. These include: use of appropriate selection criteria to identify which PLHA should participate in an activity, opportunities to participate at various levels, building self-worth, PLHA feeling appreciated, access to antiretroviral therapy (ART) and peer support, support of PLHA organisations, establishing environments within non-government organisations (NGOs) that are conducive to PLHA participation, partnerships between NGOs, employment of PLHA as counsellors, PLHA as providers of home-based care and flexibility with HIV-positive employees.
- There is a clear need for access to more training for PLHA. This will be critical in boosting the capacity of PLHA to engage in the national HIV response. Training needs to address both the ability of PLHA to manage their virus and their lives (e.g. self-care training, conflict management, training in ART literacy), and the need to boost their capacity to contribute to broader HIV initiatives (e.g. public speaking, counselling).

- Not surprisingly, there is a need for greater commitment to GIPA amongst those agencies conducting HIV work in PNG. This will require a greater understanding generally of what it is, as well as leadership from those NGOs with established commitment to and experience of working with PLHA. Oxfam and other international NGOs should also promote and exemplify the Code of Good Practice for NGOs Responding to HIV/AIDS, with implementation of GIPA as a core principle of the Code.
- While it is not anticipated or proposed that Oxfam PNG become an organisation specialising in HIV, there are still a number of discrete and manageable projects which the organisation might undertake which would greatly contribute to GIPA in PNG. These need not necessarily be expensive and Oxfam's role may be in the facilitation of activities by others rather than through direct delivery of services.
- The HIV epidemic and the developing responses in PNG show distinct differences from the situation in Sub-Saharan Africa. Lessons learnt in PNG will better inform Oxfam's HIV responses in the rest of the Pacific region.
- Oxfam's current proposals to revive its home-based care program in Goroge settlement should be reviewed. The earlier phase of the project has been completely wound down and there are significant barriers to the recommencement of this program, some of which Oxfam may be unable to overcome. The demand for home-based care services also needs reassessment in light of the increasing rates of HIV testing and expanded access to antiretroviral treatment in Port Moresby.
- Access to ART is fundamental to the capacity of PLHA to be involved in HIV responses in a sustained and meaningful way. To date, Port Moresby has been the site of the most extensive ARV rollout and of the greatest skills building opportunities for PLHA. But PLHA activity (activism, advocacy, mutual support and other forms of engagement) is building in other parts of the country. To a degree, this is occurring in tandem with access to ART. These groups should be supported for they are potential rich sources of the vital PLHA contributions needed to improve PNG's response to the epidemic.

Acronyms

AIDS	Acquired Immunodeficiency Syndrome
APN+	Asia-Pacific network of People living with HIV/AIDS
ARV	Antiretroviral drugs
ART	Antiretroviral therapy
AusAID	Australian Aid for International Development
CCM	Country Coordinating Mechanism
CSO	Civil society organisation
EPT	Expert patient trainer(s)
FHI	Family Health International
GFATM	Global Fund for AIDS, Tuberculosis and Malaria
GIPA	Greater involvement of people living with HIV/AIDS (principle)
HAMP	HIV/AIDS Management and Prevention (Act)
HBC	Home-based care
HCW	Health care worker
HIV	Human Immunodeficiency Virus
INGO	International non-government organisation(s)
MSM	Men who have sex with men
NACS	National AIDS Council Secretariat
NAPWA	National Association of People Living With HIV/AIDS (Australia)
NGO	Non-government organisation
NHASP	National HIV/AIDS Support Project
NSP	PNG National Strategic Plan on HIV/AIDS 2006-2010
OAus	Oxfam (Australia)
ONZ	Oxfam (New Zealand)
OI	Opportunistic infection
PACSO	PNG Alliance of Civil Society Organisations Against HIV/AIDS
PNG	Papua New Guinea
PLHA	Person(s) living with HIV or AIDS
PMTCT	Prevention of mother to child transmission
PNGRC	PNG Red Cross
STI	Sexually transmitted infections
TB	Tuberculosis
TOT	Training of trainers
UNAIDS	Joint United Nations programme on HIV/AIDS
UNDP	United Nations Development Program
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation

INTRODUCTION AND METHODOLOGY

Introduction

Papua New Guinea (PNG) has the highest rate of Human Immunodeficiency Virus (HIV) in the Pacific region. However, although the HIV epidemic has become generalised and now affects the broader community, HIV is still relatively invisible.

Most people infected with HIV in PNG are not aware of their HIV status. Not only does it take many years for HIV disease to progress to the signs and symptoms of Acquired Immunodeficiency Syndrome (AIDS), but HIV also remains hidden because of ignorance about HIV and stigmatisation of and discrimination against people living with HIV or AIDS (PLHA). Stigma and discrimination are major problems for both people infected with and affected by HIV, and can extend to violence against those affected.

Greater Involvement of People living with or affected by HIV/AIDS (GIPA) is essential to all aspects of an effective HIV response. Along with the scientists and health care professionals working in HIV, PLHA themselves have HIV expertise gained through living and coping with the virus. PLHA faces, voices and experiences are needed to make the epidemic visible and to develop better responses to the epidemic. However, a safe space also needs to be created within society so that PLHA can actively participate in the HIV response at all levels.

The principle of GIPA was first declared at the Paris AIDS Summit in 1994 and has been adopted at the highest levels, including by the United Nations. Yet implementation has been slow.

The purpose of this research commissioned by Oxfam Australia was to assess the commitment of organisations and groups involved in the HIV and AIDS response in PNG to the GIPA principle and to assess how they are collaborating with or meaningfully involving PLHA.

It is intended that the research will inform:

- Oxfam Australia's future HIV program and advocacy work in PNG regarding the implementation of GIPA
- Oxfam Australia's and Oxfam International's approach to GIPA
- Oxfam Australia's other country programs, its HIV advocacy work and the practices of its head office.

Background

The principle of GIPA is well documented, including in some of Oxfam's own work.

In approaching this work, the reviewers were interested in the *levels* of contribution being made by PLHA. The reviewers considered the levels of contribution noted by UNAIDS and summarised below. In this summary, those levels of contribution at the top are those that most reflect application of the GIPA principle.¹

<p>Decision makers: PLHA participate in decision making or policymaking bodies and their inputs are valued equally with all other members of these bodies.</p>
<p>Experts: PLHA are recognised as important sources of information, knowledge and skills who participate – on the same level as professionals – in design, adaptation and evaluation of interventions.</p>
<p>Implementers: PLHA carry out real and instrumental roles in interventions (e.g. as caregivers, peer educators or outreach workers). However, PLHA do not design the intervention or have much say in how it is run.</p>
<p>Speakers: PLHA are used as spokespersons in campaigns to change behaviours or are brought into conferences or meetings to ‘share their views’ but otherwise do not participate. (This is often perceived as ‘token’ participation, where the organisers are conscious of the need to be seen as involving PLHA but do not give them any real power or responsibility.)</p>
<p>Contributors: Activities involve PLHA only marginally, generally when the PLHA is already well-known. For example, using an HIV-positive pop star on a poster or having relatives of someone who has recently died of AIDS speak about that person at public occasions.</p>
<p>Target audiences: Activities are aimed at PLHA or address them as a group rather than as individuals. However, PLHA should be recognised as more than (a) anonymous images on leaflets, posters, or in information, education and communication campaigns, (b) people who only receive services or (c) as ‘patients’ at this level. They can provide important feedback which, in turn can influence or inform the sources of the information.</p>

