

"Valued Voices"

GIPA Toolkit A manual for the
Greater Involvement of People
Living with HIV/AIDS

developed by

Asia-Pacific Network of People Living with HIV/AIDS (APN+)
and
Asia-Pacific Council of AIDS Service Organisations (APCASO)

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and



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FOREWORD

It is with great excitement that the Asia-Pacific Network of People Living with HIV/AIDS (APN+) and the Asia-Pacific Council of AIDS Service Organisations (APCASO) in association with the Seven Sisters Coalition, bring you this GIPA toolkit. This is an historic achievement in that it is the first time, to our knowledge, that a toolkit has been produced to assist PLWHA networks and civil society organisations to have a clear understanding of the concept of Greater Involvement of People Living with HIV/AIDS (GIPA), and to introduce it in their work.

APN+ and APCASO are committed to promoting the GIPA agenda and the need for meaningful involvement and representation of PLWHA in all aspects of the response to the growing epidemic in this region. We therefore urge you to make full use of the practical and easy to implement suggestions and activities that are outlined in this toolkit.

GIPA is not a concept that is difficult to grasp, yet often organisations don't seem to be willing to make the commitment to acknowledge that involving those at the core of the epidemic simply makes good sense, and brings credibility and reality to projects, activities and the organisation as a whole.

By fully utilising this GIPA toolkit it will help promote the rights and needs of people living with HIV/AIDS to ensure that their voice is heard. Empowered PLWHA should play a significant part in the response be it in lobbying governments, information, education and communication, community mobilisation or service provision, prevention, treatment care and support.

Please feel free to provide us with comments or feedback on the toolkit. A lot of effort has been put in by many parties, particularly from PLWHA themselves, and we hope this toolkit will be a way to support you in your efforts in maximising the involvement of people living with HIV/AIDS. However we realise also the complex and diverse issues that the epidemic raises in our lives and communities, with stigma and discrimination being the most challenging hurdle we face. This toolkit may not provide you with all the answers but it contains a wealth of information and resources, and includes references to appropriate organisations that can provide further assistance if required. We must work together collectively in order for GIPA to be effective and viable and to have a positive impact on our communities. Thank you.

Yours positively,

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We would also like to take this opportunity to acknowledge all those who have paved the way for GIPA to become a reality in our region. Many community activists who are no longer with us didn't have the benefit of such a toolkit were the pioneers of GIPA and the PLWHA leadership movement in this region. They deserve recognition for providing us with the vision and determination to ensure that the voices of positive people are heard and more importantly acted upon; their spirit lives on with all of us.

Thank you

Greg Gray
APN+
Regional Coordinator

PREAMBLE

This toolkit has been written for anyone that wants to know more about GIPA - the Greater Involvement of People Living with HIV and AIDS. It has been prepared by consultants working for the Asia-Pacific Network of People Living with HIV/AIDS (APN+), with support from the Asia-Pacific Council of AIDS Service Organisations (APCASO) and the Seven Sisters Coalition. With this toolkit, this consortium aims to convince you that GIPA is both important *and* possible and to provide practical steps to strengthen the involvement of people living with HIV in the creation and implementation of AIDS policy and programs. GIPA is not an end in itself; it is a tool to enable us to achieve our ultimate goals: improving the quality of life of all people living with HIV in this region and preventing further HIV infections.

The processes and workshop exercises outlined in this toolkit are written for PLWHA groups and networks and community-based organisations in Asia-Pacific. It can be easily adapted for use by governmental departments and international organisations, too. This is a resource document. We suggest that anyone using it should first read it through carefully, and then pick and choose the parts that are most relevant to individual needs. The exercises can be adjusted to suit the kind of organisation or group that is targeted. It is our experience that GIPA may be seen as complex and difficult; therefore, the opening sections which introduce GIPA and develop commitment to this vital principle are an extremely important starting point for all types of groups or organizations.

Throughout this toolkit -

PLWHA = a Person living with HIV or AIDS



SECTION 1: WHAT IS GIPA?

1.1 Why is GIPA important?

1.2 People living with HIV have been involved from the start.

1.3 What are the benefits of GIPA?

1.4 Is GIPA working?

SECTION 1: WHAT IS GIPA?

- 1.1 Why is GIPA important?
- 1.2 People living with HIV have been involved from the start.
- 1.3 What are the benefits of GIPA?
- 1.4 Is GIPA working?

According to people living with HIV/AIDS across the world:

GIPA is...

..... the heart and soul of the response to HIV/AIDS ; without GIPA any response is meaningless

.....a result of our commitment to and actions toward fighting stigma and discrimination around the world

.....an opportunity to show our faces working together; HIV/AIDS presents a lot of challenges and we can do a lot to get results and bring opportunities to PLWHA

and GIPA means...

...reclaiming my life -the essence of GIPA is empowering all of us.

....nothing about us without us

... meaningful involvement at all levels of policy planning

.. the involvement of PLWHAs in the development and creation of programs that affect our lives

...empowering all of us living with HIV to rise to the ever-changing and demanding challenges that living with the virus poses and to show the world that we have a vital and decisive role to play in overcoming the epidemic; that role need not be at a decision-making level but anywhere we can change peoples perceptions and understanding of the virus and its implications in a positive way is a step in the right direction

... a deliberate, well-intended, engagement and empowerment strategy of PLWHA globally to respond to the countless challenges HIV/AIDS presents in their own communities and internationally

Introduction

In 1994, representatives of 42 governments¹ met in Paris, France, for an “AIDS Summit”. People living with HIV/AIDS (PLWHA) mobilized and organized to ensure that each government brought people living with HIV as part of their delegations and listened to people living with HIV during their meetings. At the end of the summit, these governments declared: *Greater Involvement of People Living with, or affected by, HIV/AIDS is critical to ethical and effective national responses to the epidemic.* This has since been referred to as the GIPA principle, and now almost everyone agrees that GIPA is equally critical to responses to AIDS at every level, from international policy and international funding mechanisms throughout national efforts right down to community mobilisations and grass-roots organisations.

GIPA= Greater Involvement of People Living with HIV/AIDS

¹ The Paris Declaration was signed by: 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, Zimbabwe.

The 42 governments that met in Paris promised many things: to make the fight against HIV/AIDS a priority; to protect and promote the rights of individuals; to make available the necessary resources; to work in a spirit of true partnership with PLWHA as well as affected communities. The spirit of this commitment was confirmed at the United Nations General Assembly Special Session on AIDS (UNGASS), which took place in New York in 2001. The UNGASS declaration is a powerful international statement that supports and encourages the involvement of PLWHA. Yet, more than ten years since Paris and almost four since UNGASS, we know that most governments are far from realising these commitments. What can we do to make the GIPA principle more than hopes and dreams? This toolkit is an answer to that question.

1.1 Why is GIPA important?

With over 40 million people living with HIV around the world, and over 8,000 dying each day, there is no doubt that the HIV/AIDS epidemic is one of the greatest challenges humanity faces. HIV is a complex virus, from the standpoints of both its biology and its social effects; but, even so, we now have the scientific understanding to prevent and treat HIV. Yet, despite a burgeoning “AIDS industry” dedicated to preventing the spread of HIV and cushioning those affected from its impacts, the HIV epidemic remains out of control. There is a glaring need for more and better responses to HIV. Meaningful involvement of positive people is critical to developing better responses.

People living with HIV are the experts on their own lives and can provide essential information and insights to make HIV programs effective. We also have the right to be involved in solving the problems of our own lives. Contributing our expertise can help us feel valuable and productive and counteract the stigma and discrimination we often face in our daily lives.

1.2 People living with HIV have been involved from the start.

People directly affected by AIDS have brought about some of the most important advances in tackling the epidemic so far. In 1983, a national AIDS conference was held in Denver, USA. There, positive activists announced a set of principles destined to revolutionise the way the world responds to an epidemic. The “Denver Principles” set forth standards for human rights and self-empowerment in a health crisis (see Resources, pg. 64). For example, they called for positive people to be involved at all levels of decision making, and they demanded privacy and confidentiality of medical records and disclosure. At the time, the idea that ‘patients’ should be involved in their own treatment, or in the response to what was generally seen as a medical problem, was very radical.

The first, and still the most effective, prevention strategy was created by people directly affected by HIV: it was gay² men who invented “safe sex”. The Gay Liberation Movement of the 1960s and 1970s made an open response to AIDS possible when the first officially-recognized AIDS cases were identified in 1981. While the first responses were inevitably terror and sadness, many gay men still refused to feel ashamed of their sexuality. When they were told that it was necessary to shut down places where gay men had casual sex (bathhouses) and have as few partners as possible, they looked for alternatives. As the risks associated with sex were became clearer,³ they did not want to return to the “closet” of shame and secrecy. The solution they found was “safe sex”, an idea that built on the strength of the gay movement: its celebration of sexuality. The first wave of safe-sex education took place in gay bars. There were no paid workers, no public health specialists, no panel of UN experts. It was one of the most successful public health campaigns in history. No country in the world has since managed to reverse the spread of HIV without promoting safe sex.

² The term ‘gay’ is used advisedly; this was a political movement in which the men involved consciously chose to use this term to describe themselves.

³ HIV was not identified until 1985, and it was not known that condoms were an effective barrier to HIV transmission until later.

It was also people living with HIV who led the way to access to treatment. Zachie Achmat is a South African who became HIV positive while in prison for organizing for the ANC (the political party led by Nelson Mandela, which overthrew the white apartheid government). Zachie Achmat leads a movement of positive and negative people in the Treatment Action Campaign, which fought to persuade the government to provide anti-retroviral treatment⁴ for everyone that needed it. In a developing country with almost 5 million people living with HIV, that could only be possible by providing generic drugs. Generic drugs are vastly cheaper than drugs sold by the major pharmaceutical companies. Following the victory of the Treatment Action Campaign, several countries gained the confidence to import generic drugs and even to develop their own capability to manufacture them. Generic drugs are fundamental to expanding access to treatment.

These are two important examples of the ways that people living with HIV have consistently been at the forefront of a successful response to AIDS. The level of activism we see here in the Asia-Pacific region is far less than that in some other regions of the world⁵. The voice of Asian-Pacific people living with HIV has mainly been that of a few committed individuals supported by NGOs and other agencies. In some countries in the region, a self-help movement has been quietly developing in rural areas; consequently, it is less visible than major activist campaigns but nonetheless effective and important.

Around the world, people living with HIV have demonstrated energy, vision and commitment in tackling HIV through loud activism and quiet diplomacy, through collective action and individual bravery. We have been involved at every level, from the village to the international stage.

1.3 What are the benefits of GIPA?

Involvement of people living with HIV has been shown to:⁶

- Make services more relevant and personalized
- Make all kinds of interventions (e.g., prevention messages, adherence to treatment counselling) more credible and compelling to the target group
- Raise awareness of issues from a PLWHA perspective, leading to the extension of activities to include advocacy for the rights of PLWHAs
- Increase the self-confidence, physical health and sense of well-being amongst the PLWHAs involved
- Reduce the stigma attached to and discrimination against PLWHAs amongst AIDS workers, clients of services and communities at large

Instead of developing policy and planning services by “them” for “us”, with all the possibilities for misunderstanding and misinformation that this creates, policy and planning can be done together in partnership.

People affected by HIV/AIDS also have a crucial part to play in the response to the epidemic. This group of people includes the partners, children and parents of positive people. Apart from their support role, many older affected people are more ‘respected’ and often find it easier to communicate, so they can have a strong impact on policy makers.

⁴ *Anti-retroviral drugs control and suppress the amount of HIV in the blood.*

⁵ *This does not imply there has been no activism at all; for example, there has been the Thai campaign to have treatment for OIs and ARV drugs included in state-supported health schemes.*

⁶ *The clearest evidence is provided by the Horizons Study. GIPA in NGO Service Delivery: Findings from a 4 country study. At www.popcouncil.org/horizons. Also see other references in resources section.*

Gender and Involvement

(*lay-out note: this box relates to point 1 about making services more relevant*).

Many service providers do not consider that women, heterosexual and homosexual men and transgendered people have different needs with respect to those services. By interviewing positive service users, researchers found that gender-specific needs could be identified, as outlined below. Involving positive people in planning and delivering the services allows the diverse needs to be recognized and addressed.

For HIV positive women:

- More information about motherhood, since there has been a tendency to rule out the possibility of positive women's being pregnant
- Specialist gynecological and obstetric care
- Counseling by other women
- Social support for affected children
- Training to carry out productive activities
- Identifying appropriate language to talk about issues such as safe sex and the use of condoms

For affected women:

- In the case of partners of PLWHA, more information on how to have sexual relations without becoming infected and about care of PLWHA's relatives
- Psychological support for the family

For HIV-positive heterosexual men

- Greater access to condoms
- Appropriate information about safe sex
- Counseling for partners

For HIV-positive homosexual and bisexual men:

- More open and tolerant attitudes about homosexual and bisexual men
- Confidentiality with regards to their serostatus and their sexual orientation
- Specific counseling, in pairs as necessary
- Non-discriminatory medical care
- In the area of prevention, language and content adapted to their sexual practices

From Horizons / Alliance / Kimirina (2000): involvement of people living with HIV/AIDS in the delivery of community-based prevention, care and support services in Ecuador. P10

Faye, a Filipino living with HIV, shares her experiences of HIV in schools, colleges and local government units. Faye describes how during study tours: "... facilitators simulated HIV testing and told participants that they tested positive. When asked to share how they felt upon learning they tested "positive", the participants were nonchalant - they even joked about the whole situation. But when we came in and told our own stories, they were often surprised and then the expressions on their faces changed. So we saw we had greater impact on them. When we told our stories, they cried."

For Good: Life Stories of Filipino migrant workers living with hiv/aids. ACHIEVE, Inc./CARAM-Philippines. 2004. page 36

1.4 Is GIPA working?

This toolkit is about *greater involvement*. It is not about patronizing or tokenistic “consultations” with positive people but about giving us a role in formulating policy, deciding priorities, allocating resources, and supervising, managing and delivering programs at local, national and international levels.

I've just completed a speaking tour of 7 cities. We are often used as speakers but never involved from the very beginning. I am expected to tell my life story but they don't discuss with me about the program objectives or the way the work is carried out. Sometimes it hurts. I just feel so tired. The NGO seems to feel that they own me. Asian-Pacific PLWHA.

Nowhere in the world are people living with HIV fully involved, but the situation in our region is especially discouraging. The 2004 UNAIDS report on the Global AIDS Epidemic found that Asia was second to the bottom of the list among all regions of the world for PLWHA involvement in national HIV policy forums. Educating decision-makers about GIPA is one of our tasks, and this toolkit provides arguments and case studies to help accomplish this.

The core purpose of this toolkit is recognizing and overcoming barriers to GIPA. It is about building our capacities as individuals, networks and communities to enable us to become more fully involved. The majority of people living with HIV in the Asia-Pacific region are poor, stigmatised and lack access to treatment. Can people living with HIV really find our place at the heart of the response to AIDS? Yes, but it won't happen overnight. In this long-term project, we also may need to find allies and work in partnership with others who are affected but not infected by HIV.

I got involved because people were making decisions about our lives and we had no voice. I had so much to learn, for example, about how to talk to government officials and how health systems work. But I was determined - because we are needed. And we have a right to be heard! Asian-Pacific PLWHA.

One thing we have clearly learned in the 10 years since GIPA was announced is:

Meaningful involvement of PLWHA requires our true participation, which in turn cannot be achieved without our complete empowerment.⁷

Therefore, GIPA programs must be in line with ways to ensure PLWHA have access to sustainable financial resources, access to treatment and the reduction of stigmatisation and discrimination. The nurturing of this “enabling environment” for GIPA will also be discussed later.

GIPA is a movement for social justice and for an effective response to an epidemic that is out of control. This toolkit provides ideas to begin the journey.

⁷ From *Involvement to Empowerment: People Living with HIV/AIDS in Asia-Pacific*, UNDP pg 18, November 2004. Available at www.YOUandAIDS.org

Case Study: Involvement of PLWHAs in treatment preparedness in Thailand.

The Thai Government is attempting to provide anti-retroviral therapy to all Thai citizens that need it, up to 50,000 people by the end of 2005. PLHAs are key partners in the national ARV program. They identify people in the community needing treatment, both for opportunistic infections and ARV treatment, through screening of symptoms and support them to visit health services. They provide information and insights to enable PLHAs to make informed choices about their treatment and to adhere to it. They work with whole families to support coping skills and identify and deal as far as they can with related needs such as income or tackling stigma.

PLHAs in Thailand have been providing peer support, education and advocacy for over 10 years, through a network of hundreds of self-help groups that spans the whole country. As they have developed gradually from passive consumers of health care to active partners in NGO and state health care services, they have built their confidence and pride as well as earning the respect of public health service staff. This enables their representatives to be more respected and more effective in national policy-making bodies.

Comments by key stakeholders

“In government we treat people living with HIV/AIDS as partners... they have a very important role in educating people and communities, helping to diminish stigma and discrimination, and giving mutual support. They are very important in some of our decision-making. We recognize their outstanding work.”

Dr Sombat Thanprasertsuk, Director, Bureau of AIDS, TB and STI, Ministry of Public Health, Bangkok.

“Treatment is not only an issue for doctors. People living with HIV/AIDS should be in the driving seat.”

Mr Kamon Upakaew, Chairman, Thai Network for People Living with HIV/AIDS.

“People living with HIV/AIDS (PLHA) have a lot of information about opportunistic infections and about antiretroviral therapy. This makes health staff more active as they have to stay ahead. It’s good if PLHA can screen themselves and help their friends: health staff need to discuss treatment with PLHA, but now they don’t need to spend a lot of time explaining basic information ...These trained PLHA are good to work with. They are expert trainers of their friends, they can plan their work and they can carry out their plans.”

Ms Porntip Kemngern, Nurse, northern Thailand.

“If I were not HIV-positive I would still be a housewife and be working in the rice field. I would never have learnt how to say what I want or how I feel. I would never have learnt how to discuss health problems with my doctor.”

Ms Buarian, north-east Thailand.

See the full story in **INVOLVEMENT OF PEOPLE LIVING WITH HIV/AIDS IN TREATMENT PREPAREDNESS IN THAILAND CASE STUDY** by Aree Kumphitak, Siriras Kasi-Sedapan, David Wilson, Nathan Ford, Pakamas Adpoon, Suntharaporn Kaetkaew, Jiranut Praemchaiporn, Amnuayporn Sae-Lim, Sudjai Tapa, Saengsri Teemanka, Nimit Tienudom, Kamon Upakaew



SECTION 2: GIPA AND THE RESPONSE TO HIV/AIDS

2.1 People Living with HIV in the Asia-Pacific region

2.2 What can people living with HIV contribute?

2.3 What is the Asia-Pacific response to AIDS?

2.4 What are the barriers to GIPA?

SECTION 2: GIPA AND THE RESPONSE TO HIV/AIDS

- 1.1 People Living with HIV in the Asia-Pacific region
- 1.2 What can people living with HIV contribute?
- 1.3 What is the Asia-Pacific response to AIDS?
- 1.4 What are the barriers to GIPA?

