



# Asia Pacific Network of People Living with HIV/AIDS

## APN+ Position Paper 2 GIPA

January 2004

<b>Executive Summary</b>	<b>2</b>
<b>The GIPA Principle</b>	<b>3</b>
<b>Why Do We Need GIPA?</b>	<b>3</b>
<b>History of GIPA</b>	<b>4</b>
<b>Outcomes of GIPA</b>	<b>5</b>
<b>What Does GIPA Really Mean?</b>	<b>6</b>
<b>Practical Examples of GIPA Activities</b>	<b>6</b>
<i>Peer Support</i>	
<i>Peer Education</i>	
<i>Advocacy</i>	
<i>Public Education</i>	
<i>Counselling</i>	
<i>Program Planning and Implementation</i>	
<i>Public Health Policy and Legislation</i>	
<b>Challenges to Implementing GIPA</b>	<b>8</b>
<i>Late Diagnosis</i>	
<i>Socio-Economic Differential</i>	
<i>Stigma and Discrimination</i>	
<i>Improving Counselling</i>	
<i>Keeping Positive People Alive</i>	
<i>Outgrowing Tokenism</i>	
<i>Building Confidence and Capacity</i>	
<i>Sustainability</i>	
<i>Government Attitudes</i>	
<b>The Future</b>	<b>12</b>
<b>Suggested Sources for Further Reading and Reference</b>	<b>13</b>

## **APN+ Position Paper 2 - GIPA**

### **Executive Summary**

The Paris AIDS Summit Declaration of 1994 acknowledged the central role of people living with HIV in AIDS education and care, and in the design and implementation of policies and programs towards a successful response to HIV/AIDS. Because positive people bring a unique perspective to their work, they require opportunities to spell out their needs on an equal platform with government and non-government organisations. Prevention and care are ends of a continuum. Meeting HIV-positive people has a significant and profound impact on people's attitudes to AIDS. By protecting human rights and pro-actively including positive people in the responses to HIV/AIDS, stigma and discrimination are reduced and public health is promoted. The Declaration committed governments to develop and support structures, policies and programs to reduce stigma and discrimination and break down the barriers of fear and prejudice, by the greater involvement of positive people in the response. However, to date, the involvement of positive people has been very tokenistic.

To encourage the greater involvement of people living with HIV in all levels of policy making, and project design and implementation, APN+ aims for the following outcomes:

- An end to mandatory testing; all testing carried out is to be completely voluntary and accompanied by quality counselling and information
- Training and employment of HIV-positive people as counsellors
- Voluntary counselling and testing centres run by trained positive counsellors
- Referral to peer support on diagnosis
- Help with disclosure of HIV status to family
- Provision of sustained quality treatment to all positive people including antiretroviral drugs and medicine for opportunistic illness
- Respect for the confidentiality of positive people involved in the response
- Building capacity of positive people; provision of skills and appropriate training to develop their organisations, build networks, carry out research, and design, implement, monitor, evaluate and sustain projects and programs
- Skills training and encouragement to go public about living with HIV (providing they have good personal support, secure housing and income).
- Establishment of independent Positive Speakers' Bureau, employing positive people pro-actively as public speakers in preventive education programs, as outreach workers, peer educators and treatments' advocates
- Engagement in the decision-making processes, providing input into policy design, in an equal partnership with other decision makers
- Involvement of positive people in the Country Coordinating Mechanism of the Global Fund to fight HIV, TB and malaria.
- Involvement in the WHO "Treat 3 Million by 2005" Initiative
- Encouraging more women, particularly widows and single women, to be involved
- Provision of incomes to positive people so they can survive
- Employment opportunities made available to enable these actions to happen

## **APN+ Position Paper 2 - GIPA**

### **The GIPA Principle**

GIPA means the Greater Involvement of People with HIV/AIDS, and derives from a principle embedded in the Paris AIDS Summit Declaration of 1994. At this summit, leaders of 42 nations met together to determine how they could effectively respond to the AIDS crisis.

The Declaration, signed by all nations attending the meeting, acknowledged the central role of people living with HIV (positive people) in AIDS education and care, and in the design and implementation of national and international policies and programs, in order to successfully tackle HIV/AIDS. It also acknowledged that, for positive people to take on a greater role in the response, they need increased support.

