The Greater Involvement of People Living with and Affected by HIV and AIDS (GIPA)

NGO Experiences and Implications for the Work of Oxfam International and Oxfam Australia

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1. Acronyms

ACFID	Australian Council for International Development
AHAPI	AusAID HIV/AIDS Partnerships Initiative
AIDS	Acquired Immunodeficiency Syndrome
ANARELA+	African Network of Religious Leaders living with or Affected by HIV and AIDS.
APN+	Asia-Pacific Network of People Living with HIV/AIDS
APPRC	Asia-Pacific PLWHA Resource Centre
ARV	Antiretroviral
ART	Antiretroviral Therapy
ASO	AIDS Service Organisation
AusAID	Australian Agency for International Development
CBO	Community-Based Organisation
CCM	Country Coordinating Mechanism
CHEP	Copperbelt Health Education Project, Zambia
CPN+	Cambodia National Network of People Living with HIV
FBO	Faith-Based Organisation
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
GFW	GIPA Field Worker
GIPA	Greater Involvement of People living with or affected by HIV/AIDS
GNP+	Global Network of People Living with HIV/AIDS
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
IAC	International AIDS Conference
ICW	International Community of Women Living with HIV/AIDS
IDU	Injecting Drug Users
IEC	Information, Education and Communication
IFRC	International Federation of Red Cross and Red Crescent Societies
ILO	International Labour Organisation
INGO	International Non-Governmental Organisation
INP+	Indian Network for PLWHA
ITPC	International Treatment Preparedness Coalition
JOHAP	Joint Oxfam HIV/AIDS Program in South Africa
MSM	Men who have Sex with Men
NACCHO	National Aboriginal Community Controlled Health Organisation
NAP+	Network of African People Living with HIV/AIDS
NAPWA	National Association of People Living with HIV/AIDS, Australia
NGO	Non-governmental Organisation
NUNV	National United Nations Volunteer
OAus	Oxfam Australia
OGB	Oxfam Great Britain
OHS	Occupational Health and Safety
PATSIN	Positive Aboriginal and Torres Strait Islander Network, Australia
PEP	Post-Exposure Prophylaxis

PIAF	Pacific Island AIDS Foundation
PLHA	People Living with HIV/AIDS
PLHIV	People Living with or Affected by HIV
PMTCT	Prevention of Mother-to-Child Transmission
PWN+	Positive Women's Network, Chennai, India
RC	Red Cross or Red Crescent Society
STI	Sexually Transmitted Infection
SW	Sex Worker
TAC	Treatment Action Campaign, South Africa
TB	Tuberculosis
UNAIDS	Joint United Nations Action Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNGASS	United Nations General Assembly Special Session on HIV/AIDS
UNV	United Nations Volunteer Programme
VACCHO	Victorian Aboriginal Community Controlled Health Organisation
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation

2. Executive Summary:

> *"The Greater Involvement of People living with HIV/AIDS (GIPA) can reinforce an organisation or activity by exposing it to the unique perspectives that PLWHA's direct experience can bring"*
>
> *"GIPA should stand for the Genuine Involvement of people living with or affected by HIV and AIDS"* (INGO respondent)

An underlying principle that is widely supported as being crucial to an effective response to HIV and AIDS is the principle of the greater involvement of people living with and affected by HIV and AIDS (GIPA). GIPA means acknowledging and enabling the meaningful contribution of people living with HIV and AIDS (PLWHA) to addressing the HIV and AIDS epidemic.[1]

PLWHA have the greatest experience of dealing with HIV and AIDS and must be active participants in Oxfam's response to the epidemic. While the organisation has policies in place that address this, organisational commitment must extend to implementing policies to ensure that PLWHA are actively involved, that their leadership and advocacy capacity is built, and that enabling environments are created where they feel able to openly participate.

People living with HIV (PLHIV) and PLHIV organisations can be meaningfully involved in many levels of the response to HIV and AIDS, if given the skills, resources and opportunities to do so. PLWHA may be afraid to reveal their HIV status or seek treatment due to fear of stigma and discrimination from their families, friends, workplaces, communities, and health professionals. Stigma and discrimination can lead to rejection, abandonment, and homelessness, dismissal from work, and even physical violence or murder. Stigma and discrimination due to HIV status may add to any existing social stigma already faced by marginalised groups who are the most vulnerable to HIV, such as sex workers, injecting drug users and men who have sex with men.

Findings from the research and case studies explored in this report include:
- Openly positive people do have the greatest impact in stigma reduction. However, open disclosure is rare in many resource-poor settings, resulting in the few openly public PLHIV carrying a large burden of responsibility, with risk of burnout. There is also the expectation that PLHIV should only work in the area of HIV and AIDS.

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[1] *Oxfam and the Greater Involvement of People Living with and Affected by HIV and AIDS.* Oxfam Australia document. Contact Advocacy Unit for more information.

- PLHIV are more likely to be involved at a higher or more meaningful level in PLHIV organisations or rights-based organisations. PLHIV organisations can provide a more sustainable and comprehensive response than individual PLHIV, but require organisational capacity building in order to do so. In development and health service NGOs, the lack of technical skills, and the non-supportive attitudes of NGO staff restrict PLHIV involvement.

- PLHIV involvement is both therapeutic for PLHIV as well as enhancing the effectiveness and the relevance of the NGO's work. More PLHIV need the skills and resources to take on greater roles. PLHIV working within NGOs need links with PLHIV organisations - for peer support, personal development and for sharing of collective expertise. Some PLHIV have initiated positive staff groups or positive involvement groups within NGOs.

- The personal attitudes and commitment of middle and senior management to GIPA are crucial. GIPA needs to be institutionalised in organisational policies and processes - not just dependent on an individual's goodwill and conscience. Applying GIPA within an organisation needs sustained development and effort, due to staff turnover and burnout. This resp0onsibility should be spread throughout the organisation.

- There are examples of successful partnerships and coalitions between PLHIV organisations and NGOs to mutual benefit. Since no single organisation can provide a complete response to the whole spectrum of needs and impacts of HIV and AIDS, NGOs need to develop effective collaborations with PLHIV organisations. This would then free up the expertise and resources of the NGO to focus on their core business, and provide mutual benefit to both the NGO and the PLHIV organisation. NGOs need to assess their current partnerships and ways of working with PLHIV organisations.[2]   True collaborations may require major shifts in influence and resources from the NGO to the PLHIV organisation.

There are differing levels of awareness of the GIPA principle in the development sector, and confusion about its meaning and implementation. Case studies show that GIPA is mostly interpreted in a narrow manner, which reduces the motivation and opportunities for PLHIV to be involved.

NGOs need to work with PLHIV to promote a shared understanding of GIPA, which in inclusive of:

- Different levels of disclosure and activism. GIPA is not equivalent to open disclosure or visibility. Disclosure is a complex and individual issue. It is an

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[2] VicHealth (2003) *The partnerships analysis tool for partners in health promotion: a resource for establishing, developing and maintaining productive partnerships.* http://www.vichealth.vic.gov.au/assets/contentFiles/VHP%20part.%20tool_low%20res.pdf

individual choice to decide the extent of ones visibility or involvement. However, it is recognised that the visibility and active involvement of openly positive people does have the greatest impact on the reduction of stigma and discrimination and the creation of an HIV-friendly environment.

- Both HIV-infected and non-positive people, including those personally affected by HIV (such as partners and family), the peers of PLHIV, and other committed allies need opportunities to be involved.
- PLHIV are diverse. In particular, they can include marginalised groups such as women, injecting drug users (IDU) and sex workers (SW).
- There needs to be a diversity of roles for PLHIV. PLHIV can participate and provide positive role models in a variety of positions, and should not be restricted to working solely on HIV and AIDS.

NGOs have been more responsive to the impact of HIV and AIDS through their external work, but slower to deal with the effects on their own staff and volunteers. While NGOs want to recruit or more actively involve PLHIV, a more urgent priority is to support and retain existing staff who are infected or affected by HIV and AIDS.

NGOs can facilitate capacity building of individual PLHIV and PLHIV organisations and provide opportunities for PLHIV involvement in both NGOs' internal and external work. NGOs need organisational and cultural change to make a safe and supportive environment for PLHIV and create opportunities for PLHIV involvement. To achieve this, organisations need to:

- Recognise the value of employing openly HIV-positive people.
- Provide a confidential and non-discriminatory environment.
- Provide PLHIV with opportunities in different roles and with clear job descriptions.
- Institutionalise GIPA in the culture, policies and practices of the organisation, so that implementing the principles is not dependent on individual staff members' goodwill. Commitment needs to be demonstrated at all levels of the organisation, especially from senior and middle management.
- Ensure provision of adequate resources for: training NGO managers, staff, and volunteers; employing PLHIV (including wages and the provision of medical and/or other benefits); training and supporting PLHIV staff and volunteers; psychosocial support for both NGO and PLHIV staff/volunteers; assessing capacity and reviewing progress of GIPA implementation against the NGO Code of Good Practice[3] and/or other relevant instruments.
- Ensure internal mainstreaming - that workplace policies and programs support and specify levels of PLHIV involvement or contain details of required consultation, practices and processes.
- Ensure external mainstreaming – in programming (at all stages of the project cycle), advocacy, research, publications, media and networking.

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[3] *The Code of Good Practice for NGOs Responding to HIV/AIDS*.
http://www.ifrc.org/cgi/pdf_pubs.pl?health/hivaids/NGOCode.pdf

A healthy and supportive workplace can be further enhanced through wellness policies which: respond to the whole spectrum of HIV/AIDS; encourage early diagnosis and positive living (for HIV and other health conditions); include medical benefits for other illnesses; provide training and information for staff on a wide range of health issues; and emphasise physical and mental wellbeing, including preventative health measures. Wellness policies can be applied in high prevalence and low prevalence settings.

The ultimate demonstration of GIPA is employing openly HIV-positive people as role models, preferably in managerial or leadership positions. Openly HIV-positive people can help create a safe and supportive working environment for other people infected or affected by HIV/AIDS. If it is not possible to employ openly positive people, then NGOs can create links and work together in regular and long-term partnerships with PLHIV organisations to the mutual benefit of both. In the long term, it may be more efficient and effective if some HIV-related activities are referred to, or outsourced to PLHIV organisations with appropriate capacity and resources.

PLHIV organisations have their own roles to play as social movements within civil society. The GIPA model can provide a framework to involve other marginalised groups, such as injecting drugs users, sex workers and MSM. NGOs can further facilitate the opportunities for PLHIV to contribute their voices, experience and expertise at all levels of the HIV/AIDS response. They can give PLHIV, and those affected by HIV and their organisations, the skills, resources and the opportunities for them to participate as equal partners in a sustained and comprehensive response to the HIV pandemic.

3. Methodology

The purpose of this research was:
- To collect information on global initiatives on GIPA.
- To assess how other organisations and groups have collaborated with or meaningfully involved PLHIV.
- To analyse and make recommendations to inform Oxfam Australia and Oxfam International's approach to, and implementation of, GIPA in their programs, advocacy, humanitarian and communications work, as well as in administration and management practices.

This involved a desk-based research undertaken through literature reviews, telephone interviews and/or email communication with key individuals. These individuals include HIV-positive and non-positive people who work or have worked in NGOs and other agencies, as well as experienced practitioners, who have long been involved in the response to HIV/AIDS at many levels.

The scope of the research was limited by its short duration. It was also hindered by the unavailability of people who attended the follow-up meeting in New York on UNGASS -

the Implementation of the Declaration of Commitment on HIV/AIDS in June 2006.