2.1 PEOPLE LIVING WITH HIV IN THE ASIA-PACIFIC REGION

The Asia-Pacific region is vast and diverse, and the HIV epidemics in the region reflect that diversity. The region is home to 60% of the world's population, and around 7.4 million people in this region are thought to be living with HIV.

In attempting to grasp the baffling scale of the epidemic through numbers alone, one often tends to overlook the fact that each figure conceals a man, a woman or a child, a family, a community and therein a story, a challenge and an opportunity.⁸

The range of people affected is also extremely diverse. We recognize that certain situations and sets of circumstances make people more vulnerable to HIV infection. In some countries, there is relatively high prevalence of HIV amongst some marginalised groups, for example, sex workers, men who have sex with men, injecting drug users, migrant workers, and poor farmers who sell their blood for money to survive. As the epidemic gathers momentum, HIV spreads into the general population and is increasingly found in people who do not belong to these stereotypical 'most-at-risk populations'.

The route of infection does not define who and what a person is nor the kind of contribution that person can make to addressing HIV in society. There is no such thing as a typical person living with the virus.

Many - perhaps most - Asian-Pacific people living with HIV in are completely invisible because they have not been tested. What can the people living with HIV in this region contribute to the AIDS response?

2.2 WHAT CAN PEOPLE LIVING WITH HIV CONTRIBUTE?

People living with HIV have had a powerful impact on the ignorance and stigmas surrounding HIV by speaking out about their personal experience. Their courage and wisdom provide shining examples of hope to the thousands who are isolated and afraid. They have shamed political, religious and community leaders into more compassionate and generous responses to HIV and inspired ordinary people to care about HIV and to find out their HIV status.

However, *greater involvement* entails more than speaking out and requires more than personal experience. Many different skills, both personal and technical, underlie effective engagement in the response to AIDS. These include skills in communication, leadership, group work, advocacy, fundraising, diplomacy, public speaking, and serving as representatives. Skills in technical areas are usually needed for specific functions in areas such as the science of HIV transmission, treatment education, counselling, human rights, gender analysis, and harm reduction. People should have the personal capacity to fulfil the role that they accept. Of course, skills can be developed and that is one purpose of this toolkit.

In Indonesia, some NGOs started to involve people living with HIV but they offered no support or training and the PLWHA did not have the right skills, they could not fulfil the responsibilities placed on them. This led to a backlash against the idea of involvement. Indonesian PLWHA.

⁸ From *Involvement to Empowerment: People Living with HIV/AIDS in Asia-Pacific*, UNDP pg 9, November 2004. Available at www.YOUandAIDS.org

Some well-meaning but misguided projects have thrown people living with HIV “into the deep end” with negative results. For example, PLWHAs who have not had suitable training and skills development in counselling have provided technically incorrect information. (So have many doctors and nurses, but that is not the point here.) They have tried to impose solutions based on their own experience, which sometimes has not been appropriate for the person being counselled.⁹ PLWHAs have been sent into high-level policy meetings without knowledge of the policy arena, its key agencies, assumptions and jargon, leaving them feeling confused, powerless and sometimes even humiliated.

There can be other negative impacts on PLWHAs who have become involved, too. Some of us have found it depressing to dwell on HIV so much. Some have felt sad and afraid after visiting people who are sick and dying. We usually find that our HIV status becomes known to a wider group of people when we get involved, and as a result we become more vulnerable to abuse; the more people who know your status, the less control you have over that vital, personal information.

We get involved because of a virus that is in our own blood: we can’t distance ourselves in the way that other “professionals” might do in order to cope. In fact, we are arguing precisely that the value of our contribution comes from our personal connection with the virus, even though additional skills are needed, too. So, we should not demand that all PLWHAs get involved. It has to be a personal choice. Anyone who does get involved needs a great deal of support. While many find that support of family and loved ones is essential, support must also come from the organization that person is involved with. Our contributions must be valued and rewarded appropriately.

In many countries in the Asia-Pacific region, there are people living with HIV who already have the skills needed to play an effective role. With over 7 million people living with HIV in this region, PLWHAs come from all walks of life and have many skills to offer. Whether they choose to get involved is a separate matter, and finding them and persuading them to become involved is a further challenge. But sustained involvement of people living with HIV should not depend on a few charismatic or skilled individuals. Individuals can get sick, lose hope, or move on to other things. In *all* countries, what lies ahead is the major task of developing the skills and capabilities of many more people living with HIV, to enable much broader and more effective engagement. Putting GIPA into action requires developing communities, not focusing on individuals. However, finding PLWHAs who already have the skills is a useful short-term measure.

Here are some practical examples of the roles played by people living with HIV. It is not intended to describe all the roles; there are many different ways to be involved. Do you have any other examples of roles that PLWHA are playing within Asia-Pacific?

Peer support

The first step towards empowerment of positive people is enabling them to meet other people living with the virus - peers. Such meetings allow sharing of feelings and information, and provide mutual support. Meeting peers facilitates acceptance of our status and enables us to realise that we are not alone. It can also assist in disclosure to family or loved ones, where ultimately positive people may get more support than they at first anticipate. Development of peer support groups (including groups of infected and affected people) is an essential element of GIPA. Peer support opens the door to more meaningful involvement as peer counsellors, educators, advocates and leaders.

Peer education

Living with HIV can be very complex. Difficult questions frequently arise, such as dealing with personal relationships, having children or choosing treatment options, and health care workers are frequently poorly informed or out-of-date. Many positive people find it is important for peace of mind to become expert on the many aspects of living with the virus. They are then in a prime position to pass this expertise on to peers in ways that are more appropriate to those who have

⁹ From *Involvement to Empowerment: People Living with HIV/AIDS in Asia-Pacific*, UNDP pg 9, November 2004. Available at www.YOUandAIDS.org

limited education. They can be trained to become treatments' educators, training their peers on the appropriate use of antiretroviral medication, treatment regimes, adherence issues, and side effects.

Advocacy

Positive people can be very persuasive as advocates. We can lobby for improved treatment and care on an individual or group level, as well as raise awareness of issues at policy-making level. Elected officials are sometimes more willing to support people who benefit directly from their actions (such as approving budgets for treatment and care) rather than those who benefit less directly (via targets of prevention programs).

Public education and training health professionals

Positive people who speak out openly and put a human face to HIV break the silence that surrounds HIV and AIDS. Most people untouched by the epidemic assume that HIV is nothing to do with them, and therefore pass up opportunities to learn more about it. Meeting positive people significantly impacts on people's attitudes. Positive people are changed from 'them' to 'us'. This process makes people more open to prevention programs. In particular, HIV-positive women have been found to significantly impact on young people's attitudes to AIDS (Paxton, 2002).

Positive people can also make a major impact on health care workers. Doctors and nurses are members of the community and reflect the views and prejudices of the community. Many have limited knowledge and experience of treatment of PLWHA, especially where prevalence is relatively low. They are often impressed by meeting 'patients' who are empowered and knowledgeable about their infection, and can quickly come to view such positive people as 'experts'. However, no positive people should be encouraged to go public in the media unless they have good personal support, and secure housing and income. Many people carry out public education to small, 'safe' groups, such as school classes or health workers, in places distant from their own home, and never go public in the media.

Counselling

Positive people can also be trained as counsellors. We can be very sensitive counsellors and are perceived to be much more empathetic to our peers than people who are untested or HIV-negative. Effective peer counselling alleviates the fear most people face on diagnosis. With the increased pressure of governments to test more people for HIV, the need for quality counselling is at a premium. Positive people must advocate for more opportunities to be trained and employed as post-test counsellors.

Program planning and implementation

Positive people have expertise outside the fields of peer support and treatment and it is crucial that this is used to improve programs. For example, prevention messages frequently, albeit inadvertently, add to AIDS-related stigma and discrimination. Having such messages checked by positive people before they are released can minimise this risk.

Public health policy and legislation

Positive people can and must be involved in decision making related to AIDS policy and laws, at provincial, national and international levels. There are examples of positive people being offered membership of national and provincial AIDS commissions, and provided with opportunities to participate in committees discussing AIDS-related legislation. In several cases, such involvement has avoided potentially inappropriate actions, such as invoking legislation that could result in quarantine of positive people.

Are we practicing what we preach? A challenge to all PLHIV

Many of us talk about GIPA (Greater Involvement of People Living with HIV/AIDS); however, GIPA is not just something others need to implement. The question of what steps we are taking to implement GIPA in our own PLHIV communities is a crucial one. Leadership is about mentoring others and giving them the chance to develop and become leaders too. It's about involving others living with HIV from all backgrounds, from all religions, lifestyles, and countries and of all ages. Are we really being inclusive in the work we do as PLHIV? We should all ask ourselves how we can involve more PLHIV in the work we are doing and take both collective and individual steps toward making that happen.

Extract from *CCM: Challenging, Changing and Mobilizing: A Guide to PLHIV Involvement in Country Coordinating Mechanisms*, GNP+, December 2004 page 42. Available at: <http://www.gnpplus.net/>

2.3 THE HIV AND AIDS RESPONSE IN ASIA-PACIFIC

The diversity of the Asia-Pacific region is mirrored in the variety of ways that each country has responded to HIV over the course of the pandemic. In fact, the response has closely followed the same range of reactions that most of us experience when we first test positive for HIV, from confusion, fear and denial to acceptance that moves to action, and finally to the active seeking of care, support and treatment.

With few exceptions, in country after country, the discovery of persons living with HIV has triggered fear-based discrimination. Several countries immediately banned HIV-positive travellers, a reaction not uncommon throughout the world. (Some 60 countries - including China and the USA - still require mandatory testing for travellers and apply restrictions on those testing HIV positive¹⁰). Some countries continue to deny the presence of the epidemic at all; for example, Han Kyong Ho, Director of the Central Hygienic and Anti-Epizootic Centre of the Ministry of Health of the Democratic Peoples Republic of Korea recently stated in the *Pyongyang Times*, "The DPRK is the sole country on the earth that has no AIDS-related patient so far," while admitting at the same time that some 27 HIV-positive foreigner workers were sent home "at their own request." Some countries have gone full circle and, after initial denial responded swiftly and decisively; they include nations such as Cambodia (only recently), Indonesia, Japan, the Philippines, Thailand, and to a lesser extent, China and Vietnam. Other countries took actions to control behaviours that entailed risk of HIV transmission and closed or restricted access to commercial sex establishments and places where men have sex with men, blaming the epidemic on those who, they assumed, practiced high-risk behaviours.

But, much as it did in North America and Europe, the early Asian-Pacific response to AIDS was most often characterised by activism, which continues today through organizations like APN+ and the many local and national networks of people living with HIV/AIDS throughout the region. Some have been in operation since the 1980s, while others started recently, such as LPN+ and FJN+ (the Laos and Fiji Networks of PLWHA). Although often limited in scope, almost from the beginning, advocacy efforts, community mobilisation, and volunteer-based support were undertaken driven by those who were infected and affected - usually family members, friends and neighbours. These men and women often did not realise that they were advocating for themselves and their loved ones. It is these very efforts that GIPA, and this toolkit, are intended to build upon, improve and increase.

¹⁰ <http://www.hivdent.org/publicip/inter/ppinUCHT062004.htm>, accessed March 2005

“TYPICAL” RESPONSE

Let’s look at the typical response to HIV in most countries, discuss what the response might consist of and note who usually is responsible for it. Then, let’s look at the response that has been set up in your own country or area.

- Surveillance of the epidemic: determining who is at risk and why, who is infected and how they became infected, and the dynamics and behaviours that impact both prevention and care delivery.
- Prevention: reducing the transmission of HIV, which includes VCT (voluntary counselling and testing), condom and lubricant distribution, education and efforts to heighten public awareness.
- Treatment, care and support for people living with HIV/AIDS: a broad and crucial area that includes access to health care, ARV (antiretroviral medications), treatment and prophylaxis (prevention of onset) of OI (opportunistic infections), counselling, home/clinic/hospital care and palliative (late-stage) care.
- Research on HIV/AIDS and its impacts: work vital to providing up-to-date information about the positive and negative impacts of medications, behaviour-modification interventions, cultural factors, and other matters and how they affect the positive and affected people.
- Human rights of people living with HIV/AIDS: basically, this encompasses all of the work done to fight stigmatisation and discrimination.
- Government coordination and planning: this includes national AIDS planning as well as community-based coordination and funding efforts.
- Policy development: putting into the “systems” all of the above that are necessary to make happen through governing principles, rules, regulations and laws.

Each response is usually multi-sectoral; that is, it happens at different levels of society, from the local (such as patient groups and affected networks, community-based organizations, hospitals and clinics, schools and businesses) to the national (such as human rights commissions, national ministries and national AIDS coordinating councils), regional (such as APN+, 7 Sisters, and APCASO) and international (such as the UN, International Federation the Red Cross/Red Crescent Societies (IFRC), international NGOs (INGO) and universities, which often work on the local, national and regional levels, too).



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Typical Response to HIV by Responsible Party

RESPONSE	LOCAL	NATIONAL	REGIONAL	INT'L.
Surveillance of the epidemic:				
Government		❖		❖
Networks/PLWHA	❖	❖	❖	
CBO/NGO	❖			
INGO/UN/IFRC	❖	❖	❖	❖
Hospital/clinics	❖			
University	❖			
Private sector				
Prevention:				
Government	❖	❖	❖	❖
Networks/PLWHA	❖			
CBO/NGO	❖	❖		
INGO/UN/IFRC	❖	❖	❖	❖
Hospital/clinics	❖			
University	❖			
Private sector	❖	❖		
Treatment, care and support for people living with HIV/AIDS:				
Government	❖	❖	❖	❖
Networks/PLWHA	❖			
CBO/NGO	❖			
INGO/UN/IFRC	❖			
Hospital/clinics	❖	❖		
University	❖			
Private sector	❖			
Research on HIV/AIDS and its impact:				
Government	❖	❖	❖	❖
Networks/PLWHA	❖		❖	❖
CBO/NGO	❖			
INGO/UN/IFRC	❖	❖	❖	❖
Hospital/clinics	❖	❖		
University	❖			
Private sector				
Human rights of people living with HIV/AIDS:				
Government	❖	❖	❖	❖
Networks/PLWHA	❖	❖	❖	❖
CBO/NGO	❖	❖	❖	❖
INGO/UN/IFRC	❖	❖	❖	❖
Hospital/clinics				
University				
Private sector	❖			
Government coordination/planning:				
Government	❖	❖	❖	❖
Networks/PLWHA	❖	❖	❖	❖
CBO/NGO	❖			
INGO/UN/IFRC		❖	❖	❖
Hospital/clinics				
University	❖			
Private sector				
Policy development:				
Government	❖			❖
Networks/PLWHA	❖	❖	❖	❖
CBO/NGO				
INGO/UN/IFRC		❖	❖	❖
Hospital/clinics				
University				
Private sector				

It is important to know as much about the response in our own area as possible - what it is, who is doing it and who is paying for it. The mapping or charting exercise that follows will help us identify gaps in service and knowledge, which will serve as the starting point of determining where our GIPA efforts should or could be directed.

Exercise: Charting the response in your area

The HIV/AIDS Response Chart on the next page can first be completed individually and then discussed in groups throughout your organization. For completeness and accuracy, you may want to check your observations with those of some of the responding parties in your area. This information should be updated every time a new response activity or service is discovered. It will also be the basis upon which you can build a referral database, if you do not already have one. The chart is a good test of your own knowledge of the services and activities in your area, too.

Referral information is an important tool for you to have on hand at all times. For example, PLWHAs who have just lost their jobs might call you for information about their rights. In another case, a local women's charity that wants to donate clothing to families affected by HIV but does not know the best place to take them might contact you. Having this information can be life-saving to you, to members of your organization and to positive people in your community. It is important that it be accurate and up to date.

Instructions for completing the chart:

1. Complete the chart to the best of your own knowledge.
2. Try to name the organisation conducting the activity. If you do not know an organisation name but do know that there is activity in that area, simply put a check mark (✓) in the box. In the case of governmental organizations, name the ministry and/or department, if known.
3. After you are finished, discuss your results with a group of others who have also done the exercise. (Note: a facilitator may want to have reviewed the charts and prepared the responses in advance. Whatever the case, be sure to prepare a large wall chart to record the responses for all to see.)
4. Write up the final version and circulate it first throughout your organization to obtain feedback from as many people as possible. You may be surprised at the amount of information your own members have.
5. Finally, verify all information to the extent that time allows. This may involve contacting each responding party to verify that the services and activities are still being provided, learn about changes or new activities and verify the contact information (names, phone numbers, email addresses), location and hours of operation - information that you will need for making referrals.
6. The chart is on the following page:



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HIV/AIDS RESPONSE CHART	Gov't.	Networks/ PLWHA	CBO/NGO	INGO/UN/ IFRC	Hospital/ clinics	University	Private sector	Other
Surveillance of the epidemic								
Prevention								
Treatment, care and support								
Research on HIV/AIDS and its impact								
Human rights of people living with HIV/AIDS								
Government coordination/ planning								
Policy development								

The biggest obstacles to GIPA are stigma and discrimination.

In the last 10 years of my life as a person with HIV/AIDS, the most disturbing instances that are uppermost in my mind are images of discrimination rather than those of death - people mercilessly beaten, people thrown out of jobs, people abandoned midway on surgery tables, people denied access to property, people denied shelter, people pushed to destitution.... President, Indian Network of PLWHAs.

AIDS related discrimination is widespread in Asia-Pacific. It arises from fear and misunderstanding, and early AIDS public information campaigns that emphasized risk, fear and death are largely to blame.

Stigma directly hampers the AIDS response. Studies have found that women tend to suffer more than men, being even more likely to be thrown out of the family or beaten up. The dangers of “coming out” are clear, and with so few PLWHA in Asia-Pacific having access to treatment, the advantages rarely outweigh these dangers.

Fear of stigma leads to silence, and when it comes to fighting AIDS, “Silence = Death”.

See *AIDS Discrimination in Asia*, published by APN+

2.4 WHAT ARE THE BARRIERS TO GIPA?

If putting GIPA principles into practice were easy, it would already be happening. Unfortunately, the reality is that there are many barriers that prevent and deter the meaningful involvement of PLWHA. These barriers include:¹¹

Social factors - characteristics of societies in which PLWHAs live.