The reviewers were also informed by the findings of a four-country study of PLHA in community-based programs undertaken by the International HIV/AIDS Alliance and the Population Council (Horizons Project)². In this study, researchers used agreed criteria³ to examine how PLHA were

¹ UNAIDS (1999) *From Principle to practice: Greater Involvement of People living with or affected by HIV/AIDS* UNAIDS/99.43E http://data.unaids.org/Publications/IRC-pub01/JC252-GIPA-i_en.pdf

² Horizons (2002) *Greater Involvement of PLHA in NGO service delivery: Findings from a four-country study Research summary* http://synkronweb.aidsalliance.org/graphics/secretariat/publications/hsum0602_Horizons_PLHAstudy_summary.pdf.

³ Time spent on and regularity of activities; remuneration, including financial (salary, allowance, reimbursement of travel costs), material (food, medicines), technical (training), or psychological (social support and counselling); skills used; skills development provided by the organisation; scope and autonomy of decision making; level of visibility - internal (within the NGO) and external (outside the NGO).

involved in NGOs. The research noted four⁴ distinct types of PLHA involvement (Table 2.)

Table 2: Categories of PLHIV involvement
Greater involvement: the most advanced stage of PLHA involvement. PLHA work in management and as significant policy and strategic organisational actors within the NGO and may represent it externally. PLHA may also sit on the Management Board of the NGO (usually unpaid).
Participation: PLHA deliver HIV/AIDS-related services on a formal, regular basis, as employees or volunteers; may be involved in planning or consultation. PLHA expertise is recognised and, generally, work is financially rewarded.
Inclusion: NGOs include PLHA in non-HIV/AIDS activities or as occasional volunteers in HIV/AIDS service delivery. PLHA involvement is not formally supported by structured training or wage remuneration but greater access to peer support and interaction with other PLHA are important incentives.
Access to services: This level of involvement is defined as PLHA taking part in NGO activities as beneficiaries of services. Access was the most common form of involvement observed among the 17 NGOs.

Meaningful involvement was also associated with increasing levels of "vocality":

- No voice - most commonly as a service user
- Individual voice, based on one's own experience
- Collective Voice, able to express the experience of other PLHA
- Social voice - being able to advocate on behalf of all PLHA.

This study indicated that the type of NGO or CBO influenced the level of involvement. Higher levels of involvement were more common in NGOs which PLHA had set up (with other affected people or health or social workers) as rights-based organisations and/or self-help groups.

Lower levels of involvement were more common in service delivery NGOs where specific professional qualifications or technical skills were required. However, accessing certain services could provide an entry point to empower PLHA and foster further involvement within the NGO through

⁴ International HIV/AIDS Alliance (2003) *The involvement of People Living with HIV/AIDS in community-based prevention, care and support programs in developing countries – a multi-country diagnostic study p90*
http://synkronweb.aidsalliance.org/graphics/secretariat/publications/ipl0703_PLHA_International_report.pdf. The study also identified two types of non-involvement - Tokenism and Exclusion. Although none of the study NGOs practised exclusion, the researchers were aware of other prevention-focussed NGOs and CBOs which excluded PLHA because they believed that people who were already infected had no need of any form of prevention and also ignored the potential contribution of PLHA to effective outreach education.

such activities as positive living and life skills courses, counselling and support groups⁵. However, this rarely led to greater involvement unless there was a clear policy within the organisation to facilitate this.

UNAIDS has outlined seven potential areas of involvement of PLHA⁶. These areas are:

- **Personal**
Active involvement in own health and welfare e.g. self education about therapies, positive prevention⁷
- **Treatment roll-out and preparedness**
Support of treatments roll-out through educating other people living with HIV on treatment options
- **Policy making process**
Participation in the development of HIV-related policies at all levels
- **Programme development and implementation**
Provision of knowledge and skills and participation in the choice, design, implementation, monitoring and evaluation of projects
- **Leadership and support, group networking and sharing**
Leadership of HIV support groups, resource seeking, encouragement of participation of new members
- **Advocacy**
Work towards law reform and promotion of access to services
- **Campaigns and public speaking**
Involvement as spokespersons in campaigns or at public events.

The reviewers also noted the commitment to GIPA outlined in the Code of Good Practice for NGOs Responding to HIV/AIDS (2004)⁸. This was an initiative collaboratively undertaken by many NGOs, including HIV/AIDS organisations, and was hosted by the International Federation of Red Cross and Red Crescent Societies. GIPA is a central principle of the Code; organisations that have signed the Code are committed to the implementation of the Code and all its principles, including GIPA.

⁵ p77-80 Alliance (2003) multi-country study. The characteristics of the NGOs and their service users are listed on pages 61-67. Out of the 17 NGOs, only two Zambian NGOs were listed as offering course in Positive Living (p63, p78)

⁶ UNAIDS, The Greater Involvement of People Living With HIV (GIPA) Policy Brief draft paper (November 2006)

⁷ Positive Prevention is the term used to describe the important role of PLHA in prevention of HIV transmission. Prevention interventions have often been considered more appropriate for HIV-negative people, however the relevance and importance of positive prevention has increasingly been recognised.

⁸ NGO HIV/AIDS Code of Practice Project (2004) *Renewing our voice: Code of good practice for NGOs responding to HIV/AIDS*. The complete text and list of signatory organisations is available at www.ifrc.org/what/health/hivaids/code/.

The NGO Code of Good Practice spells out how GIPA forms a prominent organisational principle and how it applies to individuals and collectively to PLHA networks⁹.

The Code specifies as follows: "*We foster active and meaningful involvement of PLHA and affected communities in our work. We need to:*

- Create an organisational environment that fosters non-discrimination and values the contribution of PLHA and affected communities
- Recognise and foster involvement of the diverse range of PLHA and affected communities
- Ensure involvement in a variety of roles at different levels within our organisations
- Define roles and their associated responsibilities; assess what a particular role requires, and the capacity of individuals to fulfil the role; and provide the necessary organisational support, including financial
- Ensure practice and policies provide timely access to information to enable participation, preparation and input, before programmatic and policy decisions are made
- Ensure workplace policies and practices recognise the health and related needs of PLHA and affected communities and create an enabling environment that supports their involvement
- Ensure when seeking PLHA and affected community representatives, that PLHA and affected community organisations and networks have strategies for accountability to their members
- Resource and support capacity-building within PLHA and affected community organisations and networks and
- Fund and/or advocate for funding of PLHA and affected community organisations to ensure they have the resources to build capacity and empower others within their own networks."

National context

It has often been suggested that PNG is heading for an African-scale epidemic, and some have been tempted to apply to PNG strategies that have proven effective in Africa. While this may be appropriate for some strategies, PNG is not Africa and there are aspects of the PNG epidemic that make it unique.