Article 1 of the Declaration resolved to facilitate this greater involvement of positive people. It states that:

*The success of our national, regional and global programmes to confront HIV/AIDS effectively requires the greater involvement of people living with HIV/AIDS... through an initiative to strengthen the capacity and coordination of networks of people living with HIV/AIDS... By ensuring their full involvement in our common response to HIV/AIDS at all - national, regional and global - levels, this initiative will, in particular, stimulate the creation of supportive political, legal and social environments.*

The Declaration committed governments to develop and support structures, policies and programs to facilitate the greater involvement of positive people. This has since been adopted by UNAIDS as the GIPA Principle.

### **Why Do We Need GIPA?**

The GIPA Principle is important for several reasons. Publicly acknowledged involvement helps to reduce stigma and discrimination and can be a powerful tool in breaking down the barriers of fear and prejudice. Positive people bring the unique perspective of their experience to the range of organisations and agencies working in AIDS.

Positive people have a great deal to contribute towards the challenges posed by AIDS, if they are given the opportunity to spell out their needs on an equal platform with government and non-government organisations. We have learnt by now that both prevention and care and support need to go hand in hand. It is a continuum. Meeting a positive people significantly improves people's attitudes to AIDS (Takai et al, 1998). When people living with HIV put a face to AIDS, speak out and become involved in policies and programs, the impact is enormous and profound. Positive people challenge the myths and misconceptions about HIV/AIDS. They make people realise that anybody can contract HIV. Positive people can perform valuable functions. They can be very powerful AIDS educators, counsellors, and policy makers. Their involvement in the response also builds up the morale of other positive people. The essential link between protecting human rights and promoting public health suggests that a greater pool of positive activists must be encouraged.

## History of GIPA

With the arrival of HIV/AIDS came the greatest global public health policy challenge ever faced by humankind and governments. 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.

The Denver Principles include:

- A refusal to be ‘victims’;
- A request for support from all people;
- A plea against stigma & discrimination;
- A call to all positive people to choose:
  - ✓ to be involved at all levels of decision making;
  - ✓ to be included in all AIDS forums;
  - ✓ to be responsible for their own sexual health & to inform all their partners of their HIV status.
- A demand for:
  - ✓ a full & satisfying sexual & emotional life;
  - ✓ provision of quality medical treatment & social service;
  - ✓ full explanations of medical procedures and risks & the right to choose or refuse treatment;
  - ✓ privacy & confidentiality of medical records & disclosure;
  - ✓ the right to die & live in dignity.

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.

In 1986 the Ottawa Charter for Health Promotion enunciated the crucial importance of empowerment of communities when attempting to improve public health for all. The Ottawa Charter states that people whose health concerns need to be met, people at the community level, must be involved in designing public health policies. In part, it states that:

*Health promotion works through concrete and effective community action in setting priorities, making decisions, planning strategies, and implementing them to achieve better health... At the heart of this process is the empowerment of communities – ownership and control of their own endeavours and destinies.*

In 1994, the Paris AIDS Summit declared the need and the support for the greater involvement of positive people in the response to the AIDS pandemic. The Paris Declaration was signed by the following 42 countries:

*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.*

Unfortunately, no mechanism was established to monitor the progress of GIPA-related activities, no countries subsequently added their signatures, and like the earlier initiatives, the declaration was seen as little more than words.

In 1997, during the XIII<sup>th</sup> International Conference for People living with HIV/AIDS in Thailand, UNAIDS hosted a meeting on the GIPA initiative which recommended action to provide positive people with appropriate skills. This became the seed for development of the GIPA Principle. In 1999, UNAIDS published the first guideline on GIPA and expanded its meaning to include all people directly affected by HIV and AIDS. A publication, "From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)" describes the rationale for involving positive people in the response, and addresses many challenges to the principle. It also put forward the importance of creating safe and enabling environments for positive people to get involved. This guide provided a foundation upon which an increasing number of activities could be built. Significant among these has been pilot initiatives in Malawi, Zambia and South Africa, in which UN volunteers promoted the GIPA Principle. Similar programs have been implemented in Cambodia and approved in Indonesia. In addition, the UN has put in place an HIV-friendly employment policy, and now employs a number of openly HIV-positive staff around the world.