- Stigmatisation and discrimination (see text box)
- Poverty and underdevelopment: most Asian-Pacific PLWHA are poor and lack access to education; many do not have access to communication tools such as email, some do not even have a telephone.
- Gender: in some Asian-Pacific countries, women PLWHAs 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 some parts of the region: that is, against sex workers, people who inject drugs, men who have sex with men, and other groups.
- Lack of solidarity amongst PLWHAs themselves, reflecting the prejudices of wider society

Institutional factors - characteristics of the organization with which the PLWHA is or could get involved.

- Lack of information about opportunities to contribute
- Policies that discriminate against PLWHA involvement, e.g., mandatory testing for HIV during recruitment, travel restrictions on PLWHAs.
- Lack of policies to encourage PLWHA involvement: affirmative employment policy; confidentiality and disclosure policy; sick leave and health insurance policies (more on this in section 3)
- Lack of funds to support volunteer PLWHA involvement, e.g., to reimburse travel expenses, pay for childcare, or cover loss of earnings while contributing
- Patronizing attitudes of staff, board of directors, or donors; looking down on PLWHAs and seeing them only as patients or victims.
- Lack of role models to positively influence and inspire more PLWHA to get involved.

Personal factors - characteristics of PLWHA who are or could be involved.

- Fear of stigma, violence
- Lack of support system
- Poor health causing inability to meet commitments to be involved consistently
- 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 for the person wishing to be involved to afford transport or childcare or other practical measures underlying the ability to contribute
- Lack of confidence in the ability to contribute, or the lack of motivation to do so.

Section 3 provides ideas and ‘real world’ examples of how to overcome these barriers.

¹¹ This section is based closely on Horizons/International HIV/AIDS Alliance/Tata Institute of Social Sciences. *The Involvement of People Living with HIV/AIDS in the Delivery of Community-based Prevention, Care and Support Services in Maharashtra, India: A diagnostic study.*



SECTION 3: PRACTICAL STEPS TO GIPA (WITH WORKSHOP EXERCISES)

Module 3.1 Analysing your organization and making a GIPA plan

Module 3.2 Employing PLWHAs

Module 3.3 Developing PLWHA capacity and networks

Module 3.4 Involvement in policy

Module 3.5 Partnerships and alliances

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MODULE 3.1 ANALYSING YOUR ORGANIZATION AND MAKING A GIPA PLAN

Research in India shows that “involvement” is both an individual process for PLWHAs and an organizational process for NGOs.¹² Community-based organizations act as incubators: they nurture and develop the skills and confidence of people living with HIV. Research indicates that many PLWHAs tend to move along a continuum from *access* to *inclusion* to *participation* to *involvement*. *Access* can be an entry point for further involvement, enabling PLWHAs to accept their HIV status, to learn about HIV/AIDS and how to cope through the services and support offered by the NGOs. Growing acceptance and confidence can lead to *inclusion*, in which positive people feel able to share their experience with other people. In some cases they offer support to others informally; in others they decide to become an official volunteer and take part in a wider range of activities. Through inclusion, PLWHAs begin to develop new skills. Further experience and skills development can lead to the opportunity for employment and *participation* in an NGO. In a conducive environment and with training to develop the required skills, PLWHAs can move on to *involvement* in an NGO. As their skills and confidence develop further, and they gain experience of working with PLWHAs from many walks of life, they may be able to represent the PLWHA voice at higher levels of policy and planning.

This typical path means that NGOs and CBOs have a greater responsibility to implement GIPA, above and beyond the beneficial effects that GIPA will have on their own effectiveness. As has already been noted, this ‘typical’ path does not imply that there are no PLWHAs that do not already have the skills needed to work as professionals within the HIV/AIDS sector.

Four Steps to GIPA

1. Secure a full commitment to GIPA by the whole organization.
2. Critically assess the organization’s GIPA status so far.
3. Identify obstacles and remedies, including existing policies that help and policies that hinder.
4. Create an action plan: the next steps for the organization.

These steps can be carried out over one 1-½ to 2-day workshop, or over a number of sessions, for example, weekly team meetings. The workshop should involve the entire organization. There are tips for managing a good workshop in the box at the end of this section (3.1).

STEP1: Establishing a GIPA vision and commitment.

This workshop exercise builds commitment and vision throughout the whole organization. Management committees can and should lead, but implementation will only be effective if everyone in the organization is convinced of its - and their -- importance. There is even a danger that affirmative action for PLWHAs will cause resentment and confusion unless everyone understands why this is important.

¹² Horizons/International HIV/AIDS Alliance/Tata Institute of Social Sciences, *The Involvement of People Living with HIV/AIDS in the Delivery of Community-based Prevention, Care and Support Services in Maharashtra, India: A diagnostic study, undated.*

Key stages:

- 1) Opening: welcome and brief speech about the purpose of the session.
- 2) Divide participants into pairs: Ask all participants to think of something they have learned from a PLWHA, something they remember because it had such a big impact on them. It could be something personal, technical, professional - anything at all. The same instructions apply to HIV-positive participants. If they believe they have never met someone who is positive, suggest that they think of a PLWHA who is visible in public life. If they cannot, suggest that they think of one of the organization's clients or service-users. All participants describe their examples to their partners. (There should be no more than 15 minutes total for this exercise). *This exercise gets people into a positive frame of mind about the topic; remembering that this is about learning from PLWHA, not just your first impressions of PLWHA, in order to draw out ideas about what PLWHA have to offer. The details of each person's experience are probably very personal and do not need to be shared with the larger group; however, if time permits, the facilitator could ask for a few volunteers to share their examples.*
- 3) Presentation: Say what GIPA is, giving some real-world examples. *You could use the introduction and case studies of this toolkit. Even better, have 2 or 3 members of the team research their own examples before the meeting and present them. There should be a Q&A and discussion, which encourages participants to talk about their own relevant experiences.*
- 4) Discussion: The topic is why we believe in GIPA. *If time permits, carry on the discussion in small groups and then have each group report to the big group. This provides an opportunity for negative ideas and attitudes to emerge; allow the other members of the group to counter them. Keep a list of all those issues that emerge that everyone agrees are real problems; do not expect PLWHAs to do all the defending of GIPA; make sure there are some GIPA champions who are familiar with the arguments and ready to counter. This may necessitate inviting some experts from outside the organization, but they must remember not to preach! The goal is for all members of the organization to take ownership of the issue.*
- 5) Agree on a vision statement: *Here is an example:* This organization will fully involve people living with HIV and those affected throughout all levels. *The vision statement must include HIV! Create a poster or several posters to stick up on the walls of the organization that states this vision, or task the creatively minded participants to do it!*



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Tips for managing this process in your organisation

- Bring in outside facilitators who have experience of GIPA, preferably PLWHAs. Naturally, outside facilitators will want to work with you to adapt this process into one they feel is valuable for the circumstances.
- If you think the staff and volunteers might be hostile or resistant to GIPA, train the board members first so that they can give a strong lead in the participatory workshop. GIPA should never be presented as optional!
- As a courtesy to PLWHAs who are already open about their status in the organization, invite them to a pre-meeting with the facilitators. Explain the intentions and plans and invite them to make suggestions. Also support them to consider how they will cope with any extra attention from their co-workers they may receive as a result of this activity. Remember that it is not fair to expect the PLWHAs within the organization to be the GIPA champions. Do not put any special demands arising from this activity onto the PLWHAs but do enable them to contribute fully.
- During the workshops and meetings needed for this process, use energisers and take frequent breaks to maintain energy and enthusiasm. The International HIV/AIDS Alliance book called “100 ways to energise groups” contains great suggestions for exercises and games to help you do this.
- Break into small groups for discussion sessions, to enable everyone’s voice to be heard. Small groups should be between 4-10 people; the ideal size is 6 or 7. The size you choose will depend on the total number at the workshop and facilities at the workshop venue.
- Involve ALL the members of the organization as much as possible. It may be necessary to repeat the workshop with different groups, but try to mix up the people so that you are building a shared organizational culture at the same time.

STEP 2: Analyse and evaluate the level of meaningful involvement of people living with HIV/AIDS and other affected communities within the organisation

Acknowledgement: with some modification, this exercise is taken from The International HIV/AIDS Alliance NGO Capacity Analysis Toolkit.

This session is based on an initial survey to determine the level of participation of people living with HIV/AIDS within the organisation. After a quantitative survey, discussion questions help to consider how meaningful that involvement is. Participants are then asked to think about the challenges to promoting more participation and how these could be overcome. These ideas will be used to develop an action plan later.

- 1) Introduce GIPA: Say what the name means and why it is important. (If this workshop follows Step 1 directly, this step is not needed).
- 2) Draw a table on a flipchart that shows the different levels of the organisation’s hierarchy, as shown in box the below.
- 3) Ask participants for the information to record the staff numbers in the columns. **Announce clearly that this exercise uses only information that is already known openly within the organization; no one is being asked to reveal personal information about themselves.** Although you are not expecting or encouraging disclosure of sensitive information at this point, facilitator should be prepared to respond appropriately if someone does decide to disclose.
- 4) Calculate approximate percentages next to the table to show what percentage of people at each level are living with HIV. Draw blocks in rough proportion to the percentages, to present this information visually.

Example

	Number	Number known to be living with HIV	%
Board	13	4	31
Advisory groups	20	6	30
Management	2	0	0
Project staff	10	0	0
Auxiliary/support staff	3	0	0
Volunteers	3	1	33
Service users	Not applicable		

5) The quantitative information revealed in the above table can be very interesting! For a qualitative understanding of these figures, you will need to consider and discuss the results further. For example, ask participants:

- What kind of contributions are PLWHAs making? For example, you may have several PLWHA members on the board, but do they actually attend board meetings and speak at them? Do they have full voting rights?
- What patterns do you see in the data? For example, are most of the PLWHAs concentrated in one level, e.g., on the board or as volunteers? Is this a problem?
- How are the different vulnerable populations involved? For example, are the people involved all men? Are people who inject drugs involved? How about sex workers? Are they all from the capital city and none from the provinces?
- If there was more representation at higher levels (e.g., the board or management levels), do you think this would encourage more recruitment of PLWHA for positions at lower levels?
- *Conclusion:* Are you satisfied with the involvement of PLWHAs and infected communities in your organization? If not, what is the problem? Remember that 'more' in numbers does not necessarily mean 'more' in terms of quality of involvement. Do you think there is the opportunity to improve the meaningful participation of PLWHAs? Where would you start with your efforts to involve PLWHA - in what roles in the organisations would they be most valuable?
- If the level of involvement of PLWHA is very low, try repeating the exercise above for 'affected people'. Keep this simple! If the organisation is Asia-Pacific Network of Sex Workers, then 'affected people' is sex workers; if the organisation serves migrant workers, then migrants are the 'affected people'. Do you have enough people from the most relevant affected communities in the organisation? *Rationale: If the organisation has not yet managed to involve their major target population, how can they imagine involving PLWHA, who are doubly discriminated against? Also, since PLWHAs are not necessarily open about their status, involving those populations most affected may be a way to increase PLWHA involvement.*

STEP 3: Identify obstacles and remedies, including existing policies that help and policies that hinder.

This step investigates what the real practical and psychological obstacles to greater PLWHA involvement may be. It uses the experience of the group, since it is the expert on the organisation's work environment and needs to feel ownership of the problems and strategies identified.

- 6) On a new flipchart, draw four columns, headed: 'Challenges', 'Actions', 'Past', and 'Future'.
- 7) In the first column, brainstorm to think of all the challenges your group has in recruiting/ involving people living with HIV/AIDS and from other affected communities.
- 8) In the next column, against each challenge, ask what the NGO could do to make it easier for people living with HIV/AIDS and other affected communities to become involved. Keep the

discussion about actions the NGO itself could take (e.g. changing its working practices, the way it recruits/interviews, or the way it trains/inducts).

Challenge	Action	Past (ever tried?)	Future (will try)
No health coverage for staff	Provide health insurance for all staff	x	✓
Short-term job contracts	Seek longer-term funding	✓	✓
Work culture: very long days	Allow flexi-time work Review workloads and reduce to reasonable levels	x x	✓ Maybe
Formal qualifications required, e.g., masters degree	Waive requirements; value experience; judge candidates on ability not paper qualifications	x	✓
Staff usually go out for lunch but most volunteers cannot afford to	Provide daily stipend Provide lunch	x x	x ✓
Staff talk about HIV status of other staff/volunteers outside the organization	Develop confidentiality policy Regular sensitivity training	✓ x	Review it ✓
How to reach potential staff /- board members from affected communities	Target areas for publicity Wider recruitment	x x	✓ ✓
Organization's name is a 'give-away, e.g., AsianAIDS	Change name Change image	x x	x ✓

- 9) Now ask which of these 'Actions' the NGO has actually taken in the 'Past' and mark with a tick (✓), or plans to do in the 'Future' and mark with a cross (X), which indicates a work in progress. Get as far as you can in this workshop, but stop when people get tired and are less imaginative.

Facilitator, please consider - it is probably time to take a break!

- 10) Create a comprehensive list of challenges and actions. Keep working on the list from item 10. Make a poster of the ideas and post in a prominent place, so people are reminded of it. Let people write more things on it. *Option:* recruit a Task Force from volunteers of representatives from each level of the organisation to continue while others take a break.

STEP 4: Create an action plan: next steps for the organization.

Introduction

This final step attempts to get an impression from the group about the possibilities and priorities of the actions identified. Management would then use this information to produce an action plan.

- 11) Add two more columns to your list: "priority" and "timing". Give each participant in the workshop 5 small stickers. Each participant then decides which 5 actions they feel are the most important and puts one sticker next to the each action. Of course, all these actions are important; that is why they are on the list. So the real question is: which actions do you think

will have most impact on this problem? Gently remind participants that this is about GIPA, not their personal preferences on working practices (but remember that these two may well be the same thing).

Count up the stickers, to see which actions the group give priority to. Do not drop any actions, but rewrite the list in order of priority. This voting system gets some ideas from the group in order to help guide management in its creation of the final action plan.

12) Then get an idea about timing. You can use stickers again or just have a group discussion. There are 3 choices: “implement immediately”, “implement within months”, “need to discuss further”. “Need to discuss further” is for actions that not everyone is convinced will make a real difference, or which have especially far-reaching implications that not everyone is comfortable with.

Challenge	Action	Priority	Timing
xxxxxxx	Provide health insurance for all staff	.	Within months
xxxxxxxxx	Seek longer-term funding	...	Discuss further
xxxxxxx	Allow flexi-time work	Immediately
xxxxxx	Review workloads and reduce to reasonable levels	...	Within months
xxxxxxxxxxx	Waive requirements	Immediately
xxxxxxxxxxx	Provide lunch	...	Immediately
xxxxxxx	Develop confidentiality policy	Within months

This table forms the basis for management to create a GIPA action plan. The plan includes the vision statement and a list of actions that the organization intends totake, with approximate deadlines. The plan should be circulated to all staff and volunteers for comment before being finalized and adopted by the board.

13) Display the plan in a prominent place in the organisation. Send a copy to partner organisations and donors. As with all plans, review it regularly.

A GIPA Action Plan should cover at least 5 categories of actions:

- Non-discriminatory staff attitudes
- Policies and procedures
- Capacity-building
- Psychological and material support
- Networking and partnerships

Two DOs	Two DON'Ts!
Create an environment where being open about your HIV status is safe.	Expect or assume that staff and volunteers will disclose their HIV status.
Reward volunteers with material benefits like good food, even cash.	Provide benefits only to HIV+ staff or volunteers; this can cause resentment and, anyway, you won't always know who is positive.

MODULE 3.2 EMPLOYING PLWHAS

“HIV/AIDS is not just a public health issue, it is a workplace issue, a development challenge and the source of widespread insecurity. Hard-won gains in employment and social protection are being reversed because of the epidemic. At the enterprise level, the effects of AIDS include loss of earnings, loss of skills, reduced productivity and the loss of markets as the consumer base is whittled away.

“We must react to the crisis unfolding in so many places where skilled and experienced workers are dying, or where children are forced to work and become heads of households because adults are either too sick to work or have died.”

*Mr. Juan Somavia, Director-General
International Labour Organization (ILO)¹³*

The goal of any business is to be productive and profitable. The village store, the post office, the 5-star hotel and restaurant, the community health clinic - and even the local office of the United Nations Development Programme -all depend on the skills and experience of their workers at all levels. From senior managers to office cleaners, everyone is needed to do their work - serve the mission - effectively and efficiently. Not unlike many of the other challenges in the today's fast-paced business world, HIV/AIDS is a something that a company must now consider in its planning and operations.

Employing positive people presents many challenges for all kinds of organizations, large and small, NGOs and private businesses alike. In 2002 in southern Africa, the international NGO, Oxfam, concluded that HIV/AIDS would soon have profound effects on the organization and that it needed to be proactive in dealing with it. It identified, among other things, increased absenteeism, financial costs from paid-out health benefits, and a decline in its ability to achieve its objectives as imminent problems. As a result, Oxfam developed policies to mainstream HIV/AIDS in their workforce, including staffing policies that included non-discrimination, confidentiality, HIV-prevention education as well as access to care, ARV treatment and support.¹⁴

Exercise: How much do we know about HIV/AIDS in the workplace?

Let's test our own knowledge related to HIV/AIDS in the workplace. The following is an exercise that can be done individually, in pairs, or as a group activity. If you are in a group, have everyone pair off and discuss the questions that are asked in the *Q&A HIV/AIDS Management <in the workplace>*.¹⁵ The questions are grouped under the key topics of Policies, Legal Obligations, Employer-Employee Relationships and Cost of Treatment. Take notes, because, after you have finished, the group will discuss each question. Try to limit completing the questionnaire to 30 minutes, or 2 minutes per question, and take turns with your partner asking and answering the questions.

¹³ *Workplace HIV/AIDS Programs: An Action Guide for Managers, Family Health International (FHI) 2002, pg 2.*

¹⁴ *Progress Report on the Global Response to the HIV/AIDS Epidemic (Follow-up to the 2001 United Nations General Assembly Special Session on HIV/AIDS), Joint United Nations Programme on HIV/AIDS (UNAIDS) 2003, pg 28.*

¹⁵ *Q&A HIV/AIDS management, Asian Business Coalition on AIDS, from <http://www.abcon aids.org>, accessed March 2005.*

Q&A: Managing HIV/AIDS in the workplace

A) Policies

Question 1: Should new employees be tested for HIV?

Question 2: What are the modes of HIV transmission?

Question 3: Should precautions be taken to prevent HIV transmission in the workplace?

Question 4: Which safety measures should be taken if an employee is found to be HIV positive?

Question 5: What is the advantage of developing an HIV policy in the workplace?

B) Legal obligations

Question 6: Currently, if an employee is found to be HIV positive, what are the hiring organisation's legal obligations?

Question 7: Are there any specific laws that employers should know and understand before employing HIV-infected people?

Question 8: Are there any special requirements that the company needs to provide for people with HIV/AIDS?

Question 9: Do employers have an obligation to inform other employees of an employee's HIV infection?