While the PNG epidemic is a generalised one, and infection rates continue to climb, HIV is still not *visible* in PNG. The signs of an epidemic are certainly there, but people have not yet learned to recognise them. There

⁹ NGO HIV/AIDS Code of Practice Project (2004) *Renewing our voice: Code of good practice for NGOs responding to HIV/AIDS*. (section 3.2 Involvement of PLHA and affected communities p41-42). The complete text and list of signatory organisations is available at www.ifrc.org/what/health/hivaids/code/.

is still some way to go before the community sees or feels the full impact of HIV and before the community *owns* HIV as a national and urgent problem. At present, there is still the temptation to see HIV as a problem for 'others'.

Fortunately, free ARVs are already being rolled out in PNG. This is at a much earlier stage of the epidemic than was the case for other parts of the world with significant infection rates. This should have a number of important impacts on service demand and PLHA engagement: in areas where ARVs are available, there should be a reduction, over time, in the need for home-based care. There should also be a larger population of PLHA living longer and less beaten down by years of grief and loss. Of course, this all presupposes that ARVs are correctly rolled out in ways that support the capacity of PLHA to take medications.

Many of the PLHA engaged in the PNG response came to the response through advocacy, whereas in older epidemics many PLHA have tended to come to advocacy through engagement in care and support services (as beneficiary and/or provider). This means many PLHA engaged in the PNG response as advocates may not have developed skills in self-care, counselling or in home-based care.

Methodology

The external reviewers, Tim Leach and Suzanne Lau Goey, were selected by Oxfam Australia through an open tender process. The tender documents specified that an in-country consultant would also be recruited and Oxfam PNG contracted Maura Elaripe for this role. The three consultants worked together in-country 14th-22nd November 2006 and have prepared this joint report.

The reviewers conducted background research before commencing the review. A list of useful resources that have informed this project is attached to this report.

Once in-country, the reviewers met with representatives of the following NGOs:

- Oxfam
- World Vision
- Family Health International
- Care and Counselling Unit, National HIV/AIDS Council Secretariat/National HIV/AIDS Support Project
- PNG Alliance of Civil Society Organisations (PACSO)
- Anglicare StopAIDS
- United Nations Development Programme HIV Project
- World Health Organisation
- Red Cross PNG

- Save the Children (Poro Sapot Project)
- Igat Hope.

With the support of Igat Hope, PNG's main positive people's organisation, a forum was held to discuss GIPA from the PLHA perspective. This two-hour forum was attended by nine PLHA. Two additional PLHA were subsequently interviewed individually. Of the eleven PLHA interviewed, five were women.

The PLHA interviewed were specifically chosen because they had all had experience participating in various aspects of the HIV response. All had undertaken training to facilitate their engagement in the response.

Project limitations

The review budget provided for fifteen days of external consultancy work¹⁰ plus five days from the in-country consultant. The budget did not allow for travel to parts of PNG other than Port Moresby.

The reviewers accept that there are many agencies in PNG with GIPA stories that were not interviewed as part of the review. It is a reality of working in PNG that meetings are often hard to schedule in advance: email systems fail and phone services are increasingly unreliable. Many organisations could not afford the time or were not prepared to be interviewed because key personnel were not in Port Moresby.

It is also true that many hard working and under-resourced services in PNG are constantly being asked to participate in interviews such as the ones sought by the reviewers. Workers within these NGOs experience an understandable degree of frustration when they are pulled away from duties to provide advice to consultants - even when the consultants are working for an agency with Oxfam's reputation.

The reviewers also note that each PLHA has his/her own story and that, while the eleven stories captured may be indicative of the PLHA experience, they could not be said to constitute a comprehensive picture.

In particular, the experience for PLHA outside of Port Moresby has not been captured as part of this limited review.

It is also true that not all PLHA in Port Moresby are affiliated with Igat Hope, however most Port Moresby-based PLHA who are active participants in the HIV response are likely to be members of the organisation.

¹⁰ 7.5 days each from the two external reviewers

OBSERVATIONS¹¹

National AIDS Council Secretariat

Importantly, there is a position on the National AIDS Council reserved for a PLHA representative. Unfortunately, this position has been vacant since the NAC was transferred to the control of the Prime Minister's department.

Several unsuccessful attempts were made to interview the Acting Director of NACS to obtain an overall view of PLHA in PNG's national HIV response. The unanticipated absence of the Director no doubt impacted on the Deputy's availability.

The reviewers looked to the PNG National Strategic Plan on HIV/AIDS 2006-2010 to get some sense of the anticipated role of PLHA in the national response. The Plan's Implementation Arrangements section specifically refers to the active participation of PLHA only in the treatment, counselling, and care and support sections (p61). While the family and community support section includes an objective to empower PLHA as advocates in community education programs (P76), PLHA are not mentioned in relation to education and prevention, leadership, partnership or coordination. The reviewers note that PLHA were represented on the project steering committee and on five of seven working committees; still the document's references to PLHA engagement seem surprisingly few in number.

The NACS Care and Counselling Unit Advisor outlined a range of training programs conducted through a collaboration between NACS and NHASP that would be of interest to PLHA. The program is committed to non-discriminatory and welcoming approaches so as to facilitate engagement of PLHA. It was not clear how many, if any, PLHA had been involved in these training programs, although there is at least one qualified PLHA TOT.¹²

NHASP did for some time employ a PLHA within the Resource Centre, but this employee left voluntarily to pursue other work.

Stop AIDS (Anglicare)

StopAIDS began as an HIV/AIDS training centre and now includes clinic and counselling facilities, as well as a drop-in centre for PLHA. In 2000

¹¹ This section is based on what the reviewers saw and were told during their meetings with agency representatives. Agencies listed conduct additional projects not referred to, but reviewers' focus has been on HIV programs.

¹² The consultants have learnt from other sources that PLHA have been amongst those trained in care and counselling, but that they are not necessarily open about their HIV status during the training.

HIV-positive advocates were employed. Currently, four PLHA (two men, two women) hold paid full-time positions as counsellors. These roles involve the provision of education and training for other PLHA, clinics, businesses and the wider public. The workers are often invited to speak at events or training sessions conducted by other organisations.

In 2007 StopAIDS hopes to recruit two more PLHA and more structured activities are planned for PLHA attending the drop-in centre.

World Health Organization (WHO)

As ART is being rolled out in PNG, PLHA play an important role as Expert Patient Trainers (EPTs) under a WHO program that has been adapted for application to PNG. EPTs facilitate training for doctors and other health care workers from the client's perspective. Initially, doctors received patient's feedback with trepidation, but most who have participated in the training have found it illuminating.

EPTs are carefully selected and trained in communication skills, how to critique and provide positive feedback, role plays and understanding diagnosis and treatment. Importantly, literacy is not essential for EPTs - only for those who facilitate training of EPTs. The training has been highly successful in improving the self-esteem of those PLHA involved.