Further follow-up is required because the short-time frame of this study excluded contact with ActionAid, and limited contact with the International HIV/AIDS Alliance - NGOs that both have affirmative action policies and specifically employ PLHIV. It would have been particularly useful to follow up HIV-positive staff at ActionAid in Africa, but OI can further explore this option in situ.

4. Background to GIPA

The idea that the personal experiences of people living with HIV could and should be translated into helping to shape a response to the AIDS epidemic was first voiced in 1983 at a national AIDS conference in the USA. It was formally adopted as a principle at the Paris AIDS Summit in 1994, where 42 countries declared the Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA) to be critical to the ethical and effective national responses to the epidemic.[4]

Today the GIPA principle is the backbone of many interventions worldwide. People living with, or affected by, the virus are involved in a wide variety of activities at all levels of the fight against AIDS; from appearing on posters, bearing personal testimony, and supporting and counselling others with HIV; to participating in major decision and policy-making activities. People living with HIV understand each other's situation better than anyone and are often best placed to counsel and advise one another and to represent their needs in decision and policy-making forums.[5]

At its most basic, GIPA means creating a space for individuals to:

- Use their experience of living with or affected by HIV/AIDS in the greater response to the epidemic, and
- Give a human face and voice to the epidemic in the minds of people not directly touched by HIV/AIDS.

Not all PLHIV have the same opportunity to participate meaningfully in the HIV/AIDS response. Women, MSM, SW, IDU, migrant workers, and Indigenous peoples are both disadvantaged in the wider community and within the PLHIV community.

Women with HIV/AIDS bear the greatest burden from HIV - as mothers and caregivers to the sick, the old and the young, while sacrificing their own health needs. Women living with HIV/AIDS face greater stigma and discrimination than men, especially in the health sector.[6] They have little time or energy, and the many cultural and economic

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[4] 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
[5] http://www.unaids.org/en/Issues/Affected_communities/gipa.asp
[6] APN+ (2004) *AIDS Discrimination in Asia* http://www.apnplus.org/doc/AIDS-asia.pdf

factors that made them vulnerable to HIV and magnify its impact upon them also severely restrict their participation in leadership roles. In Sub-Saharan Africa and increasingly in Asia, women form the majority of support group members, although men dominate the leadership roles within PLHIV networks.[7]

Progress has been slow to make the GIPA principle a reality. Instead of being taken up by those responsible for national responses, GIPA has been most strongly promoted by individuals living with or affected by HIV/AIDS, often by "going public" about their serostatus in order to give a human face and voice to the epidemic.

GIPA itself, the meaningful involvement of PLHIV, is now more sustainable because HIV-related illness and deaths are starting to be reduced by the slow (and not nearly comprehensive enough) rollout of antiretroviral therapy in resource-poor countries.

Since 2000, the role of PLHIV has been increasingly recognized, in or mobilized through:

- **Action,** such as in the forefront of movements and coalitions for HIV treatment access and literacy. Examples include the Treatment Access Campaign in South Africa (TAC), the International Treatment Preparedness Coalition (ITPC) and the Collaborative Fund for HIV Treatment Preparedness.[8]
- **Frameworks,** such as the internal and external mainstreaming of HIV and AIDS into development and humanitarian work.[9]
- **Instruments** such as the **Declaration of Commitment on HIV/AIDS: Global Crisis, Global Action**, at the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) 2001,[10] and **The Code of Good Practice for NGOs responding to HIV/AIDS (2004).[11]** This was a joint initiative developed by many NGOs, including AIDS organisations, and was hosted by the IFRC.[12] GIPA is a central principle to the Code.

Paxton and Welbourn (2004) *"Oh. This one is infected!": Women, HIV, and Human Rights in the Asia-Pacific Region*. Expert Meeting on HIV/AIDS and human rights in Asia-Pacific 23-24 March, Bangkok. http://www.icw.org/tiki-download_file.php?fileId=79

[7] Kalla, K. (2006) *Analysing Civil Society Participation in Country-level HIV/AIDS UNGASS 2006 Reviews.* CARE International http://www.care.ca/downloads/publ/HIV/care_10-5.pdf
Paxton, S. (2005) *Steps to Empowerment: Challenges to the Greater Involvement of People Living with HIV in response to AIDS in Cambodia.*
http://www.policyproject.com/pubs/countryreports/CAM_StepsToEmpower_en.pdf
Nairobi Think Tank (2005) *Revitalizing the Global Movement of People Living with HIV/AIDS* Report, Nairobi Think Tank meeting of people living with HIV 28030 November 2005.
http://www.gnpplus.net/cms-downloads/files/Nairobi_meeting_report.pdf
[8]http://www.hivcollaborativefund.org/
[9] Holden, S. (2003) *AIDS on the Agenda: Adapting development and humanitarian programmes to meet the challenge of HIV/AIDS.* Published by Oxfam GB, in association with ActionAid and Save the Children UK.
[10] http://www.unaids.org
[11]http:// www.ifrc.org/what/health/hivaids/code/
[12] 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/.

While the seminal UNAIDS (1999) document focuses more on the individual person living with or affected by HIV, the NGO Code of Good Practice spells out more clearly how GIPA should be a prominent organisational principle and how it applies to individuals and to PLHIV networks.[13]

5. Implementing GIPA

PLHIV are involved in HIV responses at different levels and in different sectors. They have a particular role to play in specific activities such as peer education, support and counselling, advocacy, public education, program planning and implementation, and public health policy and legislation.[14]

Most GIPA focus has been on the individual person living with HIV/AIDS. GIPA requires capacity building of both PLHIV and NGOs and the development of opportunities. PLHIV typically begin at the lowest level of involvement, as beneficiaries or as service users. Given the appropriate environment, skills, experience and opportunities, PLHIV can be more meaningfully involved, with wide-ranging benefits to HIV/AIDS responses at all levels.

5.1 Barriers to GIPA

There are barriers to GIPA that can prevent the involvement of individual PLHIV.[15] APN+ and the Asia-Pacific Council of AIDS Services Organisations have developed a GIPA Toolkit called "Valued Voices" which identifies the barriers to GIPA in the Asia-Pacific region as (A) social, (B) institutional and (C) personal factors.

(A) Social Barriers to GIPA

- Stigmatization and discrimination.

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[13] 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 www.ifrc.org/what/health/hivaids/code/. See also Annex 10.5

[14] APN+ (2004). *APN+ Position Paper No2: GIPA* http://www.ahrn.net/library_uploadfile/file1777.pdf

[15] APN+ and the Asia-Pacific Council of AIDS Services Organisations (2005). *"Valued Voices" GIPA Toolkit: A Manual for the Greater Involvement of People living with HIV/AIDS*, p.24. http://www.7sisters.org/resource_centre/common/apn_gipa.pdf. This section of the toolkit is based closely on the International HIV/AIDS Alliance (2002) Involvement of people Living with HIV/AIDS in the delivery of community-based, prevention, care and support services in Maharashtra, India – a diagnostic study http://synkronweb.aidsalliance.org/graphics/secretariat/publications/ipl0602_India_PLHA_study_report.pdf

- Poverty and underdevelopment: most Asian and Pacific PLHIV are poor and lack access to education. Many do not have a telephone or access to communication tools such as email.
- Gender: In some Asian-Pacific countries, women PLHIV may be less free to travel outside their homes or work with men outside their own families.
- Discrimination against marginalized groups that are most affected in the region, such as sex workers, IDU and MSM.
- Lack of solidarity amongst PLHIV themselves, reflecting the prejudices of wider society.

CARE International Study

The potential of GIPA, the Code of Good Practice for NGOs responding to HIV/AIDS, and the UNGASS Declaration of Commitment as tools for PLHIV involvement was one of the issues explored in a CARE International study of civil society involvement in the country reports it prepared for UNGASS in 2006.[16] The six countries studied were Cambodia, Kenya, Malawi, Thailand, United Kingdom and Vietnam.

Civil society respondents generally felt that they did not fully participate in the process. When governments did involve civil society, women and networks of PLHA were usually represented in the process although most of the leadership and senior/middle management of PLHIV networks was undertaken by men. Stigma continues to be a barrier to the participation of PLHIV and other vulnerable and marginalised groups, such as SW, IDU, and MSM.

The GIPA principle was the "instrument" best known and understood by most civil society respondents.[17] GIPA was interpreted as non-discrimination or the visibility of PLHIV. Several NGOs stated that GIPA meant PLHIV involvement in the design, implementation, monitoring and evaluation of interventions. However, some respondents misunderstood the GIPA principle to mean that PLHIV should work only in the field of HIV/AIDS.

The NGO Code was unknown to most organisations, because it had been established at an international level and had not yet been properly introduced at the country, local or grassroots level. One respondent noted that implementation of the Code needed a high level of capacity, and that the ability to support that level of programming was not always available or well developed in civil society organisations.

Recommendations included forming coalitions involving PLHIV and other marginalized groups as an essential component of strengthening civil society involvement at national and local levels, and that the education and use of GIPA and instruments such as the NGO Code and the Declaration of Commitment should provide a framework.

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[16] Kalla, K. (2006) *Analysing civil society participation in country-level HIV/AIDS UNGASS 2006 Reviews* CARE International http://www.care.ca/downloads/publ/HIV/care_10-5.pdf
[17] Ibid, p21.

In some countries, such as Vietnam, there were additional barriers to GIPA, because central governments closely control and limit the development of civil society and legislative frameworks and may not accommodate the formation and participation of any civil society groups, not just PLHIV.[18] These same countries usually also marginalise groups such as SW, IDU, MSM by branding their behaviour as "social evils" and through punitive legislative environments.

(B)   Institutional Barriers to GIPA

- Lack of information about ways to contribute.
- Policies that discriminate against PLHIV involvement e.g. mandatory testing for HIV during recruitment and travel restrictions on PLHIV.
- Lack of policies to encourage PLHIV involvement such as affirmative employment policies, confidentiality and disclosure policies, sick leave and health insurance policies.
- Lack of funds to support volunteer PLHIV involvement e.g. to reimburse travel expenses, pay for childcare, or cover loss of earnings while contributing.
- Patronizing attitudes of staff, boards of directors or donors - looking down on PLHIV and seeing them only as patients or victims.
- Lack of role models to positively influence and inspire more PLHIV to get involved.

Interviews conducted by the author provided further illustrations of these points. Comments about the variety of roles for PLHIV and the different expectations about what work PLHIV should do included:[19]

- "Being at UNAIDS as an out positive person is ok, but one thing that irritates me is that because you are living with HIV you are expected to take responsibility for educating and training the rest of the staff on the issues. Also, sometimes people tend to see you as a person living with HIV but do not also recognize that you are a professional - very irritating!"
- Pressure to become a focal point for all PLHA issues or programming, because of either positive status, or more experience with these issues.
- Being openly positive resulted in being burdened with any HIV issue, even when it was unrelated to their official job description.
- PLHIV employed in PLHIV positions, often related to NGOs external work (e.g. GIPA or PLHIV focal point), but felt that they had a limited impact on the NGO's internal work. Volunteers especially felt exploited, and were not given the chance to be employed in other roles as managers, project officers, directors etc.
- One positive respondent told of an HIV-positive woman working in an Asian office of an INGO. She was quiet, kind, well-liked and a very capable finance officer, who also had links with the local or national positive women's network. While she was

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[18] POLICY Project and CARE (2003). *Moving forward: Operationalising GIPA in Vietnam.* http://www.policyproject.com/pubs/countryreports/VIE_FinalGIPA.pdf Also Kalla (2006) as above.
[19] This section includes comments from both HIV-positive and non-positive contributors.

willing to link with the positive women's network, she really felt happiest and most useful being a good finance officer.