At the 2001 United Nations General Assembly Special Session on AIDS (UNGASS), a declaration agreed on by all UN member governments reaffirmed commitment to GIPA, acknowledging it as a priority concern in the response to the AIDS pandemic. Subsequently at an Asia Pacific Ministerial Meeting held to coincide with the VI<sup>th</sup> International Congress on AIDS in Asia and the Pacific in 2001, a Ministerial Statement signed by 33 Asia Pacific countries was issued. Both this Statement and the ASEAN Workplan record the importance of GIPA.

In 2003, following an earlier pilot initiative aimed at empowerment of positive people in the region, UNDP (South Asia) initiated the Asia Pacific PLWHA Coalition for Advocacy & Capacity Transfer. This joint project with APN+ and INP+ (the Indian Network of Positive People), involves fourteen countries throughout Asia and the Pacific, and will run until 2005. The outcomes of the project will include: the development of a Resource Centre in India; annual capacity building workshops focusing on advocacy, organisational development, and improved treatment, care and support; development of modules to support local training; and an annual Strategic Planning Congress.

### **Outcomes of GIPA**

Despite promotion of the GIPA Principle, there is still relatively little commitment to involving and integrating positive people in programs providing AIDS care, support, prevention and education. Few government and non-government organisations proactively include positive people in their responses to HIV/AIDS at national or local levels. Many of the positive activists who are involved in the sector come to feel exploited rather than inspired by their role. Many suffer burnt out and, without access to appropriate medication, care or support, become critically ill and withdraw from active involvement. There is often a lack of financial support for positive people's groups, and groups that receive funding are frequently driven by their donors instead of by their needs. GIPA has become yet another acronym and the true meaning and realisation of GIPA has been lost.

## **What Does GIPA Really Mean?**

GIPA is not a project or program. GIPA is a principle that will facilitate more successful local, national and global responses to HIV/AIDS. The GIPA Principle means involving positive people at every level of the response.

GIPA does not mean that there is an imperative for all positive people to reveal their status in public, although it is clear that those who do, make a major impact on public perception and the more people who are open, the greater the potential for a reduction in AIDS-related discrimination. UNAIDS has described a pyramid of possible levels of involvement of people diagnosed with HIV. At the first level, positive people are recipients of services and can provide feedback to those planning and implementing these services. Many positive people move to the next level of the pyramid, as contributors to prevention programs and as public speakers. Fewer progress higher to become implementers of programs, for example as outreach workers or peer educators. A few are recognised as experts on a level with other public health professionals. At the peak of the involvement pyramid, positive people are decision-makers in policy and project design.

For positive people to be involved as equals, rather than just as tokens, it is crucial that they possess the skills appropriate to the level of involvement. Although many positive people have the will and capability, frequently they lack education, and the process of diagnosis often results in a severe reduction of self-esteem. Positive people must be provided with training to develop appropriate skills. Self-esteem must be improved so that they *feel* equal with others to whom they must relate. Also, those with whom positive people work need to be made aware of the consequences that can rise from breaches of confidentiality, and be taught to respect the limits to which individuals may wish to reveal their status or become involved. This can only come about within a supportive environment. (See APN+ Position Paper 1 - AIDS-related Discrimination and Human Rights.)

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 or 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.

## **Practical Examples of GIPA Activities**

### 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 one's status and enables people to realise that they 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 regimen 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 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. They 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

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 by opportunities to learn more about it. It has been mentioned already that 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, 2002a).

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 HIV-infected people, 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. They make very sensitive counsellors and are perceived to be much more empathetic to their 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.

One common challenge faced by organisations working in the field of HIV/AIDS is turnover. Burnout is common, and after a few years, staff may move to less stressful work in other fields. Positive people, if they can be kept alive with antiretrovirals, tend to have more sustained commitment. However, this should not be taken as an opportunity to exploit positive people.

#### Public Health Policy and Legislation

At the peak of the GIPA pyramid is involvement in decision making related to AIDS policy and laws, at provincial and national 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.

After the UNGASS in 2001, a Global Fund was established to fight HIV, TB and malaria. Each country has a Country Coordinating Mechanism that develops the country's proposal for funding that is sent to the Global Fund. A pre-requisite of the Country Coordinating Mechanism is the involvement of positive people. On the country coordinating board it has been prescribed that members of community-based organisations must have a voice, including people living with HIV. Currently the representation by positive people remains, in many countries, very tokenistic.