C) Employer-employee relationships

Question 10: Can I terminate an employee for having HIV/AIDS?

Question 11: What can I do if any of the other employees find out about the status of an HIV-positive employee and then refuse to work?

Question 12: What should be done first if I want to employ people who are HIV-positive?

D) Cost of treatment

Question 14: What will it cost should an employee have full-blown AIDS? Think about who the cost will apply to, the company, the employee?

Question 15: What will it cost my company should I employ an HIV-positive employee?

Discuss your answers with the group. The answers of the people who developed the Q&A, the Asian Business Coalition on AIDS (ABC), can be found at the end of this section (3.2). During the follow-up discussion, record any conflicts or differences that you have at your own workplace with the answers that are provided. If you know of labour codes in your area, tell the group about those, too. Be sure to save the answers and agreements made in the group because you will want to put those ideas into your own policies and procedures regarding HIV in the workplace.

Why employ people who are HIV-positive?

Whether in southern China, urban Japan or on a remote island in the Pacific, HIV and AIDS are facts of life today. It makes good sense for any business to anticipate and prepare for the impact of a positive person as an employee, whether the business is a private, commercial entity or a community-based organization (CBO) providing care and support for people in need. But the need for CBOs and NGOs to plan and prepare in advance in this area is even more undeniable.

Exercise: “CBOs and NGOs need to plan and prepare for HIV in the workplace.”

Do you agree with that statement? Discuss each of these points as a group.

1. Many NGOs operate in areas of high HIV prevalence and/or with people who are most at risk of HIV (known as MARP) as well as other health problems.
2. As in most other businesses, employees are an NGO’s most important asset. . High employee turnover leads to undesirable losses of skills, gained knowledge and investments of time.
3. As community organizations advocate for changes in policies that are bad for their clients, they must also be leaders in demonstrating the better, more appropriate employment practices they advocate.
4. Employment helps alleviate the stigma and discrimination that positive people face in all areas of their lives.
5. The move to bring HIV care into the mainstream means that more people with HIV will depend on HIV-sensitive settings and caregivers other than those specifically focused on HIV/AIDS.
6. For HIV/AIDS service organizations, it is often better to have a person you know to be “just like you” helping you.
7. Income gives positive people much-needed financial security as well as, ideally, increased access to health care and other benefits.
8. It promotes productivity and low staff turnover to have a nurturing, open and caring work environment for everyone, regardless of their HIV status, health issues, disability, race, language, ethnic background and identity, religion, creed, sexual orientation, gender, or gender identity.
9. *It’s simply the right thing to do!*

Components of a Policy for HIV/AIDS in the Workplace

Let’s assume that you and your organisation or group have decided to recruit, hire and support HIV-positive women and men. There are many guide books, manuals and pamphlets to help with this process, some of which are listed in the section Resources in the back of this Toolkit. This process is usually driven by middle and senior management, but it should always include input from all employees in the organization or business.

Goals of a sample HIV/AIDS Workplace Policy

- i) To minimise the possibility of HIV infection for Alliance staff and their partners and dependants.
- ii) To assure a supportive work environment for staff infected and affected by HIV/AIDS.
- iii) To manage and mitigate the impact of HIV/AIDS on the work of the Alliance.
- iv) To eliminate stigma and discrimination in the workplace on the basis of real or perceived HIV status, or vulnerability to HIV infection.

- International HIV/AIDS Alliance
HIV/AIDS Workplace Policy
As revised April 2002

Next, we will review the four, following basic steps in the process:

1. Develop a strategy: Discuss the process with everyone in your organization in order to analyse your situation. We have already discussed how to do this in Section 3.1.
2. Develop/revise policies and procedures: Use the guides that are available from the examples to make it easier. A typical workplace policy will contain the following:
 - a. Clearly written policies, procedures and objectives to guide both management and staff in understanding their rights and responsibilities for starting, using and monitoring the policy.
 - b. Confidentiality agreements that guarantee employees or prospective employees that their health situation will not be discussed outside of necessary situations at work, that there is no obligation to reveal one's HIV or other health status, and that there will be no compulsory testing for HIV.
 - c. Non-discrimination guarantees that HIV status will not be used against (or for) an individual in hiring, promotion or disciplinary actions and clearly defines disciplinary actions to be taken against anyone who does discriminate against the employee.
 - d. In the event of illness or reduced capabilities, reasonable accommodation allows for changes in job requirements whenever possible (usually as long as there is no extraordinary cost to the organisation) and may also include things such as transferring the employee to another, less demanding position, creating flexible working hours, and making necessary changes to office furniture or worksites.
 - e. Education and information should be made available to all employees to raise their awareness about HIV and AIDS, stigmatisation and discrimination, prevention and care, HIV disease progression and treatments, and other related matters.
 - f. Gender issues should be taken into account here, also, to be sure that all employees are treated fairly and equally. As reported on World AIDS Day 2004, HIV affects women on more levels and to a higher degree than it does men, for a variety of reasons. Therefore, there need to be attempts to correct the inequities caused by this uneven distribution, including proactive recruitment procedures and the maintenance of proper ratios of women to men in the workplace.
 - g. Planning to prevent all workplace dangers, occupational hazards, which include possible exposure to infectious agents such as HIV, hepatitis B, and the like, should be carefully detailed. Particular attention should be paid to maintaining supplies such as first-aid kits, latex gloves, bleach and industrial disinfectants, as well as easily accessible lists of emergency phone numbers and locations for emergency care that might be needed.
 - h. Prevention: For the good of everyone - customers and clients, staff members and members of the community -- you should institute a prevention program. This is an opportunity to help your employees learn about many of the things "out there" that might cause harm to them and their loved ones (as well as affect their productivity). Condom distribution (don't forget lubricant!) is a thoughtful benefit and presents a good occasion to discuss STIs and VCT, too. Mother-to-child transmission prevention should also be covered in your training sessions. Why not consider offering VCT onsite?
 - i. Treatment and care needs to be thought through and then taught and explained. Does your health care plan (insurance) cover HIV-related needs? Can you afford to provide ARVs yourself? If not, where can an employee obtain them? This is another case in which the referral sheet we drew up in Section 2.3 can be used. OIs such as TB can be discussed and sources of treatment identified and documented, as can supportive systems and services such as counselling and support groups.
 - j. Monitoring, evaluation and review of the HIV/AIDS Workplace Policy should be built into your plan from the beginning. Employees and management alike may find ways to improve policies and procedures.
3. Develop two key programmes: Education and Prevention and ongoing Treatment, Care and Support. Your organization may want to handle this on its own, but this also offers a good opportunity to form partnerships with other groups and services in your community. They are on the list in Section 2.2.

4. **Implement the Policy:** This requires that all of the internal support mechanisms described above be in place.

Example of an HIV/AIDS Workplace Policy Plan

1. Creation of a company policy on HIV/AIDS, its dissemination to all employees, its implementation and its occasional updating;
2. Information on HIV/AIDS, ways of preventing transmission, places to seek further information and services and ongoing company and union support for responsible sexual behaviour;
3. Condom distribution at readily accessible points around the workplace;
4. STI diagnosis and treatment, whether within the company, in community clinics or in other centers where employees receive healthcare;
5. Treatment for HIV and associated diseases, such as tuberculosis;
6. Counselling and testing for HIV on a voluntary and private basis, with means to provide support for employees and/or family members who are HIV-positive;
7. Mitigation services designed to provide such follow-up activities as counselling, community support and home-based care.¹⁶

One of the best and simplest workplace policies is one that is used by the AIDS Alliance itself. Its goals are very straightforward, as shown in the text box above. The HIV/AIDS Alliance Workplace Policy is reprinted in the Resources section and can be easily adapted for most work environments.

Exercise: A discussion of a real-life situation.

Let's end this section on the employing of positive people with a group discussion of an actual case study from Indonesia.¹⁷ It shows some dos and don'ts regarding the creating of a workplace policy. After you have read the case study, use the questions that follow as discussion points. Then, read the section from the case study on what the participants felt were the lessons that they learned as reported by the Asian Business Coalition on AIDS and see if you agree.

Case study <for discussion>

Indonesia: Freeport mining company

Freeport Indonesia (PTFI) ranks among the world's largest mining companies. PTFI is one of a growing number of large enterprises in Indonesia that are engaged in HIV/AIDS prevention and care efforts.

Company background

PTFI, operating in Timika, Irian Jaya, is the largest local employer. Approximately 75,000 people live in the Timika area, including 14,000 men of single <marital> status who work for the PTFI mine. Accommodation is made for families of senior staff only.

Families of junior personnel usually stay behind, in the home province. The Timika community consists of dozens of ethnic and racial groups. A large commercial sex industry has sprung up to serve the many bachelors and other customers in this rapidly developing area.

¹⁶ *Workplace HIV/AIDS Programs: An Action Guide for Managers, Family Health international (FHI) 2002, pg 9*

¹⁷ *Country Related Documents, AIDS Business Coalition on AIDS website, <http://www.abcon aids.org/ABC/asp/DispDoc.asp?DocID=276>, Accessed March 2005*

Local vulnerability

The remoteness of the site, the extraordinary isolation, being in a foreign culture yet relatively wealthy, and being bored makes recreational sex an attractive outlet for personnel. In addition, the often high-risk, high-tech, high-stress day-to-day activities that constitute the job make ordinarily timid employees much more daring as they search for outlets from these pressures.

There is great concern about the possible rapid spread of HIV in the vulnerable, migrant employee population. Six factors contribute to the possible swift dissemination of HIV in this community:

- A rapidly, expanding sex industry (1 SW for every 100 residents).
- High STD <STI> rates in the SW population. 72% of SW's had 1 or more STDs <STIs> on initial exam.
- Poor understanding of HIV infection risks because of limited available information.
- A large, male, bachelor worker population living away from their regular sexual partners.
- High-risk traditional sexual practices in the indigenous population.
- Rapid spread of infections in nearby Papua New Guinea.

Because of these concerns, the local community health centre, in cooperation with the Freeport Public Health and Malaria Control Department, launched a multifaceted HIV/STD prevention and control program.

PTFI HIV/AIDS program

The goal of the program is to reduce the risk of HIV/AIDS and STD transmission among PTFI employees, their families and the local community. This is done through an integrated program, consisting of:

1. Ongoing risk assessment for HIV/AIDS transmission
2. Provision of STD treatment and counselling
3. Education and information provided to health care workers
4. Encouragement of responsible sexual behaviours and raising awareness of personal responsibility for HIV/AIDS prevention
5. Condom availability (*Editor's note: These condoms were branded with the Freemont Mining Company logo.*¹⁸)

What is your reaction to this case study? Here are some points to discuss:

1. Why did the Freemont Mining Company undertake this program?
 - a. Who were its intended beneficiaries?
 - i. Were they included in the design of the program?
 - b. What is the company's non-discrimination policy?
2. What do you think this program?
 - a. Was it meant to be non-judgemental?
 - b. Was it designed to be culturally sensitive?
 - c. Did it educate about other risk behaviours, such as using injection drugs or have male-to-male sex?
 - d. Did it show that the company was concerned about those who might be affected?
 - e. Did it assure that access to treatment, care and support was available to anyone who tested HIV-positive?
 - f. Would you want to work for the Freemont Mining Company?

¹⁸ Partnership Report, December 2003, International Finance Corporation (IFC Against AIDS), [www.ifc.org/ifcext/aids.nsf/AttachmentsByTitle/Indonesia+-+December+2003/\\$FILE/Indonesia+-+December+2003.doc](http://www.ifc.org/ifcext/aids.nsf/AttachmentsByTitle/Indonesia+-+December+2003/$FILE/Indonesia+-+December+2003.doc), Accessed March 2005

Now let's read the "Lessons Learned" from the Freemont Mining Company case study. Please note that these lessons are repeated, word for word, from the Asian Business Coalition on AIDS report. Do you agree or disagree with these lessons?

Lessons learned (from PTFI HIV/AIDS program at the Freemont Mining Company)

Non-judgmental discussion of sexual behaviours and risks in a multi-ethnic, mixed-belief environment can be a sensitive if not explosive issue. The message of sexual responsibility needs to be carefully crafted. The threat, the challenges and reasons for program implementation need to be carefully explained to company, community and religious leaders before any HIV/AIDS/STD awareness campaign is instituted. Senior management is receptive to development of potentially sensitive but important programs such as HIV/AIDS and STD awareness if they are completely informed of the issues and threats in an unbiased and comprehensive fashion. Previous attempts at condom distribution failed at the PTFI jobsite for failure to inform and educate senior management. The same principles apply to employee education. Information must be factually based, presented in a non-judgmental and open forum with responsible behavioural alternatives presented.

Wherever possible use existing structures to disseminate information. Safety education programs, other site-wide educational forums can be used to deliver information. Careful coordination between departments whose activities will be used as education vehicles to ensure that they understand and brought on board as participants and partners in this important effort. The results of these education and implementation efforts need to be re-evaluated frequently to ensure that they achieve their desired result.

HIV/AIDS and STD outreach programs need to focus not only on SWs, but also on their clients. Largely male employee populations provide a unique opportunity to influence these men. Male clients are often the most difficult to reach and this 'captive' audience will respond to company initiatives on their behalf.

Answers to Q&A: Managing HIV/AIDS in the workplace from the Asian Business Coalition on AIDS (ABC)

Editor's note: Some of the answers have been modified by the writers of the GIPA Toolkit. These answers may not always apply to your actual situation or to the labour laws that govern your place of work.

A) Policies

Question 1: Should new employees be tested for HIV?

Answer: Everyday person-to-person contact does not transmit the HIV virus. Therefore, there is no need to require HIV testing in the context of employment in general.

Question 2: What are the modes of HIV transmission?

Answer: HIV is known to be transmitted in only three ways: 1) bodily fluid exchange through unprotected vaginal and anal intercourse; 2) having infected blood enter one's bloodstream, e.g., through blood transfusions or breaks in the skin; 3) through an infected mother to her baby during childbirth and/or through breast milk.

Question 3: Should precautions be taken to prevent HIV transmission in the workplace?

Answer: Since AIDS is a blood-borne or sexually transmitted disease that is not spread through casual contact, there is no need to be concerned about transmission in most workplaces. The HIV virus is a fragile virus that does not survive outside the human body.

Question 4: Which safety measures should be taken in case an employee is found to be HIV-positive?

Answer: No additional measures need to be taken, except in the case of those working in the Food and Beverage industry or in places in which there can be skin-breaking accidents, as well as health-

care employees who are involved in direct contact with potentially infected blood or bodily fluids. In these cases gloves should be worn at all times. In addition, extra gloves and bleach should be available in case there are blood spills. All blood spills should be treated as potentially infective for many things, such as hepatitis and cholera as well as HIV.

Question 5: What is the advantage of developing a workplace HIV policy?

Answer: The advantage of formulating an HIV policy is that the issues that may arise will already have been thought through. This will ensure that a ready policy decision is in place to deal with issues such as: discrimination fears and prejudice in the workplace, health care and life insurance, absences for medical care and continuation of employment and/or benefits.

B) Legal obligations

Question 6: Currently, if one of my employees is found to be HIV-positive, what are my legal obligations?

Answer: An HIV-positive worker should be allowed to continue in his/her employment. The employee is under no legal obligation other than to treat his/her illness as any other long-term illness, such as cancer. If he/she is unable to work in the end stages, he/she should be taken off duty. To be certain, applicable local and national labour laws should be researched to determine the exact answer to this question.

Question 7: Are there any specific laws that employers should know about before employing HIV-infected people?

Answer: Again, applicable local and national labour laws should be researched to determine the exact answer to this question. Generally, the relationship between an employer and employee is governed by the employment contract between them and the common law. In addition, for employees who come under the employment act (generally, those who are not employed in managerial, executive or confidential positions), the terms of their employment are also subject to this act. Employers should consult their lawyers for a more detailed and precise legal position with regard to specific issues, should the need arise.

Question 8: Are there any special requirements that the company needs to provide for people with HIV/AIDS?

Answer: Again, applicable local and national labour laws should be researched to determine the exact answer to this question. Employers have the responsibility under common law to provide a safe and healthy environment, and, since HIV is not transmitted through normal work contacts, employers need not take any special measures with respect to protecting employees, customers and suppliers from HIV/AIDS infection in most work situations.

Question 9: Do employers have an obligation to inform other employees of an employee's HIV infection?

Answer: Most likely, there is no statutory obligation requiring management to inform anyone in the company that a certain employee is HIV-positive or has AIDS. In fact, confidentiality should always be maintained about all employees' personal life situations.

C) Employer-employee relationships

Question 10: Can I terminate an employee for having HIV/AIDS?

Answer: A contract of service in the private sector can usually be ended by the employer or employee without giving any reason within the provided 'notice of termination' in accordance with the contract of employment. Reasonable notice must be given if the contract of service does not provide for the length of such notice. In general practice, "reasonable notice" is one month, but it can be up to three to six months for highly qualified employees. Again, applicable local and national labour laws should be researched to determine the exact answer to this question. Contracting an HIV infection is a valid ground for terminating an employee's service without notice, if certain conditions hold true. These are: 1) He/she is incapable of performing his/her duties; 2) All statutory or contracted personal leave time to which he/she is entitled has been exhausted.

Question 11: What can I do if any of the other employees find out about the status of an HIV-positive employee and then refuse to work?

Answer: Because there is no risk of infection through casual contact among employees, an employee may not legally refuse to work with a colleague who is HIV- positive or has AIDS.

Question 12: What should be done first if I want to employ people who are HIV- positive?

Answer: As a pro-active employer, you should develop an HIV/AIDS workplace policy and make the policy known to all staff members. Also, conduct education programs for your staff and involve management at all levels in policy development.

D) Cost of treatment

Question 34: What will it cost should an employee have full-blown AIDS?

Answer: In the case of someone with advance HIV disease, productivity is likely to be reduced, and one might consider termination of that employee. The quantum of medical benefits depends on the contract that has been drawn up between the employer and employee at the time of engagement.

Question 14: What will it cost my company should I employ an HIV-positive employee?

Answer: Like any other employee who may have or develop a chronic illness, an asymptomatic HIV-positive worker, will be healthy and productive and is unlikely to be any more or less costly than a non-infected employee. ABC notes that it has been argued that HIV-positive people are grateful for the chance to be employed and will be motivated to be productive for the organization. All employees - regardless of health status - are grateful to have an employer who sees the value of the employees, cares enough to be flexible and regards it as a duty to care for the total well-being of all of the employees.

MODULE 3.3 DEVELOPING PLWHA CAPACITY AND NETWORKS

Next we will look at the issues of capacity and how we can increase capacity when it is necessary to facilitate greater involvement by people living with HIV and AIDS.

“Community participation also means building capacities in communities to advocate and bring about the political, social and economic changes, as well as improved access to health and information services that will enable them to participate more fully in national efforts.”¹⁹

What is capacity?

