

# POLICY BRIEF

## The Greater Involvement of People Living with HIV (GIPA)

### Context

Nearly 40 million people in the world are living with HIV.<sup>1</sup> In countries such as Botswana and Swaziland, people living with HIV make up a quarter or more of the population.

People living with HIV are entitled to the same human rights as everyone else, including the right to access appropriate services, gender equality,<sup>2</sup> self-determination and participation in decisions affecting their quality of life, and freedom from discrimination<sup>3</sup>.

All national governments and leading development institutions have committed to meeting the eight Millennium Development Goals, which include halving extreme poverty, halting and beginning to reverse HIV<sup>4</sup> and providing universal primary education by 2015. GIPA or the Greater Involvement of People Living with HIV is critical to halting and reversing the epidemic; in many countries reversing the epidemic is also critical to reducing poverty.

### What is GIPA?

GIPA is not a project or programme. It is a principle that aims to realize the rights and responsibilities of people living with HIV, including their right to self-determination and participation in decision-making processes that affect their lives. In these efforts, GIPA also aims to enhance the quality and effectiveness of the AIDS response.

The idea that personal experiences should shape the AIDS response was first voiced by people living with HIV in Denver in 1983.<sup>5</sup> The GIPA Principle was formalized at the 1994 Paris AIDS Summit when 42 countries agreed to “support a greater involvement of people living with HIV at all...levels...and to...stimulate the creation of supportive political, legal and social environments”<sup>6</sup>.

In 2001, 189 United Nations member countries endorsed the GIPA Principle as part of the Declaration of Commitment on HIV/AIDS. The 2006 Political Declaration on HIV/AIDS unanimously adopted by 192 Member States

at the 2006 High Level Meeting on AIDS also advocated the greater involvement of people living with HIV.

### Why GIPA?

People living with HIV have directly experienced the factors that make individuals and communities vulnerable to HIV infection—and once infected, the HIV-related illnesses and strategies for managing them. Their involvement in programme development and implementation and policy-making will improve the relevance, acceptability and effectiveness of programmes. Measuring involvement of people living with HIV in policy is not an easy or exact science. However, experiences<sup>7</sup> have shown that when communities are proactively involved in ensuring their own well-being, success is more likely. GIPA seeks to ensure that people living with HIV are equal partners and breaks down simplistic (and false) assumptions of “service providers” (as those living without HIV) and “service receivers” (as those living with HIV).

The engagement of people living with HIV is all the more urgent as countries scale up their national AIDS responses to achieve the goal of universal access to prevention, treatment, care and support services.

The benefits of GIPA are wide ranging. At the individual level, involvement can improve self-esteem and boost morale, decrease isolation and depression, and improve health through access to better information about care and prevention. Within organizations, the participation of people living with HIV can change perceptions, as well as provide valuable experiences and knowledge. At the community and social levels, public involvement of people living with HIV can break down fear and prejudice by showing the faces of people living with HIV and demonstrating that they are productive members of, and contributors to, society.

Openly acknowledging one’s HIV-positive status demolishes myths and misconceptions about HIV and

<sup>1</sup> Only one in 10 people who are living with HIV have tested for HIV and know their status. Global HIV Prevention Working Group (2003) Access to HIV Prevention, Closing the Gap.

<sup>2</sup> Gender inequalities in access to education and services, domestic and child care responsibilities, and financial dependence on men prevent many HIV-positive women from becoming involved. Horizons (2003). Greater Involvement of PLHA in NGO Service Delivery: Findings From a Four-Country Study. [www.popcouncil.org/horizons](http://www.popcouncil.org/horizons)

<sup>3</sup> Discrimination can occur in many areas—even after death through refusal to handle the body.

<sup>4</sup> The Greater Involvement of People Living with HIV and AIDS (GIPA) Declaration was signed in 1994. UNAIDS prefers the umbrella term “people living with HIV”. For historical reasons, this policy brief continues to use the acronym GIPA.

<sup>5</sup> The Denver Principles. Available at <http://www.aegis.com/pubs/bala/1999/BA991201.html>

<sup>6</sup> UNAIDS (1999). From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA). Best Practice Key Material.