- "I know a number of highly placed staff (not HIV workers), who have been on ARVs the last 5 years plus. They are well adjusted to care and treatment, and their work input is above standard. They are not PLWA activists, not at all, they have done minimal/ selective disclosure to family and friends, and they are contributing to development from a different perspective."[20]
- One HIV-positive adviser in an advocacy and policy NGO in Vietnam said that he and three other PLHIV made up about half the staff. "We knew that they were open about their HIV status. That's why we recruited them because we wanted advocates."

Responses to organisational issues about PLHIV involvement included:

- PLHIV being limited to certain roles.
- Feeling not fully free to be an activist, because of the need to keep to the NGO's mandate.
- Dependent on the personal commitment of managers.
- Direct managers not interested in HIV/AIDS work, despite potential synergies with other crosscutting issues e.g. with gender.
- Feeling unsupported - not getting more training to improve their work capability, not getting opportunities to train-up staff.
- NGOs need to show commitment to develop the skills and capacity of PLHA once employed, rather than just showing that they have PLHA on staff.
- There are differences between NGOs having a good policy on paper, and practicing what they preach e.g. PLHIV not being consulted in program design or implementation.

A general comment on disclosure was that:

- Within UNAIDS, there are four openly positive staff in Geneva and about 51 in the field, including two UNAIDS Country Coordinators.[21] Otherwise, very few PLHIV openly disclose their HIV status, even within NGOs with positive policies and which provide safe and supportive environments.

Reasons for non-disclosure or selective disclosure included:

- Stigma, stereotypes and class differences within the PLHIV community
- Privacy and the prevailing culture about to whom and whether one discusses personal matters.
- Only on a-needs-to-know basis (for example to access medical benefits).
- Expectations of PLHIV to play a public or activist role, or do certain kinds of work. . "Most people are not keen on being high-profile activists: why should being HIV+

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[20] Dr Harriet Kivimbi, Oxfam International, Uganda.
[21] Emailed 19/6/06 by Kate Thomson, Partnership Adviser, UNAIDS, Geneva.

make any difference? There are plenty who are already members of support groups and are looking for suitable outlets for their talents apart from public activism. " [22]

- Disclosure is a very individual matter, with no hard or fast reasons. Some people find it easier than others - depending on their personality and personal experience.
- Keeping a personal and individual identity and avoiding being stereotyped by an HIV label.
- Varied with level of responsibility and need. Often PLHIV in senior positions were less likely to disclose.
- "Fear of stigma and discrimination could be a barrier to joining (the positive staff group). But staff seem less likely to join if they work outside the HIV or health areas, and therefore think that they have less to contribute."

Many respondents commented that few PLHIV could safely disclose and become activists, and that there must be ways to be inclusive of less public PLHIV in a variety of roles, and opportunities spanning a spectrum of involvement:

- "Do not assume that activists and those who publicly disclose always represent the voice of PLHIV. Recognise that the opinions of all staff in the workplace may already be those of PLHIV or reflective of their experiences as affected people. Create a culture that encourages respect for the spectrum. "[23]
- "Redefine GIPA broadly to mean affected communities. Work with activists who are openly active about their HIV status. Also work with grassroots communities, using open approaches on identifying the chronically ill PLWA, to give opportunities to the not so vocal PLWA to articulate their needs….and for the group of positive persons who distance themselves from HIV/AIDS openly, we should accept them as they are, and just keep our ears open. We should not drag them into HIV work. Or if they prefer private confidential input into HIV work, we should accept it as such "[24]

The range of these contributions provides many insights. It is not only a safe environment that encourages PLHIV participation, but also being offered opportunities and appropriate support. PLHIV can make huge contributions from their experience as counsellors and treatment educators. However, PLHIV can contribute in a diverse range of roles, not just as activists, and not only in HIV/AIDS work. The level of disclosure and degree of involvement is an individual choice and must be protected and respected. This includes a clear role for positive people to ensure that they are not burdened by the expectations of providing support and education to colleagues and managers.

(C) Personal Barriers to GIPA

- Fear of stigma and violence.
- Lack of a support system.

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[22] Glen Williams, Strategies for Hope series editor. He states that Rev. Gideon Byamugisha makes a similar point in their video, 'What can I do?'
[23] Bridgette Thorold, Oxfam Australia.
[24] Dr Harriet Kivimbi, Oxfam International, Uganda.

- Poor health causing inability to meet commitments and be consistently involved.
- Concern about the risk of exposure to opportunistic infections such as TB, or the risk of psychological impacts.
- Language barriers, including not being able to read or only knowing a minority language(s).
- Lack of education or relevant technical skills.
- Poverty and the need to earn a living that makes it impossible to take time off work, or to afford transport or childcare or other practical measures affecting the ability to contribute.
- Lack of confidence in the ability to contribute, or the lack of motivation to do so.

GIPA and current leadership paradigms are mostly focused on individuals as leaders. However, there also needs to be recognition of the limited scope of individual leadership and a move made to include organisational leadership, as part of more sustainable and extensive change. For example, PLHIV support groups are often set up by charismatic leaders or by the first PLHIV to go public. However the groups and their activities may be difficult to sustain after the departure or death of that individual. TASO (Uganda), SASO (Malawi) [25], and Spiritia (Indonesia)[26] are examples of how, with appropriate resourcing, time, support and development, individual leadership can be transformed into organisational leadership, so that PLHIV organisations have the capacity to be major stakeholders and contributors in the HIV sector.

Case Study: TASO

The AIDS Support Organisation (TASO)[27] in Uganda has been successful in contributing to the reduction in the country's HIV/AIDS prevalence. One of the keys to this success has been community initiatives and the active participation of PLHIV at both an individual and organisational level.

TASO was founded in 1987 by 16 volunteers, including 12 PLHIV, to provide support for families affected by AIDS through counselling, medical and nursing care, material and social assistance. It also pioneered the concept of "Living Positively with AIDS" to counteract the fear, denial and stigma resulting from existing prevention education campaigns at that time. It has been a major contributor to the change in community attitudes and openness about HIV and AIDS.

Two British NGOs, ActionAid and World in Need, provided start-up financial support for TASO with the assistance of other international agencies. It was also endorsed by the Ugandan government. As a result, TASO became one of the most influential NGOs in

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[25] UNDP (2006) *Evaluation of UNDP's role and contributions in the HIV/AIDS response in southern Africa and Ethiopia*. Evaluation Office, UNDP May 2006, page 51, Text box 3.6
http://www.undp.org/execbrd/pdf/Evaluation%20of%20HIV%20AIDS%20Programme%20-%20May%2023.pdf
[26] APN+ (2004) *APN+ Position Paper No2: GIPA*
http://www.ahrn.net/library_uploadfile/file1777.pdf page 13, Textbox: Spiritia - A GIPA Model in Indonesia
[27] Kaleeba, N et al (2000). *Open Secret: People facing up to HIV and AIDS in Uganda*. Strategies of Hope No.15. ActionAid, UK, p21-23.

Uganda, training health workers and establishing counselling services and special treatment clinics in government and non-government hospitals. In 1995, TASO decided not to expand its operations further, but to replicate its approach with a focus on training, supervision and ongoing support to other NGO and government organisations involved in HIV/AIDS care and support work.

5.2   PLHIV Experiences of Involvement with NGOs

Fear of stigma and discrimination poses a major barrier to disclosure of HIV-positive status. It therefore reduces the opportunities to access services and become more meaningfully involved in the HIV response.

Susan Paxton's' research has described the benefits of public disclosure of HIV-positive people, not only within the community in terms of breaking down fear and prejudice, but also at an individual level in terms of freeing PLHIV from the burden of secrecy and shame.[28] She describes the paradox of coming out openly:

> *"The very thing that seems the most dangerous to do, openly confronting stigma and facing possible discrimination and rejection, ultimately can be the most liberating".*[29]

Disclosure is a complex process, to be carefully negotiated as the individual weighs up the possible benefits and harms. Some people may lead parallel lives to hide their status, with their HIV/AIDS life separate from their normal everyday life with their family.

Support groups are an essential component of positive living with HIV/AIDS. The peer support group provides a safe space for PLHIV, to learn personal coping skills and the collective experience shared by other PLHIV. Over time, a person can become a role model, to mentor and support others.

Being meaningfully involved in HIV/AIDS responses provides many therapeutic benefits for PLHIV. Many PLHIV evolve from service users (beneficiaries) to becoming service providers – mostly as counsellors, educators and trainers within AIDS organisations, health services and support groups. They are usually volunteers and do not receive adequate or regular training, or resources, thus limiting their ability to work effectively. In addition, being involved with AIDS NGOs or HIV support groups may bring some risk of being identified as PLHIV. Often PLHIV would like to play a greater role outside of HIV work or to work in different areas or organisations. However, few are offered the opportunities for further employment or for training to develop skills.

Even skilled PLHIV, who have lost their jobs through discrimination or after prolonged illness, but have since recovered their health after starting ART, may need further training to update their job skills and restore their confidence in returning to work. There

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[28] Paxton, S (2002). *The impact of using HIV-positive speakers in AIDS education*. AIDS Education and Prevention, 14(4), p.282-294.
[29] Paxton, S (2002). *The paradox of public HIV disclosure.* AIDS Care, 14 (4), p.559-567.

are also PLHIV who have given up professions or well-paid jobs, which provided greater financial security but much less personal satisfaction than work in HIV/AIDS, who volunteer in AIDS organisations. The experience of GIPA and PLHIV in the workplace is not well documented, mostly because many PLHIV choose not to disclose their HIV status.

PLHIV experience in the NGO or ASO workplace is rather more diverse and complex, as shown by the comments from those contacted by the author.[30] Comments included:

- Meaningful involvement can be varied, depending on what knowledge, skills or experience the person has and what opportunity is given to the person.
- As an openly positive person, you can be a good role model to others.
- Enjoyed the experience in a big technical organisation and felt useful. Problems encountered were unrelated to HIV status. However, suggestions to consult more widely or involve positive people were ignored.
- PLHIV staff are accessing treatment through Oxfam workplace benefits. However, only a few have openly expressed thanks or appreciation, as most only selectively disclose, or do this through anonymous claims. In some countries, staff still face barriers to ARV access, arising from, among other things, poor infrastructure and lack of confidentiality (OGB, Central and Eastern Africa).
- Working in HIV/AIDS and bringing about change can be very therapeutic - rebuilding self worth, leading meaningful and fulfilling lives.
- People who have been deprived by HIV/AIDS of their traditional roles in society - such as women who, through choice or chance, have no partner or who have remained childless - find benefit and comfort in new roles.
- People from marginalized groups, such as IDU, gained respect and credibility with their local communities, from their involvement in peer groups, which were part of, or supported by, INGOs.

5.3   PLHIV and Service Delivery

Inter-Country Study of PLHIV Involvement in NGO Service Delivery

The most comprehensive study of PLHIV involvement in community-based programs was undertaken jointly by the International HIV/AIDS Alliance and the Population Council (Horizons Project). The study was conducted in four countries with different patterns of HIV - Burkina Faso, Ecuador, Zambia and Maharashtra State, India[31]. PLHIV are highly stigmatized in all four countries.

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[30] This section includes comments from both HIV-positive and non-positive contributors.