In order to do anything, first we have to have the *capacity* to do it. For instance, if you want to go to a karaoke bar, sing, maybe dance and relax with friends this weekend, here are some of the steps involved, with some recommended “capacity building” things that will help you get there.

Goal: Go to a karaoke bar on Friday night		
Task/ability	Capacity needed	Capacity building needed
1. Go to a karaoke bar.	Have the desire to go.	You have it! None needed.
2. Have the time to go out.	Have 3 - 6 hours of free time in your schedule.	Tell your boss and family that you are not free on Friday night.
3. Have friends who are going to go.	a) Have friends; i) Have friends willing; ii) Have friends available.	a) Call some friends to go with you or meet you there. b) Dress nicely, so you can make new friends at the bar.

¹⁹ Larsen HJ, Narain JP, *Beyond 2000: responding to HIV/AIDS in the new millennium*, New Delhi, World Health Organisation, 2001.

4. The money to spend.	a) Have money of your own. b) Be able to get money. c) Have friends or family with money.	a) Save enough by Friday. b) Do some extra work and earn some money. c) Borrow from your family or ask your friends to pay this time.
5. Get to the karaoke bar and back somehow - walk or ride.	a) Ability to walk. B) Have money for a bus or motorbike taxi. c) Have a friend with car.	a) Wear comfortable shoes. B) Back to #4! c) Call the right friends in #3!
6. Be able to sing.	a) Have a good singing voice.	Guess what? This is not a requirement at karaoke bars so you can cancel those singing lessons!

So, capacity refers to the having the ability and resources to do something that will accomplish your goal. It includes the means to do it (having the physical capability, such as space, materials and money) and the commitment to do it (individually, organizationally and culturally). When referring to positive people, networks and organizations, capacity refers to having the ability to serve the mission effectively.

For instance, a CBO whose mission is to prevent HIV decides to add an ARV adherence program that conducts treatment support groups for people who have tested HIV- positive. They will need several things, including a comfortable, private meeting room big enough to hold 10 or 15 clients that is accessible to the participants, and skilled facilitators knowledgeable about group dynamics as well as ARV adherence issues and interventions. The program must also be able to attract people who are HIV-positive and interested in learning about ARV and who themselves, either through the program or other local sources, have access to medications and ongoing health care. The *capacity* of this program is limited by the space (room availability, room accessibility, room size), by the number of interested people, by the skill level of available staff and/or volunteers (as facilitators), and by the availability of health care and antiretroviral and OI medications.

Goal: add ARV support through support groups		
<i>Task/ability</i>	<i>Capacity needed</i>	<i>Capacity building needed</i>
1. Make the commitment.	Statement of need with support from involved people (management, staff, clients and outside community partners)	Written situational analysis Meetings with the involved people
2. Procedures and policies	Review and revise policies as they relate to the program, including planning to integrate with existing services	Research other similar services and adapt them to the situation Decide eligibility for service
3. Action plan	Create a timeline of necessary activities	a) Bring in local HIV medical specialist to create a training b) Conduct in-service for program staff about ARV and support groups c) Train volunteer facilitator (send to HIV hospital for outside training) d) Identify appropriate BCC* and ARV educational materials e) Conduct client workshops about ARV f) Conduct workshop training for other CBOs about ARV g) Create flyers about new service
4. Monitor and evaluate	Create a system to monitor key indicators of program success.	a) Buy new computer for program staff b) Build database for statistical tracking

*Behaviour Change Communication

Building capacity

Capacity-building is defined in many ways, but most commonly it means actions that are taken to improve effectiveness or that strengthen people or organizations so that they can perform effectively. A PLWHA network, for example, might present an advocacy training session for its members prior to a trip to meet the national AIDS planning committee to increase their skills in telling their stories and thus better influence the committee's leadership. A local CBO might have two new computers donated by the factory down the road and recruit a volunteer to develop a client database for them (thus increasing their ability to provide timely quarterly reports to their donors).

When planning for capacity-building, the full impact of the process needs to be thought about. Consider what the capacity-building will do in addition to reaching the intended goal. A positive woman who attends an advocacy-training programme may learn communication and negotiation skills that could help her communicate with her family. Her family would better understand her situation and needs even if she and her group are not able to “win” the commitment of the local clinic director they visited for an advocacy meeting.

Capacity and capacity-building are synergistic. That is, building capacity is not a “stand alone” function that serves a short-term purpose and then leaves. Yes, training a volunteer caseworker to become an ARV treatment specialist will let you add a support group and serve more PLWHAs - but will it also bring in new clients as word spreads of the new service. It might as easily have a negative impact that should be planned for: the new client demand might require more intake staff in the front office; the local health clinic may need more medications on hand and need to add more clinic hours. The local health ministry department might suddenly become aware of higher numbers of positive people in the area and increase prevention allocations and condom distribution but also notify the local police; and the police might “crack down” on local commercial sex workers -- all because of one simple, capacity-building action on the part of the CBO: the training of a worker.

What about capacity and GIPA?

Individuals, networks and organizations alike must have the capacity to begin making GIPA a reality in the Asia Pacific region. Capacity needs will vary greatly in every individual, in each geographic area, within each organization or network and for each issue (e.g., policy and advocacy, program skills and technical assistance).

Exercise: Areas of capacity for individuals

The most important part of GIPA lies in the *P* and *A* of the title itself: the people living with HIV and AIDS who will be significantly and effectively involved. The capacity and capacity-building needs of the positive people, then, should be first on the agenda.

As a group, discuss the following list of things that typically need to be addressed and prepared for by positive people who will be working to make GIPA a reality in their communities. Add your own ideas to the list. As you discuss each idea, keep in mind the following things:

1. Why is the area an important issue for a PLWHA and/or for GIPA?
2. Who might need help in this area?
3. What activities can you think of to build capacity in this area?
4. Where could you go to get help in this area?

Area of need:	What it means.
Disclosure	Talking about your HIV-positive status and your personal situation in public places.
To friends and family	
To neighbours	
To employers	
To public officials	
To the media	
Effects of involvement	Things that might come from getting involved, good and bad.
Positive effects	
Negative effects	
Accurate information	You, as a PLWHA, should know the facts about HIV for your own health and care but, as you “come out” about being HIV+, you will be asked many questions and need to have accurate information.
HIV pathogenesis	How HIV infects and what it does in the body
Epidemiology	The most current facts and figures of the local, national, regional and world HIV epidemic
Resources/referrals	What others are doing for PLWHA (local and national).
Economic stability	Being able to pay for basic human needs such as food, housing, transportation and childcare.
Access to care/support	Health/medical care (home, clinic, hospital)
Access to treatments	ARV and OI treatment and prophylaxis
Communication skills	You will need to understand and be comfortable with speaking in public, one-on-one, in front of groups, and maybe in front of a microphone or camera. Sometimes your audience will be caring and concerned, but sometimes they will be harsh and unfriendly.
Story-telling	Effective ways to convey your message by telling (true) stories.
Negotiation	Bargaining to get part of what you want when needed
Talking “under fire”	Making your point and keeping self-control even when the other people have lost control.

Areas of capacity for organizations and networks

Very often, the capacity of organizations and networks that will be carrying out GIPA activities will need building, too. As in other areas discussed in this toolkit, capacity-building should be approached in four simple stages:

1. Develop a strategy (including a situational analysis)	We've got a problem! What's the current situation; what do we have, what do we need? What should we do about it? Here's the road map to solving it.
2. Agree on the policies and procedures	How will it be fair and effective? Who gets to benefit from it? What will it cost?
3. Create a program (action plan)	What and when exactly are we going to do about it? Who can we partner with for help? How will we pay for it?
4. Monitor and evaluate the program	How do we know it is working? What changed as a result of the program?

In 2001, the UNDP Regional HIV and Development Programme initiated the UNDP/Sahara GIPA Initiative. At the regional GIPA Workshop for South Asia, a model for capacity building was developed. The representatives from the regional GIPA network of 17 PLWHA groups in Bangladesh, India, Nepal, Pakistan and Sri Lanka, meeting together for the first time, identified three basic areas of need for capacity-building for their organizations and networks:

1. Organisational development
2. Learning, awareness building and sensitisation
3. Care and support activities

The following text box is also taken from the UNITAR Tech Note on GIPA.²⁰ It describes some things that have been observed in communities that have successfully developed an AIDS response (what UNITAR calls "AIDS-competent"), including the involvement of positive people.

It has been further noticed that in AIDS-competent communities PWHA are equipped with a range of skills and nurtured in human capacity development:

- PWHA organisations are strengthened and provided with the resources to establish adequate infrastructure, including secretarial support.
- Skills-training leads to self-reliance. PWHA are therefore provided with capacity-building in such areas as:

Language and Computer Literacy	Advocacy
Proposal Writing	Train-the-Trainer
Organisational Management	Community-Based Research
Financial Management	Leadership
Counselling	Partnership Development
Legal and Human Rights	Facilitation of Organisational Change

- PWHA networks are linked and strengthened to reach the people most affected.
- PWHA advocate for and develop appropriate standards of treatment and care.

Once PWHA are adequately and appropriately trained, they are a powerful force for change.

²⁰ *Technical Note on the Greater Involvement of People Living with HIV/AIDS in Local Responses*, <http://www.unitar.org/acp/annexescmconstellation/technotegipa.doc>, accessed March 2005

Exercise: Capacity-building activities

First, break into small groups of 4 to 5 people each. Depending on the total number of groups, take an equal share of the capacity-building areas and discuss what you think are the activities related to it. First, discuss only the activities themselves. Examples have been added to some areas as a guide.

AREA	ACTIVITY (may be more than one)
Computer Literacy	<i>Computer training</i>
Language Literacy	
Proposal Writing	
Organisational Management	
Financial Management	
Counselling	
Legal and Human Rights Advocacy	
Train-the-Trainer	
Community-Based Research	
Leadership	
Partnership Development	<i>Open house for local CBOs</i>
Facilitation of organisational change	

Next, in the same groups, add to your activities list the resources that you think are available that might make the activities happen. Think about the following things:

1. Internal resources, knowledge and abilities
2. Other organizations in our area, country or region
3. Trainings, workshops or conferences
4. Donors to underwrite expenses

AREA	ACTIVITY (may be more than one)	RESOURCE
Language and Computer Literacy	<i>Computer training</i>	<i>Volunteer with computer skills</i>
Language Literacy		
Proposal Writing		
Organisational Management		
Financial Management		
Counselling		
Legal and Human Rights Advocacy		
Train-the-Trainer		
Community-Based Research		
Leadership		
Partnership Development	<i>Open house for local CBOs</i>	<i>Local restaurant to donate the food and drinks</i>
Facilitation of organisational change		

Outside resources: you're not alone

There is a significant amount of resources and organizations in the Asia-Pacific region that can be tapped for capacity-building, including those sponsored by the creators of this toolkit, APN+ and APCASO. They can help refer you to resources in your area and various materials such as training manuals, guides and other toolkits that will help as well. The Resources section in the back of this Toolkit provides contact information for these organizations.

Experience has shown that involving people living with HIV in a meaningful way is a core element of an effective response to the epidemic. Strengthening and sustaining this role requires:

- i) that people know their HIV status (which, in turn, requires vastly increased access to voluntary counselling and testing facilities);
- ii) keeping people alive with antiretroviral treatment so they can remain active in their chosen fields of work; and
- iii) creating the practical and political space for people living with HIV to expand their role and contribution by addressing HIV-related stigma and discrimination; promoting appropriate legal and policy environments; and supporting participation with resources, including organizational development.

From UNAIDS 2004 Report on the Global AIDS epidemic, pg 188

MODULE 3.4 INVOLVEMENT IN POLICY

A policy is a course of action within a framework that guides decision-making. Governments, businesses, NGOs, religious organizations - in fact, any kind of organization - can and usually does have policies. Policies usually take the form of general statements about priorities, written regulations or guidelines, procedures and/or standards to be achieved. Policies are not always written down; they may just be widely recognized practices within the organization.²¹

For example:

- A government may have a policy of refusing ARV treatment to injecting drug users, or a policy of providing free schooling for orphans.
- An NGO may have a confidentiality policy to respect the right to privacy of HIV+ staff and service users, or a policy to fire staff who have had more than 10 days 'sick leave' in a year.
- A hospital may have a policy of providing all patients with travel expenses to attend clinics,, or of testing for HIV without informed consent.
- A business may have a policy of compulsory HIV testing for all new recruits, or a policy of donating 5% of its profits to HIV charities.
- A religious, organization may have a policy of caring for 'AIDS, orphans', or of condemning the use of condoms.
- A trade union may have a policy of campaigning against discriminatory legislation, or for the human rights of PLWHAs.
- A PLWHA network may have a policy of reserving 30% of positions on its governing board for women, or of rotating the location of its Annual General Meeting so that it is held in a different part of the country each time.

Even this short list shows how many different kinds of organizations have an impact on people living with HIV. It may be possible and desirable to get involved with any of them, and in each organization, there may be many different levels (e.g., national, regional, local) and many different committees, working groups or activities in which your contribution can make a difference. So, the first step is

²¹ *Unwritten policies are often the most difficult to change, because their existence can be denied.*

to find out about the organizations and structures in your area and identify where the opportunities for getting involved are. One critical forum for PLWHA involvement is the national HIV/AIDS forum (the name varies from country to country) but this is certainly not the only forum that PLWHAs should consider. For example, you may be able to accomplish more by being on the board of your local hospital and working directly to change negative attitudes of health care workers than by attempting to change staff training policy at the national level.

National Policy Forums

Almost every country in the Asia-Pacific region has a national HIV/AIDS board or committee that develops national HIV/AIDS policy. The membership, roles and powers of these committees vary from country to country, but there are some similarities.

These committees are often multi-sectoral, meaning that they should involve all the different parts of government and society that need to be addressing HIV/AIDS issues. Some of these committees already involve civil society and people living with HIV. All of them ought to! Each committee will have its own procedures, jargon and styles of operating. It is very helpful to observe the committees in action, so you can start to learn the style.

The National AIDS Committee oversees the drawing up and implementation of a National AIDS Plan. For example, in Thailand, the National AIDS Committee has been responsible for all the major HIV programs in the country, such as the “100% condom campaign” and the ARV scale-up to cover the whole country. These Committees may also address conflicts between the actions of different ministries and government departments in the cases in which they result in negative impacts on HIV issues. For example, in one Southeast Asian country, the Ministry of Public Health inspected a sauna frequented by men who have sex with men and praised the sauna management for providing free condoms and lubricant to patrons. The next day, the sauna was raided by police, who confiscated the condoms and lubricants because they saw them as evidence that “public” sex was taking place at the sauna in violation of the law; the management was arrested and fined. The sauna continued to operate, but, as a result, the sex that took place was far less likely to be safe because condoms were no longer supplied by the sauna. A multi-sectoral committee is the place where conflicts such as these can be discussed and addressed.

For example, in Thailand, the National AIDS Committee is based in the Office of the Prime Minister, and includes over 30 representatives from:

- The Thai Network of People Living with HIV/AIDS
- Civil Society Organisations such as the Thai NGO Coalition on AIDS , Thai Red Cross Society and the Thailand Business Coalition on AIDS
- Ministries of Health, Finance, Defence, Interior, Labour and Social Welfare, Education, University Affairs
- National Committees on Drug Control and Suppression; Economic and Social Development; Women; Youth
- Bangkok Metropolitan Administration
- Parliamentarians such as M.P. Committee on Public Health, and Senate Committee on Public Health
- Many academics

The powers of these boards and committees are limited. Committees that are chaired by a Prime Minister or President tend to be more powerful than committees chaired by Ministers of Public Health, since one Minister has no power to command other Ministries. And the influence of the Ministry of Health over other key Ministries such as Interior or Defence is often fairly weak in the Asia-Pacific region. However, even when they are chaired by Premiers, these committees usually need to go to the Cabinet for approval of major actions.

Despite the limitations of their powers, these committees are still a very important coordinating mechanism that can have a major impact on the lives of people living with HIV in the country.

In 2004, UNAIDS launched a new policy called *The Three Ones*, which aims to create (or strengthen) one agreed comprehensive and coherent national HIV/AIDS system, including:

- *one* national AIDS coordinating authority with a broad, multi-sectoral mandate,
- *one* national AIDS action framework that provides the basis for coordinating the work of all partners, and
- *one* national AIDS monitoring and evaluation system.

UNAIDS is firmly committed to GIPA, and, in promoting *The Three Ones* policy, they will be pushing for PLWHA involvement in each of the ‘ones’. The UNAIDS Country Coordinator can explain more about the national policy system in your country and support you to advocate for PLWHA involvement.

Real vs. Token involvement

PLWHAs have a critical contribution to make to the national policy forums. However, it can be very hard to make that contribution. We may find that our opinions are not respected, that we are treated in a patronizing way, or that we are excluded from certain parts of the work of the committee. Decision-makers may like the idea of consulting with PLWHAs far more than the reality of it, especially when PLWHAs start to ask difficult or challenging questions.

Meaningful involvement?

I feel that that sometimes we are being used by donors and governments for their own credit without meaningful involvement. For example, they can no longer get Global Fund money without us. GIPA should be a good thing, but I feel there is a real danger that it can become a tool to exploit us. An Asian-Pacific PLWHA

I stay quiet and just sign what has been decided without understanding why it has been decided as discussions and decisions are not in my language. A PLWHA commenting on his involvement in the Global Fund Country-Coordinating Mechanism.

It seems that the PLWHA is always the last person to be invited to a meeting. I guess someone says: ‘oh, we forgot the PLWHA...’. Then there’s a mad scramble to find someone who can go, they don’t have time to prepare, they are not ready to make a contribution. It happens all time and it is so frustrating. An Asian-Pacific PLWHA

Here are some tips for effective involvement in policy committees:

- 1) **Be clear about your role on the committee** (working group, steering committee, advisory group or whatever it is): Both you and all the committee members should understand your role clearly. Know the following:
 - Whom do you speak for? Whom are you representing?
 - What powers do you have on the committee? For example, are you a full voting member? Can you speak whenever you want to or only when asked for an opinion by the meeting chair?
 - Can you send a representative if you are unable to attend a meeting?
 - Will you get paid? (Government officials sometimes get a ‘meeting fee’, so why shouldn’t you as well?). Will that fee go to you or to your organization? Will your expenses, such as travel, childcare, or replacing lost earnings because of needing time off work, be paid?
 - Does the committee understand that it might take you some time to consult your members about important issues? You may not always be able to give an immediate response to their request for a PLWHA perspective.