### **Challenges to Implementing GIPA**

#### Late Diagnosis

Most people who have HIV do not know that they are infected. Most positive people are diagnosed late in their infection when they already have an AIDS-related illness, and this clearly reduces their ability to make an impact. As costs for antiretroviral therapy fall, and access is extended massively, we must ensure that those who are 'living' GIPA continue to do so.

#### Socio-Economic Differential

As noted earlier, many positive people come from very different backgrounds as to those involved in program management or policy development. Many are much younger. In environments where age is respected, this makes it difficult for many positive people. Even if people are able and willing to be involved, they may not have the confidence. HIV diagnosis is renowned for shattering people's self-esteem. We can work to overcome these challenges, although many may never be comfortable relating with those in positions of power.

#### Stigma and Discrimination

Stigma and discrimination are perhaps the greatest catalysts for the spread of HIV. People with HIV are stigmatised as different because they are assumed to have been involved in 'immoral' behaviour such as pre- or extra-marital sex or injecting drug use. This is curious - for example, the greatest risk factor for the majority of women who contract HIV is their husband/partner. Because in many countries HIV leads to AIDS-related illness and ultimately death, people also stigmatise those with HIV because they are ignorant of the modes of HIV transmission and are afraid of contracting HIV from casual contact.

Most people do not imagine that HIV will ever enter their lives. They isolate people with HIV, ostracise them, harass them, ridicule them, and in some instances kill them. They don't want to associate with people who are HIV-positive because they are afraid of the shame and blame.

Positive people with HIV are frequently treated in morally disdainful and judgmental ways. Breaches of confidentiality frequently precede discriminatory acts. Often positive people are denied treatment, treatment is delayed, they pay more for health services than untested or HIV-negative people pay, and health workers patronise them. In the home, some positive people are not allowed to associate freely with family members and are forced to eat and sleep separately. Many people have lost their employment because of their HIV status. For example, among the relatively highly educated population of positive people in the Philippines are very high unemployment rates - this is a waste of the country's human resources. Many people's skills are lost simply because they are diagnosed as positive and then subsequently lose their work opportunities.

Many positive people's universal human rights are violated. A person known to be an injecting drug user, a sex worker or a man who has sex with men are usually further stigmatised. This leads to a vicious cycle: most people diagnosed as positive experience self-imposed stigma; many decide not to disclose their HIV status to anybody because they are terrified of how people will treat them. Invariably, there is very little to be gained by being open about one's status but a great deal to be lost, so most people choose to keep quiet and carry the burden of their secrecy in silence and isolation.

The strongest tools to fight stigma and discrimination are the voices of positive people. People can be encouraged to start with limited disclosure; however, if they experience discrimination at any stage, further disclosure and involvement may be hindered.

#### Improving Counselling

Much discrimination originates from testing without due process: inadequate or no pre- or post-test counselling, lack of informed consent, violation of confidentiality. For optimal public health outcomes, testing must be completely voluntary and accompanied by quality counselling and information. The recent APN+ documentation of AIDS-related discrimination indicates that approximately half of the people tested for HIV in several Asian countries were tested without being fully aware of what HIV was or the consequences of an HIV-positive diagnosis; they were tested without appropriate (or any) counselling. These people subsequently were most likely to experience greater levels of discrimination compared with people who were informed about HIV before their diagnosis and who willingly chose to go for an HIV test.

In the first instance, we must examine the context of HIV testing and the conditions under which people test for HIV. Positive people need tools to move beyond the news of their diagnosis - the support of counselling and referrals to any social networks of support available in the community. Quality pre- and post-test counselling can prevent somebody who tests HIV-positive from dropping out of the system and failing to get access to essential information regarding their health management.

Many people need a range of counselling following an HIV-positive diagnosis. This includes: couple counselling for those considering having children; counselling on legal matters such as making a will; counselling for those considering starting antiretroviral

therapy; and counselling for families and partners. For many of these tasks, positive people are best placed to provide empathic responses and guidance. A massive effort to provide training guidelines and training of trainers is urgently needed. In addition, many issues are rapidly changing, and trained counsellors must be connected into a network that provides them with updated information.

With increased access to antiretroviral medication, an even greater effort to scale up voluntary counselling and testing is required; otherwise, there is considerable risk that counselling standards will slip further. Positive people are uniquely qualified to take on these counselling tasks.