WHO applies selection criteria for PLHA interested in becoming EPTs. These criteria have been specially modified for PNG and include:

- Participants must be willing to publicly disclose in a mock-clinic setting and be willing to risk disclosure from confidentiality breaches¹³
- Participants must be willing to engage with others
- Participants must have an ability to travel¹⁴
- Participants must appreciate the importance of being a positive role model as other PLHA tend to see EPTs as role models.

EPTs are paid when they are involved in training and given per diems when travelling. Training courses are sporadic, but happen around every two months or so on average.

More PLHA trainers will be recruited by WHO for a new District Care Course to be piloted in 2007. The course is aimed at engaging non-health professionals to support treatment adherence at village level. This will

¹³ The program promotes confidentiality of HIV information but acknowledges there is a degree of disclosure inherent in participating in the program.

¹⁴ Women and men seem to be equally able to travel (except in the case of women from the Highlands). The extra per diem paid for travel is much appreciated by participants and seen as an additional source of income.

involve preparing PLHA to be effective treatment supporters for their fellow PLHA and for an additional role in providing support to health care workers (freeing them up for other activities).

Family Health International (FHI)

FHI has been committed to strengthening Igat Hope. An example of partnership with Igat Hope was the "Lukautim Yu Yet" project, involving the translation of a Cambodian self-care manual into Pidgin. Eleven PLHA, about equal numbers of women and men, were also trained and then paid to deliver the self-care training course at PLHA drop-in centres and day-care centres in Port Moresby.

As part of this program, PLHA trainers would meet monthly with FHI program staff to debrief and to be mentored.

More than 100 PLHA have now been trained at drop-in and day-care centres. This number has included some children who attended because their parents could not read. As a result of the outreach program, Igat Hope's membership has increased and PLHA are more willing to speak publicly about their HIV status. There have also been benefits to the PLHA trainers' health and well-being.

The program ended in September 2006, but many PLHA trainers continue to train other PLHA as unpaid volunteers. These trainers and other PLHA will be recruited for a new training course in sexual health, pregnancy, PMTCT and family planning. FHI is also awaiting approval from the Ministry of Justice to start a new program in which PLHA will be trained to support village court systems to understand and implement the HAMP Act. In the preparation of this proposal FHI engaged a local PLHA to conduct surveys of HAMP awareness amongst village courts.

FHI also works with other partner organisations – Save the Children, Hope Worldwide, PNG Red Cross, Salvation Army, the Baha'i faith – on training and other activities relevant to PLHA.

World Vision

World Vision's HIV program began as a service for female sex workers but has developed into a broader program. The organisation offers VCT services and a drop-in centre Mondays to Fridays. On two days per week training is offered in life and other skills. Literacy classes are planned for 2007.

During 2006 World Vision New Zealand has funded a program in which four PLHA are contracted for three-month periods as paid volunteers. These volunteers are paid according to the activities performed, including

outreach education, encouraging clients to attend for VCT, distributing condoms etc. After each three month period, new PLHA are engaged so that a total 16 PLHA will have the opportunity to be paid volunteers over a year.

United Nations Development Programme (UNDP)

Under the UNDP Support Project, four PLHA (two men and two women) have been employed in part-time positions since 2004. Each works in one of four component areas – workplace policy, gender, socio-economic impact studies and leadership development.¹⁵ They assist visiting consultants and the project manager with content, and help organise and facilitate training workshops.

The PLHA are contracted to work 3 days per week (12 days per month). In practice, however, the PLHA work many more hours than this. UNDP has been flexible about its positive employees in terms of them taking time to fulfil other PLHA functions, either inside PNG or overseas e.g. APN+ commitments and various training workshops.

These contracts finish in December 2006 and the workers have not been offered alternative employment within UNDP. Not surprisingly, there is some concern about how the loss of these roles will impact on PLHA inputs at a national level.

PACSO

The PNG Alliance of Civil Society Organisations Against HIV/AIDS (PACSO) is an emerging umbrella civil society organisation focusing on HIV/AIDS. Its three main functions are:

- Advocacy in HIV/AIDS
- Promoting networking between CSOs and acting as an interface between donors and CSOs
- Promoting capacity building – small CSOs need technical assistance in a range of areas.

Around 300 organisations have applied to be members of PACSO. PACSO will need to undertake capacity building with smaller CSOs to enhance their ability to involve PLHA. The Board, which was elected in 2006, includes a representative from Igat Hope.

PNG Red Cross (PNGRC)

PNGRC were joint partners with FHI in training eleven PLHA to provide self-care training for PLHA at drop-in centres (the Lukautim Yu Yet project

¹⁵ Unfortunately, the woman PLHA assigned to the gender unit died in 2005 and was not replaced.

referred to in the FHI section). PNGRC will also partner FHI in the new training course for PLHA trainers on reproductive health and PMTCT (again, see FHI note).

PNGRC also runs HIV refresher courses for its volunteers, but it was not clear if PLHA also facilitate this training or whether PLHA are RC volunteers.

PNGRC has also negotiated an arrangement with Nestlé in which the company will fund a PLHA position at PNGRC to undertake specific HIV work.

Community-based awareness programs will be conducted in all twelve PNG RC branches, but the care and support program will be rolled out in three provinces – Western Highlands, Morobe and Milne bay. In Western Highlands, the RC HIV coordinator liaises with an emerging PLHA group.

Poro Sapot Project

Save The Children's Poro Sapot project operates a drop-in service and clinic for sex workers and men who have sex with men (MSM). The clinic operates two days per week for sex workers and on Wednesdays for MSM. The project also operates a program whereby a small number of outreach workers are paid on a part-time basis for their efforts in support of the project. These volunteers have included PLHA.

The Poro Sapot Project is a response to the levels of discrimination against sex workers and MSM in PNG.

Igat Hope.

Igat Hope was the first PLHA group to be established in PNG. The group is now an incorporated entity and has recently taken out a lease on office premises and employed a coordinator. Funds have also been secured pursuant to the National Strategic Plan with the support of NACS and AusAID. Igat Hope's future plans include:

- Ensuring an effective secretariat through the maintenance of an office and a paid coordinator
- The establishment of Igat Hope in other provinces
- A PLHA speaking program
- A 'living well' education program for PLHA.

Igat Hope has an ongoing partnership with NAPWA, Australia's peak PLHA organisation, and is also a member of the Asia-Pacific Network of People Living with HIV/AIDS (APN+). The group has also received support from UNDP, FHI, StopAIDS, NACS and NHASP (particularly the Care and Counselling Unit).

Recent outreach by Igat Hope members to drop-in and day-care centres (as part of the FHI/Red Cross program) has encouraged many more PLHA to join the organisation, and its membership now stands at 88.

Igat Hope has begun to network with other PLHA groups in PNG. While it is working towards establishing some offshoots, Igat Hope is not a peak organisation for all the country's positive groups.

Oxfam Australia

In 2004 Oxfam established a small home-based care project in Gorobe settlement (the Hope for Living Project). A coordinator was employed and twenty carers were trained (mostly non-PLHA). A drop-in centre, built in 2002, was used as the focal point for the project. A range of logistical challenges forced the suspension of this program in 2005.