[31] Most of this section is based on the research summary 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 However, the International HIV/AIDS Alliance (2003) was also accessed and is highly recommended for further reading and research. 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.* http://synkronweb.aidsalliance.org/graphics/secretariat/publications/ipl0703_PLHA_International_report.pdf

This study provides a useful model for other NGOs in being able to identify, analyse, and increase PLHIV involvement at higher levels, to the benefit of both the PLHIV and the NGO. For more information, OAus and OI should refer to the individual studies for Zambia[32] and Maharashtra, India[33], as these are the most relevant to Oxfam's regions of work. A tool, based on the Maharashtra study, to help NGOs increase the involvement of positive people is currently being developed.[34]

All the 17 selected CBOs focussed on HIV prevention, care and support and represented different types of organisations and levels of PLHIV involvement. The study interviewed 745 individuals, including HIV-negative and positive service users, NGO staff, volunteers and other important people. Approximately 55% of study participants in India were PLHIV, 50% in Zambia, 35% in Ecuador and 15% in Burkina Faso. Only those PLHIV who had disclosed their HIV status at some level were included.

The research examined PLHIV involvement in NGOs in terms of:

- Time spent on activities and regularity of input.
- Remuneration: financial (salary, allowances, reimbursement of travel costs), material (food, medicines), technical (training) or psychological (social support and counselling).
- Skills contributed.
- Skills development provided by the organisation.
- Scope and autonomy of decision-making.
- Level of visibility: internal (within the NGO) and external (outside the NGO).

The research noted four distinct types of PLHIV involvement.[35] Higher levels of involvement and participation were more common in rights-based and/or self-help NGOs that PLHIV had set up with other affected people, or health or social workers. PLHIV were also service users. Lower levels of involvement were more common in

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The individual country studies may also be found in the International HIV/AIDS Alliance publications on civil society development at http://www.aidsalliance.org/sw7442.asp

[32] International HIV/AIDS Alliance (2002). *Involvement of people living with HIV/AIDS in the delivery of community-based, prevention, care and support services in Zambia – a diagnostic study.* http://synkronweb.aidsalliance.org/graphics/secretariat/publications/zpl0602_Zambia_PLHA_study_report.pdf

[33] International HIV/AIDS Alliance (2002). *Involvement of people living with HIV/AIDS in the delivery of community-based, prevention, care and support services in Maharashtra, India – a diagnostic study.* http://synkronweb.aidsalliance.org/graphics/secretariat/publications/ipl0602_India_PLHA_study_report.pdf

[34] The Alliance's office in India, which was one of the study partners, requested the development of some tools for NGOs/CBOs to increase the involvement of positive people. These tools are being edited, designed and produced in India at the moment, but the Alliance plans to adapt and further develop these tools for wider audiences (Email communication, Pam Decho 11/5/06).

[35] International HIV/AIDS Alliance (2003) p.90. The study also identified two types on non-involvement - Tokenism and Exclusion. Although none of the studied NGOs practiced exclusion, the researchers were aware of other prevention-focussed NGOs and CBOs that excluded PLHIV. They believed that people who were already infected had no need of any form of prevention and ignored the potential contribution of PLHIV in effective outreach education.

service delivery NGOs, where specific professional qualifications or technical skills were required.

The study found that accessing certain services could provide an entry point to empower PLHIV and foster further involvement within an NGO - through positive living and life-skills courses, counselling, and support groups[36]. However, unless there was a clear policy within the organisation, accessing services rarely led to greater involvement. In one development NGO, greater involvement was achieved by recruiting PLHIV, who were not service users but were already visible and had the experience and skills to be involved in formal service delivery and/or management.

The research showed that PLHIV involved in management, policy making and strategic planning had completed secondary education and came from middle-income socio-economic groups. Most had been involved in the fight against the HIV epidemic for many years, had considerable training, represented PLHIV perspectives in different forums and were often part of advocacy efforts in national or regional networks of PLHIV (these characteristics were also true of the PLHIV respondents contacted for this research project). The fear and reality of stigma and discrimination was the most commonly reported reason mentioned for limited involvement.

The study concluded that NGOs can overcome many of the organisational factors that limit PLHIV involvement in service delivery by implementing the following recommendations:[37]

- Promote positive and non-discriminatory attitudes and policies toward PLHIV.
- Build the capacity of PLHIV to enable involvement.
- Offer psychological support, including peer support.
- Promote material support to PLHIV who have few resources.
- Network with other organisations and services to foster PLHIV involvement.
- Form and sustain PLHIV support groups.

5.4   PLHIV Involvement in Policy

Policy Project Study of PLHIV Involvement in Policy

A decade after the 1994 Paris Summit, POLICY project conducted a study of PLHIV involvement in policy formulation in five countries, with different HIV epidemics, national responses and PLHIV communities. These countries were Benin, Brazil, Cambodia, South Africa, and the Ukraine.[38] The importance of PLHIV networks and the institutionalisation of GIPA were found to be key to PLHIV involvement in policy.

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[36] See p.77-80. International HIV/AIDS Alliance multi-country study (2003).
[37] See the Horizons (2002) research summary and the International HIV/AIDS Alliance (2003) multi-country study for more detail.
[38] Stephens, D (2004). *Out of the Shadows: Greater involvement of people living with HIV/AIDS (GIPA).* POLICY Working Paper series No.14. The POLICY Project.
http://www.policyproject.com/pubs/workingpapers/WPS14.pdf

The project found that the majority of senior policy makers and national PLHIV leaders were aware of the principles of PLHIV involvement that GIPA represents, and how these relate to policy and program design, planning, implementation and evaluation. Respondents specifically referred to the need to have PLHIV voices and opinions heard and integrated into decision-making processes.

Levels of PLHIV involvement in the development of and implementation of national HIV/AIDS strategies, legislation and other relevant HIV/AIDS policy instruments varied between countries. Participation was achieved through advocacy or invitation, then formalized through HIV/AIDS structures and processes. PLHIV involvement was the most extensive in South Africa, both in principle and through action in the development of strategic plans and through the UN's GIPA Workplace Model. PLHIV involvement benefited individual PLHIV in re-establishing a feeling of self-worth and ending social isolation.

Stigma remained the greatest barrier to GIPA in all five countries, as well as the lack of appropriate skills and experience and the lack of support for GIPA in policy or legal frameworks. The project found that PLHIV needed to understand and be able to articulate the personal and collective experience of HIV/AIDS. They needed basic knowledge about HIV and its impact at both a personal and policy level, as well as policy negotiation skills and familiarity with the national HIV/AIDS response.

The study found that leadership and legitimacy of representation was a major issue. This was because there were very few PLHIV open about their serostatus, who then bore a heavy burden in trying to represent the diversity of PLHIV. Some PLHIV groups insisted upon membership and representation based on a positive serostatus, while other PLHIV groups recognised the need to involve non-positive people, who may have been personally affected by HIV, or simply committed allies. For example, Group Pela Vida, a Brazilian PLHIV group includes both positive and non-positive members, based on a core set of ethical, political and ideological principles supported by PLHIV. A "mixed" membership also addresses the concerns of PLHIV who are unwilling to disclose their HIV status.

5.5   Capacity Building of PLHA

Capacity Building of Individual PLHIV

PLHIV need an extensive skill-set for involvement in programming and policy.[39] At a basic minimum, PLHIV need resources to build self-confidence and to strengthen

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[39] Stephens, D (2004). *Out of the Shadows: Greater involvement of people living with HIV/AIDS (GIPA).* POLICY Working Paper series No.14. The POLICY Project.
http://www.policyproject.com/pubs/workingpapers/WPS14.pdf

personal coping mechanisms. At an organisational level, they need skills in public speaking, computer literacy, advocacy and negotiation. At an operational level, they may need:

- Policy analysis training and mentoring support for policy involvement.
- Technical support (e.g. HIV/AIDS treatments, human rights advocacy and social research skills).
- Language skills to be able to participate in national and international forums (preferably English language skills).
- Proposal and report writing skills.
- Strategic planning skills.

NGOs (and governments) can be involved in capacity building of PLHIV by:[40]

- Building skills to enhance the expertise of HIV positive people and develop policies to mentor them into positions of responsibility.
- Supporting the development and employment of teams of HIV-positive AIDS educators, treatment educators and counsellors.
- Establishing groups of accredited HIV-positive speakers whose expertise can be employed to speak out in health care settings, schools and communities, and via village leaders and religious leaders, in order to reach youth and mobile populations.
- Training HIV-positive people as peer counsellors and treatment educators and encouraging their employment at all testing centres.
- Supporting autonomous HIV-positive women's associations to become models in collective sustainability and positive advocacy.

PLHIV peer support groups are essential to the individual and collective growth and development of PLHIV. In industrialized countries, these have coalesced into vigorous advocacy movements, speaking out against stigma and discrimination, the rights of PLHIV and their access to care and treatment services.

However, in resource-poor settings, PLHIV organisations are challenged by:

Paxton, S (2005). *Steps to Empowerment: Challenges to the greater Involvement of people living with HIV in response to AIDS in Cambodia.* The POLICY Project.
http://www.policyproject.com/pubs/countryreports/CAM_StepsToEmpower_en.pdf
GNP+ (2005) *Challenging, changing and mobilizing: A guide to PLHIV involvement in country coordinating mechanisms.* Pages 38-40.
http://www.gnpplus.net/cms-downloads/files/handbook-EN.pdf
Nairobi Think Tank (2005). *Revitalizing the Global Movement of People Living with HIV/AIDS Report*.
Nairobi Think Tank meeting of people living with HIV 28030 November 2005.
http://www.gnpplus.net/cms-downloads/files/Nairobi_meeting_report.pdf
[40] Paxton, S (2005). *Steps to Empowerment: Challenges to the greater involvement of people living with HIV in response to AIDS in Cambodia.* The POLICY Project.
http://www.policyproject.com/pubs/countryreports/CAM_StepsToEmpower_en.pdf

- Stigma and discrimination - where vulnerable groups lack a safe and supportive environment - especially MSM, SW, IDU and migrant workers.
- Poverty and poor health of PLHIV - the lack of access to services and resources, and the need for skills and a living wage.
- Poor capacity - lack of skills, funding, resources and the loss of leadership through the deaths of PLHIV leadership.
- An unwillingness of governments and other funders to invest in capacity building and resourcing.

These barriers are further exacerbated by the lack of access to life-saving ARV treatment. In many resource-poor countries, PLHIV organisations remain fragmented and have no voice at a national, regional or global level. Legitimacy of representation is a major challenge and is linked to a number of issues.[41] These include the shortage of skilled PLHIV and leaders, questions over the role of non-positive people, inadequate governance and networking, and the need to represent a diversity of PLHIV populations.

PLHIV Organisational Perspectives

Many NGOs do work with PLHIV organisations, but reports about these relationships from PLHIV respondents were mostly negative[42]. Comments included:

Tokenism and Lack of Awareness:

- NGOs unaware of PLHIV organisations - their existence, activities, capacity, resources and therefore the PLHIV organisations were not invited to meetings.
- PLHIV organisations were not consulted by NGOs at all or consulted only when everything had been planned.
- PLHIV organisations were not included in the conceptual design and planning phase of projects – they were only invited to participate when everything was set to go.
- PLHIV organisations were not given adequate notice and information before meetings – which limited their ability to attend and participate.

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[41] Stephens, D (2004), *Out of the shadows: Greater involvement of people living with HIV/AIDS (GIPA).* POLICY Working Paper series No.14, The POLICY Project.
http://www.policyproject.com/pubs/workingpapers/WPS14.pdf
Paxton, S (2005). *Steps to Empowerment: Challenges to the greater involvement of people living with HIV in response to AIDS in Cambodia*
.http://www.policyproject.com/pubs/countryreports/CAM_StepsToEmpower_en.pdf
GNP+ (2005). *Challenging, changing and mobilizing: A guide to PLHIV involvement in Country Coordinating Mechanisms.* Pages 38-40 http://www.gnpplus.net/cms-downloads/files/handbook-EN.pdf
Nairobi Think Tank (2005). *Revitalizing the Global Movement of People Living with HIV/AIDS Report.* Nairobi Think Tank meeting of people living with HIV 28030 November 2005.
http://www.gnpplus.net/cms-downloads/files/Nairobi_meeting_report.pdf
[42] Oxfam does work with and involve PLHIV and PLHIV organisations in their internal and external work in Eastern and Central Africa. Please note that the comments in this section originate from non-African PLHIV because there were no African PLHIV interviewed.

