

# WORKING

IN PARTNERSHIP WITH

NETWORKS OF PEOPLE LIVING WITH  
HIV IN ASIA AND THE PACIFIC

A Guidance Note for Development Practitioners





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# ABBREVIATIONS & ACRONYMS

<b>AIDS</b>	Acquired Immunodeficiency Syndrome
<b>APN+</b>	Asia-Pacific Network of People living with HIV/AIDS
<b>APPRC</b>	Asia-Pacific PLHIV Resource Centre
<b>CBO</b>	Community-Based Organisation
<b>EI</b>	Empowerment Initiative
<b>GIPA</b>	Greater Involvement of People Living with HIV
<b>GNP+</b>	Global Network of People living with HIV/AIDS
<b>HIV</b>	Human Immunodeficiency Virus
<b>INP+</b>	Indian Network for People Living with HIV/AIDS
<b>M&amp;E</b>	Monitoring and Evaluation
<b>NGO</b>	Non-Governmental Organisation
<b>OD</b>	Organisational Development
<b>PLHIV</b>	People Living with HIV
<b>UN</b>	United Nations
<b>UNAIDS</b>	Joint United Nations Programme on HIV/AIDS
<b>UNDAF</b>	United Nations Development Assistance Framework
<b>UNDP</b>	United Nations Development Programme
<b>UNDP RCC</b>	UNDP Regional Centre in Colombo
<b>UNGASS</b>	UN General Assembly Special Session (on HIV/AIDS)

# FOREWORD



**“This Guidance Note provides important practical tips for working with groups of people living with HIV in the Asia-Pacific region.”**

Recently, a number of strong, effective support and advocacy groups and networks have been established among people living with HIV in the Asia-Pacific region. Their involvement in the response to the HIV epidemic has challenged stigma and discrimination and made communities more knowledgeable about access to treatment resources and the need for policy change. Despite this, the involvement of HIV positive people in the struggle against the epidemic and its consequences remains largely tokenistic. Governments, bilateral and multilateral agencies and NGOs have struggled to implement the Greater Involvement of People Living with HIV Principles and to work in genuine partnership with HIV positive people. Yet the engagement, support and active participation of affected people are vital to any effective, humane response to the epidemic.

Since 1994, the Asia-Pacific Network of People Living with HIV (APN+) has been working to address issues of importance to HIV positive people in the region. It now has members in 28 countries and continues actively to promote the rights of positive people, including their right to be meaningfully involved in all aspects of the response to HIV and AIDS. In partnership with the UNDP Regional HIV and Development

Programme and networks of positive people in the region, APN+ has developed and supported a number of events and activities for HIV positive groups and individuals in the region over the past few years. In doing this, the organisation has always sought and encouraged the active participation of HIV positive people.

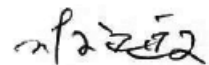
One example is the Empowerment of PLHIV Initiative, conducted over the past three years in 14 countries, which strove to involve positive people in network-building, organisational and leadership development, and advocacy-skills training. The Initiative has contributed to the gradual emergence of empowered leaders and groups among people living with HIV in the region, many of whom participated actively and confidently in it, vividly demonstrating their potential to influence community, national and international responses to their needs and to the course of the epidemic.

This Guidance Note provides important practical tips for working with groups of people living with HIV in the Asia-Pacific region. It was developed in association with a number of such groups, all of whom were participants in the UNDP/APN+/INP+ Empowerment Initiative. I hope you will find it useful as you strive to

increase the meaningful involvement of HIV positive people in your work and that it will, in time, prove itself an important contribution to the worldwide response to the HIV epidemic.

I would like to thank all those whose contributions have resulted in this publication and in particular the HIV positive individuals who participated in the Empowerment Initiative as well as in the development of this Guidance Note.

I hope it will encourage all stakeholders and the positive groups in the region to join hands and ensure working together towards the improved wellbeing of the millions of PLHIV in our region.



**Shiba Phurailatpam**

Regional Coordinator

The Asia Pacific Network of

People Living with HIV and AIDS (APN+)

## A MESSAGE FROM UNDP REGIONAL HIV AND DEVELOPMENT PROGRAMME FOR ASIA AND THE PACIFIC



**“UNDP has spearheaded efforts to support PLHIV movements under the Asia-Pacific Initiative for the Empowerment of People Living with HIV.”**

**W**hile the features, extent and pace of the HIV epidemic vary from country to country across the Asia-Pacific region, the challenges faced by 5 million people living with HIV in these countries share many common characteristics. Prominent among these challenges are the frequent gross violations of human rights they and their families must endure as a result of stigma, discrimination and systematic marginalisation that deprives them of jobs, social capital and hope.

People living with HIV represent the quintessence of the epidemic: the nexus at which human rights, gender, governance and human development issues intersect. It is they who bear the greatest burden and pay the highest price. The frequent opportunistic infections facilitated by HIV often carry away breadwinners, or require treatment that rapidly exhausts whatever scant savings and assets the afflicted household may possess. Such are the burdens of living with HIV. Yet the people who bear them - the people most affected by the epidemic - are often excluded from participation in the response to it.

Over the past few years, the Asia-Pacific region has seen increasing efforts to rectify this situation through the formation of self-help networks intended to strengthen PLHIV empowerment and involvement in the response. These networks serve many useful purposes: they allow PLHIV to speak out and discuss their needs and concerns in a safe environment, offer a range of useful services and provide a sturdy collective platform from which PLHIV can claim their rights.



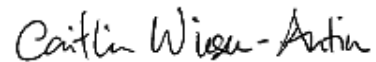
Women, too, are coming together in the face of the growing feminisation of the epidemic, which places disproportionate burdens on them and contributes to their impoverishment in the region. Women living with and affected by HIV in many countries are joining hands to address and act collectively upon issues and challenges specific to them and their children.

UNDP has spearheaded efforts to support PLHIV movements under the Asia-Pacific Initiative for the Empowerment of People Living with HIV. Important achievements of the initiative include the emergence and growth of PLHIV networks and leaders; the development of regional-level platforms for mutual support; the extension of previously unavailable services to PLHIV and their families; the growth of collective regional advocacy on rights, needs, and issues; and growing public recognition that the contribution of PLHIV is critical to the success of the collective response to the epidemic. This last achievement is of particular importance because it has promoted the formation of organisations extending support to PLHIV networks; there are more such organisations active today than was the case even a few years ago, before the Initiative commenced.

Notwithstanding these signs of progress, large gaps still exist in the capacity of PLHIV networks in the region. Substantial strengthening and scaling-up will be needed before the potential contribution of PLHIV can be fully realized regionally, nationally and locally. Meanwhile, existing networks need support from and partnerships with various stakeholders on a continuing and equitable basis.

This Guidance Note, based on the wealth of knowledge and experience accumulated during the three-year span of the Empowerment Initiative, is designed to help forge such relationships, thus facilitating an optimal response to the HIV epidemic in the region. Its production would not have been possible without the collaboration and support of APN+ and the positive networks that participated in the Empowerment Initiative and SWASTI.

I would like to express my gratitude to all these individuals and groups for their unstinting partnership and their dedication to the development of a strong, effective and people-centred response to the HIV epidemic in Asia and the Pacific.



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Regional HIV/AIDS Practice Team Leader  
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UNDP Regional Centre in Colombo



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Section 1

# INTRODUCTION

**“If we break our silence and play a cooperative and proactive role in society, it can change the stigma and discrimination against people living with HIV”**

- Habiba Akthar, Executive Director,  
Ashar Alo Society, Bangladesh

It is now widely recognized in development circles that local ownership and the participation of beneficiaries are indispensable if one wishes to secure sustainable results from any initiative. It is similarly accepted that meaningful participation in programme and policy initiatives by people living with HIV is indispensable to any effective HIV/AIDS response. Unfortunately, the inclusion and participation of positive people in the Asia-Pacific region has so far tended to be marginal.

Although the GIPA (Greater Involvement of People Living with HIV/AIDS) Principle<sup>1</sup> was articulated more than a decade ago, putting it into practice has proved to be a challenge. In fact, the principle cannot be implemented without social and institutional changes at several levels. Yet it is clear that this must be done before an effective response to the epidemic can be mounted.

## The importance of working in equal partnership with people living with HIV cannot be overstated.

### Such partnerships are necessary in order to ensure several important results:

- Positive people locate the HIV response within the framework of human rights, dignity and gender equality enshrined in international treaties and covenants and bring it within the scope of the Millennium Development Goals;
- They bring to bear valuable real-life lessons, derived from the experiences of people living with HIV, on the discourse regarding HIV policy, planning and programming; and
- They help combat stigma and discrimination, which drive the epidemic underground and lead to the spread of HIV.

<sup>1</sup> See Box 1.2 for more information on the GIPA Principle

<sup>2</sup> See Annexure 1 for a list of participating networks.

“To me, GIPA used to mean Greater Involvement of People Living with HIV to ensure a better quality of life for us. But now I know that the way it is practised has flaws that need to be addressed.”

- An HIV positive activist from Sri Lanka

The purpose of this Guidance Note is to facilitate equal, effective and synergistic partnerships between development organisations/practitioners and PLHIV networks. Ethically, it is grounded in the same human-rights principles as those of GIPA: empowerment, non-discrimination, ownership and active, meaningful participation. Functionally, its aim is to improve future interventions by groups working with PLHIV networks in other contexts. It is a practical guide, based on a wealth of experience and learning drawn from PLHIV networks and their supporting partners in several countries across the Asia-Pacific region.

The data on which it draws were obtained during the course of the Asia-Pacific Initiative for the Empowerment of PLHIV (abbreviated hereinafter as EI or the Empowerment Initiative), a three-year project supported by the UNDP Regional HIV and Development Programme and implemented in partnerships with APN+ and INP+. Based on the GIPA Principle, EI focused on building the capacity of PLHIV for empowerment, in part through increasing their capacity to promote implementation of the principle itself.

## 1.1 The context: from involvement to empowerment

EI facilitated the setting up and strengthening of 17 positive networks in 12 countries of the Asia-Pacific region<sup>2</sup> over the period 2002-2005. Its key stakeholders were networks and groups

of people living with HIV at country level in partnership with APN+ and with country offices of UNDP, and partner NGOs working with networks at the country level.

Through EI, a variety of examples of the ways in which national and regional positive networks form, develop and progress was made available for study and comparison. In addition, the initiative assembled a useful overview of country situations with respect to prevalence rates, state and civil society responses, political and legal frameworks, network origins and structures, and the socio-cultural contexts that fuel stigma and discrimination. These data, together with the experiences gained, challenges faced and lessons learned by participating networks, constitute a valuable pool of resources: from it, useful guidelines could be developed for organisations working in partnership with networks and groups of positive people on capacity building and empowerment and on addressing stigma and

**“I promise that AIDS will remain a system-wide priority for the United Nations.”**

- Secretary-General Ban Ki-moon,  
addressing the General Assembly, New York, 21 May 2007

discrimination in order to achieve a more effective HIV/AIDS response.