The consultants did hear that some home-based carers have continued to provide care on a voluntary basis with other services or as individuals, but that most have not pursued these activities in the absence of a framework to facilitate such work.

Code of Good Practice for NGOs Responding to HIV/AIDS.

The consultants were not exposed to evidence of awareness of the Code or its implementation by any agency within PNG. For example, while the IFRC hosted the project which developed the NGO Code, those PNGRC representatives interviewed were not aware of its existence. There is no evidence that any PNG NGOs were involved in the development of the Code.

ANALYSIS

Overall, the participation of PLHA in PNG appears to be concentrated at the lower levels. Levels of participation are highest in Port Moresby, where there are several PLHA who deliver HIV/AIDS services or training and whose expertise is financially rewarded. However, few PLHA working in HIV have permanent jobs and most are engaged on an ad hoc basis.

Small numbers of PLHA were active in all of the relevant areas of involvement, but participation was weakest in program development and implementation. Only a small percentage of PLHA had received training to be actively involved in managing their own health and welfare.

There was no apparent awareness of the NGO Code of Good Practice.

There was a high level of agreement between PLHA and service providers about how GIPA is being implemented in PNG. Indeed, the reviewers were somewhat surprised by the number and range of shared views. To divide findings into 'PLHA perspectives' on the one hand and 'service provider perspectives' on the other would be to misrepresent the convergence of views. The findings are divided into two sections: 'Barriers/problems' and 'What works'.

Each finding represents an observation made by both service users and service providers, unless otherwise stated.

Barriers/problems

Through their discussions with service providers and PLHA, the reviewers have identified a range of barriers to the implementation of GIPA in PNG. These are outlined below:

Stigma and discrimination

Almost everyone interviewed noted the enduring stigma and discrimination experienced by people with HIV in PNG. This is perhaps the greatest barrier to participation by PLHA in the response.

PLHA relayed personal experiences where they felt their public contribution to the response had exposed them to great personal risk.

Stigma and discrimination were the most commonly cited reasons for the failure of highly educated, management-level or professional PLHA to be involved in HIV work. These PLHA prefer to seek treatment from private doctors and hospitals because they do not want to risk exposure by using government facilities. They also do not join PLHA groups, such as Igat Hope. This makes it more difficult to provide these PLHA with information and support and for Igat Hope to access management and professional skills from within its membership.

Expectations relating to disclosure

Some agencies and individual PLHA have wrongly assumed that in order for PLHA to make any contribution to HIV services they must disclose their status. Sometimes, this is associated with a desire on the part of the agency to publicly demonstrate its acceptance of PLHA. Few agencies have developed the sorts of HIV workplace policies that might encourage PLHA to contribute as workers who just happen to have HIV, rather than as 'HIV workers'.

Limited PLWHA capacity

To participate in the national response, PLHA have to possess the personal capacity that allows them to allocate time and effort. This requires a minimum level of health. Widespread poverty and a poor national health system are two of many factors that rob PLHA of the level of health necessary to enable them to participate in responses.

Fortunately, ART is available free from government facilities, but less so outside Port Moresby. However, while access to ART is increasing, there remain serious concerns about treatments literacy, the capacity of many PLHA to maintain strict treatments regimens and the ability of health care workers to provide the necessary advice and support. Poor adherence creates further health problems and will greatly undermine the ability of PLHA to contribute to HIV policy and programs.

The process of preparing the National Strategic Plan also provides a demonstration of the need to enhance PLHA capacity and contribution. The consultants understand that the PLHA contributions to the NSP steering and working committees were of variable quality, based not only on individuals' skills levels, but also the degree to which their contributions were appreciated and facilitated by other committee members. The resulting is a National Strategic Plan that includes few references to PLHA participation.

Many decision-making fora require levels of education, knowledge and/or communication skills that exclude many PLHA from actively participating in these activities. Capacity to understand health systems and policy processes, or the ability to read background papers and reports in English, are required skills for many of these forums.

Having said this, many forums are unnecessarily complex and do not really try to accommodate people with varying levels of education. Efforts should be made to make these more accessible. Even so, there will still be situations where a particular level of educational background will be legitimately required.

Limited willingness to seek 'higher level' inputs

Many services seek 'lower level' inputs from PLHA. Feedback is sought on draft resources, appearances are requested for awareness activities, views are sought in meetings and faces are sought for poster campaigns. But PLHA are rarely asked about the quality of services offered. Nor are they engaged in the design, implementation or evaluation of programs – these 'higher level' (or more meaningful) inputs are less frequently sought.

Barriers preventing access to training

Many PLHA employed by agencies have not received training during their employment. However, all of the PLHA interviewed had undertaken some informal training that had facilitated their engagement in HIV work. Many had very positive reports of these training experiences and were keen for further training opportunities.

There are, however, many barriers to proper training for PLHA. Where PLHA could be assisted to participate more effectively in HIV responses with appropriate training, they were often thwarted by the absence or poor quality of such training.

PLHA reported that they had not been able to access training in a range of areas that they thought relevant to their capacity to contribute to HIV responses. These areas include:

- Self-care
- Treatments
- Literacy
- Peer support
- Positive prevention
- Communication
- Relationships/conflict management.

PLHA interviewed also reported that some training had been too rushed, some had been undermined by a lack of refresher courses and some had failed to cover key topics, such as prevention of mother-to-child transmission (PMTCT). Again, it seemed that few had been consulted about the sort of training they wanted – instead, they were invited to attend training with pre-determined curricula.

It also seems to be the case that, where there is relevant training, many training providers don't seek out PLHA to participate in these courses. Courses in home-based care and counselling (including counselling attached to testing), for example, are extremely appropriate for PLHA – in fact, PLHA have a unique capacity to undertake these roles with appropriate training and support. Yet there are limited efforts to engage PLHA in these training initiatives.

'Charity models' of working with PLHA

Many services seem to perceive PLHA solely as recipients of services and as otherwise incapable of being a part of the broader response. Many of these services provide quality services and treat PLHA with an admirable degree of charity and compassion, but opportunities are lost for more meaningful interaction.

One of the key disadvantages of this charitable model is that it may encourage PLHA to develop a welfare mentality. PLHA with such a

mentality only view agencies as sources of handouts, rather than as means of engaging with the HIV response. For some PLHA, this may be the appropriate and preferred mode of interaction between service provider and individual, but many PLHA are seeking more dynamic relationships.

Job insecurity and irregular employment

Few PLHA hold permanent full-time positions in HIV/AIDS work. Some have part-time work on short term contracts; others are engaged on an ad hoc basis.

Of course, employment security is a national problem in PNG, but in relation to GIPA the lack of job security for PLHA reduces their ability to meaningfully contribute to their workplaces.

Poor remuneration

There are lots of ways that PLHA are rewarded for their contributions to services. These include heightened self-confidence and self-esteem as a result of meaningfully contributing to an important cause. There appears, however, to be a tendency to expect PLHA to be satisfied with this kind of no-cost reward.