- PLHIV organisations were not treated as equal stakeholders in meetings; the NGOs had already set the agenda.
- PLHIV organisations had nominal partnerships with NGOs, but often the initiatives came to be seen as owned by the NGO.
- NGOs took control and didn't listen to what the PLHIV organisations had to say.
- Some individual staff and managers very aware, inclusive and sought contributions from PLHIV, but this was highly dependent on individual goodwill.
- If there was no visible PLHIV within an NGO, the NGO did not take the initiative to seek advice from outside the NGO from PLHIV groups.
- PLHIV got more recognition from some academic research institutions, than from NGOs.
- NGOs didn't recognize the fact that PLHIV organisations also have real-life expertise and experience in health, advocacy and community development.
- NGOs didn't fund PLHIV/PLHIV organisations in order for them to provide technical assistance to other PLHIV organisations.

Lack of NGO Funding to Support PLHIV Organisational Capacity:
- Funding was usually only for activities and time-limited by project cycles.
- No core funding was provided for: staff salaries and other entitlements, extra staff needed for program coordination and management, rent, utilities or legal liabilities (e.g. insurance, work cover)
- PLHIV were expected to be volunteers - no funding was provided for incentives or financial or material benefits. Volunteers' expertise needed to be recognised and compensated.
- There was no funding given to develop capacity of staff - training, attending conferences etc
- There was no funding given for staff to attend meetings, workshops or to support travel and accommodation (including meetings organized by the NGO). If a PLHIV did attend such a meeting, this lack of support failed to acknowledge the opportunity cost of the PLHIV representative doing something else in lieu of attending the meeting.
- There was no funding given to establish, develop or support better national PLHIV networks - to reach higher or lower level PLHIV groups - especially grassroots groups in rural areas.

Competition:
- NGOs were aware of the benefits of increased availability or sources of funding if PLHIV were involved.
- As PLHIV organisations gained more capacity, they were sometimes seen as competing with NGOs for funding and "territory".
- NGOs had the resources to attract skilled PLHIV, who needed to earn a living and could not afford to be a volunteer at a PLHIV group.

Capacity Building of PLHIV Organisations

Most PLHIV groups may need assistance and support in the form of:

- Skills development.
- Funding and resources.
- Mentoring.
- Ways of accommodating the diversity of PLHIV (probably require separate groups for women, MSM, IDU, SW etc).
- Organisational development, such as:
  - Developing accountable and transparent management, including financial management.
  - Forming a board of management elected by HIV-positive people.
  - Developing clear processes for election of Board representatives, as well as for representatives of national and regional boards/committees.
  - Mentoring of HIV-positive people on national committees.
  - Improving two-way communication between national, provincial and local-level support groups about national, regional and global issues affecting PLHIV.

Where there is no PLHIV organisation, NGOs and other PLHIV organisations can encourage and support its development. In order for this to happen, there needs to be consideration of the following:

How is the capacity-building best delivered?
- Individually or through PLHIV organisations?
  - Individual development versus collective development.
  - The need to train as many PLHIV as possible.
  - All PLHIV need the knowledge and skills to cope personally with HIV or AIDS.
  - Those PLHIV who show the talent and /or interest can undergo further training.
  - More effective for PLHIV to train PLHIV in a group and to train PLHIV to deliver ongoing training.

By whom? By NGOs or PLHIV or PLHIV organisations?
- NGOs and PLHIV can complement each other.
- NGOs have an in country-presence with the skills, experience and resources in programming. They can also train and employ PLHIV and can develop ways of working with PLHIV and PLHIV organisations.
- PLWHA groups and networks are the best placed to provide specific technical assistance to other PLHIV organisations through peer mentoring and peer support, and can offer other specific skills such as advocacy.

Many PLHIV organisations already have considerable technical capacity,[43] but few have documented their achievements, due to lack of organisational capacity. Global and regional PLHIV networks[44] have also produced many resources[45], either alone or jointly

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[43] For example , see ICW website www.icw.org
Also APN+ (2006) *Who we are, what we've done, where we're going…1994-2006 and beyond.*
APN+, Bangkok, Thailand. Email:info@apnplus.org
[44] See page 47: Global PLHIV Networks.
[45] See page 49: PLHIV Organisations - Publications and Resources.

- to share their collective knowledge and experience with other PLHIV. These range from fact-sheets and self-help information to manuals, toolkits and policy papers. These have been extremely well received – they are practical, accessible, written by PLHIV for PLHIV, inspiring for other PLHIV and proof of what PLHIV can do.

Some of the most useful of these resources are:

- The GNP+ Guide[46] provides tools for strengthening PLHIV involvement in the Global Fund's Country Coordinating Mechanisms, and can be used more generally as a resource for enhancing civil society participation. It was compiled from contributions of 400 PLHIV in 30 countries.
- Positive Development: Setting up Self-Help Groups and Advocating for Change. A Manual for People Living with HIV.[47]
- Training modules and manuals for public speaking.[48]

Capacity building between PLHIV and similar organisations can occur at various levels. In Victoria (VIC), Australia, Paraquad, a disability and accredited training organisation, invited PLWHA VIC members to undergo training in Certificate IV in Assessment and Workplace Training. This is an Australia-wide accredited training qualification. Trained members have now gone to other ventures, working as trainers inside and outside the HIV or disability sectors. Other PLWHA VIC members are also undertaking training in small business management through Paraquad. The success of the programs was recognized through the 2005 Community Services and Health Industry Training Award for Innovative Service Delivery.

The National Association of People Living with HIV/AIDS, Australia (NAPWA) has been funded by the Australian Government, under the AusAID HIV/AIDS Partnerships Initiative (AHAPI), to work with regional PLHIV groups for 2005-2007. This work has involved capacity building of the Asia-Pacific Network of People Living with HIV/AIDS (APN+) and Igat Hope, the latter being the main PLHIV group in Papua New Guinea. NAPWA is also supporting the establishment of a PLHIV group in East Timor, including provision of training in treatment preparedness

As part of UNDP's South Asia GIPA initiative, the Asia Pacific Initiative for the empowerment of PLWHA[49] provided direct support for 17 PLHIV groups in 12 countries.

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[46] GNP+ (2005). *Challenging, changing and mobilizing: A guide to PLHIV involvement in country coordinating mechanisms. (*English, French, Spanish, Arabic, Russian) Also available on ICW and POLICY project websites. http://www.gnpplus.net/cms-downloads/files/handbook-EN.pdf
[47] GNP+ (1998). *Positive Development: setting up self-help groups and advocating for change. A manual for people living with HIV.* GNP+ and Healthlink. http://www.gnpplus.net/cms-downloads/files/Contents.pdf
[48] APN+ (1999). *Lifting the burden of secrecy – A manual for HIV-positive people who want to speak out in public*. http://www.gnpplusnet.net/regions/files/speakers_manual.pdf
APN+ (2001). *Lifting the burden of secrecy – A training module for HIV-positive speakers.* http://www.youandaids.org/unfiles/apn_training_module_.pdf
[49] UNDP (2004). *From involvement to empowerment: people living with HIV/AIDS in the Asia-Pacific* .http://www.youandaids.org/unfiles/frominvtoemp.pdf

This was done in partnership with APN+, and the Indian Network for PLWHA. Capacity development included facilitating networking, organisational development and advocacy training. It also involved leadership development, such as the Positive Women's Network (Chennai) beginning to organize HIV positive women in India and contacting other positive women in the region. A virtual Asia Pacific PLWHA Resource Centre (APPRC) website[50] was less successful, because few PLHIV organisations had the capacity to access or use the web.

Positive Professionals

A long standing-barrier to GIPA has been the scarcity of highly skilled and professional PLHIV to become visible and engaged in HIV responses. Because they have access to information, health services and treatment, they have managed to remain hidden in the community. However, new groups of positive professionals are beginning to emerge - health professionals, teachers and religious leaders.

Positive health professionals in Africa and other regions are beginning to take on a greater role. GNP+ is soon to sign an MOU with WHO to start a register of HIV-positive health professionals in order to be able to draw on their expertise. The 2006 International AIDS conference in Toronto had a satellite meeting of HIV-professionals working in HIV.

Two positive teachers founded the Kenya Network of HIV-positive Teachers (KENEPOTE) in 2003. This organisation, with links to World Vision, claims to have more than 3000 members - despite the Department of Education trying to stop funds from foreign donor agencies.[51]

Religious leaders and teachers in Africa took the courageous step of forming their own PLHIV network. In 2003, at the International PLWHA Conference in Uganda, ANARELA+ was launched - the African Network of Religious Leaders Living with or Affected by HIV and AIDS. ANERELA+ is an inter-faith organisation, and now has about 1000 members in about 15 African countries. Members are mainly Christian but there are also a significant number of Muslims and some Buddhists and Bahais. There is also now KENERELA in Kenya.

6. Expanding and Strengthening GIPA

NGOs and CBOs lack capacity to implement GIPA within their organisations, such as the ability to be able to support staff (employees and volunteers) who may be infected or affected by HIV and AIDS, and the ability to work with PLHIV and PLHIV organisations.

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[50] http://www.plwha.org
[51] Email communication, Glen Williams.

NGOs face a number of challenges similar to, and in addition to, those previously described for PLHIV such as:

- Supporting staff and volunteers, who may be infected or affected by HIV and AIDS by providing:
    - Psychosocial support.
    - Material and/or financial support.
    - Flexibility and reasonable accommodation.
- Lack of disclosure and openness about HIV/AIDS within the organisation - which may be due to the environment or other issues.
- Issues to do with confidentiality - to protect the infected or affected person. But confidentiality can also be counterproductive e.g. it limits the amount of support that can be offered.
- Recruiting PLHIV - what sort of work roles are they expected to do? What is part of their job description and what is not?
- Existence of appropriate organisational policies and practices.
- Appropriate training for staff.
- Lack of financial resources - including for medical benefits.
- Lack of human resources and personnel – does there need to be a separate staff position to do the "internal" HIV/AIDS work? Or will this be added onto someone's existing job, in addition to their other duties?

Ways of working with PLHIV organisations also needs consideration:

- How to implement GIPA through individual PLHIV working with NGOs, without taking capacity away from PLHIV groups?
- Short-term development of individuals is easier than long-term organisational development of PLHIV organisations.
- It takes time to gain the trust of PLHIV organisations.

NGOs must develop workplace programs, based on sound workplace policies, and institutionalize ways of working with PLHIV and PLHIV organisations. Workplace policies are essential in managing HIV in the workplace and creating an enabling and supportive environment for PLHIV.

Novib Study of HIV and AIDS in the Workplace in Africa

In sub-Saharan Africa, NGOs and CBOs struggle to respond to the ever-increasing demands of a still escalating AIDS epidemic, with diminishing resources. The organisations themselves face issues of productivity and sustainability, because HIV has infected or affected their own staff and communities.

In 2003-2004, Novib studied nine Oxfam partners in South Africa, Zambia, and Zimbabwe. [52] Programming had been affected by reduced staff productivity due to illness, family care needs, funeral attendance, staff changes and deaths. NGOs lacked the financial and skilled human resources to respond to staff and/or dependents' needs - including the need for medical treatment and financial, emotional and psychosocial support. They also lacked understanding and awareness of the impact of HIV/AIDS, available options for support, and the need for strategic planning to cope with these issues.