To this end, a workshop was held in Bangkok, Thailand in May 2006 to deliberate the experiences and processes of the Empowerment Initiative. Participants included representatives of positive networks from seven countries and from the Asia-Pacific Network of Positive People (APN+), as well as from partner NGOs working with the networks, HIV focal points from three UNDP country offices and the UNDP Regional HIV and Development Programme. The workshop had two objectives: first, to take stock and plan forward for the next phase of EI; second, to create a participative environment for the development of guidelines on how to engage PLHIV groups and networks as equal and meaningful partners in programme and policy work.

Box 1.1

### **The Empowerment Initiative**

The Empowerment Initiative focuses on the empowerment of PLHIV and their groups through national and regional networking for mutual support, experience-sharing, advocacy and capacity development in order to:

- establish and strengthen PLHIV organisations
- facilitate care and support for group members; &
- enhance advocacy and leadership skills

The Initiative is implemented in partnership with the Asia-Pacific Network of PLHIV (APN+) and the Indian Network for PLHIV (INP+). Direct support for capacity development is provided to 17 networks in 14 countries across the Asia-Pacific region. A virtual Asia-Pacific PLHIV Resource Centre has been established to take forward regional advocacy, facilitate capacity transfer among PLHIV groups, disseminate information, provide space for all Asia-Pacific PLHIV groups to set up their own Web sites and facilitate networking among these 17 groups as well as among a coalition of PLHIV individuals and groups from 23 countries of the region.

- *From Involvement to Empowerment: People living with HIV/AIDS in Asia-Pacific.*

## **1.2 Multilateral support for the HIV/AIDS response: the role of development practitioners**

The UN system has a significant role to play in any member country's national response to the HIV epidemic. Within the United Nations Development Assistance Framework (UNDAF) for each country, the UN is mandated to provide technical assistance to the government. Since development goals are now inextricably linked to the causes and consequences of the HIV epidemic, this mandate implies UN involvement in the response to the epidemic.

In its areas of comparative advantage, UNAIDS co-sponsors work on the HIV/AIDS response. In many countries, it supports the work of national AIDS authorities through the

Expanded Theme Group on HIV/AIDS. This forum includes bilateral donors and technical agencies. **More importantly, in terms of the concerns of this document, it is supposed to include representatives from networks and groups of people living with HIV.**

Because of the breadth and depth of its involvement with member countries, the UN system is very well placed to advocate a multi-sectoral HIV response, support national leaderships and encourage the political commitment needed for effective action at the national level. Moreover, the United Nations is mandated to uphold, promote and respect human rights in its work. Human rights-based approaches to development emphasize non-discrimination, attention to vulnerability and empowerment. This fits well into the work on HIV/AIDS, particularly with respect to work in partnership with networks of positive people. It is well documented that involving PLHIV is one of the most effective ways to respond to the epidemic (particularly in helping to reduce stigma and discrimination<sup>3</sup>, the greatest obstacles to an effective HIV response).

The core mandate of UNDP is to work on human development, poverty alleviation, governance and, as one of the UNAIDS co-sponsors, HIV. This puts UNDP in a good position to facilitate meaningful implementation of the GIPA Principle, the empowerment of PLHIV networks and the promotion of human rights. The position of UNDP is further strengthened by its very large country-level presence and its regional work with groups and networks of people living with HIV and on issues such as gender, mobility, human trafficking and other aspects of human development and governance. Globally, UNDP is the lead agency among UNAIDS co-sponsors for addressing the human development, gender, human-rights and

governance aspects of HIV/AIDS.<sup>4</sup>

### 1.3 Using the Guidance Note

This Guidance Note draws upon the experiences of participating PLHIV networks in diverse settings and situations in the Asia-Pacific region. The following central principles were used in its development:

- The GIPA Principle (see box 1.2), which must be at the core of the HIV response;
- Empowerment of networks and groups of people living with HIV;
- Equal and meaningful partnerships between PLHIV networks, groups and various support organisations; and
- Experiential learning from PLHIV networks, groups and the organisations supporting them.

These principles can provide guidance for many different types of organisations involved in working with positive networks and groups on the response to the epidemic. For example, the term ‘support organisations’ includes the following:

- Multilateral donors and agencies (UN agencies, Asian Development Bank, EU, ASEAN and SAARC secretariats at country, regional and global levels);
- Bilateral donors working at country and regional level (AusAID, DFID, CIDA, JICA);
- National AIDS authorities, sub-national government agencies and their counterparts involved in prevention, capacity building, care and support, advocacy and related work; other government agencies involved in

<sup>3</sup> Position Paper on GIPA. 2004.: APN+

<sup>4</sup> For more information on UNAIDS co-sponsors' division of labour, see Technical Support Division of Labour: Summary & Rationale. 2005, UNAIDS. Available at [http://data.unaids.org/una-docs/JC1146-Division\\_of\\_Labour.pdf](http://data.unaids.org/una-docs/JC1146-Division_of_Labour.pdf)

- mainstreaming the HIV response;
- Non-governmental organisations (NGOs) involved in prevention, capacity building, care and support, advocacy and related work;
- Community-based organisations (CBOs),
- faith-based organisations, and community groups working on HIV as well as related development issues; and
- Business entities such as private companies and federations of business entities such as chambers of commerce.

Box 1.2

## The GIPA Principle

GIPA stands for Greater Involvement of People with HIV/AIDS, and derives from a principle embedded in the Paris AIDS Summit Declaration of 1994. At this summit, the leaders of 42 nations met together to determine how they could respond effectively 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 programmes, to tackle HIV and AIDS more effectively. 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 programmes that would facilitate the greater involvement of positive people. This has since been adopted by UNAIDS as the GIPA Principle, which was reaffirmed in 2001 at the United Nations General Assembly Special Session on HIV/AIDS.

## Why Do We Need GIPA?

The GIPA Principle is important for several reasons. Publicly acknowledged involvement of empowered positive people helps reduce stigma and discrimination and has great power to break down fear and prejudice.

Positive people bring the unique perspective of their experience to the range of organisations and agencies working in AIDS. They have a great deal to contribute towards the challenges posed by the epidemic provided they are given the opportunity to spell out their needs on an equal platform with government and non-governmental organisations. We have learnt by now that prevention must go hand in hand with care and support; they form a continuum.

Meeting positive people significantly improves others' attitudes to AIDS (Takai et al., 1998). When people living with HIV put a face on AIDS, when they are heard to speak out and seen to be involved in policies and programmes, the impact is enormous and profound. Positive people challenge the numerous myths and misconceptions about HIV/AIDS. They make people realise that anybody can contract HIV. In short, positive people are the ones who can humanise the epidemic.

Thus positive people can perform many valuable functions. They can, for example, be very powerful AIDS educators, counsellors and policy makers. Their involvement in the response also builds 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.

– APN+ Position Paper 2: GIPA



## WOMEN AND WEALTH PROJECT

The Women and Wealth Project (WWP) was initiated by the UNDP Regional Centre in Colombo as a regional pilot project in 2006 for the socioeconomic empowerment of women living with HIV. It is currently implemented in Cambodia, China and India by Thailand's Population and Community Development Association (PDA) headed by Mr. Mechai Viravaidya, in partnership with UNDP ECC and support from country offices, and various international agencies.

The project aims to generate profits to be used as funding for PLHA network organisations in implementing microfinance projects at the community level. The 'WE' brand - **WOMEN EMPOWERED** - was conceptualized to promote the growth of these small enterprises. The specific goal and objectives are to improve livelihoods for women living with and affected by HIV, their families, and network groups, as well as reduce the level of stigma and discrimination associated with HIV/AIDS. The project takes a two-phased approach.

The first phase is the establishment of a sustainable small social enterprise to provide employment opportunities for positive women and generate revenue for the women's groups of PLHA network organisations.

The second phase is the implementation of a microfinance program based on PDA's 'Positive Partnership Model', which is recognised by the *UNAIDS Best Practices* publication series.



Photo: SLC

*This Guidance Note is intended to help in the formulation, planning, monitoring and evaluation of the HIV/AIDS response and to help delineate and clarify the roles of key stakeholders at national, sub-regional and regional level. By clarifying the roles of various stakeholders, it can help development practitioners map and optimise available resources, avoid duplication and, consequently, strengthen the overall response.*

*This Note can also be used by networks and groups of people living with HIV that are looking to build partnerships and obtain access to appropriate support.*

## Section 2

# ISSUES OF IMPORTANCE TO NETWORKS OF PEOPLE LIVING WITH HIV

“I was a student when I found out that I was positive. Now, I am working for the CPN+ women’s wing and helping positive women cope with their status. We have branches of the positive network in many provinces of Cambodia; we are starting self-help groups for positive women, working with collectives of women in sex work on human-rights violations.”

– An HIV positive activist from Cambodia.

**W**hen positive people become partners in the response to the HIV/AIDS epidemic, they are required to play new and important roles, both as individuals and as members of groups and networks.<sup>5</sup> These roles are critical to the overall containment and reversal of the epidemic.

As individuals, positive people must cope with changes in lifestyle, livelihood and income, as well as in their social and family relationships. When they join HIV positive groups and networks, they must learn to work effectively alongside other people from different backgrounds.

As network members, they must set to work on issues such as stigma and discrimination, care and medical treatment, and national and international policy and programme implementation. This work calls for courage and determination. It also demands a variety of resources, both internal and external. The help and ongoing support of able and sensitive collaborators and partners is essential if they are to play their vital part in the response to the epidemic.

Organisations and individuals who support positive people and their networks need to keep this context in mind. Several key issues of importance to positive people are discussed in this section based on the discussions and recommendations of representatives of positive networks in the Asia-Pacific region.

## **Financial support of networks and individual members**

Before they can become active as members of networks, the financial needs of positive people

need to be addressed. These include increased healthcare expenses on the one hand and, very often, reduced incomes on the other. Some will require special nutrition, others housing (their current environment may be unhealthy and conducive to infection, or they may simply be thrown out of their homes because of HIV-associated stigma). Unless these concerns are addressed, it is difficult for positive people to devote time and effort to network activities.

Positive groups and networks need financial resources to set up, develop, sustain and grow. Their need for financial support is gradually being put on the agendas of governments, the donor community and other funding entities. Often, however, the response does not match the need. Funding to positive networks continues to be sporadic rather than planned. Furthermore, any funding received is usually project-based and does not cover organisational costs such as salaries, travel and office rent.