Agencies should at least consider a broader range of remuneration options. These may include cash payments, reimbursement for the costs of participation, food or other types of material support, access to training opportunities or access to counselling and other forms of support.

This is not to say that all PLHA contributions need to be compensated. However, organisations should consider the:

- Extent of the contribution
- Degree to which it enhances the program
- Individual's need for food and other basic life requirements
- Value of ensuring PLHA feel appreciated
- Various ways of rewarding people that might not cost money e.g. access to training programs that are already funded.

Lack of organisational support

A commitment to engaging PLHA is an important first step, but this needs to be supported by an organisational environment that facilitates this engagement. Some PLHA interviewed reported that they had been discouraged from being involved in HIV organisations because of discriminatory or unwelcoming staff attitudes, (associated) poor staff training about HIV, and a lack of understanding of the rights of PLHA (including those outlined in the PNG HIV/AIDS Management and

Prevention Act). It was suggested that the absence of workplace HIV policies facilitated these unwelcoming attitudes.

Poor role models

Some people with HIV who have pursued public roles and sought to represent PLHA have been poor role models. This will be the case in any population group, of course, but has discouraged some agencies from seeking to work more closely with PLHA and, presumably, discouraged some PLHA from 'coming out' as positive.

Burnout

There are too few PLHA able or willing to participate at required levels. Where participation in a required forum involves such high-level capacities as ability to understand the science of HIV, research data, health delivery systems or policy processes, there are very few PLHA available to take on these roles. Key PLHA are overstretched and prime candidates for burnout.

The core group of PLHA who are training experts is also small. Demands are made upon this group by an ever-increasing number of agencies and the effect of this burden is keenly felt by those within the group.

Disorganised agencies

Some agencies, while keen to involve PLHA, were let down by systems failures. For example, some engaged PLHA to travel to other parts of PNG as part of training or awareness raising teams, but did not make per diems available until after the tour was over. For some PLHA who do not have regular sources of income, this made the trip almost impossible.

Some PLHA noted that they were not kept informed of changes to rosters or timetables, but were expected to be continually available. This affected the degree to which they felt valued for their efforts.

Nepotism and favouritism

Roles within the HIV response – as committee members, speakers, trainers etc. – require effort but also offer rewards. Many of these roles are sought after by many PLHA. Interviewees noted that selection of people to fill these roles was not always done through a clear process. There were reports of agencies just choosing their favourite people. Igat Hope's selection processes were similarly criticised as not always being based on merit.

Poor dissemination of learnings

It seems that a small number of high profile PLHA get the lion's share of opportunities to travel to international conferences or meetings and are consequently exposed to new ideas and networks. Some interviewees complained that information, learnings and knowledge gained through these international experiences are not passed on to the wider PLHA membership.

Unreasonable demands on PLHA employees

PLHA staff of some agencies are frequently invited to be involved in other organisations' work. While most employers are flexible and happy to support the work of other bodies – and see it as a contribution to the greater HIV response – external agency demands can become quite onerous. Where this impacts negatively on the employee's capacity to undertake his/her paid work, there is a risk that support for employing PLHA may be jeopardised.

Past instances of poor financial management by Igat Hope

Igat Hope has not always appropriately managed funds provided to the organisation. This has resulted in reluctance on the part of some agencies to fund Igat Hope and, more generally, caused people to question the capacity of PLHA to manage their own activities. While the organisation has taken appropriate steps to improve financial management, including the employment of a coordinator and the adoption of a new financial management policy, memories of past mismanagement take some time to fade.

Unhelpful competition for PLHA amongst agencies

There is significant donor money available for agencies conducting HIV work. There is also particular willingness on the part of some donors to fund projects that target PLHA. This can lead to competitiveness amongst NGOs for PLHA: people with HIV can come to be seen as a source of funding. On first glance this might seem desirable and likely to lead to improved services. In fact it can act as a barrier to appropriate referral and lead to an occasional unwillingness on the part of an NGO to 'release' its PLHA to other NGOs. Of course, PLHA are not really captive, yet there are some reported instances of PLHA fearing they will be refused services by one agency if they are seen to be supporting other 'competitor' agencies.

Conflicts of interest for PLHA

Some employed PLHA reported that they were occasionally placed in a conflict of interest position where they were asked to advocate for PLHA in

circumstances where this might require them to be critical of their employer.

WHAT WORKS

While the reviewers recognised many barriers to implementation of GIPA, there were also some good examples of what facilitates GIPA in PNG.

Use of appropriate selection criteria

While all PLHA require education in self-care and positive living, not all PLHA have the appropriate attributes to be more meaningfully involved in HIV activities.

Having appropriate criteria for the selection of people to participate in HIV training and other programs was hailed as a key to success. Appropriate criteria should be developed by the agency conducting the initiative and may include factors relating to:

- Literacy
- Familiarity with relevant areas (e.g. health care, service delivery systems, policy development, government structures etc.)
- Understanding of issues relevant to people with HIV
- Capacity to work with PLHA
- Demonstrated capacity to act as a good role model.

Importantly, criteria need to be assessed to ensure they are genuine and appropriate for PNG. The success of the EPT program has been partly due to the adaptation of criteria for PNG context – literacy requirements were removed because, on closer analysis, it was recognised that participants could learn and implement their roles without the need for literacy.

It is also the case that sometimes it will be appropriate for opportunities to be restricted to PLHA: the EPT program reasonably selects only PLHA.

The need for appropriate selection criteria is also apparent in relation to the selection of PLHA representatives for high-level policy making processes. For example, recommended criteria for the PLHA representative on the CCM include organisational affiliation, personal qualities, ability to meet the time requirements, education, experience and technical skills.¹⁶

Opportunities to contribute at various levels

¹⁶ GNP+ (2005) *Challenging, changing and mobilizing: A guide to PLHIV involvement in Country Coordinating Mechanisms* pages 38-39
<http://www.gnpplus.net/cms-downloads/files/handbook-EN.pdf>

People with HIV need to be able to participate in HIV responses at the level at which they feel comfortable. It is good to have a choice when it comes to ways and levels of participating – some will feel most able to contribute through self-care or through living positively, while others may choose advocacy or service delivery roles. Systems that accommodate multiple avenues of contribution work better than those that do not.

The FHI self-care initiative, which recognises the expertise which comes from lived experience of managing HIV, was favourably noted.

Some PLHA would also like to work in non-HIV areas in ways that use their existing interests, skills and experience.

Building self-worth

Both PLHA and agencies noted how undertaking training and education really boosted the confidence and self-esteem of those PLHA involved. It especially stimulated them to assist and educate other PLHA. This effect was magnified when PLHA were engaged as trainers themselves.

The families of PLHA also indicated pride in the efforts of involved individuals. More broadly, community perceptions began to change from negative perspectives of PLHA to an understanding of their role as useful contributors to society and worthy of respect.

PLHA feeling appreciated

People with HIV who contribute to the HIV response do so for many reasons – from self-interest to altruism and for every reason in between. But for many, continued contribution will be made easier where they feel appreciated and recognised for their efforts. Remuneration, material reward, access to training and other opportunities, support, certificates of achievement and involvement in decision-making are all different ways of encouraging ongoing participation.