- 2) **Choose your own representative.** Do not let the committee impose their choice on you by choosing the person they feel most comfortable working with or over whom they feel they might have some influence. Develop criteria for representation and ensure openness and transparency in the selection process.
- 3) **Prepare well for the meetings.** Read the report of the last meeting. Find out about any terms or issue you don't understand. Check back through your notes to see if the report is accurate. If you have trouble understanding the official report, consider requesting a verbal briefing or pre-meeting with the chair or secretary of the committee. Or, try to get together with sympathetic members of the committee (if there are any) to review the report. This is also an opportunity to lobby them to support you on any issues you plan to raise in the meeting. Review the agenda of the upcoming meeting. If possible, rehearse the points you want to raise in the meeting. Take your name-cards and some material about your organisation, so you can make the most of the opportunity to network with other people working in the HIV/AIDS field. Consider what you wear, too, as it is important to create a good impression and build credibility for yourself and the PLWHAs and organisations that you represent.
- 4) **Be clear about your mandate, and be accountable.** This means that for each committee meeting that you attend, you should have a preparation meeting with your PLWHAs group and a debriefing session (these could be combined, i.e., debrief from one meeting and prepare for the next).

In the preparation meeting, you should work through the agenda, asking the group what they want you to say about each item. You may also need to be proactive in consulting more PLWHAs about specific issues. For example, if there is an item about women's participation in vaccine trials and no women came to the preparation meeting, you should try to consult them in other ways, for example, phone them.

For the debriefing, you should summarise the discussion that took place at the meeting and explain what you contributed. Try not to get defensive if the members disagree with what you said: remind them what was discussed at the preparation meeting. If you deviated from it, explain why. Perhaps you heard new information or a very persuasive argument in the committee meeting that caused you to change your mind. If they are still unhappy with your contribution, you must be prepared to go back to the committee and explain the group's view. If you are not willing to be representative of the PLWHA group in this way, the group will need to replace you with a new representative.

In addition to the debrief meeting, you should write your own report of each meeting that you attend and circulate it amongst the members of the PLWHA group.

- 5) **Have confidence in yourself.** Don't be afraid to ask questions. All questions are valid. Learn to resist group pressure for consensus by practicing the 'broken record' technique. This simply means that if you have tried very hard to persuade the group of something but they are still putting pressure on you to go along with them, you can simply repeat yourself over and over again: *"No, the PLWHA group cannot agree to that policy... No, the PLWHA group cannot agree to that policy... No, the PLWHA...."* This may lead to a stalemate, but at least they cannot 'use' you to say that PLWHAs agreed to this decision. Don't get pushed into committing to anything major without referring back to the group, unless you had a clear mandate from your group on this issue already. Identify allies in the committee who can support your position. Most committees also have NGO members who may be willing to support you.

Sitting in these policy meetings - it's not something that comes naturally. The stress builds up. Once I was the only PLWHA in a regional meeting of 150 'experts'. I knew I could not speak for 7 million PLWHAs but I was the only one invited. It was a huge responsibility and I felt so inadequate. What's really important is finding a way to debrief, calm down, cope with your own stress. This is very difficult work. An Asian-Pacific PLWHA

- 6) **Be assertive.** Assertiveness means expressing your opinions clearly. Sometimes you will have to directly contradict or oppose the opinions of senior people in the meeting, and this can be very difficult to do. It's best if you speak in a calm, polite but firm manner. Sometimes the meeting chairman may use complicated terms and procedural rules to confuse or 'bulldoze' you. Simply respond with a reply something like this: *"Actually Mr Chairman, I feel we need to have more discussion on this issue."* It is OK to let your emotions show sometimes, and this can make your arguments seem more authentic and compelling but don't get so angry that you are abusive or storm out of the room. You will need to prepare yourself to face patronizing and discriminatory attitudes: unfortunately, not all government officials, or even NGO workers, are immune from the prejudices of the wider society.
- 7) **Bring an 'alternate' representative.** It can be very hard to be the only person speaking up for the PLWHA perspective, especially when the issues are personal to you. An 'alternate' can support you, help you to wind down after the meeting, and even take your place if you cannot go some time. You will need to get committee approval to have an 'alternate' but they will probably like the idea, since it leads to greater consistency of involvement. 'Alternates' are often not eligible to receive meeting fees or other remunerations, but try to negotiate that the PLWHA alternate should, since this is a real way in which the Committee can demonstrate its commitment to PLWHA involvement.

If the structure and mandate of the committee permits, lobby for more PLWHA representation.

- 8) **Be positive.** Whenever you criticize or reject a policy, try to have a constructive suggestion to take its place. For example, if you are criticising a drug trial and refusing to recommend PLWHA participation, explain what could be changed in order to make the trial acceptable. This may not always be possible but try to do it whenever you can.
- 9) **Regularly assess, with the whole PLWHA group:**
- **Are you a token?** Is this a useful committee? Does the committee include the right range of people and organizations? Does the committee have a democratic working culture, with open and efficient methods of chairing, so that everyone can have a say and those with less confidence are not intimidated (whether for reasons of gender, lifestyle or language)? If the answer to these questions is clearly no, and you do not see any hope for improvement, you may need to reconsider your involvement. The bottom line is that you shouldn't waste time on a committee that doesn't listen to you, in which you are not making a difference. But, before giving up, first try to improve the committee.
 - **How is your involvement affecting the organization?** Is it taking up too much time? Is other important work being neglected as a result? Are conflicts in the committee spilling over to other areas of work? Is it useful for building credibility for your organization and maintaining relationships with key stakeholders? You need to balance your involvement with all the other important work being done by your group or network.

Skills to practice: assertiveness, negotiation, advocacy

There are many good exercises for practicing these skills in *Positive Development: A Manual for People Living with HIV*, published by GNP+, and the *Advocacy Toolkit*, published by the International HIV/AIDS Alliance. Refer to the Resources section in the back of this toolkit for a list of these and other publications and toolkits.

Exercise: Countering prejudice: be ready to face it.

Unfortunately, PLWHAs who are involved in the HIV/AIDS response have to be ready to counter negative attitudes, ranging from the simply stupid to the patronizing to the outright offensive. Examples are given below.

Letting these comments slip by unchallenged creates a bad atmosphere in any meeting, a greater distancing between “them” and “us”. Forgetting that PLWHAs are people with legitimate rights, feelings and needs leads to bad policy and bad programs. Not confronting these attitudes directly can leave you feeling paralysed and upset and thus unable to make an effective contribution to the meeting. You may also be faced with intrusive and impertinent personal questions, which you do not have to answer.

Brainstorm examples of statements you (or people you know) have faced that need to be countered. Here are some real examples to get you started.

We apologise for repeating these ugly statements but there is an important purpose to this exercise - it will better prepare you for getting involved.

- How did you get HIV? I bet you’ve had loads of boyfriends.
 - Why waste treatment on people who are dying anyway?
 - Children are the only true victims of HIV.
 - People who inject drugs get what they deserve; why should we do anything to help them?
 - What do you mean: men who have sex with men? We don’t have any homosexuals in this country.
 - Decent people don’t talk about sex all the time; it’s private; you are just embarrassing everyone.
 - Why should the government give free condoms? People who engage in risky behaviour, such as sex workers or migrant workers, can afford them.
 - *Add your examples.*
- 1) Discuss how you felt when you heard these statements: did you manage to counter them, or were you just too upset, angry or embarrassed? Does anyone in the group agree with some of these statements? If so, why?
 - 2) What do you wish you had said? Brainstorm possible responses.
 - 3) In pairs, role-play the statements. One person makes the statement, the other practices responding in a firm and constructive way. Then swap roles. Try it with several statements.
 - 4) To build up your confidence, you need to demonstrate your new skill to the larger group. First, each person chooses a statement to counter. When everyone has had a turn, let the others fire a statement at you, and you respond. Keep going until everyone has had several turns.

Conclusion

Each PLWHA group will need to decide for itself which policy forums to get involved in. It will depend on your own capacity and the situation in your country. With very limited capacity, you may do better to stick to just one committee, with consistent and effective involvement, than to try and cover many committees. If you spread yourselves too thin, you may end up having no impact at all. Look for allies to help you lobby for your involvement, such as sympathizers from NGOs and UN agencies.

The Global Fund to Fight AIDS, Tuberculosis and Malaria

Extracts from *CCM: Challenging, Changing and Mobilizing: A Guide to PLHIV Involvement in Country Coordinating Mechanisms*. GNP+ December 2004 Available at: <http://www.gnplplus.net/>

“The Global Fund is a financing mechanism, set up in 2001, that seeks to combat AIDS, TB, and malaria by channelling large amounts of additional resources to the countries and communities most in need.

From a PLHIV perspective, what is particularly inspiring about the establishment of the Global Fund is its commitment to...creating the potential for real and meaningful involvement of PLHIV in its processes. The Global Fund operates in a way that allows PLHIV to be far more than passive beneficiaries of its grants. Instead, PLHIV, along with other key stakeholders in the global battle against the three diseases, have the opportunity to play active parts in the Global Fund’s governance structures and in-country processes. This is achieved by bringing PLHIV into broad partnerships involving representatives drawn from all sectors, including those who represent vulnerable or hard-to-reach populations.

PLHIV have played a crucial role in the Global Fund since its inception, and their input has been of immense influence in helping shape how the Global Fund operates today. One of the ways PLHIV have been able to maximize their influence at the global level is through participation on the Global Fund Board. The board is made up of 23 members, each with a delegation of up to 10 people. The delegation of communities living with the diseases (or “Communities delegation,” as it is sometimes referred to) is one of the most focused and active of the delegations—for obvious reasons, since the Global Fund is about our lives. The Communities delegation includes PLHIV representatives from all regions, although the working language of the delegation is English. Delegation members are selected because of their knowledge, experience and credibility in their communities. They play a vital role in supporting, assisting and advising the board member in his or her work. In 2004 the Communities delegation was successful in advocating for and achieving voting rights at the board. Another essential role for PLHIV is at the country level, through the CCMs. In general, PLHIV have been less successful in achieving influence in this arena - hence the need for this handbook.”

We have not attended any CCM meetings, but we really want to attend meetings to know what is going on. If we are involved we can support and add our voice to the work of the CCM. It is really important that the CCM has positive people to ensure an understanding of the real situation of people living with HIV/AIDS in Viet Nam. It is PLWHA who understand the real difficulties and needs of PLWHA, and through us so will the CCM.

—PLHIV groups Vietnam

PLHIV have a right to be members of their national CCM, not just because it is a requirement of the Global Fund, but because the experience and expertise of people who live with HIV/AIDS makes a vital contribution to our shared response to HIV/AIDS.

— PLHIV, Australia

This handbook is highly recommended. It provides excellent advice on how to get involved in the country-level work of the Global Fund. At the same time, sections such as ‘Being HIV Positive is not a Profession: Acquiring skills and knowledge and experience to be effective...’ are relevant to many kinds of PLWHA involvement.

MODULE 3.5 PARTNERSHIPS AND ALLIANCES: THE ROLE OF HIV NEGATIVES

In the Asia-Pacific region as a whole, PLWHAs form less than 1% of the population. Our needs are great, and they are not only medical; we need respect, protection from human rights abuses, shelter and economic opportunities, education for our children, and other things. We won't get all of this by working alone. Partnership should be embraced and allies sought. We also want greater control over important aspects of our lives, respect for what we can contribute to society and empathic support for what we are going through. So, sometimes we need to organize separately. What is the right balance? Different people and different organizations will have different answers. Your opinion may depend a lot on things that have nothing to do with HIV, such as your world view and your understanding of what creates change. It is an issue that may never be resolved. But what is clear is that the issue needs to be confronted. Why?

- Unrealistic targets are very demoralizing. If we think we have to manage these huge tasks alone, the only positive people we will attract to join our organizations are masochists and martyrs who are likely to “burn-out” quickly.
- Lack of authenticity undermines credibility and makes our work harder in the long run. If we pretend that all our work is carried out by PLWHAs when this is not the case, and then this deception is discovered, others can feel cheated or manipulated and switch off to everything that we have said. Thus, we are undermining the opportunities to get valuable support.

Everyone must take responsibility for PLWHA involvement. We cannot expect PLWHAs themselves to be the only ones to stand up and make a fuss when positive people are not being treated with respect. Asian-Pacific activist.

We have argued elsewhere in this toolkit that a strong PLWHA movement is essential to developing an effective response to HIV/AIDS. Section 3.3 has addressed issues of developing PLWHA capacity and building organizations. But we recognize that it will take time to build a strong and inclusive PLWHA movement where none now exists. What do we do in the meantime? We need to clarify the question of whether working in partnership and receiving support from HIV-negatives is merely an interim stage or something we will continue to value? And, while PLWHA self-organisation is weak in almost every country in Asia, we are faced with difficult questions about where to focus our energy. Which tasks can be undertaken by supporters and under what conditions?

The following two discussion points can be used to initiate a constructive discussion of the issues of self-activity vs. partnerships and the role of HIV negatives. Use these points to initiate discussion within your organization. Do you agree or disagree? Can you imagine a time when there is no more stigmatisation and discrimination against people living with HIV? Or will advocacy for our rights and our needs always be required?

Discussion Point 1: Utopia?

PLWHA leader in Thailand: *Once society has come to terms with AIDS as an ordinary disease, there should no longer be PLWHA groups or networks. Having reconciled to society, the PLWHA need not form or belong to separate groups to solve the AIDS problem.*

Quoted in Experience in the Formation of Groups of PLWHA in the Upper North of Thailand, 1998

Discussion Point 2: How much can non-PLWHAs understand about our experience?

Indonesian activist: *I married an HIV-positive woman in 1998. It was love at first sight. She was a very strong spirit for positive people.. Because of her, I learned to understand better what people with HIV feel, think - their vision. I learned to be more sensitive. I felt as if I were a positive person by being married to one. I know what stigma feels like.*

Today, I am a little confused with the positive people's movement. They want no stigmatisation or discrimination, but these groups are exclusive - they only want positive people in them and are not open to anyone who is poor or transgender or simply ordinary.

Quoted in Portraits of Commitment, APLF 2004

Exercise: Maintaining control

- 1) Brainstorm some tasks that your PLWHA organization might choose to, or be requested to, undertake. Here are some examples:
 - Represent PLWHAs on the National AIDS Committee
 - Provide a PLWHA commentary on a government report
 - Coordinate the PLWHA network
 - Interview PLWHAs about their experiences for a research project on coping with stigmatisation
 - Draft a letter to the newspaper to respond to a article that spreads misunderstanding and prejudice about HIV
 - Review a research protocol for an ethics committee requesting a PLWHA perspective
 - Organise a demonstration to protest against compulsory HIV testing
 - Work as secretary in the PLWHA network office
 - Provide counselling for ARV treatment literacy and adherence
 - Represent PLWHAs in a television interview on World AIDS Day
 - Provide counselling to a woman who has been raped and is being offered an HIV test
 - Write a toolkit on GIPA
- 2) Decide whether each task must be done by a PLWHA. Create a table with 4 columns, as shown below. Place each task into the first column, and use the other columns for 'ticks' to indicate your view:

Task	Must be done by PLWHAs only	Preferably done by PLWHAs	Could equally be done by non-PLWHAs
1. Represent PLWHAs on the National AIDS Committee	✓		
2. Draft a letter to the newspaper		✓	
3. xxxxx			✓

- 3) Fill in the table individually. Record your first instinctive reaction. You don't need to take too long over this. You don't need to show anyone your results. For columns 3 and 4, ask yourself: *Why is it preferable?* and *What are the most important characteristics of the person who should do this task?*
- 4) Have a small group discussion about your answers. Explain your reasoning and debate and discuss the issues. Try to arrive at a group consensus.

- 5) Write out each task (or the number) on a sticky piece of paper (a 'post-it' note), and place it on the board in the relevant column (to see if all groups agree). The facilitator should pick up on any disagreements between groups, inviting the groups to explain their reasoning.
- 6) Record your conclusions. Can you identify any general principles? Are there any areas of major disagreement? How will you resolve these differences?

There are few easy answers to the question of what work must be carried out by people living with HIV themselves and a very large "grey area". Given our current strength and resources, APN+ believes that there are many areas in which accepting help from HIV-negatives is important; the key issue is who is in control of the work. Many tasks can be carried out by people who are not living with HIV as long as positive people oversee the work and have the final say about what is implemented. Across the Asia-Pacific region, PLWHA groups will have to make a frank appraisal of how much they can handle, and it is advisable that they communicate their approaches openly and honestly.

Partnership Case study: Ashar Alo Society and CCDB

The partnership between the Ashar Alo Society, a Bangladeshi PLWHA group, and the Christian Commission for Development in Bangladesh (CCDB) is a successful example of synergy between a PLWHA group and an NGO. Bangladeshi registration formalities demand that a minimum number of 21 members be required to form a society. The names and contact details of key office bearers also had to be given to the authorities. CCDB helped the PLWHA organisation with these formalities. An innovative formula of including people who were not HIV-positive in the board as members, with the clause that they would have to leave the board once the group reached the required size, enabled Ashar Alo to get official registration. Members of the CCDB, friends and family showed willingness to fill the empty slots in the membership and the board. Today, the society has grown in organisational strength and has established district level groups in Chittagong and Sylhet. Ashar Alo also coordinates a national network of PLWHA support groups belonging to various NGOs.

From UNDP: From involvement to empowerment, p36



*Seven Sisters Pilot
GIPA workshop
April 2005*



**Section 4:
The Enabling Environment:
Little changes need big changes, too.**

SECTION 4: THE ENABLING ENVIRONMENT:

LITTLE CHANGES NEED BIG CHANGES, TOO.

The vast majority of Asian-Pacific people living with HIV and AIDS face enormous challenges. The PLWHA movement is slowly building momentum, and a few PLHA have reached positions of greater involvement; still, it is clear that it will be many years before their impact is felt by most PLHA. Furthermore, the obstacles to developing the skills of PLWHAs and enabling them to gain influential positions remain entrenched. In light of this, a commitment to GIPA is a long-term commitment not only to the kinds of capacity-building actions outlined in this toolkit but also to wider societal involvement. There are 4 areas that are especially relevant to securing significant improvements in the quality of life of people living with HIV, to which all PLHA groups and networks need to dedicate part of their working effort:

- Human rights
- Involving Women
- Access to VCT and Treatment
- Economic Empowerment

Human Rights

HIV acts as a kind of highlighter pen, showing up all the inequality and discrimination that exist in our societies. HIV infection is most common amongst people who are poor, marginalized and abused. People with few or no rights, or whose rights are not being respected, are far more vulnerable to HIV because they have less ability to make safe choices. Thus, a poor woman may 'choose' to have sex with many men in exchange for money or food, and to accept more money for not using a condom if she is really desperate. A migrant worker earning less than a dollar a day will hardly be able to spend 50c on a packet of condoms, but a worker with rights who can earn far more will have more chance of paying for protection. A man with a rectal sexually transmitted infection may be too scared to seek treatment in a country where homosexual sex is illegal, and he then becomes far more vulnerable to HIV infection. Safeguarding people's fundamental human rights improves their ability to protect themselves and others from HIV.