In many cases, positive people providing expert information and ideas to groups working in HIV/AIDS are expected to volunteer their efforts. In unfair contrast, the other participants in these working processes are usually the paid employees of various organisations.

## **Capacity and skills development**

More often than not, the only factor network members have in common is their HIV positive status. Coming from diverse educational, social, economic and linguistic backgrounds, their skill sets are often at variance with those demanded by their function as network members. Moreover, they are often coping with the personal and social consequences of their positive status while attempting simultaneously to play their part on the network.

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<sup>5</sup> In EI, the generally accepted distinction between a group and a network is that the group is more informal and not registered. A network is usually registered. There may, however, be local variations. In Lao PDR, for example, registration is not possible under current legal provisions; yet for all practical purposes, the country's HIV positive group functions like a network similar to those in other countries of the region. Another important distinction is that a network is sometimes made up of representatives from several groups, who may be drawn from diverse backgrounds or geographical locations.

Management of a network and its members is not easy. It demands special skills and capacities. If positive people are to participate in and contribute to policy design, programme implementation, networking, advocacy and capacity-building, they must have specialized training and experience.

In the past few years, positive persons all over the world have demonstrated that, with appropriate capacity building, they can take up these new roles and achieve significant results in them. Thus, adequate support for capacity-building among positive people and networks is of great importance.

## Membership diversity

As stated earlier, positive networks often include members from different sections of society whose only common attribute is their HIV positive status, who may have different needs for emotional, physical and financial support. Their social position, language, religion, education, wealth, caste, ethnicity, gender, sexuality, and culture are all highly variable.

Hence they will also vary widely in their need for support and capacity-building. For example, better-educated and relatively well-off positive people, who are able to take care of their own needs, often do not seek support or contribute to the network. Very poor and poorly-educated people, on the other hand, may need a great deal of support without being able to contribute much. The network therefore has to evolve common issues, plans and actions that take into account the diversity of its membership and the fact that only a relative few have the capacity to take up its most challenging tasks.

## Care and support

Strong networks can emerge only if the fundamental care and support needs of

**“Lack of access to antiretroviral treatment is a global health emergency... To deliver antiretroviral treatment to the millions who need it, we must change the way we think and change the way we act.”**

- LEE Jong-wook, late former Director General, WHO

members and potential members are met. A network member must be healthy and active, both physically and mentally, in order to play her/his role in designing, enhancing and implementing the HIV/AIDS response.<sup>6</sup>

Consequently, one important area of involvement for networks lies in helping HIV positive people obtain treatment, care and support. Besides preserving these individuals' health, care and support activities have other benefits: they build network membership, enhance the influence and status of the network (as it is seen as providing an important community service) and help reduce HIV-related stigma and discrimination.

## Network operations

Different networks operate in different ways, depending on their socio-cultural context as well as on the factors listed above. Network meetings, for example, can take different forms. Small group meetings may be more appropriate in the early days of a network or when the comfort level of new members has to be given special consideration.

Advocacy and networking, on the other hand, often demand large group meetings, which may be difficult to arrange in certain socio-economic contexts or where stigma and discrimination are severe. In some tribal or rural cultures, outdoor meetings may be preferred. Often, members who live far from the network centre may be unable to participate as actively as they wish.

<sup>6</sup> 'Accessing Resources', Positive Development: Setting up self-help groups and advocating for change. A manual for positive people. 1998: GNP+

## Network constitution, structure and processes

The way a network forms will influence its composition and subsequent functioning. For example, one that has come into existence based on the common concerns of a group is likely to function in a democratic, non-hierarchical fashion. But whatever its origins and however informal its functioning, a network needs proper systems and documentation for its organisational health, strength and sustainability.

Sometimes a network may have only a few active members – those with language and other relevant skills that are required at the outset. Such members tend to be overworked with so much responsibility at local, national and regional levels. But over-dependence on a few key individuals slows the process of capacity-building and the taking-up of network tasks by a larger number of members. This retards the healthy growth of the network and the broad-basing of responsibility among members, potentially compromising the sustainability of the network.

On the positive side, the development of a strong corpus of second-line leadership has been observed within the HIV positive movement. The number of positive networks is increasing and the movement as a whole is daily growing in strength. The death of some important founding members has not reversed this trend; positive networks and groups continue to grow and move on.



Photo: PWN+

**“The Health Minister of Bangladesh visited Ashar Alo Society (AAS) for an advocacy workshop. After AAS members spoke to the Minister, he promised to write to the Department of Health to ensure that doctors provide treatment and home care facilities.”**

- Habiba Akthar, Executive Director,  
Ashar Alo Society (AAS), Bangladesh

## Section 3

# **SUPPORT OFFERED AND REQUIRED BY NETWORKS OF PEOPLE LIVING WITH HIV**

**“There are many skills and strengths that PLHIV can offer. We are not just receivers of support.”**

– An HIV positive activist from India.

**P**eople living with HIV offer a diversity of skills and experiences that can greatly enrich the response to the epidemic. While they may not possess detailed medical knowledge, for example, they are in an unusually advantageous position to encourage other HIV positive people to obtain proper treatment and to adhere to their treatment regimens. They are also in an excellent position to collect information about the treatment, care and support needs of positive people. Such potential can be put to best use in partnerships between positive groups and support organisations such as multi- and bilateral donors, NGOs, CBOs and academic institutions.

This section deals with the kinds of support offered and required by networks and groups of positive people in key areas of the response to the epidemic.

## Assessments and monitoring of HIV responses

### What PLHIV networks can offer

- Positive groups and networks are able to provide the most accurate information on the impact, both positive and negative, of policies and programmes that are part of the response.
- They are in a good position to identify gaps in the response and point to where new or different policy intervention and programmes are needed.
- The experiences of PLHIV help them provide detailed information on the vulnerability of different sections of the population, as well as on stigma, discrimination and human-rights violations.
- PLHIV networks can provide human resources for conducting research and for monitoring and evaluating programmes.

Box 3.1

### The meaning of GIPA

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 so 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 programmes and as public speakers. Fewer of them progress higher to become implementers of programmes, 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.

**“We heard that there are funds for setting up a National Network of PLHIV. But we don’t know where to get the official information, where should we follow up.”**

—An HIV positive activist from Pakistan

Such initiatives also provide capacity-building opportunities with respect to network members.

Programme feedback and contributions to learning in the form of members’ first-hand experience.

Role models for good practice.

### What PLHIV networks need

- Positive people will need updated information in their own language on national and international policies and programmes, their rights and entitlements, and potential sources of funding.
- Positive people need the opportunities and

skills necessary to research and evaluate programmes meant for them. Support organisations can advocate the provision of such opportunities in various decision-making forums and provide funds for such training.

## Treatment, care and support

### What PLHIV networks can offer

- PLHIV networks can provide links between positive people seeking treatment and appropriate service providers, resulting in improved target group access, follow-up and feedback in care and support initiatives. For example, in Pakistan, the New Light AIDS Control & Awareness Society, a positive people's network, acts as a bridge between positive people seeking treatment and service providers.
- Evidence shows that where people living

Box 3.2

### Positive people bring positive results

"If there's one thing we've learned about testing and treatment, it's that the involvement of the community is decisive. If "3 by 5" is to make the intended impact, it must call on the community for help, and jettison the lip-service to which so many are addicted.

And the key element of the community is the People Living With HIV/AIDS, who are the real experts, and must be acknowledged as such. They should be consulted on every aspect of the treatment process, and they should be seen as helping to mobilize the community to work, in an equal partnership, with the medical facility dispensing the treatment.

Wherever this formula has been genuinely applied, testing increases exponentially, stigma and discrimination drop significantly, and adherence rates are generally higher - I repeat, higher - than they are in this city of San Francisco."\*

**Stephen Lewis**

*Former UN Special Envoy on HIV/AIDS in Africa  
\*In his key note lecture at 11th Conference on  
Retroviruses and Opportunistic Infections, 8 February  
2004, San Francisco, USA*

**"Now I realise that there are people who need help and support from me I can fight against the epidemic and reach out to those in need."**

—Tamir Norgim, Mongolia

with HIV are involved in the HIV response, the results include better adherence to ARV medicine, reduced stigma and discrimination, and more people taking HIV testing (see Box 3.2).

- In Sri Lanka, for example, members of Lanka Plus provide hospital and home-visit services for people who have been diagnosed as HIV positive, helping them develop coping mechanisms and reducing stigma and discrimination.
- With so many HIV interventions and programmes available, there is an ever-present and increasing demand for counselling services. Network members can be of great value in providing and strengthening the quality of peer counselling, pre- and post-test counselling and home-based care. Positive people can give a human face to the epidemic that is often reduced to just statistics and reports.

### What PLHIV networks need

- Information about the availability and means of accessing treatment, care, support and funding for medical expenses are among the critical needs of positive people. Many also require nutritional support, alternative means of livelihood and ways to augment their income so that their additional expenses can be met.

## Meaningful participation in the HIV response

### What PLHIV networks can offer

- The experiential learning of positive people



about various aspects of the epidemic is a great asset when they are involved in the planning, implementation, monitoring and evaluation of programmes. They can provide important inputs on human rights, stigma and discrimination that can be factored into programme design, implementation and M&E.

- Positive people come from diverse backgrounds. Many have experience in development sectors such as education, health, microfinance, employment generation and public services, which have a direct bearing on initiatives to mainstream the response to HIV/AIDS.
- Networks can provide links between positive people from diverse backgrounds and the planners and implementers of programme interventions. Routing an intervention through a network benefits the network as well as the support organisation and the target group for the intervention.

### What PLHIV networks need

- All responses to the epidemic, whether to do with prevention, care, treatment or education, must recognise and respect human rights based on the dignity and autonomy of the individual.
- PLHIV need to be empowered technically, socially and financially, so that they can participate actively in the response and live with dignity.
- PLHIV networks require funding and technical support so as to participate in HIV-related programmes and interventions.
- The support organisation needs to demonstrate its commitment to the GIPA Principle and build the knowledge, capacity and commitment of its employees on implementing GIPA.

Box 3.3

### Advocacy by positive networks

- In **Iran**, Persia Plus has lobbied the government for first-line ARV medicines and is now starting a campaign for second-line medicines.

- **Nepal+** is involved in an advocacy campaign for legislation protecting the rights of positive people. Efforts are under way to create an umbrella organisation of positive people consisting of many local networks.

- In **Bangladesh**, the positive network Ashar Alo Society has been successful in incorporating the GIPA Principle into the national programme.