Access to ART and peer support

Participation by PLHA is facilitated by good physical and emotional well-being. Access to ART, increased treatments literacy, peer support with treatments and health maintenance, and family and social support are all ways to facilitate improved health.

PLHA interviewed strongly linked access to free ART with their capacity to participate in HIV work.

Support of PLHA organisations

Individuals are greatly assisted to cope with HIV through access to peer support from other positive people. PLHA organisations also support them to participate more meaningfully in HIV responses. PLHA interviewed spoke of the importance of Igat Hope and other positive groups (such as informal gatherings at drop-in centres) to their work.

Efforts to foster this group support will enhance individual engagement.

PLHA groups need to be supported wherever they exist. Igat Hope is an important organisation, but it is not the only positive group in PNG and all are deserving of attention and assistance.

Establishing conducive environments

Ensuring the organisation is a welcoming environment - through training of all staff and the development of relevant workplace policies - encourages engagement of PLHA. A number of agencies have taken these steps and PLHA noted the importance of these measures to their ability to participate in NGO activities.

Partnerships between NGOs

Engaging PLHA in PNG is not without challenges and it makes sense for NGOs to work together to overcome some of the greatest barriers. Some agencies have collaborated to ensure there are no scheduling clashes between various training programs; others have worked together to ensure that PLHA trained in one program can be engaged in another. These efforts have had positive outcomes for the agencies, individual PLHA and overall PLHA engagement.

A number of agencies also noted the benefits of working with Igat Hope.

Employment of PLHA as counsellors

There was strong support for the involvement of people with HIV as counsellors, and the employment of four HIV-positive counsellors within StopAIDS was seen as a good example of GIPA. This example was seen to have benefits for the individuals employed, service users, the agency and the broader HIV response.

PLHA as providers of home-based care

Many PLHA are already providers of home-based care, whether trained or untrained. In circumstances where PLHA are rejected by their own families, PLHA have become the sole providers of home-based care to their friends. The reviewers heard multiple stories of Igat Hope members providing care to other members, often in circumstances where the

families of sick PLHA had abrogated their responsibilities. This was seen as an appropriate back-up mechanism in a country with enduring high levels of stigma and discrimination.

Flexibility with HIV-positive employees

Agencies accept that the health of a PLHA may vary even when taking ART, and PLHA may be absent because of illness or the need to go for regular clinic visits.

Several agencies also demonstrated a willingness to release their HIV-positive employees to work for other HIV initiatives – for example, to travel somewhere else to participate in another agency’s training program or to attend another service as a public speaker. The employer is not usually compensated for what must occasionally be an inconvenience. On at least one occasion, this was described as a part of the employer’s commitment to promoting the engagement of positive people in the HIV response.

This approach seems to work well – it allows PLHA to develop expertise through more varied work activities and it facilitates positive contributions within more fora.

WAYS FORWARD/RECOMMENDATIONS

Training

There is a need for training initiatives that are accessible for PLHA. Ideally, these will be training activities which are:

- Appropriately located (e.g. at drop-in centres, day-care centres and PLHA centres)
- Of appropriate quality and accredited
- Competency based and that offer certification of successful completion
- Inclusive of quality control components
- Accessible through some transparent selection process.

Some of these initiatives will need to be new as there are not sufficient training opportunities overall. But in some cases what is required is that current training exercises do a better job of involving PLHA. This is particularly the case for courses in home-based care and counselling where PLHA are uniquely positioned to provide these services with appropriate training.

There will be a need for some of this training to occur outside of Port Moresby to foster the capacity of PLHA wherever they are across PNG.

The overall package of available training needs to include:

- Training that enhances the ability of PLHA to manage their virus and their lives (e.g. self-care training, conflict management, training in ART literacy)
- Training that increases the capacity of PLHA to contribute to broader HIV initiatives (e.g. public speaking, counselling training).

GIPA will be especially facilitated where there are opportunities for PLHA to be trained as trainers. Some PLHA interviewed are already acting in this way and others expressed interest in developing these skills.

Support of GIPA

There is a general need for greater effort in taking GIPA from a principle to a practice. In HIV organisations and services, where PLHA are already employed or volunteers, there is still a need for greater involvement in more aspects of the agency work – such as consultation at earlier stages of program planning, and involvement in implementation, program evaluation and advocacy. Non-HIV organisations need to work harder to provide an enabling environment and to develop workplace policies and practices that protect and support HIV-positive staff and that might encourage other PLHA to become employees.

There are some strategies that may assist:

- PACSO might foster efforts in this area, or at least facilitate links between agencies where GIPA is working and those that have yet to try it
- Oxfam and its partners might actively support positive groups wherever they are operating
- Oxfam might add HIV advocacy to its core advocacy work in PNG; in part this will involve working with and supporting Igat Hope
- Oxfam might work with other training providers to ensure the provision of relevant training for PLHA.

Gender issues

Implementation of GIPA is so piecemeal, and generally poor, that it was not possible for the consultants to determine within the scope of this project whether there is a gender bias in the way GIPA is being implemented. Gender was not generally raised as an issue by those interviewed.

However, most INGOs – and many PNG NGOs - are highly conscious of gender issues. For example, FHI advised that it ensured that equal numbers of women and men were trained in self-care. And partly in recognition that illiteracy affects women more than men, WHO adapted its selection criteria and training methods for the Expert-Patient Trainer

program so that illiteracy did not of itself exclude people from participating. Some NGOs, such as FHI and Save The Children are also specifically focusing on marginalised subgroups such as sex workers and MSM.

Some women PLHA are better skilled because they have been exposed to new ideas at international conferences or have undertaken specific training for positive women at overseas workshops. For example, OAus funded three PNG HIV-positive women (who are now prominent activists) to attend APN+'s first Leadership Workshop for HIV-positive women in the Asia-Pacific region in 2004.

Certainly, women have over the years featured prominently amongst Igat Hope office bearers, as employees in HIV-specific roles (within the UNDP project and StopAIDS), and amongst the trainees selected for FHI and WHO programs. Many of PNG's best known PLHA activists are women, although it is also noted that three of the four Igat Hope office bearer positions, and most Igat Hope committee positions overall, are currently filled by men.

The status of women generally in PNG is so low that it is safe to assume women will be disadvantaged also in the implementation of GIPA. Oxfam's commitment to redressing gender inequality is consistent with a call for implementation of GIPA in ways that focus on the special needs of PLHA who are women. Igat Hope's women's network might be a useful source of information on how women are experiencing GIPA and on the women's issues that Oxfam might like to address in any advocacy program.

More practically, Oxfam will need to be mindful of gender in filling training positions, although it is assumed that this is standard Oxfam practice.

Promoting the NGO HIV/AIDS Code of Good Practice

Again, it should be noted that the Code is relatively new so it will take more time for it to become widely regarded as best practice. Even so, there is already progress in PNG against the Code's objectives – and not only by signatories. FHI reported its work in ways that reflect some of the best practice aspects of the Code, even though FHI is not a signatory. The Code's signatories include global bodies or federations (such as Oxfam International, the IFRC and the World Council of Churches), but there is wide variability in awareness and implementation of the Code by the individual members or national-level organisations within these international umbrella agencies.