Equally important, respect for the human rights of all people living with HIV is essential for enabling them to deal with the impacts of HIV infection. For example, actions to assert and protect the rights of injecting drug users make it less likely that they can be excluded from public-health treatment. Actions to protect the rights of children are needed in many societies to prevent them from being excluded from school if their HIV status becomes known. Other well-documented abuses of the rights of Asian-Pacific PLWHAs include being refused hospital admission and/or treatment, HIV testing without consent and/or without proper counselling, breaches of confidentiality, being sacked from work despite remaining able to carry out the job, physical and verbal assault and many other practices that effectively deny the chance to live a dignified and peaceful life. While these abuses take place, we can hardly be surprised that most people living with HIV are not open about their HIV status and are reluctant to get involved in HIV services or self-help groups.

GIPA depends on PLWHAs' being able to speak openly about their HIV status and their experiences without fear of recrimination and abuse toward themselves or their families. Thus, human rights across the whole of society, as well as specific protections for people living with HIV, are fundamental to GIPA. As the PLWHA groups and networks campaign and work toward better human rights for all, as a short-term measure towards GIPA, they should ensure mechanisms to access legal advice and support for their members should any such difficulties arise.

Involving Women

Women are biologically and socially more vulnerable to HIV than men. In 2005, more than half of all the people living with HIV worldwide are women. In the Asia-Pacific region, women are thought to make up about one-third of people living with HIV. One of the most rapid rates of growth in HIV infection is among young, poor, married women whose only 'risk behaviour' seems to have been

having sex with their husbands.²² Throughout the region, women tend to carry greater responsibility for care for children, the elderly and the sick and disabled. Recent research in the Asia-Pacific region shows that women are far more likely than men to be rejected by their families once HIV is diagnosed in them, while 1 in 5 women living with HIV have been forced into having abortions or being sterilized.²³ Thus, a clear gender perspective on HIV/AIDS must be actively addressed by any comprehensive rights-based approach to HIV/AIDS.

A PLWHA movement that seeks to involve and empower women living with HIV needs to respond to the special circumstances that women face. Women's added burdens in most societies create practical obstacles to their involvement. This will have become evident throughout the discussions provoked by the exercises in this toolkit. In addition, cultural expectations of women's behaviour create added psychological pressures that hold women back. For example, women tend to have greater difficulty than men in speaking about intimate sexual matters, in asserting their opinions, and in confronting people in authority (who are usually men). It is hard to generalize about a place as diverse as the Asia-Pacific region, and there is no doubt that many individual men have similar difficulties, especially those lacking education and from stigmatized groups. It is important not to make sweeping generalisations about women's vs. men's experiences or capabilities but rather to be aware that a deep-rooted and complex oppression of women exists in our societies: involvement of women will be affected by this. Since we want and need positive women and positive transgendered people involved, as well as men, every GIPA plan needs to include a gender perspective.

Access to Treatment and Prevention Services

Most people living with HIV in Asia do not know their status, though they may suspect it, because they have never been tested. There is little incentive for them to do so. Fewer than 8% of PLWHAs in this region have access to life-saving ARV treatment. Most do not even have access to treatment for opportunistic infections. Weighed against the potential advantages but scarcity of treatment are the serious disadvantages arising from stigmatisation and discrimination if HIV infection is confirmed and becomes known through breaches of confidentiality, as well as the psychological impact on the newly diagnosed PLWHA. The quality and vary standards of voluntary testing services in this region does little to encourage people to get tested.

Lack of treatment is a major impediment to GIPA. While positive women and men are tired or sick or worrying about their futures, how much time and energy can they devote to the AIDS movement? The movement has lost so many brave and experienced champions for PLWHA rights and involvement to premature deaths. PLWHA networks must constantly train and nurture new talent as the first wave of leaders becomes too unwell to continue.

Access to treatment and prevention services are key determinants of the quality of life of people living with HIV and are equally critical to GIPA. As the PLWHA groups and networks campaign and work towards better access to treatment for all, as a short-term measure towards GIPA, they should consider how to help their members gain access to ARVs and treatment for opportunistic infections.

Economic Empowerment

Before positive people can contribute to the AIDS response, they have to meet their own basic needs for shelter, food and the rest of life's necessities. HIV infection can have a drastic effect on income: though in good health, positive people may lose their jobs simply because they are HIV-positive or perhaps because their psychological health is affected and they need to take a break. If they get sick, their earnings steadily decrease while savings are used up to cover loss of earnings and to pay

²² *Research in antenatal clinics in both India and Thailand indicated that 80% of the pregnant women living with HIV had had only one sexual partner.*

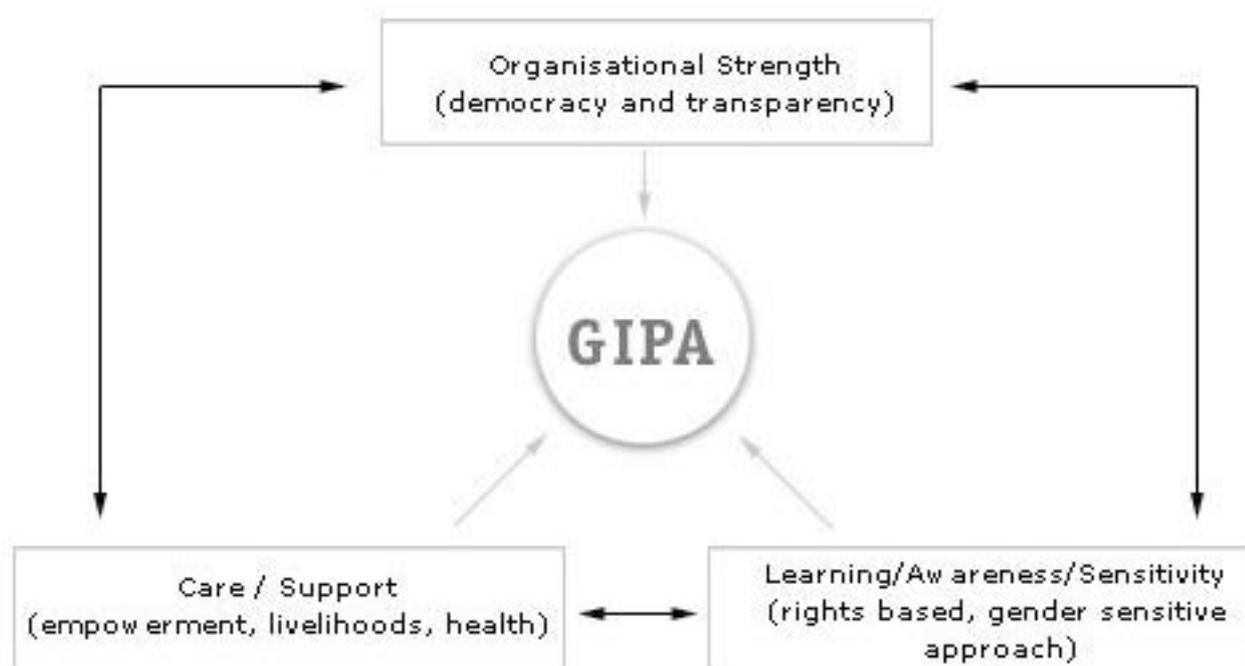
²³ *AIDS Discrimination in Asia, APN+*

for treatment. Thus PLWHAs are gradually impoverished, a vicious cycle with poverty and worry making recovery from bouts of illness even more difficult. PLWHA groups should therefore regard efforts to improve the income of positive people and the economic opportunities for them as a priority for the organization. As a short-term measure, any organization expecting to involve HIV-positive people should consider paying for their time or at the very least reimbursing costs such as transport, childcare or earnings lost from work that they could or otherwise would be doing.

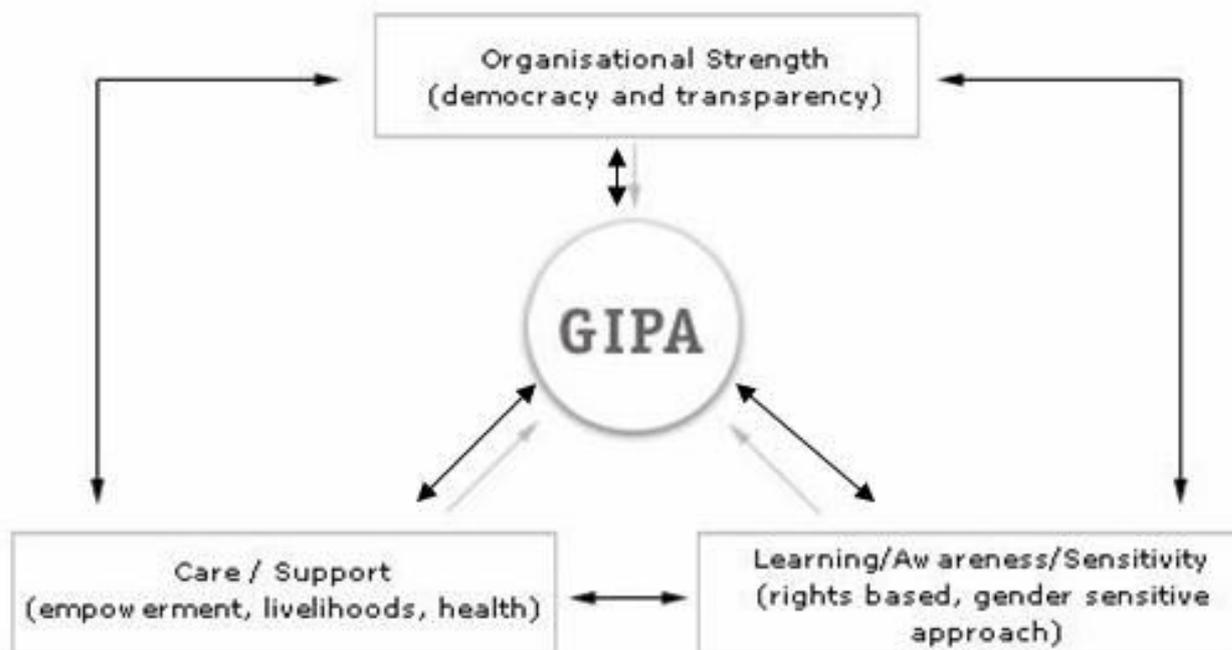
Addressing these 4 core issues helps to develop an environment that encourages and supports involvement of positive people. This is often referred to as an “enabling environment”. As the discussion above has indicated, there is an intricate connection between implementing GIPA within the response to AIDS and developing this enabling environment that empowers the people who are affected by HIV. For example, as stigmatisation decreases, people with HIV are able to become more visible and advocate for their rights.

CONCLUSION

The South Asia GIPA workshop mentioned previously developed the chart below, showing the process of capacity-building and GIPA. It makes important points, and what follows is not to slight its value. But, if we look at it from the standpoint of the concepts we have explored throughout this toolkit, something is missing. Can you guess what it might be? (Hint: follow the arrows carefully.)



The model below adds the missing element. Look at the inner arrows that connect the major areas of development to GIPA.



GIPA is a two-way street! Capacity-building enables GIPA, but the greater the involvement by people living with HIV and AIDS, the stronger organizations and their communities become. Simply put, GIPA equals strength.

We need to see more and more positive people with the skills, ability, confidence and willingness to get involved. Stigma and discrimination must be overcome so that it is safe for them to do so.

We need governments, international organizations, NGOs and communities to fully respect and facilitate the essential contribution of positive people to the AIDS response.

In 2004 at the close of the XV International AIDS Conference, people living with HIV and AIDS in Asia-Pacific issued the following declaration: you can be a part of making it happen!



*Seven Sisters Pilot
GIPA workshop
April 2005*

BANGKOK DECLARATION

by

People Living with HIV/AIDS

in Asia Pacific July 11, 2004

A decade has passed since world leaders ratified the principle of GIPA (Greater Involvement of People Living with HIV/AIDS) at the Paris AIDS Summit in 1994, but its practice in the Asia Pacific region has been woefully feeble. We, the people living with HIV/AIDS in the region, painfully realise that the disempowering presence of stigma and discrimination; lack of access to treatment and support services; lack of capacity; and poor knowledge on GIPA among governments, other stakeholders and PLWHA networks prevent hundreds of thousands of experienced PLWHA from actively participating in the responses to the epidemic.

Our categorical learning in dealing with HIV/AIDS over the last two decades has been that without the well-being and empowerment of PLWHA, GIPA can only be a pipe dream. True practice of GIPA requires total empowerment of People Living with HIV/AIDS - power that is both generated from within and imparted from outside. This empowerment relates to a healthy and dignified life; a rights and gender sensitive environment that is free of stigma and discrimination; availability of livelihood options, political and decision making capacity; and access to affordable treatment including ARV.

We, representatives of PLWHA networks in Asia Pacific region, therefore, urge all Governments, political parties, civil society organisations, UN, bi- and multilateral agencies, corporates, public and private sectors and the media in the region to create an empowering environment for PLWHA and people affected by HIV through the following measures:

Policy and Decision Making

1. PLWHA representatives should be given direct access to relevant ministries dealing with HIV/AIDS issues.
2. PLWHA representatives should be part of decision making bodies related to HIV/AIDS in every country, both in the Government and Non-Government sectors.
3. GIPA should be incorporated into national policies as a prevention strategy.
4. Legal reforms should be undertaken expeditiously in every country to protect the rights of PLWHA.
5. A budget-line dedicated to supporting PLWHA groups should be included in the budget of every country.

Access to Treatment and Support Services

1. Universal and free ARV, laboratory tests and OI treatment should be made available in all the countries.
2. Every company should have a comprehensive workplace policy, conforming to global guidelines, that protects the rights of infected employees.
3. Quality, confidential counselling services should be made available up to the primary health care delivery points.

Social and Economic Empowerment

1. National AIDS Committees should be made multisectoral.
2. Governments, corporate, public and private sectors should help PLWHA groups, particularly women's groups, with income generation activities, micro credits, grants and revolving funds.
3. HIV should be mainstreamed into existing poverty alleviation programmes.
4. Social security measures must be initiated for poor PLWHA.
5. Large scale leadership and capacity building efforts should be initiated for PLWHA.
6. Governments should earmark special programmes and budgets for people affected by HIV, widows and children.

Issued by the 2nd Asia Pacific PLWHA Congress, July 10-11, 2004, Bangkok

RESOURCES

This section provides a number of resources (organizations, documents, publications and websites) that can help you in many aspects of your work including carrying out the goals of GIPA and this toolkit. This list of resources is only a beginning. Through some fairly simple research, you will be able to find much more information. Most resources are available for free and often downloadable from the internet. If you have difficulty finding them, or have limited internet access, contact any of the Seven Sisters Coalition members (listed below), especially the Asia-Pacific Network of People Living with HIV/AIDS (APN+) or Asia Pacific Council of AIDS Service Organisations (APCASO).

1. SEVEN SISTERS COALITION (www.7sisters.org)

Asian Harm Reduction Network (AHRN)
Asia Pacific Rainbow (APR)
AIDS Society of Asia and the Pacific (ASAP)
Asia Pacific Council of AIDS Service Organisations (APCASO)
Asia-Pacific Network of People Living with HIV/AIDS (APN+)
Co-ordination of Action Research on AIDS and Mobility in Asia (CARAM-ASIA)
Asia-Pacific Network of Sex Workers (APNSW)

Here are some publications available at www.7sisters.org:

- All of us count part 1
- All of us count part 2
- APN+ Discrimination Human Rights Position Paper
- APN+ GIPA Position Paper
- APN+ Human Rights Initiative
- Gender Sexuality Consultation Report
- Governance
- Guidelines For Prospective Hosts of an International Congress on AIDS in Asia and the Pacific
- Prevention and Care: You Can't have One without the Other by ASAP

2. Reports and Analyses of GIPA

A Multi-Country Study of the Involvement of People Living with HIV/AIDS (PLWHA) in the Country Coordinating Mechanisms (CCM), The Global Network of People Living with HIV/AIDS (GNP+) 2004. Available at: <http://www.gnpplus.net>.

Aree Kumphitak et al, *Involvement of People Living with HIV/AIDS in treatment preparedness in Thailand: Case Stud*, World Health Organization Perspectives and Practice in Antiretroviral Treatment, Geneva 2004.

David Stephens, *OUT OF THE SHADOWS: Greater Involvement of People Living with HIV/AIDS (GIPA) in Policy*, Policy Project Working Paper Series No. 14 October 2004.

Janine Simon-Meyer and Dan Odallo, *Case Study The faces, voices and skills behind the GIPA Workplace Model in South Africa*, UNAIDS Best Practice Collection June 2002.

Jens Van Roey, *From Principle to Practice Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)*, UNAIDS Best Practice Collection September 1999.

Moving Forward: Operationalising GIPA In Vietnam, Care/Policy Project October 2003.

Pablo Magaz and Karen Hardee, *Implementing GIPA: How USAID Missions and their Implementing Partners in Five Asian Countries Are Fostering Greater Involvement of People Living with HIV/AIDS*, Policy Project January 2004.

UNDP, *From Involvement to Empowerment: People Living with HIV/AIDS in Asia-Pacific* November 2004. Available at www.YOUandAIDS.org.

WHO World Report: *Community Participation: advocacy & action*, Chapter 3, pg. 43 - 55. Available at http://www.who.int/whr/2004/en/05_chap3_en.pdf.

ICASO. 1996. *Special Report: The Legacy of the Paris Summit*. International Council of AIDS Service Organisations. Toronto, Canada.

Paxton S. 2002a. The impact of utilizing HIV-positive speakers in AIDS education. *AIDS Educ & Prev* 14:282-294.

Paxton S. 2002b. The paradox of public HIV disclosure. *AIDS Care* 14:559-567.

Scollay P, Doucett M, Perry M, Winterbottom B. 1992. AIDS education of college students: the effect of an HIV-positive lecturer. *AIDS Educ Prev* 4:160-171.

Takai A, Wongkhomthong S, Akabayashi A, Kai I, Ohi G, Naka K. 1998. Correlation between history of contact with people living with HIV/AIDS (PWAs) and tolerant attitudes toward HIV/AIDS and PWAs in rural Thailand. *Int J Std & AIDS* 9:482-4.

UNAIDS. 2000. *Enhancing the Greater Involvement of People Living With or Affected by HIV/AIDS (GIPA) in sub-Saharan Africa*. UNAIDS.

3. Related Manuals and Toolkits

Positive Development, GNP+ 1998. Available in multiple languages at <http://www.gnpplus.net>.

CCM: Challenging, Changing and Mobilizing: A Guide to PLHIV Involvement in Country Coordinating Mechanisms, GNP+ December 2004. Available at <http://www.gnpplus.net/>.