**“Stigma, silence, discrimination and denial, as well as lack of confidentiality, undermine prevention, care, and treatment efforts and increase the impact of the epidemic on individuals, families, communities and nations.”**

- United Nations Declaration of Commitment on HIV/AIDS

## Advocacy

### What PLHIV networks can offer:

- PLHIV are at the centre of the HIV/AIDS epidemic and are therefore of critical importance to the success of any response to the epidemic.
- Many positive people have the skills and experience to undertake public advocacy on issues of importance to them. They can help clarify understanding of their needs as a group and bring focus to advocacy.
- Their involvement strengthens the call for positive change. Their presence builds campaign solidarity and strength by adding numbers and diversity.
- Positive people put a human face on the reality of the HIV epidemic, which is too often represented by statistics, rumours and

sensational media coverage.

### **What PLHIV networks need:**

- In terms of advocacy, it is essential for support organisations to recognize and emphasize that the decision to go public with one's status rests entirely with the HIV positive person.
- Once this is recognized, positive people need support for their advocacy in the form of funds, materials, skills and capacity-building.
- Support is also needed to plan and sustain advocacy.
- Access is needed to decision-making forums where PLHIV can advocate and win support for their issues. This means access to public events such as conferences as well as to decision-making bodies such as governments and donor or technical-assistance consortiums. This access needs to go beyond tokenism.
- Networks need strong, sustained support to help build capacity in several areas. These include leadership skills, organisational development, administration and finance, communication and advocacy, networking and media relations. National networks can draw considerable strength and support from their counterparts in other countries, provided they are able to communicate effectively; this makes it vital that at least some network members acquire capability in English communication.
- An important demand made by positive people is that they be given opportunities to use their skills and be supported with continuous capacity-building rather than stand-alone workshops or sessions.

**"Many women would rather not get the treatment they need to save their lives or stop their children from contracting HIV/AIDS because they do not want, or do not know how, to cope with the fear and stigma of HIV/AIDS."**

- Sheikha Haya Rashed Al Khalifa,  
U.N. General Assembly President



## Section 4

# GUIDELINES FOR SUPPORT ORGANISATIONS

**“Responding to AIDS with blame, or abuse towards people living with AIDS, simply forces the epidemic underground, creating the ideal conditions for HIV to spread. The only way of making progress against the epidemic is to replace shame with solidarity, and fear with hope.”**

- Dr. Peter Piot, Executive Director, UNAIDS

**T**his section provides guidelines for organisations working, or wishing to work, with networks and groups of people living with HIV (PLHIV). Such organisations, called support organisations in this Note, include non-governmental organisations (NGOs), community-based organisations (CBOs), academic institutions, and bilateral and multilateral donor organisations engaged in the HIV response in a particular country or region.

General guidelines and principles for effective partnerships are listed at the beginning of the section. Those relating to specific areas (country scenarios, the selection of partners, resource and funding, technical support, governance, coordination and systems, and monitoring and evaluation) are discussed in separate sub-sections.

These guidelines may be applied to any multilateral or bilateral organisation with a national presence and the capacity to work with national partners, including governments and civil society. Such organisations may, in addition, have regional and global links.

## 4.1 General guiding principles

Some principles that will help build effective partnerships between groups or networks and support organisations are given below.

- **Develop and implement a work place policy on HIV.**

It is critical that organisations supporting positive groups and networks have in place a strong work place policy on HIV to ensure there are no discriminatory policies and practices against people living with HIV and that their management and staffs are sufficiently sensitised on issues related to HIV and positive people. Organisations can refer to the *ILO Code of Practice on HIV/AIDS and the World of Work* in establishing such policy.

Box 4.1

### The importance of involving positive people in the HIV response

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. We have learnt by now that both prevention and care and support need to go hand in hand. It is a continuum.

Meeting 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 programmes, 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 policymakers. 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.

- **Plan and implement your response within the framework of the GIPA Principle, human rights, equity and gender equality.**

Ensure that there is clear understanding of GIPA within the organisation, and of what it implies for programme implementation.

There are several challenges and social barriers that an organisation planning to support positive networks will have to take into account. For example, the GIPA Principle clearly articulates the importance of working in equal partnership with positive networks. In most countries, however, stigma and discrimination play an important part in reducing the effectiveness of interventions taken up by support organisations.

HIV/AIDS is a relatively new and rapidly-changing field of work. Detailed planning will be needed to ensure greater and more meaningful involvement of positive people in any proposed programme intervention. Accordingly, the relevant staff capacities will

“(Numbers) don’t convey the full and true reality of AIDS. They do not tell us of the human implications for the individuals directly affected, for their families and their communities.

That is why I will be meeting today with a group of United Nations staff living with HIV. I am proud that these staff members, in coming together as the UN+ group, have the courage and strength to speak up, to challenge stigma and discrimination, and to work to make the UN a model of how the workplace should respond to AIDS.”

- Ban Ki-moon, UN Secretary General

have to be reinforced before programme formulation and implementation can commence.

- **Positive groups and networks are equal partners in all processes and outcomes, in planning and implementation and in monitoring and evaluation.**
- **Positive people will be the prime movers in all decisions and actions regarding their activities; support organisations will inform, support and facilitate but not ‘do,’ ‘implement,’ or ‘control.’**

The experience of the Empowerment Initiative shows that, once a group or network is formed, it will prioritize and take up issues of importance to its members. For example, in Korea, the positive network KANOS is one of the key groups protesting human-rights violations in a move to provide blood banks with lists of positive people.

- **The empowerment of positive people means they must have the time and space to learn, act, make mistakes and innovate. Accept mistakes as part of learning and strengthening.**

HIV positive people have shown repeatedly that, even with minimal support, they are equal to such tasks as group-building or advocacy. A key demand they make of

support organisations is to help them develop the capacity to take on such responsibilities.

To build, expand and sustain a positive group or network, it is necessary to develop leadership capacity among a second and third line of potential successors to its current leadership. It is also important to build the group’s capacity to handle a variety of responsibilities – from finance and office management to the treatment, care and support of members, from advocacy to partnerships with government.

- **Set up early, and sustain, a system for regular and meaningful interaction with stakeholders.**

An important lesson to be drawn from EI concerns the need for regular interactions with partners in the HIV response. In China, where Marie Stopes International played the role of support NGO to AIDS Care China (a network of positive people), substantial interaction with the network began quite late in the project. A donor agency can avoid this by helping to set up a system for learning and sharing at the outset of any partnership.

- **Be mindful of contradictory messages and positions among different partners.**

Forums that allow for regular interaction

between positive people and other stakeholders in the response will help their participants evolve a common and consistent stand on relevant issues. Still, there will be areas where stakeholders disagree. Regular dialogue can help to secure agreement on roles and responsibilities and on what action is best suited to address a particular issue.

- **Ensure the broadest possible participation and sharing.**

One of the realities of EI was that network activities tended to be confined to big cities. A number of difficulties faced by positive people from small communities and rural locations who wished to participate. Many had to travel long distances. Language differences, too, were often a barrier to participation.

To overcome these difficulties, more resources have to be invested in local-language materials and transactions. Also, since positive people have different skills and come from diverse backgrounds, it is important to match available skills as closely as possible with suitable tasks and functions and to invest in appropriate, sustained capacity-building programmes.

- **Ensure that all processes and actions are transparent and accountable to the positive community.**

An important role support organisations can play is that of timely information provider, enabling networks to make informed choices about such aspects of the response as providing resources for positive people, learning opportunities, treatment options, policy changes and livelihood choices. Accountability to the positive community demands that support organisations take the initiative in this area.

Another important aspect of accountability is the maintenance of confidentiality. In this context, it is important that decisions with regard to interactions with the public and media are led by the network.

- **Have risk-management strategies and backup plans in place.**

The unique social dimensions of the HIV epidemic include stigma and discrimination that can result in hostile reactions to group or network initiatives and programme interventions from the public or some

**“There needs to be a fully concerted effort on behalf of all partners to play a more participatory role in the response to HIV/AIDS. The problems and, therefore, the solutions need to be addressed by every sector of society. Stigma and discrimination issues facing PLWHA need to be further addressed and access to treatment, care and support for PLWHA should be made available to all.**

**This can be achieved by further strengthening the meaningful involvement with PLWHA to create an enabling environment, one that involves promoting human rights, empowering PLWHA and encouraging the widespread participation in policy and program development as equal partners and without relying on tokenistic representation.”**

- Greg Gray, former Regional Coordinator, APN+

sections of it. To deal with these, it is necessary to have more than one plan of action in place. It is also vital to undertake step-by-step planning, taking all factors into account, before any action commences. The agreed plan should contain ideas for coping with anticipated problems and alternative strategies for reaching the original objectives.

- **Ensure that actions do not increase stigma, discrimination and marginalization.**

Support organisations and partners should build support in key constituencies for issues related to positive people. This can help offset the effect on public perceptions of group or network interventions that might otherwise increase the stigmatization of positive people and discrimination against them.

Such stigmatization and discrimination are faced by networks and their members in many countries. Apart from compromising the effectiveness of interventions, they also cause deep personal distress. An active member of the South Korean network KANOS points out newspaper photographs of a human-rights campaign taken up by the network, saying, 'look at this photograph of our human-rights campaign. The person with the face covered is me. I cannot appear in the photo without this because there is a lot of stigma and discrimination.'

- **Support organisations should be open to innovation.**

Networks can usually obtain funds for such activities as capacity building and meetings. Funds to set up, staff, sustain and expand the network are, on the other hand, less readily available. One of the demands of positive people and their supporters is that donor agencies innovate and redesign their funding

policies so that core funding support can be given to networks. This would take care of organisational costs – office rent, salaries, travel and management expenses – as well as the recurring costs of an operating network.

Further, if a human rights- and GIPA-based view is applied, positive people have the right to form their own associations in order to take up issues of concern to them. Organisations that support them should respond with appropriate flexibility and creativity rather than offering standardized solutions.

- **Commit to holistic approaches, with flexibility to changing needs over time, group or region.**

Giving the rapidly-changing character of both the regional HIV epidemic and the societies it affects, the needs and priorities of a network are likely to change over time. Partners should have the flexibility to adapt to such changes, for example by revising work plans through a consultative process in order to reflect changing needs, priorities and capacities.

- **Help sensitise the media.**

The media plays a critical role as the way they report on HIV and positive people strongly influence how the public in general respond to HIV and view positive people. Insensitive reporting by the media, which includes breaching confidentiality and the use of derogatory and disempowering expressions to describe positive people and the epidemic, has led to strong fear, aversion, and discrimination against positive people. On the other hand, sensitive media reporting can greatly advance the interests, needs and issues of positive people. Partner organisations can play a bridging role between positive networks and the media to ensure effective and appropriate reporting to the public.