Less than half of the NGOs had workplace policies. Six NGOs had undertaken some staff training in HIV and AIDS, but not the three involved in HIV/AIDS-focused programming. Despite training, fear of HIV/AIDS-related stigma and discrimination continues to deter disclosure in the workplace setting, and prevents an accurate assessment of the scale and needs of staff impacted by HIV/AIDS.

The major lesson from the study was that funding organisations need to understand the extremely difficult context in which NGOs operate in southern Africa and should assist their partner organisations to cope better.

Funders could assist NGOs in supporting GIPA in the workplace through (but not limited to):
- Helping NGOs to better understand the issues concerning HIV in the workplace and to negotiate setting more realistic targets and improving management of these issues.
- Developing and refining comprehensive workplace policies.
- Training for staff.
- Providing or facilitating options to access to medical benefits, treatment packages and other services.
- Providing wider funding support - negotiating with donors on "allowable costs", such as funding of staff benefits and other special needs related to HIV/AIDS.
- Providing lengthier funding timeframes; and addressing reporting pressures.

A workplace strategy typically includes:
- A clear policy statement covering: clear procedures, confidentiality, non-discrimination, gender, education, prevention, treatment and care and monitoring and evaluation. A policy can be supported by guidelines to help management implement it.
- An education and prevention program.
- A treatment and care program.

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[52] O'Grady, M (2004). *Managing HIV/AIDS in the workplace: examples of nine non-governmental organisations in South Africa, Zambia and Zimbabwe*. Novib.
http://www.oxfam.org/en/files/pp041129_HIV_NO_PHOTOS.pdf

Nine members of the UK Consortium on AIDS and International Development developed a practice guide, including case studies, to assist with developing workplace policies.[53] The guide details the complexities of workplace strategies such as developing local or organisational policies, dealing with chronic illness or developing separate HIV/AIDS policies and different program delivery approaches.

Care International has been reviewing its workplace policies in Southern and Western Africa.[54] Emerging issues include:
- HIV/AIDS policies need to address the full continuum of needs - prevention, positive living, access to treatment and mitigation of impacts.
- The need to develop a minimum package of support, according to the local context and impact, and availability of resources. There is enormous variation between regions in HIV prevalence and availability of resources.
- "AIDS exceptionalism" can be problematic, where HIV/AIDS gets special attention, while other major health concerns are not addressed.
- A focus on treatments and late stage illness, coupled with fear of stigma and disclosure, results in late diagnosis and low uptake of available support.
- How to move from an HIV/AIDS-specific policy to a general wellness policy.

In considering a move from an HIV/AIDS specific policy to a broader health policy, the advantages of a wellness policy to be weighed up are:[55]
- Does not distract from other pressing health concerns, e.g. cancer, mental illness, and physical disabilities.
- It frames HIV/AIDS as a chronic manageable disease, such as diabetes.
- It could help to reduce the stigma about HIV and AIDS.
- It encourages staff to understand broader health issues.
- It promotes general health and wellness, in ways that tie into Positive Living (such as good nutrition, safer sex practices and prompt medical treatment for illnesses).

Additional reasons for a wellness policy, rather than an HIV-specific policy are that it supports:
- Early diagnosis, so as a result people stay well as long as possible (allowing the employee and employer to plan ahead).
- Positive living – giving a holistic health and self-care message which is broadly based and suitable for both HIV-positive and non-positive people.
- Continued prevention of infectious disease (especially STIs) which keeps viral load low.

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[53] UK Consortium on AIDS and International Development (2003). *Good practice guide and case studies*. http://www.aidsconsortium.org.uk/Workplace%20Policy/workplaceintro.htm also available on CD-Rom. UK Consortium on AIDS and Development (2003). *Working positively: a guide for NGOs managing HIV/AIDS in the workplace.* http://www.synkronweb.aidsalliance.org/graphics/secretariat/publications/ukconsortium1203_working_positively.pdf
[54] CARE International (2005). *Lessons on addressing HIV and AIDS in the workplace: Briefing papers*. http://www.careinternational.org.uk/download.php?id=195
[55] ibid. pages 5-6.

- Safer sex to protect the employee and partners from further infection with HIV (and prevent further transmission in the community).
- Chronic illnesses such as diabetes and cardiovascular disease, which also impact on PLHIV in their management of treatment adherence and dealing with side effects of ART.
- The need to acknowledge the connection between mental health and well-being and physical health – the impact that poor mental health (stress, depression) can have on physical health.
- Long-term access to treatment for a variety of illnesses. Facilitating access to ART and other HIV-related treatment is more likely to be a short-term bridging measure. In high-prevalence regions, ART will eventually become widely available, and at an accessible cost, through government health systems - due to donor programs such as the Global Fund. However, there is unlikely to be public subsidies, cost reductions for treatments or surgery offered for conditions such as cancer or transplants for end-stage organ failure.

6.1   Education and Information in the Workplace

Education programs aim to inform employees about HIV/AIDS and to break down stigma and discrimination. Typical core subjects are:

- Basic facts about HIV/AIDS and modes of transmission.
- Prevention.
- Testing and treatment and where to access these services.
- Importance of treatment of sexually transmitted diseases and symptoms of opportunistic infections.
- The NGO's HIV/AIDS policy and employee rights.
- National regulations and international conventions.

Most NGOs now try to openly discuss issues such as discrimination, stigma and confidentiality in order to encourage a supportive environment and to help to break down the barriers that stop people accessing benefits. Some organisations have broadened their workplace programs to include general health and nutrition, diversity and other areas of employee wellbeing. Workplace education programs that focus mainly on prevention have limited scope. Standard Chartered Bank [56]launched its first education campaign "Staying Alive," in 2000. This was primarily a basic facts and prevention campaign, but the need for more was soon apparent in order to support staff who were infected or affected by HIV and AIDS.

In 2002, the Bank launched its "Living with HIV" campaign across all regions and focused on issues such as:
- If you are infected with HIV - what to do next?
- How can you care for and support someone who is infected with HIV?

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[56] Standard Chartered is one of the case studies available at UK Consortium on AIDS and International Development (2003) *Good practice guide and case studies*.
http://www.aidsconsortium.org.uk/Workplace%20Policy/workplaceintro.htm

The program also included information about nutrition and health, safe food and water, HIV and children, treatment and adherence, TB and other opportunistic infections. The Living with HIV program campaign was awarded the 2003 Award for Business Excellence in the Workplace from the Global Business Coalition on HIV/AIDS.

NAMDEB diamond company in Namibia provides another good example of adapting programs and sustaining interest in educational activities by remaining relevant to the changing and broadening needs of employees.[57] NAMDEB ran peer education programs on HIV/AIDS and also provided comprehensive services. However employees became bored with the HIV/AIDS education sessions, but did show interest in other issues. Consequently, the content of peer education was broadened to include a different topic each month, such as malaria, TB, family planning, healthy lifestyles, child abuse, alcohol and drug abuse, stress and child care as well as updates on HIV/AIDS and STIs. These activities also illustrate the need to move to broader health policies, rather than HIV/AIDS-specific policies.

6.2   The Involvement of PLHA in Workplace Programs[58]

Involving HIV-positive people is one of the most powerful tools for breaking down stigma and discrimination as it promotes positive role models and presents to employees the reality of living with HIV/AIDS. Crucially it helps to bring home the message that HIV/AIDS can affect anyone from any background, country, education level or position.

Most organisations typically involve positive people as visiting speakers for awareness education. However PLHIV feel that they can make a much more significant contribution to workplace policies and programs:[59]

ActionAid[60] and the International HIV/AIDS Alliance[61] are two NGOs known to have affirmative action policies in order to employ HIV-positive staff. However, few NGOs have people within their organisations who are open about their HIV status, with some organisations actively looking to recruit HIV positive staff or volunteers. If NGOs recruit PLHIV, they must also be willing to train and support PLHIVs to do their job.

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[57] Holden, S (2003). *AIDS on the Agenda: Adapting development and humanitarian programmes to meet the challenge of HIV/AIDS.* Published by OGB in association with ActionAid and Save the Children UK. Pp130-131.

[58] UK Consortium on AIDS and International Development (2003). *Working positively: a guide for NGOs managing HIV/AIDS in the workplace.* Pp57-58. http://www.synkronweb.aidsalliance.org/graphics/secretariat/publications/ukconsortium1203_working_positively.pdf

[59] *Case study: Experience of People Living with HIV/AIDS*. UK Consortium on AIDS and International Development (2003) Good practice guide and case studies http://www.aidsconsortium.org.uk/Workplace%20Policy/workplaceintro.htm

[60] http://www.actionaid.org

[61] http://www.aidsalliance.org

" Actively recruiting PLHIVs is important …however, I have seen some organisations employing positive people almost as a way of making a statement, regardless of the person's experience and expertise, not supporting them adequately, and then being disappointed when things don't work out. That's not helping anyone and further, is patronizing".[62]

Organisations are also turning to external networks of People Living with HIV/AIDS. [63] These include the International Community of Women Living with HIV/AIDS (ICW) or the Global Network of People Living with HIV/AIDS (GNP+), both of whom have a presence in many regions. These organisations focus on: advocacy and the rights of HIV-positive individuals, reducing stigma and discrimination through increased awareness and lobbying for access to treatment and care. Such networks can help identify People Living with HIV/AIDS for recruitment purposes or to participate in education programs. They also can provide enormous value and insight when an organisation is developing a workplace strategy. Their experience can ensure that policies and programs are reflective of the physical, social and psychological needs of PLHA.

6.3   Positive Staff Groups

An interesting new initiative is the formation of PLHIV or positive involvement groups within or associated with some NGOs. These serve the purpose of providing: peer support, a medium to increase the contribution of PLHIV to an organisation's work and a way of increasing recognition of the group's expertise.

At the International HIV/AIDS Alliance, staff have started the Positive Involvement Working Group (PIWG). The purpose of the PIWG is to facilitate the involvement of PLHIV at the Alliance Secretariat, through research and lobbying and keeping up momentum during this process. The group has been given the backing of management and has involved the HR department. They have produced a number of documents and contributed to policy and programming. They have also initiated a program where people with HIV can take up internships within the organisation's headquarters at Brighton.

In Britain, HIV-positive staff from various NGOs have started a new group - initially as a social network - but also with an aim of influencing policy and programming. The group has already been influential in getting GIPA on the agenda at the UK Consortium on AIDS and International Development, as part of its current strategic plan.[64]

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[62] Dan Mullins' email 23/5/06.
[63] UK Consortium on AIDS and International Development (2003). *Working positively: a guide for NGOs managing HIV/AIDS in the workplace.* P57-58.
http://www.synkronweb.aidsalliance.org/graphics/secretariat/publications/ukconsortium1203_working_positively.pdf
[64] Emailed Fiona Pettitt, ICW.