APN+. 1999. *Lifting the Burden of Secrecy - A Manual for HIV-Positive People Who Want to Speak Out in Public*. Asia Pacific Network of People living with HIV. www.hivasiapacific.apdip.net

A series of Horizons Reports and Research Summaries available at www.popcouncil.org/horizons, including:

- Horizons/International HIV/AIDS Alliance/Kimirina, *The Involvement of People Living with HIV/AIDS in the Delivery of Community-based Prevention, Care and Support Services in Ecuador*, December 2000.
- Horizons / International HIV/AIDS Alliance/Tata Institute of Social Sciences. *The Involvement of People Living with HIV/AIDS in the Delivery of Community-based Prevention, Care and Support Services in Maharashtra, India: A diagnostic study*, not dated.
- Horizons *Greater Involvement of PLHA in NGO Service Delivery: Findings from a four country study*, 2002.

An excellent resource, the **International HIV/AIDS Alliance** offers many toolkits, “how to” training guides, and best practice documents in four categories of publications that are all available at <http://www.aidsalliance.org/> or you can request copies to be sent to you on a compact disk, for free. Here are the categories:

- **Technical support publications:** training and best practice materials aimed at improving HIV/AIDS programmes. They are intended for individual trainers and facilitators, training institutions and NGOs/CBOs.
- **Lessons learnt reports and studies:** document the experiences and learning of Alliance linking organisations and partners at international, regional and national levels and are intended primarily for NGOs/CBOs and NGO support programmes.

- Policy reports and briefing papers: present the Alliance’s policy on a range of themes and aim to influence and strengthen the policies of international institutions such as UNAIDS and the Global Fund to Fight AIDS, Tuberculosis and Malaria. They are intended for institutions and individuals involved in international policy making.
- Fact sheets on treatment, prevention and civil society development: provide accurate, accessible and reproducible information for NGOs and CBOs to support their work in these areas.

Here are some of the HIV/AIDS Alliance’s documents that are especially useful for the purposes of GIPA:

- **Advocacy in Action**: A toolkit to support NGOs and CBOs responding to HIV/AIDS
- **Building Partnerships**: Sustaining and expanding community action on HIV/AIDS
- **Documenting and Communicating HIV/AIDS Work** - This toolkit focuses on how NGOs and CBOs can plan and develop specific skills to document and communicate their work more effectively and share good practice experiences with others.
- **Involving People Living with HIV/AIDS in Research**: Guaranteeing the rights of HIV positive study participants
- **NGO Support Toolkit** - This publication, CD-ROM and on-line toolkit features over 500 resources useful for those providing support to NGOs in a variety of ways.
- **Pathways to Partnerships Toolkit** - for building partnerships
- **Positive, Engaged, Involved**: The participation of people living with HIV/AIDS (PLHA) in community-based organisations
- **Raising Funds and Mobilising Resources for HIV/AIDS Work**
- **Working Positively**: A guide for NGOs managing HIV/AIDS in the workplace

4. Training Agencies and Opportunities

This could be for different levels

International - e.g., the leadership training initiative, International AIDS Conference, Harm reduction conferences, (mainly for the skills-building program)

Regional - e.g., UNDP South Asia Empowerment Initiative, ICAAP

National and local - e.g., ? is it true that both Vietnam and Thailand have English language training specifically for PLWHA

Other key agencies, e.g.,

Care

FHI

IFRC and Red Cross National Societies

Policy Project

PSI

UN agencies

5. HIV groups, associations, and networks in Asia-Pacific

AUSTRALIA

Network of Australian People Living with AIDS

PO Box 51

Newtown 2012

NSW Australia

Email: johnrock@bigfoot.com

admin@napwa.org.au

BANGLADESH

Ashar Alo Society
House#3/3 (Ground Floor),
Road#3, Block-A, Lalmatia
Mohammadpur, Dhaka-1207
Bangladesh.
Ph: 880-2-011045114
Email: akter_habiba@hotmail.com

CAMBODIA

Cambodian Network of PLWHA (CPN+)
House No. 450, Totoutompont 2 St.,
Phnom Penh
Ph: 855-23216399
Mobile : 855-12934777
Email:cpn@camnet.com.kh

CHINA

AIDS Care
160/611 Tianhebel Rd
Tianhe Dist,
Guangzhou 510630
China
Ph: +86 20 38473175
Fax: 86 20 38742937
Email: aidscarecn@hotmail.com

Mangrove Support Group (MSG)
Mr Xiao Li, Director,
Mangrove Support Group
Beijing
E-mail: adam_sky2002@yahoo.com.cn

FIJI (FJP+)

Fiji Network of People Living with AIDS
2nd Fl., Narseys Bldg., GPO Box 12718,
Ellery St.,
SUVA FIJI,
Ph: +679 3313844
Fax: +679 331 4199
Email: tmudunavosa@yahoo.com

GUAM

GUAHAN HIV/AIDS Network Project
P.O. Box 20640
Barrigada, Guam 969
Ph: +671 632 6815, 777 2437
Email: alexsilverio@hotmail.com

HONG KONG

Positive Living Group (PLG)
c/o AIDS Concern
AIDS Concern
17B, Block F, 3 Lok Man Road, Chai Wan, Hong Kong.
Tel: + (852) 2898 4411
Fax: + (852) 2505 1682
Email: loretta@aidsconcern.org.hk

INDIA

Indian Network for People living with HIV/AIDS (INP+)
Flat No 6, Kash Towers
93 South West Boag Road, T.Nagar
Chennai- 600017
Email: inppplus@eth.net
inppplus@vsnl.com

INDONESIA

Spiritia
Jl.Radio IV No.10, Kebayoran Baru
Jakarta Selatan, Indonesia
Ph: 62-811-988827
Email: freaky_sparkz@yahoo.com

INDONESIA

Bali Plus
H. Kehtha Dalem III/8, Sidakarya
Denpasar- Bali 80224
Ph: 62-361-722473
Email: bpf@dps.centrin.net.id

IRAN

Persia Plus
44, W41st, Jahan Ara Ave,
Teheran, Iran
Ph: 98-21-802-7102
Email: persia_plus@yahoo.com

JAPAN

Japan network of PLWHA (JanP+)
103, Amnesty House, Araki-cho, Sinjuku-Kn
Tokyo, Japan
Ph: +813 53678558
Fax: +813 53678559
Email: pinkbear@popo2.odn.ne.jp

LAO PDR

Laos Network of PLWHA (LNP+)
c/o HQ Care/Support Project Officer.
Lao Red Cross, Box 2948,
Vientiane
Ph: +856- 21- 215763
Email: anouxay@laopdr.com
bxay@hotmail.com

MALYAYSIA

Malaysian Positive Living Group
Ph: 0060 123278812
Kuala Lumpur
Malaysia
Email: erd_2000_1999@yahoo.co.uk

MONGOLIA

NAF+1 - Nat'l AIDS Foundation
9A Peace Ave., Sukhbaatar Dist.
C.P.O. Box 117
Ulanbaatar-13
Ph: +976 11318016
Fax: +976 11 321659
Email: zoltamir@yahoo.com

NEPAL

Nepal Plus
P.O.Box
Kathmandu, Nepal
Ph : +9771-4478402
Email : nepalplus2002@yahoo.co.nz

NEPAL

Blue Diamond Society
Shiv Bhakta Marg-344, Khursani Tar, Lazimpat,
Kathmandu,
Nepal
Postal Address: GPO Box: 8975, EPC NO: 5119
Ph: +977 1 4443350, 4445147
Fax: +977 1 4438600
Email: info@bds.org.np
bluediamondsociety@yahoo.com

NEPAL

Nav Kiran Plus
Dhabashi Kathmandu
P.O. Box 8801
Kathmandu, Nepal
Ph: +9771-372623
Email: rkafle@yahoo.com

NEW ZEALAND

Body Positive
1/3 Poynton Terrace, Auckland City. PO Box 68-766, Newton, Auckland
Ph: +64 93093 989
Fax: +64 9309 398
Email: office@bodypositive.org.nz
Website: <http://www.bodypositive.org.nz>

PACIFIC ISLANDS

PIAF
Pacific Islands AIDS Foundation
P.O. Box 888, Avarua
Rarotonga, Cook Islands
Ph: +682 23102
Fax: +682 23102
Email: piaf@oyster.net.ck

PAKISTAN

New Light AIDS Control Awareness- Group,
766/5, D-1, Green Town, Lahore, Pakistan
Ph : +92-42-5113084/5113837
E-mail: newlightaids@yahoo.com

PAPUA NEW GUINEA

IGAT Hope
C/O National AIDS Council Secretariat
PO Box 1345 Boroko NCD
Papua New Guinea
Ph: +675-323-6161
Email: ighathope@yahoo.com.au

PHILLIPINES

Pinoy Plus Association Inc.
1066 Remedios St. Malate
Metro-Manila, Philippines
Ph: +632-524-0924
E-mail : quintojun@yahoo.com

SINGAPORE

Club Genesis - Life Goes On
C/O DSC Clinic #2-16
31 Kelantan Lane
Singapore 200031
Ph: +65 94576275 (mobile)
Fax: +65 62565903
Email: hemispheresg@yahoo.com.sg

SRI LANKA

Lanka+ - Sri Lank network of PLWHA
70/3, Kadawatha Road
Kalubowila
Dehiwala
Sri Lanka
Ph: 941-2765234
Email: wilrand@sltnet.lk

SOUTH KOREA

KANOS
Korea HIV/AIDS Network of Solidarity
Central P.O. Box 1192
Seoul - 110 061
Republic of Korea
Ph: 82-11-310-2652 (mobile)
Email: kanos@kanos.org
ohdream@hotmail.com

TAIWAN

PDF, Taiwan
Positive Development Family, Taiwan
2FI, #19, Chuan Fu Lane, Chuan Hsin St.,
Tai Shan Hsiang,
Taipei Hsien, Taiwan, R.O.C.
Ph: +886 2-2909-8098
Cell: +886 9136-348-1169
Email: lgeorge@ms21.hinet.net

TIMOR LESTE

c/o UN House - UNDP Timor Leste
Caicoli Street,
Dili- Timor- Leste
milena_rangel@hotmail.com
Mobile: +670 723 5601
Fax no: +670 3312408
Email: milena.rangel@undp.org

THAILAND

Thai Network of People Living with HIV/AIDS (TNP+)
885 Soi Tappakdee Ladprao 101
Wangthonglang Bangkok
Bangkok Thailand 10240
Ph: +66-2376-0175-6
Email: tnpth@loxinfo.co.th

VIETNAM

Centre for Community Health and Development, 127- Lo Duc
Hanoi, Vietnam
Ph: 84-4-9721452
Email: trungthanh@cohed.org.vn
VIETNAM
102/D4 Le Van Tho street, ward 11, GoVap district
Ho Chi Minh city,
Vietnam
Email : darctruong@yahoo.com

6. International Agreements and Frameworks that are supportive to GIPA

The following four documents provide text from various proclamations that have been made by positive people and by international organizations about the involvement of people living with HIV/AIDS. From the beginning of the HIV epidemic until today, the need for greater involvement of PLWHA has been recognized and called for at many levels.

THE NGO HIV/AIDS CODE OF PRACTICE PROJECT 2004

The most recent initiative is The NGO HIV/AIDS Code of Practice Project 2004. Driven largely by the International Federation of Red Cross and Red Crescent Societies, this Code is being agreed to by organizations around the world. Here are the guiding principles of the Code:

- We advocate for the meaningful involvement of PLHA and affected communities in all aspects of the HIV/AIDS response.
- We protect and promote human rights in our work.
- We apply public health principles within our work.
- We address the causes of vulnerability to HIV infection and the impacts of HIV/AIDS.
- Our programmes are informed by evidence in order to respond to the needs of those most vulnerable to HIV/AIDS and its consequences.

The complete text of The NGO HIV/AIDS Code of Practice is available at www.ifrc.org/what/health/hivaids/code/ along with updated lists of organizations that have formally adopted the code and, thereby, made the commitment to live by it.

GIPA PRINCIPLES (Declaration of the Paris AIDS Summit)

The term “GIPA” was popularized by the Declaration of the Paris AIDS Summit, issued on 1 December 1994 at a world AIDS summit convened by the World Health Organization and attended by 42 countries who all signed the document. The declaration calls for, among other things, support for the involvement - *the greater involvement* - of PLWHA. Here are excerpts from the 50-page Paris Declaration that are most closely related to GIPA:

- To support the greater involvement of people living with HIV and AIDS (PLWHA) through initiatives to strengthen the capacity of and coordination of networks of PLWHA and CBOs stimulating the creation of a supportive political, legal and social environment;
- To involve PLWHA fully in decision making, formulation and implementation of public policies;
- To protect and promote the rights of individuals, in particular those living with or most vulnerable to HIV/AIDS, through legal and social environments;
- To make available necessary resources to better combat the pandemic including adequate support for PLWHA, NGOs and CBOs working with vulnerable and marginalised populations;
- To strengthen national and international mechanisms connected to human rights and ethics related to HIV/AIDS.

The full document can be found at <http://www.ecpp.co.uk/parisdeclaration.htm>.

UNITED NATIONS GENERAL ASSEMBLY SPECIAL SESSION ON HIV/AIDS (UNGASS)

In June 2001, the United Nations convened the first ever General Assembly Special Session on HIV/AIDS (UNGASS) in New York City at the UN Headquarters. During these two days, the “state of the epidemic” was reviewed and a “Declaration of Commitment on HIV/AIDS: Global Crisis, Global Action” was crafted and accepted by the member countries of the United Nations. This declaration covers more than 50 pages and can be found, in its entirety, at:

http://www.unaids.org/html/pub/publications/irc-pub03/aidsdeclaration_en_pdf.pdf.

103 points were made in the declaration covering many aspects of the response to the HIV epidemic, including:

- Leadership
- Care, support and treatment
- Prevention
- Children orphaned and made vulnerable by HIV/AIDS
- Reducing vulnerability
- Alleviating social and economic impact
- human rights
- Research and development
- Resources
- Conflict and disaster-affected regions

Here are some extracts with special relevance to GIPA (emphasis added in italics):

Acknowledgement that:

(from Point 14): Stressing that gender equality and the empowerment of women are fundamental elements in the reduction of the vulnerability of women and girls to HIV/AIDS;

(from Point 27): Welcoming the progress made in some countries to contain the epidemic, particularly through: strong political commitment and leadership at the highest levels, including community leadership; effective use of available resources and traditional

medicines; successful prevention, care, support and treatment strategies; education and information initiatives; *working in partnership with communities, civil society, people living with HIV/AIDS and vulnerable groups*; and the active promotion and protection of human rights; and recognizing the importance of sharing and building on our collective and diverse experiences, through regional and international cooperation including North-South, South-South and triangular cooperation;

(from Point 33): *Acknowledging the particular role and significant contribution of people living with HIV/AIDS, young people and civil society actors in addressing the problem of HIV/AIDS in all its aspects, and recognizing that their full involvement and participation in the design, planning, implementation and evaluation of programmes is crucial to the development of effective responses to the HIV/AIDS epidemic.*

Commitment to:

(from Point 74) By 2003, ensure that all research protocols for the investigation of HIV-related treatment, including antiretroviral therapies and vaccines, based on international guidelines and best practices are evaluated by independent committees of ethics, in which persons living with HIV/AIDS and caregivers for anti-retroviral therapy participate;

(from Point 94): Conduct national periodic reviews(...of this declaration...) with the participation of civil society, particularly people living with HIV/AIDS, vulnerable groups and caregivers , of progress achieved in realizing these commitments.

The Denver Principles

There is no better way to show the history of self-empowerment brought by the PLWHA “movement” than to quote the Denver Principles as they were written in Denver, Colorado, USA in 1983.

A small group of people, “PWAs” as they wished to be called - people with AIDS and not “AIDS victims” as was popular in the news media and on the street at the time, lobbied AIDS organizations to pay their way to an early AIDS conference in 1983. There, they came together and drafted a manifesto, spread out a banner and took over the stage during a plenary session of the conference. One by one, they read aloud what is now known as The Denver Principles. The audience included doctors, nurses, social workers, and gay activists who were at first stunned by this action. However, the audience slowly rose to its feet in a thunderous and enthusiastic standing ovation.²⁴ The greater involvement of people with AIDS - PLWHA - deciding for, fighting for and participating in their own future, had begun - only two years after the first cases of AIDS were officially recognized. The Denver Principles are as relevant and powerful today as they were over 20 years ago.

Note that The Denver Principles were written before the discovery of HIV as the virus that causes AIDS and, therefore, also before the use of condoms was proven to effectively stop the spread of HIV.

THE DENVER PRINCIPLES (Statement from the advisory committee of the People with AIDS)

We condemn attempts to label us as “victims,” a term which implies defeat, and we are only occasionally “patients,” a term which implies passivity, helplessness, and dependence upon the care of others. We are “People With AIDS.”

²⁴ Walt Senterfitt, *The Denver Principles -- The Unfinished Struggle for Self-Empowerment and Leadership, Being Alive* 1999. From <http://www.aegis.com/pubs/bala/1999/BA991201.html> accessed April 2005.

RECOMMENDATIONS FOR ALL PEOPLE

1. Support us in our struggle against those who would fire us from our jobs, evict us from our homes, refuse to touch us or separate us from our loved ones, our community or our peers, since available evidence does not support the view that AIDS can be spread by casual, social contact.
2. Not scapegoat people with AIDS, blame us for the epidemic or generalize about our lifestyles.

RECOMMENDATIONS FOR PEOPLE WITH AIDS

1. Form caucuses to choose their own representatives, to deal with the media, to choose their own agenda and to plan their own strategies.
2. Be involved at every level of decision-making and specifically serve on the boards of directors of provider organizations.
3. Be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.
4. Substitute low-risk sexual behaviors for those which could endanger themselves or their partners; we feel people with AIDS have an ethical responsibility to inform their potential sexual partners of their health status.

RIGHTS OF PEOPLE WITH AIDS

1. To as full and satisfying sexual and emotional lives as anyone else.
2. To quality medical treatment and quality social service provision without discrimination of any form including sexual orientation, gender, diagnosis, economic status or race.
3. To full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment and to make informed decisions about their lives.
4. To privacy, to confidentiality of medical records, to human respect and to choose who their significant others are.
5. To die--and to LIVE--in dignity.

“Remember that someday the AIDS crises will be over. And when that day has come and gone there will be people alive who will hear that once there was a terrible disease, and that a brave group of people stood up and fought and in some cases died so others might live and be free.”
- Vito Russo²⁵

²⁵ Statement by Vito Russo (1946 - 1990), author, film critic and AIDS activist, made in 1988, from <http://www.actupny.org/documents/documents.html>, accessed April 2005.



COALITION OF ASIA PACIFIC
REGIONAL NETWORKS ON
HIV/AIDS



APCASO
ASIA PACIFIC COUNCIL OF
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