## 4.2 Country scenarios: one size does not fit all

Before commencing work on GIPA or undertaking partnerships with PLHIV networks in any country, a good understanding of the local situation and conditions is essential. Such understanding bears directly on the identification and prioritisation of issues and on the corresponding response. The EI experience underlined the differences that exist in country situations: beyond common factors, challenges, and consequences of the epidemic, country has a complex set of unique interwoven factors, ranging from the socio-cultural context to the nature of the national response. A deeper understanding of these realities is essential to the planning and implementation of HIV initiatives.

### ■ HIV prevalence

The level of HIV prevalence influences the general environment in which networks are built up and sustained. The network in Cambodia, a relatively high-prevalence country, has over 8,000 members and includes an effective women's wing. It receives strong support from the National AIDS Authority. Generally speaking, it is relatively easy for positive people in Cambodia to go public with their status.

In contrast, Bangladesh and Sri Lanka have low prevalence rates, though many factors of HIV vulnerability are present. In such countries, positive people are hesitant to come forward, to join networks or involve themselves in HIV-response activities because of strong stigmatization and discrimination. It is significant that in Sri Lanka, currently only one positive person is publicly open about their status for this reason. Such societies pose a particular challenge to positive groups and networks.

When prevalence levels are high, there will

usually be more funding available and more organisations working in the field. Governments in such countries are also, on the whole, more likely to give due attention to the need for including positive people in the national HIV response.

### ■ Socio-cultural environment

The socio-cultural context of a country influences attitudes to sex and sexuality. It often determines the space available for legal and human rights interventions. Social as well as economic and political factors influence the extent of stigma and discrimination and the space available for positive people to take action that will address their concerns. By and large, the epidemic in the Asia Pacific region is characterized by silence, denial, fear and stigma.

Gender inequality and gender relations, based on power, are also central to the Asian epidemic and need to be addressed specifically. HIV/AIDS is spreading rapidly among women and girls in the region because of gender inequality. For example, in many countries in the region, marriage is seen as a very important institution and even in situations where young women could be vulnerable to the virus they enter into arranged marriages with little knowledge of the HIV risk behaviours of the men they marry, often putting themselves at risk.

In this case, gender equality is not a matter of justice or respect for human rights, gender inequality is fatal. Therefore, it is important that HIV/AIDS interventions and activities are

**“There were thousands like me who carried on with verve. I didn't want to look back. I just wanted to move forward.”**

- Helen, an HIV positive activist, Port Moresby, Papua New Guinea

not gender-blind and an analysis of how gender inequality shapes the economic, political and social factors driving the HIV epidemic are crucial.

Geographical factors are also important. In Fiji, for example, access is constrained by geography, with some areas only accessible by the “bilibili” or local rafts. While there is sometimes considerable support from the government and the influential Church Council, there are problems because of low commitment levels and high expectations from the positive people themselves.

#### ■ **Country responses, situations and national policies**

The Empowerment Initiative highlighted variations in the national policies and programmes across the region. Variations were found in fund allocation, programme design, the proportion of funds assigned to prevention efforts, the type and frequency of focused interventions among vulnerable populations and – most important in the present context – the priority given to PLHIV support programmes concerning access to care and treatment, socio-economic and livelihood support or addressing stigma and discrimination.

Where it is present, government support makes a positive difference. In Cambodia, for example, where linkage to the National AIDS Authority is strong. This has helped the women’s wing of the Cambodian People Living with HIV/AIDS Network (CPN+) make remarkable advances in the short span of a year.

National policies in countries like China and Lao PDR have resulted in a situation where there is hardly any civil society. This limits the support available to positive networks and

affects the quality of response in these countries. There are currently no provisions for registering a network in Lao PDR. In Nepal and Sri Lanka, political unrest has diverted attention from the epidemic. In offering policy advice to governments in the region, the United Nations and other country-level actors play a key role of stressing the importance of partnering with PLHIV groups, stressing the added value they can provide in terms of developing and implementing effective, sustainable, and far-reaching solutions.<sup>7</sup>

#### ■ **Donor agencies**

The presence or absence of donor agencies affects the existence and functioning of networks. As mentioned earlier, does the agencies’ ability to adapt flexibly to the needs of the networks they support. In countries like Korea that are perceived as ‘developed’, the availability of donor funding is relatively low.

The donor agenda has to be supportive of and conducive to the operation of networks. The extent to which the donor community, including multilaterals and bilaterals, are involved in the national response is a contributory factor to the functioning and sustainability of PLHIV networks.

#### ■ **Presence, strength and capacities of groups and networks**

In some countries, groups and networks are very small and must work under conditions of severe stigma and discrimination. In Mongolia, for example, the ‘network’ consisted, until recently, of just two people.

It is also important to ascertain whether positive groups share a common agenda or whether they are fragmented. In some

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<sup>7</sup> For useful information on human rights and HIV/AIDS, see *Human Rights and HIV/AIDS: Now More than Ever*: Law & Health Initiative and Open Society Institute Public Health Programme.

countries, the capacities and initiatives of civil-society partners, such as NGOs and CBOs, have been helpful. In other cases, experience from a neighbouring country has helped; a good case in point is the network in Papua New Guinea, which was set up with the help of positive people from other countries in the region.

### 4.3 Selecting partners and support organisations

In the early stages of partnership between a positive network and a support organisation, the emphasis should be on developing efficient, transparent systems. Common needs and priorities have to be worked out, and space needs to be made to accommodate diversity and cater to group-specific needs.

The core principles could be as follows:

- The inclusion of positive people from different backgrounds will make it possible for the network and its partner to take up different issues of concern to positive people. Make sure to include PLHIV from different interest groups (e.g. injecting drug users, sex workers, men who have sex with men, and ex- or current migrant workers).
- Women and youth in particular have special vulnerabilities and are often among the first victims of discrimination. In many societies they form the most vulnerable, least empowered groups, and particular efforts are needed to include them in the network.
- Larger network memberships, representing diverse groups of positive people, will also make it possible to distribute work more widely, reducing fatigue and the tendency to overburden a few key members. The process of building a second line of leadership is now under way in many of the networks participated in EI, but first-line leaders continue to carry a heavy load.

**“I met several PLWHA from outside China through the networking opportunities that the UNDP Regional Programme provided. These occasions have helped me make contact with government officials and NGOs. But more needs to be done at the grassroots level, for those who are unable to access the internet or those living in complete isolation.”**

- Thomas, Coordinator, AIDS Care China

### Other issues of importance regarding the selection of partners

- A commonly-agreed priority focus in terms of needs;
- Space for accommodating diversity in a spirit of sensitivity to individual and group needs;
- Respect for diversity in the planning and implementation processes; and
- The broadest possible participation and sharing in the selection process (which will require the creation of appropriate systems to promote and facilitate it).

The positive networks set up under EI are now between three and five years old. In most, the members are conscious of the need to mobilize positive people from different backgrounds as part of the network. This will strengthen the networks' influence on core issues including human rights, stigma and discrimination, treatment access, care and support.

The EI experience shows that, while it is desirable to diversify, there also remain challenges that need to be addressed, as illustrated by the following comment from a Fijian participant: 'FJN+ also works with positive people from poor socio-economic backgrounds. The network helps them access



Photo: APN+

treatment and care. However, it would help if they showed more commitment to network activities.'

#### 4.4 Resource mobilization

This section discusses two important areas of focus: resource mobilization for networks and fund management by networks.

The roles that can be played by a support organisation in resource mobilization are as follows:

**“Despite government support, positive people are still stigmatised in Korea. They are thrown out of jobs, refused treatment and school admission and badly discriminated. Things have to change.”**

- Hyun Lee, an HIV positive activist, Republic of Korea

- Leverage more funds for programmes planned in partnership with positive people by using its position and access to potential funding sources
- Facilitate network linkages with other sources of financial support, including government schemes
- Promote micro-credit, micro-finance and other schemes and initiatives for the economic empowerment of members and networks, leading in the long term to the sustainable financing of network activities
- Mobilise resources from the business sector as part of their corporate social responsibility for the provision of treatment and care to positive people requiring such services

Commitment to the empowerment of positive people needs to be manifested by giving priority to capacity-building in the area of fund

management. In specific terms, this means:

- Help and support to enable the network to manage funds on its own
- Helping to build individual skills and network capacities
- Setting up systems to ensure transparency, accountability and efficiency

## 4.5 Technical support

Technical support should be planned and implemented in equal partnership and through collaboration with the positive network or group concerned. It should cover two broad areas. First comes identification and a clarification of issues; this is followed by creation of the appropriate capacity-building packages, including training programmes, mentoring support and the development of resource materials.

Issues need to be identified and understood in relation to the local cultural, language, socio-economic, geographical and political environment. This deeper understanding is vital to the communication processes too.

The experience of EI has highlighted several challenges in the area of capacity-building and shown that more resources must be invested in this area over the long term in order to ensure the growth and sustainability of networks.

Technical support can be provided to help positive networks to:

- Identify issues where technical support is needed and can be provided
- Develop situation-specific perspectives and clarity
- Design appropriate communications strategies
- Identify areas of technical support in response to diverse needs

- Develop capacity-building plans and programme designs for providing training, follow-up support, the production of resource materials and handouts, and mentoring.

## 4.6 Planning, monitoring & evaluation

Planning and review entail the assessment of needs, both internal and external, and the mapping of resources.

Internal needs are those related to capacity-building for organisational growth and development. The starting premise is that networks should be sufficiently empowered to run themselves. Internal needs are therefore organisational, administrative and financial. They relate to human resources, accounting and teamwork – including necessary interpersonal skills and the management of group dynamics.

Some of these ‘internal’ needs have an external component. These are related to communications with other groups and networks and with the general public through the media, as well as to advocacy and lobbying, network facilitation and linkage development. External needs assessment is somewhat different. Essentially, what is assessed is the socio-cultural context in which the group or network must operate, since this determines its operational scope within the overall programme scenario. In specific terms, it means mapping the available external resources – human, financial, organisational, and social – and the possibilities for training and documentation.

Following GIPA, all these assessments should be participatory – planned and implemented with the active involvement of positive people.

In the case of monitoring and evaluation, simple, easy-to-use systems to track institutional growth and programme impacts should be developed in partnership with positive networks. Their involvement will help ensure user-friendliness and ownership.

The objective of EI was to facilitate the formation and development of networks of positive people in the Asia-Pacific region. At the inception of the project, setting up systems and partnerships with positive groups for planning, monitoring, review and evaluation proved to be a challenge. Despite this, a qualitative baseline study was carried out, which served as a useful tool for assessing the environments in which the networks would have to operate and the challenges they would face. Now, with networks in place in most of these countries, it will be easier to undertake planning, monitoring and evaluation on future projects in partnership with positive people.