Within the United Nations, HIV-positive staff from UNAIDS have set up the UN+ group for PLHIV staff of all the UN agencies. About one hundred members attended the initial meeting in early 2006. Eleven UN agencies, plus the Global Fund (GFATM), were represented, but there may be more agencies included in the overall membership. Many PLHIV are not working in HIV and some are openly living with HIV, but not in the workplace.[65]

The International Federation of Red Cross and Red Crescent Societies does not have a support group or network of PLHIV. RCRC staff are encouraged to join local PLHIV organisations, and there is overlap in membership between RC and PLHIV groups e.g. the HIV Program Manager of the Argentine RC is also an active member of REDLA[66]. PLHIV are able to be part of National Societies as openly positive people, but there are reports that when some have come out as gay men, they have been excluded from the workplace and sacked. This has happened in South America and Latvia, but the Federation has not formally objected to such discrimination.[67]

In Asia, at country level, the Cambodian Network of PLHIV (CPN+) is part of a pilot support group for HIV-positive members and volunteers of the Red Cross Society. [68]

6.4   Positive Partnerships: PLHIV Organisations and NGOs

At its most basic, the requirements for GIPA for both PLHIV and NGOs are:

- Appropriate skills development.
- Access to resources - including material, financial, ART and health care.
- Access to Opportunities - an enabling environment, ways of working with and within NGOs, policies, processes and partnerships**.**

Many PLHIV and PLHIV organisations have worked in partnership with NGOs, such as the POLICY Project and the International HIV/AIDS Alliance and ActionAid. ICW has been particularly effective in collaborations, global networking and working on issues for HIV-positive women around the world. Partnerships can exist at different levels and on different scales - from small scale to regional or global initiatives. Recent partnerships with the IFRC or through the Collaborative Fund have shown that when PLHIV are properly resourced and supported - to be equal partners - they can produce innovative and effective programs of change.

The International Treatment Preparedness Coalition (ITPC) was founded in 2003 after a meeting in Capetown, South Africa. It is made up of treatment activists and their allies.[69] The ITPC was instrumental in the push for donations to the Global Fund for Fighting

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[65] Emailed 19/6/06 by Kate Thomson, Partnership Adviser, UNAIDS, Geneva.
[66] REDLA+ is a regional Spanish speaking network of PLHIV in Latin America and the Caribbean.
[67] Email 20/6/05 Bernard Gardiner, Unit Manager, HIV/AIDS Global Programme, IFRC, Geneva.
[68] Baldwin, R (2005). *Draft report ART HIV discrimination project*. ARC, APN+
[69] Fact sheet in ITPC (2005). *Missing the target - a report on HIV/AIDS treatment access from the frontlines.* Pp90-93. http://www.aidstreatmentaccess.org/itpcfinal.pdf

AIDS, Tuberculosis and Malaria, and supporting the meaningful participation of PLHIV in each of the Global Fund's Country Coordinating Mechanisms (CCMs).

The Collaborative Fund for HIV Treatment Preparedness consists of a partnership of the ITPC with the TIDES Foundation (a philanthropic management NGO) to select proposals from PLHIV groups and disperse grants of up to $10,000 to work on treatment preparedness. The World Health Organisation gave an initial grant of US$1 million, and has now been joined by other donors. The initial evaluation report is available at www.hivcollaborativefund.org. The Tides Foundation/Collaborative Fund has invited ICW to coordinate a new fund of US$225,000 for treatment literacy initiatives for women and children in Africa, under the Women and Children's Collaborative Fund for Treatment Literacy in Africa.[70]

Partnership Case Study: IFRC and GNP+

The most outstanding success in a partnership, in terms of concept and scale, has been that forged between the International Federation of Red Cross and Red Crescent Societies (IFRC) and GNP+. This has come about despite initial scepticism by GNP+ to the Federation's invitation:

> *"Rather like the alliance between an elephant and the flea."* [71]

The Memorandum of Understanding (MOU) between the two organisations was signed in 2001, reflecting a special relationship between IFRC and GNP+ to work closely in partnership with PLHIV towards the eradication of stigma and discrimination. Stigma reduction complements the IFRC'S other pillars of prevention, care and treatment. It is also an essential component of the IFRC's own workplace directive.[72]

Partnership Case Study: IFRC and APN+

Case studies of the partnership have been well documented,[73] with the exception of the collaboration between APN+ and Australian Red Cross (ARC) Regional Office in Bangkok. But it is perhaps this partnership[74] which might be most relevant to Oxfam Australia's focus on the Asia and Pacific region.

A similar MOU was signed between the IFRC and APN+ in late 2002. In May 2003, APN+ accepted the ARC's offer to move its secretariat into the ARC office. At that time, APN+ had no core-funding, infrastructure or equipment. The ARC, with support from

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[70] See the ICW website www.icw.org for a report of treatment preparedness skills-building workshop focusing on Women, Families and Children 28th – 30th November 2005, Kampala, Uganda.
[71] Stu Flavell, then GNP+ International Coordinator at the original meetings.
[72] International Federation Secretariat/Delegation. *HIV/AIDS in the Workplace Directive.*
[73] UNAIDS (2003). *A vital partnership: the work of GNP+ and the International Federation of Red Cross and Red Crescent Societies on HIV/AIDS.* UNAIDS/0.3.52E http://www.ifrc.org/docs/pubs/health/hivaids/UNAIDS_bestpractice.pdf There is also an IFRC CD-Rom kit *Leading by example: A tool kit for the reduction of HIV-related stigma.*
[74] Personal communication and PowerPoint presentation Elden Chamberlain, ICAAP 2005, Kobe, Japan.

the IFRC, provided APN+ with space and facilities free of charge and worked with them to submit proposals for core funding. Initially neither organisation was quite sure about how the partnership would work, but this changed over a few months as the organisations developed a better understanding of what each was trying to achieve.

In September 2003, ARCAIDS (the Australian Red Cross AIDS) held their first program meeting in Kunming, China. APN+ was invited to the meeting and facilitated key sessions for ARC on treatment, discrimination, injecting drug use and GIPA. As a result of that meeting, collaboration was discussed on a number of projects amongst the country team. Projects were developed for China, Cambodia, Laos and PNG. The ARCAIDS/IFRC was similarly invited to take part in APN+ projects. APN+ was also invited to take part in the Asian Red Cross and Red Crescent HIV/AIDS Network regional strategic planning workshop in Bali.

In October 2003, APN+ received core funding from the POLICY Project to employ staff and set up an office. Rather than do that, ARC suggested moving into a larger space and to continue to share infrastructure, rent and staff. All agreed it was the best way forward. In December 2003, the two organisations moved to a larger space that accommodated their needs yet enabled them to retain separate entities.

The arrangements under the current MOU are to:

- Share the costs of office space
- Jointly employ two staff - an administration assistant and a project officer
- 5 hours per week of the ARC Office Manager's position is dedicated to APN+ for training and support with their financial systems
- Support and infrastructure from ARC/IFRC is available to APN+
- Collaboration on projects

Collaborations in 2005 included:

- Developing a peer-based counselling manual [75]
- Proposal to develop two appendices to the GNP+ Positive Development Manual, on stigma and discrimination, and treatments
- Peer support program with Bali+ (a PLHIV group)
- The Dong Da Drop-in Centre in Hanoi
- Supporting the set-up of the national PLHIV support group in Laos (LNP+)
- PMI hotline evaluation (a volunteer telephone counselling service) with the Indonesian RC
- Tsunami PLHIV project (following up PLHIV needs in tsunami areas, Aceh)
- Support to Mongolia Positive Life (a PLHIV group)[76]

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[75] APN+ and Australian Red Cross (2005). *Asia Pacific participant's manual and training resource on basic HIV training skills.*
http://www.apnplus.org/doc/Basic%20HIV%20participant%20counselling%20manual.pdf
[76] Mongolia Red Cross Society may be setting up a co-location with the Mongolian PLHIV group.

- Workplace policy project with National Societies.[77] An Asian Red Cross HIV Workplace Policy was developed, using the Federation HIV Workplace Directive and best practice HIV Workplace Policies.
- Joint funding for emergency support.
- Discrimination in Health Sector Project (Asian Red Cross Health Care Worker HIV Discrimination Training Package and resources developed).[78]
- Core competencies project (for people working in HIV).
- Establishing and supporting a regional support network/mechanism for HIV+ people and others affected by HIV, including Red Cross employees, delegates and volunteers.[79]

The partnership results include:

- APN+ is functional and mobilised.
- APN+ has faith and understanding of IFRC.
- Increased ARC/IFRC ability to respond to needs.
- ARC/IFRC programs more focussed on GIPA.
- Asian RC/RC Network strategic plan reflects partnerships with PLHIV.
- Country level strategic plans driven by GIPA and partnerships with PLHA.
- ARC programs depend on direct input by PLHIV.
- Country level programs now much more engaged with PLHIV and their organisations.

Challenges for the ARC/IFRC include:
- Understanding GIPA principles - involving APN+ from the beginning of a project, and moving beyond tokenism - such as inviting APN+ to a meeting at the last minute, or developing a project, and then going to APN+ for their approval.
- Sitting at a round table where we all have equal say and ownership in decision-making (having to hold back from the 'charity approach' of taking the lead and "helping" APN+).
- Institutionalizing arrangements, through policies and procedures, so that GIPA is part of the system and not dependent on the goodwill of individuals [80]who may leave the organisation.
- Understanding clearly the different roles of the organisations - how best they can complement each other (e.g. ARC/IFRC advocacy is restricted), but that they also don't always have to agree or work together.
- Providing support so that PLHIV staff, volunteers and members of both organisations can fully participate.

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[77] Baldwin, R (2005). *Draft report ART HIV discrimination project.* ARC, APN+
[78] ibid.
[79] ibid.
[80] This partnership may very well not have succeeded because at the time, the ARC was not very engaged in the whole process when the MoU was signed between the IFRC and GNP+. The personal commitment from Elden Chamberlain, who had just joined as the regional ARC manager, and had some background at the Northern Territory AIDS Council, assisted with the success of the partnership.

- Providing resources and opportunities so that APN+ staff and members are paid for their input and involvement.

ARC's assistance has allowed APN+ to travel to different meetings and countries to work with both the national RC societies and national PLHIV support groups. APN+ was able to complement the ARC's emergency response by finding PLHIV affected by the tsunami and address their need for medications etc. This opportunity has allowed APN+ to help set up a support group for local Acehnese PLHIV.

Increased synergies between IFRC, APN+ and ICW are expected when ICW receives donor funding for an ICW Regional Women's Coordinator, who will be co-located in the same office, and will coordinate activities for ICW and WAPN+, the nascent Women's Asia-Pacific Network (WAPN+).

7. Publications and Resources

7.1 International Agreements and Frameworks that support GIPA

Declaration of the Paris AIDS Summit, 1994
The full document can be found at http://www.ecpp.co.uk/parisdeclaration.htm

The signatories were: Argentina, Australia, Bahamas, Belgium, Brazil, Burundi, Cambodia, Cameroon, Canada, China, Cote d'Ivoire, Denmark, Djibouti, Finland, France, Germany, India, Indonesia, Italy, Japan, Mexico, Morocco, Mozambique, Netherlands, Norway, Philippines, Portugal, Romania, Russian Federation, Senegal, Spain, Sweden, Switzerland, United Republic of Tanzania, Thailand, Tunisia, Uganda, United Kingdom, United States of America, Vietnam, Zambia and Zimbabwe.

United Nations General Assembly Special Session on HIV/AIDS, 2001
In June 2001, the United National convened the first General Assembly Special Session on HIV/AIDS (UNGASS) in New York, to review the state of the HIV epidemic.
A "*Declaration of Commitment on HIV/AIDS: Global Crisis, Global Action*" was accepted by UN member countries. The full document can be found at
http://www.unaids.org/html/pub/publications/irc-pub03/aidsdeclaration_en_pdf.pdf

The Code of Good Practice for NGOs responding to HIV/AIDS (2004)
The NGO HIV/AIDS Code of Good Practice was a joint initiative developed by many NGOs, including AIDS organisations, and was hosted by the IFRC. GIPA is one of the guiding principles of the Code.

The complete text of the Code is available at www.ifrc.org/what/health/hivaids/code/ along with a list of organisations that are signatories and have therefore committed to the implementation of the Code and its principles.