#### Keeping Positive People Alive

All positive people need access to treatment and care. But GIPA has often failed because many positive people who have gained skills and self-esteem and started to make an impact have fallen sick and died, and a wealth of expertise has been lost. Those who make a real impact on the epidemic should have high priority for provision of treatment. Today it is possible to keep positive people alive on triple combination antiretroviral therapy for less than US\$1 per day (not including cost of CD4/viral load testing and diagnostics); this is within the means of the global economy, providing the will to do so is created. There is a need to lobby and persuade governments that it is in the greater economic interests of the nation to keep people who are in the most productive period of their lives alive and healthy. We must also solicit support from people in the developed world who owe their lives to free health services.

On 1 December 2003, WHO and UNAIDS launched a global initiative aiming to provide antiretroviral therapy to 3 million people with HIV/AIDS in developing countries by the end of 2005 (3 x 5 Initiative). WHO acknowledges that this target cannot be met without very determined participation by the community and in particular by positive people. APN+ members have already played an active role in the lead up and development of the 3 x 5 Initiative at community consultation meetings and other bi-lateral WHO organised roundtables. WHO sees positive people as indispensable partners at all levels of programming and the involvement of positive people is clearly placed at the centre of the Initiative. WHO plans to strengthen human capacity and facilitate the training of 'key groups' of affected communities so that they can be fully involved in planning, delivering and scaling up antiretroviral therapy programs. WHO will develop standardised training materials for community treatment supporters and educators necessary for the 3 by 5 Initiative. It will also develop training to support the greater involvement of positive people in operational research and quality assurance of services.

Besides their role as advocates and counsellors, positive people will need to monitor side effects of drugs and ensure that there are no gaps in supply of medication to individuals. This initiative will require massive scaling up of facilities for voluntary counselling and testing but its success will also add vast numbers of people to the pool of those who are aware that they are infected. Many people will be identified much earlier in their disease progression than is currently the case. This offers the prospect of significantly scaling up GIPA activities also.

#### Outgrowing Tokenism

Developing relationships with organisations on an equal basis can be a very productive way of developing capacity, and there are instances of this starting to happen, such as the work being done by the International Federation of the Red Cross / Red Crescent.

Unfortunately, in many countries, involvement has translated into finding a positive person, attaching them to an organisation and bringing them out to speak at events such as World AIDS Day. In some cases positive people are persuaded to participate in this tokenism by the offer of a small stipend, and then suffer abuse and discrimination as a consequence, often with no support or assistance from the organisations that involved them in the first place. There is a consensus that many positive people have been exploited by organisations and sometimes used as avenues for them to obtain a greater slice of funding. Many organisations tend to create strong 'victim – saviour' dependent relationships instead of equal partnerships.

Where this kind of relationship is apparent, positive people are now becoming more empowered and are voicing their opinions that they are not prepared to be used as tokens and that they want to take ownership of their own affairs. In order for this to happen, they have to be provided with appropriate skills.

#### *Building Confidence and Capacity*

It is essential that positive people be provided with adequate skills and opportunities to participate fully in the response to HIV/AIDS. Many HIV-positive people are articulate and intelligent but, coming from diverse backgrounds, they often lack the necessary skills required to operate within the HIV/AIDS sector. Because people are uneducated does not necessarily mean that they are incapable of being educated; usually it is a reflection of the lack of opportunities in their country. Women are usually less fortunate than men to receive a decent education yet many women are willing to speak out about HIV. Even if people are willing to be involved and identified as HIV-positive, and even if they have a good education, it still does not necessarily mean that they are capable of playing an effective role without appropriate training.

Skills training is necessary to increase people's capacity to manage their lives effectively while living with the disease. Positive people need skills to build networks, carry out their own research, design and implement their own programs, and sit down with government and take part in the design of policies that will protect their rights and improve the quality of their lives.

Many people may need basic skills such as computer and Internet literacy. To work more effectively in the regional context, some may require English classes. They need skills in proposal writing. The skills needed are wide-ranging and there is no formula for the perfect skills-training package before positive people can build an 'equal partnership'. Different people are skilled in different aspects of the changes needed to overcome the challenges posed by HIV. It is necessary to find out what skills people require. There is no point aiming to develop an advocacy agenda if people do not have the skills or confidence to speak out in public or basic knowledge about HIV. People need guidance on how to develop their organisation when they are working with people from diverse socio-economic and educational backgrounds and with diverse interests and needs. They need skills in how to communicate effectively and deal with conflict. Emerging activists need to be carefully mentored on how to bring people together towards a common cause, so that they can speak with a strong, unified voice on behalf of all people living with HIV.