#### **4.7 Governance and coordination**

Effective and transparent governance mechanisms are critical to the success of any partnership.

The first step in setting them up is to identify all stakeholders and consider the potential support role each could play in the proposed project. Having identified all stakeholders and their potentials, a common understanding of the roles, strengths, capacities and responsibilities of the positive networks, the support organisation and the supporting

partners will have to be established. There should be regular information transfer and feedback among key stakeholders during this process.

It will be necessary from the outset to ensure that all stakeholders have a common understanding of GIPA in principle and practice.

The next step is to draw up and agree upon a clear plan of work (including systems for monitoring and evaluation) before project or programme implementation commences. The planning process should, of course, be participatory. The partners should also set up systems for regular joint reviews, problem-solving and periodic assessments of the policy environment.

In doing all of this, care should be taken to ensure that:

- The chosen approach is one that builds on existing systems;
- Systems that might polarize groups are avoided; and
- Resources are prioritised and their optimum use pursued.



Section 5

# KEY ISSUES FOR SUPPORTING-PARTNER ORGANISATIONS

**“Investment in AIDS will be repaid  
a thousand-fold in lives saved and  
communities held together.”**

- Dr. Peter Piot, Executive Director, UNAIDS



**T**his section deals with roles of supporting-partner organisations such as UNAIDS and its co-sponsors, non-governmental organisations, community-based organisations and other civil society groups involved in the empowerment process. Broad areas of relevance to all supporting partners are described first.

In order to ensure that the GIPA Principle is central to a national response, all partner organisations need to do the following:

- Develop a clear understanding of the country scenario with respect to HIV/AIDS and share it with key stakeholders and partners working with positive people. Both globally and nationally, HIV scenarios are dynamic. The environment shifts and issues change. It is necessary to follow and understand these changes and the challenges they present, and to make the most of whatever opportunities arise for the greater involvement of positive people.
  - Advocate a clearly articulated national GIPA policy and prioritisation of the GIPA Principle in the national response.
  - Identify commitments made by government and lobby for translating words into action. National and international forums and events can provide opportunities for inter-governmental information exchange. However, commitments made by governments at these events (e.g. UNGASS 2001 and +5 in 2006) are rarely converted into action unless they are promoted by strong lobbies. Support organisations have a critical role to play here.
- Identify allies and partners in government, in the positive community and in multilateral and civil society organisations who will work on implementing GIPA.
  - Facilitate action that will establish a clear understanding of the GIPA Principle among these allies and partners and help ensure that it is implemented in their organisations.
  - Advocate the meaningful inclusion of positive people in all important bodies and forums.
  - Ensure the participation of different positive groups, such as drug users, sex workers, men who have sex with men, women and youth.
  - Ensure that the special needs of women living with and affected by HIV and other gender concerns are included in discussion and action.
  - Facilitate and ensure information transfer to positive networks.
  - Facilitate and ensure capacity building of positive networks.
  - Facilitate the strengthening and broad-basing of positive networks.

Section 6

# CONCLUSION

**“We have moved from ‘talk and cry’ to ‘talk and smile’.”**

– HIV positive activist at Taking Stock and Ways Forward  
Strategic Planning Workshop, 10–12 May 2006, Bangkok

**T**he spread of the HIV/AIDS epidemic continues to outpace the response to it. Far more urgent, sustained and sincere national and international efforts, supported by sufficient resources, are needed if the spread of HIV/AIDS is to be halted and reversed as stipulated in the goal 6 of the Millennium Development Goals. Despite the limitation of resources, however, much can still be done to respond to the immediate and medium-term needs of people living with HIV. This will require coordinated action and meaningful partnerships between positive people on the one hand and donors, civil society partners and governments on the other.

The forging of partnerships with PLHIV networks presents numerous challenges. These arise from the intrinsic difficulties of working with positive people on issues that may expose them to stigma and discrimination, as well as from the need to cover a large number of needed interventions with the limited resources available. However, the Empowerment Initiative yielded important lessons regarding these challenges. In particular, EI:

- Gave clear and conclusive evidence of how much positive people are able to make positive impacts if they are given timely support;
- Demonstrated the many ways in which positive people can contribute to the response to the epidemic;
- Helped reiterate the importance of the GIPA Principle;
- Demonstrated that, in order to achieve meaningful GIPA and the empowerment of positive people, a sustained investment of sufficient resources – time, funds and technical support in PLHIV groups and networks – is essential; and
- Demonstrated clearly the value of regional

initiatives. This can be seen in the mutually beneficial relationships established between the national networks and the Asia Pacific Network of People Living with HIV/AIDS (APN+). APN+ has expanded its membership from eight countries in 1994 to 28 at time of writing. It has also provided a regional platform and system for sharing and planning regional action based on national experiences, and vice versa.

Widespread ignorance about HIV and AIDS is undermining efforts to fight the spread of the virus worldwide. The social stigmatization and discrimination associated with HIV is still pervasive and is still the major factor preventing many men and women from seeking support and obtaining services, thereby significantly impeding prevention efforts.

To be better able to respond to the important differences between women and men in the underlying mechanisms of HIV infection and in the social and economic consequences of HIV/AIDS, positive people and their networks are powerful allies: they understand and have lived the reality at first hand.

Experience from around the world makes it clear that no community or country can tackle the consequences of the epidemic without building on the strengths and first-hand experience of those living with HIV and AIDS. They are a source of knowledge and inspiration for policy and effective programming. Their empowered voices and positive lives provide millions of positive people with hope and dignity.

Countries where networks and support groups of PLHIV are established, functioning and acknowledged by donors and governments as equal partners in the response, display constructive responses, resulting in declines in infection rates as we have witnessed in Cambodia and Thailand and a more sensitive approach to prevention, care, treatment and support.

# ANNEXURES

**“The global HIV/AIDS epidemic is an unprecedented crisis that requires an unprecedented response. In particular it requires solidarity -- between the healthy and the sick, between rich and poor, and above all, between richer and poorer nations. We have 30 million orphans already. How many more do we have to get, to wake up?”**

- Kofi Annan

# 1 List of networks in the Empowerment Initiative

## BANGLADESH

### Ashar Alo Society

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## CAMBODIA

### Cambodian People Living with HIV/AIDS Network (CPN+)

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### AIDS Care China

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E-mail: [aidscaresn@hotmail.com](mailto:aidscaresn@hotmail.com)  
Website: <http://www.aidscaresn.org/>

### Mangrove Support Group

Contact Person: Adam Lee  
No.8, Xitoutiao, Youanmenwai, Beijing, 100054, P.R. China  
E-mail: [msg@chinams.org](mailto:msg@chinams.org)

## FIJI

### Fiji Network of People Living with HIV and AIDS (FJN+)

c/o Ministry of Health  
PO Box 2223, Government Buildings  
Old Government Pharmacy Building, Suva, Fiji.  
E-mail: [jljuveni@yahoo.com](mailto:jljuveni@yahoo.com), [tmudunavosa@yahoo.com](mailto:tmudunavosa@yahoo.com)

## INDIA

### Affected and Infected Women's Association in Churachandpur (AIWAC)

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### Council of People Living with HIV/AIDS in Kerala (CPK+)

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## IRAN

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## LAO PEOPLE'S DEMOCRATIC REPUBLIC

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## MONGOLIA

### Positive Life (formerly NAF+1)

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## NEPAL

### Nepal Plus

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### Makanwapur Women's Group

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## PAKISTAN

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### Positive Action Society

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## PAPUA NEW GUINEA

### Igat Hope

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## REPUBLIC OF KOREA

### Korea HIV/AIDS Network of Solidarity (KANOS)

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## SRI LANKA

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# **KEY DECLARATIONS DEVELOPED UNDER THE EMPOWERMENT INITIATIVE**

## **THE BANGKOK DECLARATION**

by People Living with HIV/AIDS in Asia-Pacific

## **THE COLOMBO DECLARATION**

on Universal Access to Affordable HIV medicines by People Living with HIV in Asia and the Pacific

## **THE VIENTIANE STATEMENT OF COMMITMENT**

on the Greater Involvement and Empowerment of People Living with HIV

# 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 PLHIV networks prevent hundreds of thousands of experienced PLHIV 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 PLHIV, GIPA can only be a pipe dream.

**T** rue 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.

**W** e, representatives of PLHIV 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 PLHIV and people affected by HIV through the following measures:

## **Policy and decision making**

1. PLHIV representatives should be given direct access to relevant ministries dealing with HIV/AIDS issues.
2. PLHIV 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 PLHIV.
5. A budget-line dedicated to supporting PLHIV 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 multi-sectoral.
2. Governments, corporates, public and private sectors should help PLHIV 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 PLHIV.
5. Large-scale leadership and capacity-building efforts should be initiated for PLHIV.
6. Governments should earmark special programmes and budgets for people affected by HIV, widows and children

**Released at the Second Asia-Pacific PLHIV Congress, July 10-11, 2004, Bangkok**

# THE COLOMBO DECLARATION

## on Universal Access to Affordable HIV medicines

By

### People Living with HIV in Asia and the Pacific

August, 2007

The Asia-Pacific region has the world's 2<sup>nd</sup> largest number of people living with HIV - 5.9 million. The region has the capacity to manufacture its own generic HIV medicines (ARVs). Today, however, only 19% of those who need ARVs in the region are receiving them.

Over 300,000 people die from AIDS in the Asia-Pacific region every year. Many die prematurely due to lack of access to affordable ARVs. Access to affordable ARVs is about the lives of millions of people in our own countries, and much more than profit margins, patent rights and intellectual property.

Without sustainable access to affordable ARVs for all, any HIV response will be incomplete, largely inadequate, and in the end ineffective. This includes prevention and voluntary counselling and testing.

The growing number of free trade agreements (FTA) imposed by developed countries in the region is seriously threatening the right and the ability of developing countries to purchase or produce affordable generic ARVs. These rights are guaranteed by the WTO TRIPS agreement, but countries are being forced to sign them away. Not only do affordable generic ARVs save governments millions of dollars, but they also allow them to provide treatment to a large number of people.

In this context, **WE, the people living with HIV in Asia and the Pacific, hereby:**

**Support and acknowledge** with appreciation the efforts made by some governments to issue compulsory and government use licenses for life-saving ARVs.

**Strongly oppose** any FTAs that would jeopardise the rights of both positive people and developing countries to access affordable ARVs.



#### **Reaffirm our rights to:**

- The highest attainable standard of physical and psychological health;
- Affordable ARVs and care of the highest quality to remain healthy and productive members of society; and
- Information on the latest medicines and research findings relevant to improving our health conditions.