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UNAIDS (2003) *A Vital Partnership: The Work of GNP+ and the International Federation of Red Cross and Red Crescent Societies on HIV/AIDS.* UNAIDS/0.3.52E
http://www.ifrc.org/docs/pubs/health/hivaids/UNAIDS_bestpractice.pdf

UNDP (2004). *From Involvement to Empowerment: People Living with HIV/AIDS in the Asia-Pacific* ISBN 81-902-585-1-6. http://www.youandaids.org/unfiles/frominvtoemp.pdf

UNDP (2006). *Evaluation of UNDP's Role and Contributions in the HIV/AIDS Response in Southern Africa and Ethiopia*. Evaluation Office, UNDP May 2006
http://www.undp.org/execbrd/pdf/Evaluation%20of%20HIV%20AIDS%20Programme%20-%20May%2023.pdf

UNV/UNAIDS (2004) *Feasibility Study Report: Greater Involvement of People Living with HIV/AIDS in Vietnam.*
http://www.unaids.org.vn/about/cosponsor/docs/Feasibility_Study_Report.pdf

VicHealth (2003). *The Partnerships Analysis Tool for Partners in Health Promotion: A Resource for Establishing, Developing and Maintaining Productive Partnerships.*
http://www.vichealth.vic.gov.au/assets/contentFiles/VHP%20part.%20tool_low%20res.pdf (or resources on Mental health and wellbeing at
http://www.vichealth.vic.gov.au/Content.aspx?topicID=239#cs_576

VicHealth *Mental Health Promotion Framework 2005-2007*
http://www.vichealth.vic.gov.au/assets/contentFiles/vhp%20framework-print.pdf

WHO (2004) *Facilitator's Guide to the Preparation of Expert Patient-trainers for the WHO Basic ART Clinical Training Course and the ART AID Course.*
http://ftp.who.int/htm/IMAI/Firstlevel/EPT/EPTfacilitator.pdf

7.3   Global PLHIV Networks

PLHIV peer support groups are essential for the individual and collective growth and development of People Living with HIV.

Since response to GIPA has been slow, PLHIV around the world have been the first to form their own networks and partnerships. Twenty-five years on from the beginning on the pandemic, and 23 years since the Denver principles, the same priorities for the PLHIV movement remain:

- Reduction of stigma and discrimination
- Access to treatment
- The meaningful involvement of PLHIV

From 1996, the far-reaching impact of Highly Active Antiretroviral Therapy (HAART) changed PLHIVs' lives and increased the sustainability of GIPA.

The treatment access movement was catalysed in 2000 by South Africa's Treatment Access campaign (TAC) and the International AIDS Conference (IAC) in 2000 in Durban, South Africa. This was the first time that the IAC had been held in a resource-poor country, affected by the AIDS pandemic. As a result, clinicians and activists from the North were faced with the realities and scale of the epidemic devastating the South, resulting in the creation of several North-South alliances.

There are three global PLHIV networks: GNP+, ICW and the ITPC.

GNP+: Global Network of People Living with HIV/AIDS[81]
GNP+, founded in 1993 and based in Amsterdam, is the umbrella body for the regional PLHIV groups in Africa (NAP+), the Asia-Pacific (APN+), Latin America, North America and Europe. Young Positives, a PLHIV network for HIV-positive youth under 30, is hosted through GNP+ infrastructure.

ICW: The International Community of Women Living with HIV/AIDS[82]
ICW is the only international network run for, and by, HIV-positive women.
It was founded in 1992 and is based in London. ICW-Latina has evolved as the ICW branch for Spanish-speaking women. ICW has also started a caregiver's group for positive and non-positive women who are looking after people infected with HIV. ICW is currently undertaking a research project *"Silent Voices"*, with HIV-positive female injecting drug users.

ITPC: The International Treatment Preparedness Coalition
ITPC was founded in 2003 after a meeting of treatment activists and their allies in Capetown, South Africa.[83] The ITPC was instrumental in the push for donations to the

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[81] www.gnpplus.net. Many resources available online.
[82] www.icw.org . All ICW resources available online. Read about current activities at
http://www.icw.org/tiki-index.php?page=Current%20Activities

Global Fund to Fight AIDS, Tuberculosis and Malaria, and in supporting the meaningful participation of PLHIV in each of the Fund's Country Coordinating Mechanisms (CCMs).

These global and regional PLHIV networks have been particularly active in engaging in issues to do with policy and carrying out their own research. Programming is more problematic than policy work because of the lack of capacity and resources.

The networks also produce their own resources, either alone or jointly, to share their collective knowledge and experience with other PLHIV. These range from fact-sheets and self-help information to manuals, toolkits and policy papers.   These have been extremely well received – they are practical, accessible, written by PLHIV for PLHIV, and have inspired other PLHIV as proof of what PLHIV can do. One of the most useful examples of a resource produced is the GNP+ guide[84], which provides tools for strengthening PLHIV involvement in Global Fund Country Coordinating Mechanisms, and can also be used as a resource for enhancing civil society participation.

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[83] Fact sheet ITPC pp90-93 in ITPC (2005) *Missing the target - a report on HIV/AIDS Treatment access from the frontlines* http://www.aidstreatmentaccess.org/itpcfinal.pdf
[84] GNP+(2005) *Challenging, changing and mobilizing: A guide to PLHIV involvement in Country Coordinating Mechanisms. (*English, French, Spanish, Arabic, Russian) Also available on ICW and POLICY project websites. http://www.gnpplus.net/cms-downloads/files/handbook-EN.pdf

7.4 PLHIV Organisations - Publications and Resources

This list is only indicative of the range of resources produced by PLHIV organisations, but it is by no means a complete inventory. More are available online at organisations' websites and other websites such as UNDP's www.youandaids.org or on the Asia-Pacific PLWHA Resource Centre website www.plwha.org. All ICW resources are available at http://www.icw.org/tiki-index.php?page=Publications

Presentations and Reports

APN+ (2004) *AIDS Discrimination in Asia* http://www.apnplus.org/doc/AIDS-asia.pdf

APN+ and POLICY Project (2005) *Baseline Survey on GIPA and Stigma and Discrimination in the Greater Mekong Region – Report on Qualitative surveys in Lao PDR, Thailand, Vietnam and Guangxi and Yunnan Provinces, China.* http://www.apnplus.org/doc/Baseline_survey_report__final_to_USAID%20rz.pdf

APN+ (2006) *Who we are, What we've done, Where we're going…1994-2006 and beyond.* APN+, Bangkok, Thailand Email:info@apnplus.org

GNP+ (2003) *A Multi-country Study of the Involvement of People Living with HIV/AIDS (PLWHA) in the Country Coordinating Mechanism* http://www.gnpplus.net/cms-downloads/files/multi_country_study.pdf

ICW (2002) *Voices and Choices Zimbabwe Project – Reports*.

ICW (2004) *Voices and Choices Thailand Project – Reports*.

ICW (2005) The Tides Foundation/Collaborative Fund invited ICW to coordinate a new fund of US$225,000 for treatment literacy initiatives for women and children in Africa. *Report of a treatment preparedness skills building workshop focusing on Women, Families and Children* 28th – 30th November 2005, Kampala, Uganda.

International Treatment Preparedness Coalition (2005) *Missing the Target - A Report on HIV/AIDS Treatment Access from the Frontlines*. http://www.aidstreatmentaccess.org/itpcfinal.pdf

Nairobi Think Tank (2005) http://www.gnpplus.net/cms-downloads/files/Nairobi_meeting_report.pdf

Paxton S, Welbourn A et al (2004*) "Oh, This one is Infected!": Women, HIV and Human Rights in the Asia-Pacific Region.* Expert Meeting on HIV/AIDS and human rights in the Asia-Pacific 23-24 March, Bangkok. http://www.icw.org/tiki-download_file.php?fileId=79

Position Statements and Policy Documents

APN+ (2004) *APN+ Position Paper No.1: AIDS-Related Discrimination and Human Rights.* http://www.ahrn.net/library_upload/uploadfile/file1778.pdf

APN+ (2004) *APN+ Position Paper No2: GIPA* http://www.ahrn.net/library_uploadfile/file1777.pdf

APN+ (2005) *We Have Rights.* http://www.apnplus.org/doc/Rights%20Advocacy%20Tool-16%20Feb%2705.pdf
ICW (2004) Guidelines on ethical participatory research with HIV positive women

GNP+ and ICW (2005) Position Statement: Injecting Drug Users and Access to HIV Treatment. http://www.icw.org/tiki-index.php?page=Publications

ICW (2004): Vision papers
• HIV Positive Young Women
• Access to Care, Treatment and Support (ACTS)
• HIV Positive Women, Poverty and Gender Inequality
• HIV Positive Women and Human Rights
• Participation and Policy Making: Our rights

ICW (2004) Visibility, Voices and Visions: A Call for Action from HIV Positive Women to Policy Makers.

Toolkits and Manuals

APN+ (1999) *Lifting the Burden of Secrecy – A Manual for HIV-Positive People who want to Speak Out in Public*. http://www.gnpplusnet.net/regions/files/speakers_manual.pdf

APN+ (2001) *Lifting the Burden of Secrecy – A Training Module for HIV-Positive Speakers.* http://www.youandaids.org/unfiles/apntraining_module_.pdf

APN+ and NAPWA (Australia) (2003) *Organisational Development Manuals: 1 (Group project planning); 2 (Obtaining funding and Proposal Writing); 3 (Accountability).* http://www.plwha.org/resources?bstart:int=20

APN+ and the Asia-Pacific Council of AIDS Services Organisations (2005) *"Valued Voices" GIPA Toolkit: A Manual for the Greater Involvement of People Living with HIV/AIDS.* http://www.7sisters.org/resourcecentre/common/apngipa.pdf

APN+ and Australian Red Cross (2005) *Asia Pacific Participant's Manual and Training Resource on Basic HIV Training Skills.* www.apnplus.org/doc/Basic%20HIV%20participant%20counselling%20manual.pdf

GNP+ (1998) *Positive Development: Setting up Self-help Groups and Advocating for Change. A Manual for People Living with HIV.* GNP+ and Healthlink available in several languages http://www.gnpplus.net/cms-downloads/files/Contents.pdf

GNP+ (2005) *Challenging, Changing and Mobilizing: A Guide to PLHIV Involvement in Country Coordinating Mechanisms.* Provides tools for strengthening PLHIV involvement in Global Fund Country Coordinating Mechanisms *(*English, French, Spanish, Arabic, Russian) Also available on ICW and POLICY project websites.
http://www.gnpplus.net/cms-downloads/files/handbook-EN.pdf

GNP+ (2005) *Guidelines for Improving CCMs through Greater PLHIV Involvement*. These guidelines can be used as an advocacy tool to assist all stakeholders in Global Fund processes to help ensure that PLHIV concerns and issues are addressed as fully as possible (they can also be adapted for use when working with other multisectoral or coordinating bodies at local, district, provincial or regional levels). Available in English, French, Spanish, Russian and Thai. Also available on ICW and POLICY project websites http://www.gnpplus.net/cms-downloads/files/Contents.pdf

ICW (1999) *A Positive Women's Survival Kit*. The kit has been produced in English, French, Spanish and Russian, Urdu, Thai, Kiswahili and Portuguese and distributed to thousands of women across the globe. The Survival Kit is also used by HIV positive women in many parts of the world when running workshops for other HIV positive women. Can be downloaded in English, French and Spanish from ICW website.
http://www.icw.org

ICW and SIPAA (2005) *Positive Women Measuring Change.* A monitoring tool on access to care, treatment and support, sexual and reproductive health and rights and violence against women. It was created by and for HIV positive women, May 2005.
http://www.icw.org

7.5   Contact List

Individuals contacted by email only are indicated by an asterisk*. All others were interviewed by telephone and contacted by email.

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