Oxfam PNG has a particular role to promote awareness and implementation of the Code amongst CSOs (for example, PACSO) and

other INGOs active in PNG. However, Oxfam International should also seek to progress the awareness and implementation of the Code by its own members and their partner organisations.

Monitoring and evaluation of GIPA

GIPA is relatively new; implementation of GIPA is even newer and evaluation of GIPA is definitely a developing science. There are some references included in this report that detail different measurements of engagement and these might be useful sources when thinking about evaluation¹⁷. A key challenge is to go beyond measuring the numbers of PLHA who attend something, towards measuring the *sort* of engagement that PLHA have.

Some basic measures of GIPA might be:

- Number of PLHA attending workshops or training sessions
- Number of times Oxfam speaks out on HIV issues
- Opportunities for PLHA to influence Oxfam agenda (involvement in planning sessions or as members of working groups)
- Participation of PLHA in Oxfam strategic planning, program and policy development (attendance at meetings, feedback on drafts, shaping positions etc.)
- Involvement of PLHA as trainers, counsellors, employees, advocates, policy makers, researchers, managers
- Support provided to groups of PLHA to facilitate capacity of individual PLHA to contribute to HIV responses
- Training of staff and others in PLHA issues and/or GIPA
- Financial resources for training, contracting or employment of PLHA, or for any other form of remunerating PLHA.

Another way to review implementation of GIPA would be by Oxfam and other NGOs auditing their practices of involving PLHA with reference to the Code of Good Practice.

¹⁷ Horizons (2002) *Greater Involvement of PLHA in NGO service delivery: Findings from a four-country study Research summary*
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ANNEXES

1. **References**
2. **Key Contact List**
3. **Igat Hope forum 18th November, 2006**

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Annex 2: Key Contact List

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Annex 3: Igat Hope Forum

18th November, 2006, Igat Hope Office, Boroko.

Facilitators: Tim Leach, Maura Elaripe, Suzanne Lau Gooley

Igat Hope Members present: 6 men, 3 women

Observers: Julie Kumabore and Helen Havora (Oxfam)

Program

A. Opening prayer (Maura)

B. Purpose of Forum and Oxfam's research on GIPA (Tim)

C. Introductions

D. Rules

E. What is GIPA? (Maura)

"Nothing about us, without us"

"Speak with us, not for us"

F. Levels of GIPA (Suzanne, Maura to translate)

- Decision makers
- Experts
- Implementers
- Speakers
- Contributors
- Target audiences

G. Brainstorming exercise (see below)

1. What have you been doing and how often/regularly?
2. What were the benefits/rewards to you?
3. What were the barriers/challenges?
4. What would make it better for you?

(Also later optional – what other jobs, education have you done)

H. Close/ Lunch

What have you been doing and how often/regularly?

- StopAIDS full-time counsellors (2 participants) – train and counsel other PLHA, public speaking and general awareness training for clinics and businesses – testimonials and education
- Alternate APN+ representative (new); NAC member (new)
- FHI volunteers (6 participants) – 3 months of Positive Living training (self-care training of peers) 2hrs x 2days per week = 4hrs per week.

- World Vision Volunteers (2 participants) – (3 month contract) 2 days a week, paid 100K/fortnight if have done certain activities e.g. bring clients for VCT. Also continue to do unpaid work as volunteers
- Positive speaker (1 participant) – called to speak by different NGOs, average 3 days per week
- WHO expert patient trainers (5 participants) 1 weeks paid work training doctors and nurses, but irregular depending on how ART rollout scheduled (about every 2 months for government health staff)

What were the benefits/rewards to you?

- Paid work
 - WV – 100K/ 2 weeks
 - FHI – 250K/month
 - WHO Expert Patient Trainers – paid a per diem when training and extra when travelling
- Drugs now free from WHO (available to everyone, not just EPT)
- Travelling
- A blessing
- Meeting other positive people and sharing experiences and learnings
- Formal training
 - UNDP – no training
 - STOPAIDS –did a communication workshop, but no public speaking training
 - FHI provided Training of Trainers training
 - WV – 3 months of Positive Living Training , 2 days a week
 - WHO EPT training – included HIV knowledge, ART, OIs, and communication and assessment (the 5As) to prepare for training health staff. However, no certificate was issued – would like recognition for training attended/completed,
- Learning by observing others/role models
- Confidence and self-esteem

What were the barriers/challenges?

- More training is needed for HBC, communication skills, car and counselling skills, PMTCT
- Training not provided – e.g. UNDP provided no training to the 4 positive staff ; FHI provided their volunteers training in self-care , but not in PMTCT (because PMTCT manual as not been translated?) so volunteers had to use their own experience to advise/train in PMTCT
- Insufficient training – FHI only 1 weeks training and then volunteers had to immediately start training others
- Training too rushed
- No refresher training provided
- Risk to personal safety and security (PLWHA in real danger in Highlands) – but felt made a big breakthrough

- Feeling exploited
- Disorganized organizations
 - No rosters or plans
 - Poor communications – not inform pos people of delays ; positive people have to do the chasing up
 - Poor organizational arrangements – e.g. failed to organize meals at right time – PLWHA need adequate food; some need to take their ART with meals
 - Delays in paying per diem (so cant buy food when need to) – sometimes paid AFTER a trip has been completed
 - Volunteers bring clients for VCT, but staff are not there when they are supposed to be
- Organizations fail to recognize stress, travel – need for rest and meals
- Nepotism and favouritism

What would make it better for you?

- Want to be VCT counsellors – need training
- Involve PLWHA more in VCT training
- Separate training for men and women on PMTCT, sexual issues, gender issues e.g. gender violence
- Other training wanted includes
 - Treatments training – ART, OIs, antibiotics (and also how fits with traditional health practices)
 - HBC so that PLWHA can do HBC
 - PMTCT
 - Nutrition
 - BCC – behaviour change communication
 - HAMP act and human rights, legislation
 - Gender issues?
 - Communication skills – e.g. public speaking , media skills
- NAC increase involvement of PLWHA
- Create employment of PLWHA in advocacy and awareness
- National funding for Igat Hope to run activities
- NGO need to make a more conducive environment (knowledge and attitudes of staff, confidentiality breaches) so need train their staff how to treat people living with HIV/AIDS
- Opportunities for PLWHA outside POM.
- Involve PLWHA at all stages of project cycle (not just as beneficiaries or implementers)
- Financial recognition – pay allowances in advance
- Opportunities of PLWHA to do other things, not only HIV/AIDS work
- Support for children of PLWHA – for education

What other jobs/education have you done?

- Nurse and dispensary assistant
- Soldier, intelligence operator specialising in data collection

- Caterer, chef, administration, finance
- Hotelier, administration, OHS (occupational health and safety)
- Shop assistant and rugby player
- Delivery clerk
- Hotelier, cashier
- Hotel waitress