#### **Reaffirm our duties as responsible citizens to:**

- Contribute to HIV prevention efforts;
- Educate and support all people living with HIV; and
- Strive to maintain high adherence to ARVs to minimise the development of drug resistance.

#### **Demand that governments, the UN, and other organizations working in this field:**

- Provide easy access to affordable ARVs of the highest quality, including second-line ARVs and essential medicines for opportunistic infections, tuberculosis and hepatitis C for all who require them;
- Keep the promise of Universal Access to ARV treatment by 2010, as pledged in the 2006 UNGASS final declaration;
- Ensure sufficient resources, legal systems and a supportive social environment to provide quality treatment, care and support for positive people and their families;
- Support capacity building of positive people in treatment literacy;
- Enact intellectual property laws to protect the right of developing countries to use the safeguards enshrined in the TRIPS agreement and Doha Declarations such as compulsory licenses, as endorsed by the 2007 WHO General Assembly (for WTO member countries);
- Involve PLHIV and civil society representatives in preparatory meetings and negotiations for relevant free trade negotiations; and
- Join hands with other concerned countries and parties to collectively protect the right and ability of developing countries to produce or purchase life-saving generic ARVs.

Issued at the 8<sup>th</sup> International Congress on AIDS in Asia and the Pacific (ICAAP), Colombo, Sri Lanka.



# Vientiane Statement of Commitment on the Greater Involvement and Empowerment of People Living with HIV



Vientiane, Lao PDR, 9 May 2008



**WE**, the representatives of ASEAN Task Force on AIDS and People Living with HIV (PLHIV) of the Member States of the Association of Southeast Asian Nations (hereinafter referred to as ASEAN), attending the ASEAN Regional Consultation on Project Development for Finalising the Regional Proposal and Plan of Action for Greater Involvement and Empowerment of People Living with HIV (PLHIV) on 7-9 May 2008 in Vientiane, Lao PDR:

**REAFFIRMING** the principle of greater involvement of people living with HIV (GIPA) as integral to forging effective responses to the HIV epidemics in ASEAN, as firmly stated in the Third ASEAN Work Programme on HIV and AIDS 2006-2010 (AWP/III), the 2001 UNGASS Declaration, and the 2008 Report of Commission on AIDS in Asia;

**EXPRESSING** the need for further regional and national efforts to involve and empower PLHIV to achieve genuine realisation of the GIPA principle;

**ACKNOWLEDGING** that PLHIV in ASEAN still face stigma, discrimination and other barriers to treatment and care services, and to a life with hope and dignity;

**RECOGNISING** that PLHIV in ASEAN come from diverse backgrounds, such as injecting drug users, men having sex with men, transgender and other sexual minorities, sex workers and their clients, migrants and mobile populations, housewives and women-headed households, and therefore require responses that address their unique circumstances and challenges;

**ACKNOWLEDGING** that without the social, economic and political empowerment of PLHIV and universal access to affordable treatment, GIPA will remain unfulfilled and HIV responses incomplete, as expressed in the 2004 Bangkok Declaration on PLHIV Empowerment; the 2007 Colombo Declaration on Universal Access to Affordable HIV Medicines; and the 2008 Goa Declaration on the Rights of Drug Users Living with HIV;

**APPRECIATING** various efforts carried out by ASEAN Member States and PLHIV networks towards the involvement and empowerment of PLHIV;

**APPRECIATING** that the realisation of GIPA requires continuous dialogue and collaboration between ATFOA and PLHIV;

**AFFIRMING** the strong desire of ATFOA and PLHIV networks to work hand in hand to advance the empowerment and involvement of PLHIV and thereby contribute to more effective HIV responses;

**REAFFIRMING** through this Statement the commitment to the improvement of the quality of life of PLHIV in ASEAN;

**HEREBY DECLARE** our commitment to bridging the gap between existing declarations and action on the ground that truly empowers PLHIV, by undertaking concerted efforts and through the following measures:

1. Establish a team or strengthen the existing mechanism comprising representatives of various government sectors, national PLHIV networks, UN, civil society and faith-based organisations, and health care providers to identify the most useful, culturally appropriate and effective approaches being used and impact they have had in involvement and empowerment of PLHIV at national, sub-regional and regional levels;

2. Work together to ensure access to affordable medicines, including the second- and third-line antiretrovirals (ARVs), paediatric formulations, and medicines for TB, other opportunistic infections and Hepatitis C, with due attention to the potential impact of intellectual property regimes, free trade agreements, and various safeguards for developing countries protected under WTO's TRIPS;

3. Adapt and implement the ASEAN Regional Framework on Increasing Access to Antiretrovirals and Diagnostic Reagents based on the unique regional and country situations;

4. Facilitate the establishment and support of PLHIV networks in mobilising resources, organisational development and their interactions with government at all levels;

5. Continue to scale-up the involvement and empowerment of PLHIV for positive prevention programmes as well as for prevention of HIV transmission among most-at-risk and general populations, including prevention of parent-to-child transmission; harm reduction among IDUs such as needle exchange and drug substitution therapy; increased attention to unique needs and issues of women, sex workers, men having sex with men (MSM), injecting drug users (IDUs), their partners, and migrants; ensuring greater community involvement; and building life skills and health-seeking behaviours for young people;

6. Address barriers to reducing stigma and discrimination to foster greater involvement and empowerment of PLHIV;

7. Create an environment that protects the rights of people living with and affected by HIV and most-at-risk populations in ensuring their accessibility to HIV prevention, treatment and care services towards achieving Universal Access and MDG 6;

8. Address special needs of migrant and mobile populations and ensure their access to HIV prevention, treatment and care throughout the migration process;

8. Enhance good examples of the continuum of care for PLHIV at national and sub-regional levels;

9. Protect and support people living with and affected by HIV and AIDS by implementing effective and appropriate strategies as part of national welfare and social protection systems;

10. Mobilise technical, financial and human resources needed for adequate and sustainable policy, programmes and services for PLHIV, and ensuring that these resources are appropriate and cost-effective;

11. Support and promote the resolution of issues and challenges faced by PLHIV and their families, and assure their access to essential health and welfare services, as well as access to employment and education;

12. Produce guidelines, multi-media advocacy tools and training packages to assist governments of Member States and PLHIV to make choices for the betterment of their health and then facilitate the most useful methods of involving PLHIV in their own contexts.

We reaffirm our commitment to implement the principles and measures set out in this Statement through maximum efforts that are consistent with national laws and policies.

ADOPTED in Vientiane, Lao People's Democratic Republic this Ninth Day of May in the Year Two Thousand and Eight.



### 3 The Asia-Pacific Initiative for the Empowerment of PLHIV: history and achievements

The UNDP Regional HIV and Development Programme supported the Asia-Pacific Initiative for the Empowerment of PLHIV, or EI, which was implemented in partnership with the Asia-Pacific Network of People Living with HIV and AIDS (APN+) and the Indian Network for People Living with HIV/AIDS (INP+). The pilot phase was carried out in 2001 and the second, three-year phase over 2003-2005. The aim of EI was to strengthen the voice of PLHIV in the Asia-Pacific region by developing capacity within selected PLHIV groups for policy advocacy, prevention strategies and care-and-support responses.

#### A brief history

The first-generation response to the HIV epidemic was characterized by interventionist approaches in which positive people were considered 'victims' of disease, 'targets of interventions' or 'subjects of research'. The Denver Principles (see Annex 6) marked a fundamental shift in the approach, with PLHIV asserting the right to responsible roles in shaping the response to the epidemic.

The emergence of the 'Greater Involvement of People Living with HIV/AIDS' (GIPA) concept in the Declaration of the Paris AIDS Summit held in 1994 marked the second-generation response. It was a strategic change from a top-down to a more participatory approach, one that involved vulnerable people in the design and implementation of responses to HIV/AIDS. The UNGASS Declaration of 2001 reinforced the principles of GIPA.

The main object of the third-generation response was the empowerment of PLHIV. This emphasis was the result of two decades of experience, which showed that true participation cannot be achieved without complete empowerment of PLHIV.

Empowerment brings benefits in terms of individual well-being, better access to health information and services including quality counselling and peer support, the reduction of fear, shame, stigma and discrimination, a rights-sensitive legal and ethical environment, leadership, access to economic opportunities and the capacity of PLHIV to contribute to the response. This third-generation response recognizes empowerment as a right of people living with HIV and lies at the heart of EI.

The UNDP Regional HIV and Development Programme began working with PLHIV in the Asia-Pacific region in the late nineties. The visibility of PLHIV in the region was extremely poor; groups were either absent or nascent and of low capacity. Therefore, a pilot project focusing on five South Asian countries – Bangladesh, India, Nepal, Pakistan and Sri Lanka – was initiated in 2001.

The first step under this initiative was a stocktaking and mapping exercise. This was followed by a participatory problem analysis. The pilot phase made it clear that PLHIV did not consider GIPA as an end in itself, but rather as a tool to achieve objectives they had set for themselves and their networks. This led to the project known as Asia-Pacific Initiative for the Empowerment of PLHIV, which was implemented from 2002 to 2005.<sup>8</sup> This project was also known as the Empowerment Initiative (EI).

#### Coverage and activities

The second phase of EI was initiated in 2003. A planning meeting held in Marawila, Sri Lanka in October 2002 brought PLHIV from China, Mongolia, Korea and Iran in contact with the South Asia Group that had taken part in the pilot study. Shortly after this workshop, in

<sup>8</sup> *From Involvement to Empowerment: People living with HIV/AIDS in Asia-Pacific*. 2004: UNDP

March 2003, a strategic planning meeting provided an opportunity for positive people from Cambodia, Thailand, Vietnam and PNG to meet the Marawila participants. Thus EI became representative of PLHIV concerns across the Asia-Pacific region.

Financial and technical support was provided

to selected PLHIV groups in Bangladesh, China, Cambodia, Fiji, India, Iran, Lao PDR, Mongolia, Nepal, Pakistan, Papua New Guinea, Republic Of Korea and Sri Lanka. In addition, the Initiative sought to include all Asia-Pacific PLHIV groups in regional advocacy, mutual support and the process of sharing experiences and lessons learned.