#### *Sustainability*

If GIPA is to be taken seriously, funders must address the issue of core funding of positive people's organisations as opposed to just funding projects with tangible

outcomes. Positive people need funding in order to operate and have enough staff to identify and respond to their needs.

Positive people need the capacity to plan, monitor and evaluate their projects and most importantly, to maintain and sustain them. Without a sustainable income, positive groups cannot function. In developing countries, people's basic survival needs are often immediate and acute. Therefore, if positive people's involvement in the response is important and necessary, they need financial support in a way that is appropriate to their situation, just as workers in other organisations and government are supported for their time, expertise and effort.

#### Government Attitudes

In how many countries are positive people involved in the National AIDS Planning? In most cases, the reality of GIPA is not being 'lived'. Many governments pay lip service to GIPA yet at the community level people lack adequate health care and provision of antiretroviral medication. Positive people need to be active on all local, provincial and national AIDS policy-making boards and committees. The Global Fund is a great opportunity for governments to allow GIPA to work, via the involvement of positive people in the Country Coordinating Mechanisms.

#### **The Future**

Many groups are now establishing their own independent Positive Speakers' Bureau. They are going out and pro-actively educating others about HIV and making a change. Some groups have voiced their desire to set up their own voluntary counselling and testing centres although wherever it has been suggested in Asia, it has faced resistance.

We need to encourage more women to be involved. Widows and single women face the brunt of AIDS-related discrimination. Many have dependant children and little income, yet they are often the most passionate and committed educators, and those who go public do so sooner after their diagnosis than men do (Paxton, 2002b). So harness the skills of women. They may be the most important element of GIPA.

We need to see more and more positive people with the skills, ability, confidence, willingness and the mandate to take part in decision-making bodies, voice their needs of access to information, education, treatment, care and support. We need people who can articulate the rights of all people to lead productive lives in dignity, advocate for the right to optimal health, including sustained access to antiretroviral drugs, and advocate for the right to earn a living and to run income generation projects and have access to micro-credit schemes.

When people with HIV have the same rights as all citizens, when they can live in dignity, without fear of discrimination, when they are able to sustain their families and organisations and are provided with all the skills necessary to take on the role of equal partnership in the response to HIV/AIDS, then we can expect them to take on the responsibilities that GIPA implies.

**SPIRITIA**  
**A GIPA Model in Indonesia**

Spiritia was started by Suzana Murni, the first Indonesian woman to talk openly about living with HIV in the media. (Suzana died in June 2002.) The organisation is an umbrella for several support groups that have developed throughout the Indonesian archipelago. The organisation's structure includes an executive director and three program directors. In the first instance, people affected by HIV, people who had lost siblings or partners to AIDS, held each of the program director positions. They work closely as mentors to positive people, who are being skilled up so that they can take on these positions. The organisation also carries out 'strengthening visits' whereby a few members of the organisation travel around the country and visit out-patient departments, STI clinics and testing centres to make direct contact with positive people. This has proved to be very fruitful in stimulating the establishment and growth of new peer support groups and expanding the network throughout the country. Spiritia has also developed a strong skills-building component. During their first national capacity building workshop, four people were trained as trainers and were then mentored as they delivered training in public speaking skills to fifteen other positive people. This organisation has proved to be very effective and has spawned many new positive people's groups throughout the country. Spiritia also has a place on national committees involved in AIDS policy design. Now that antiretroviral drugs are available to keep people alive, the network has grown from strength to strength and is maturing rapidly.

**Suggested Sources for Further Reading and Reference**

- 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](http://www.hivasiapacific.apdip.net)
- GNP+. 1998. *Positive Development*. Global Network of People living with HIV and AIDS. [www.gnp.org](http://www.gnp.org)
- Horizons. 2002. *The Involvement of people living with HIV/AIDS in the delivery of community-based prevention, care and support services in Zambia - A diagnostic study*. Horizons - Population Council & the International HIV/AIDS Alliance.
- Horizons. 2002. *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*. Horizons - Population Council & the International HIV/AIDS Alliance.
- 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. 1999. Best Practice Collection. *From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)*. UNAIDS.
- UNAIDS. 2000. *Enhancing the Greater Involvement of People Living With or Affected by HIV/AIDS (GIPA) in sub-Saharan Africa*. UNAIDS.