**The following table gives the activity components of the Empowerment Initiative.**

ORGANISATIONAL DEVELOPMENT	CARE AND SUPPORT	ADVOCACY
Employing and training PLHIV as project management	Positive living: empowering and training PLHIV members	Developing advocacy skills to take up interactions with governments, NGOs, politicians & community leaders
Setting up office infrastructure	Developing skills of PLHIVs as peer counsellors	Public speaking and media advocacy
Training PLHIV members on administration, finance, accounts and organisational development	Setting up peer counselling services for PLHIVs and family members	Policy advocacy: strategizing exercises to influence policymakers and implementers
Building partnerships with NGOs, CBOs, medical professionals, etc.	Referral system for quality care of OIs and social services; promoting establishment of day care centres	Developing appropriate advocacy materials

Currently, the Empowerment Initiative is in the 3<sup>rd</sup> phase implemented by UNDP in partnership with APN+, with a focus on the strengthening of the APN+ secretariat, establishment of the Quiet Storm Fund to support activities of positive networks in the region, and socioeconomic empowerment of positive women. (visit the Women and Wealth Project at [www.wwp-we.org](http://www.wwp-we.org))

### 3a Milestones from the Empowerment Initiative

YEAR	PROJECT MILESTONES	KEY ISSUES
2002	First pre-EI meeting, Sri Lanka	Needs mapping and strategic planning
2003	A Regional Baseline Study	Mapping of environment in which the participating positive networks were operating
	Establishment of the Asia-Pacific PLHIV Resource Network (www.PLWHA.org)	A virtual network of positive people from across the Asia-Pacific region facilitated by a co-ordinator
	First Working Group Seminar, Pattaya, Thailand	Leadership training, general and media advocacy, organisational development, treatment literacy, positive speakers' bureau, positive living
2004	First PLHIV Congress, Bangkok, Thailand	Sharing experiences, needs mapping, regional strategy, preparation for the PLHIV Declaration
	Second PLHIV Congress, Bangkok, Thailand	Advocacy plan for International AIDS Conference, Bangkok
	Second Working Group Seminar, Bangkok, Thailand	Sharing experiences, M&E, web site development, TOT on counselling (provided by APN+ and Australian Red Cross).
	Release of the Bangkok Declaration at the World AIDS Conference	The Bangkok Declaration released in a press conference attended by Peter Piot and other prominent people.
2005	Third PLHIV Congress, Kobe, Japan	Progress on the Bangkok Declaration & ways forward
2006	Strategic Planning Meeting, Bangkok, Thailand	Strategic assessment of EI and development of a Guidance Note
	A regional project on the socioeconomic empowerment of groups of positive women in Cambodia, China and India	Economic and organisational strengthening of positive women's groups through the development and management of small social enterprise and creation of livelihood opportunities for positive women
2007	Establishment of the Quiet Storm Fund at the APN+ secretariat	Small financial resources from the sale of Quiet Storm to support activities of positive networks in the region
	A regional workshop on TRIPS, Trade and Access to generic ARV medicines for PLHIV leaders, Bangkok	Capacity building of PLHIV leaders on TRIPS, trade and access to generic ARVs drawing from good practices from positive networks from India, Malaysia, Korea and Thailand.
	Release of the Colombo Declaration at 8 <sup>th</sup> ICAAP	The Colombo Declaration released in a press conference, focusing on universal access to affordable HIV medicines as well as the need for PLHIV involvement in relevant trade policy discussions
2008	The ASEAN workshop on PLHIV involvement and empowerment	Technically and financially supported by UNDP, the workshop provided the first-ever opportunity for PLHIV representatives to act as resource people in a meeting of ASEAN Task Force on AIDS. Regional and joint national plans were developed and the Vientiane Statement of Commitment on PLHIV empowerment adopted.

## 3b Publications under the Empowerment Initiative

TITLE	AUTHOR
Snapshots of GIPA: Greater Involvement of People Living with HIV/AIDS in South Asia	UNDP
The Bangkok Declaration by People Living with HIV/AIDS in Asia-Pacific	APN+ & UNDP
From Involvement to Empowerment: People Living with HIV/AIDS in Asia and the Pacific	UNDP
Empowerment Accounting (Excel tool and manual)	Kazuyuki Uji
Organisational Development Manuals Vol.1., Group Project Planning Vol.2., Obtaining Funding and Proposal Writing Vol.3., Accountability	National Association of People Living With HIV/AIDS Australia (NAPWA)
A Practical Guide to Drop-In Centres	NAPWA
A Manual to Establish a Positive Speaking Bureau	Umesh Chawla
A Practical Guide to the Basic of Referrals	NAPWA
Media Advocacy Manual for People Living with HIV/AIDS	Sanchita Sharma
A Guide to Monitoring and Evaluation of the EI	Wassana Im-Em
Celebration of Life (short film)	G. Pramod Kumar & Narayanan
Quiet Storm Japanese Edition	G. Pramod Kumar, Kazuyuki Uji & Hiroshi Hasegawa
Working in Partnership with Networks of People Living with HIV and AIDS: a Guidance Note for Development Practitioners	SWASTI
The Colombo Declaration on Universal Access to Affordable HIV Medicines	APN+
The Vientiane Statement of Commitment on the Greater Involvement and Empowerment of People living with HIV	ASEAN and APN+

## 4 Key global events of relevance to GIPA and EI

YEAR	EVENT	KEY ISSUES
1994	Paris AIDS Summit	Declaration of GIPA Principle (see annex 2); representatives of 42 countries pledged to fully involve PLHIVs in the formulation and implementation of public policies.
2000	Millennium Development Goals (MDG)	All 191 UN member states have pledged to meet the MDG by 2015. One of the eight goals, MDG 6, is to 'halt and begin to reverse the spread of HIV/AIDS, TB and malaria'.
2001	UN Special Session on HIV/AIDS (UNGASS)	Declaration of Commitment on HIV/AIDS by world leaders to enhance coordination, intensify national, regional and international response and mobilise resources in a more comprehensive way
	Global Fund for AIDS, TB, Malaria	Establishing partnership between governments, civil society, the private sector and affected communities. The Global Fund represents an innovative approach to health and social-sector financing.
	Doha Declaration on TRIPS agreement and Public Health	142 member States of the World Trade Organisation (WTO) agreed that the minimum patent protections required by the Trade-Related Aspects of Intellectual Property Agreement (TRIPS) of WTO 'cannot and should not' be enforced in a manner that limits States' right to take measures to protect public health. The Doha Declaration reaffirmed what was already recognized by numerous experts and by TRIPS itself, which is that States must have the flexibility to relax patent protection, and thus lower drug prices, in times of public-health emergency.
2003	WHO 3 by 5 Initiative	Initiative to treat 3 million by 2005 (WHO and UNAIDS)
2004	SUVA declaration on HIV/AIDS by Pacific parliamentarians	Reiteration of UNGASS commitments for the Pacific region
	7th Meeting of Commonwealth Ministers for Women's Affairs, Nadi	Called for response to feminisation of epidemic
	International AIDS Conference, Bangkok, Thailand	BANGKOK PLHIV Declaration ( <i>see Annex. 2</i> )
2005	International Conference on AIDS in the Asia-Pacific (ICAAP), Kobe, Japan	Bridging science and community
	Pan-Pacific Conference on HIV and AIDS	Called for fully-funded testing, counselling and treatment in Pacific countries
2006	ASEAN Declaration (Hanoi, Vietnam)	For greater commitment to, and action for, children under 18 years of age who are vulnerable to, infected or affected by HIV/AIDS.
	UNGASS meeting	Update of the 2001 UNGASS declaration and adoption of a final UNGASS Declaration, pledging universal access to prevention, treatment and care services by 2010
	International AIDS Conference, Toronto, Canada	Access to medication, greater involvement of people living with HIV, especially women.
2007	International Conference on AIDS in the Asia-Pacific (ICAAP), Colombo, Sri Lanka	The Colombo Declaration ( <i>see Annex 2a</i> )

## 5 The Denver Principles

### THE DENVER PRINCIPLES - RECOMMENDATIONS FOR ALL PEOPLE

#### We recommend that 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. (1\*)
2. Not scapegoat people with AIDS, blame us for the epidemic or generalize about our lifestyles.

#### We recommend that people with AIDS:

1. Form caucuses to choose their own representatives to deal with the media, to choose their own agenda and 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 involved in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.
4. Substitute low-risk sexual behaviours for those that could endanger themselves or their partners. We feel that people with AIDS have an ethical responsibility to inform their potential sexual partners of their health status. (2\*)

#### People with AIDS have the right:

1. To as full and satisfying sexual and emotional lives as anyone else's.
2. To quality medical treatment and quality social service provision without discrimination of any form based on 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, confidentiality of medical records, to human respect, and to choose who their significant others are.
5. To die and to LIVE in dignity.

1\* HIV and the first proof that AIDS was an infectious disease was only discovered in 1985

2\* In 1983 it had not yet been scientifically proven that condoms effectively protect against HIV transmission

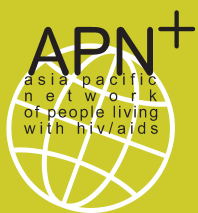
## 6 Further reading

**Below is a selection of useful and relevant documents for further reading that relate to the involvement and empowerment of people living with HIV/AIDS:**

- *APN+ Position Paper*. 2004. Asia-Pacific Network of People Living with HIV and AIDS (APN+). [http://www.gnpplus.net/cms-downloads/files/APN\\_GIPA\\_position.doc](http://www.gnpplus.net/cms-downloads/files/APN_GIPA_position.doc)
- *AIDS Discrimination in Asia*. 2004: APN+.
- APN+ Strategic Plan Document 2006-2010. 2006: APN+.
- *From Involvement to Empowerment*. 2004: UNDP RCC. <http://www.undprcc.lk/Publications/Publications/frominvtoemp.pdf>.
- *Law, Ethics and HIV/AIDS in South Asia*. 2002: UNDP RCC <http://www.undprcc.lk/Publications/Publications/LawEthicsandHIVAIDS.pdf>.
- *Quiet Storm: Celebrating the Triumph of Human Spirit over HIV/AIDS*. 2004: UNDP and Penguin Enterprise.
- *Positive Development Manual* (GPN+ document). *Positive Development*. 1998: GPN+.
- *Lifting the Burden of Secrecy – A Manual for HIV-Positive People Who Want to Speak Out in Public*. 1999: APN+. [www.hivasiapacific.apdip.net](http://www.hivasiapacific.apdip.net)
- 'Valued Voices', *GIPA Toolkit: A Manual for the Greater Involvement of People Living with HIV/AIDS*. APN+ and APCASCO <http://203.121.182.73/apnplus/documents/Valued%20Voices%20APN+%20GIPA%20Toolkit.pdf>
- UNGASS Declaration of Commitment on HIV/AIDS. <http://www.unaids.org/en/Goals/UNGASS/default.asp>
- *Renewing Our Voice: Code of Good Practice for NGOs Responding to HIV/AIDS*. 2004: NGO Code of Practice Project.







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