<sup>7</sup> International HIV/AIDS Alliance and Horizons (2003). The Involvement of People Living with HIV/AIDS in Community-based Prevention, Care and Support Programs in Developing Countries.

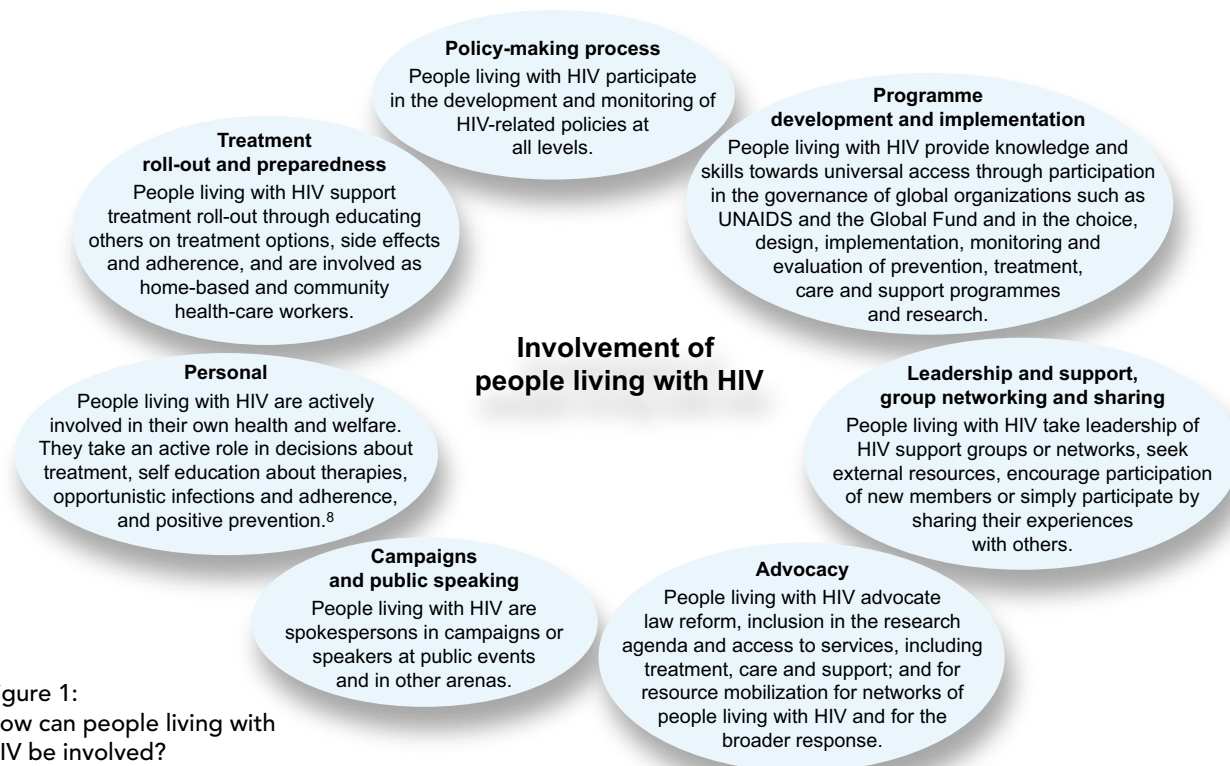


Figure 1:  
How can people living with HIV be involved?

people living with HIV. Disclosing one’s status can be an empowering process if it starts by combating internal stigma and shame. People living with HIV may need support in managing this process and choosing to whom, when and how they disclose their status. However, disclosure can also reinforce prejudices, for example, against homosexuals or based on race. GIPA does not require disclosing one’s HIV status to the public. It does not mean “no visibility = no involvement.” GIPA is about “meaningful involvement,” not tokenistic participation.<sup>9</sup>

## Challenges to achieving GIPA

Organizations and networks of people living with HIV are central to the achievement of GIPA; yet they face many challenges. These challenges, as identified by people living with HIV, include: weak management, low skill levels, funding constraints, difficulties in representing the diversity of people living with HIV, a lack of documentation of their histories of self-empowerment and a lack of evaluation of successes and failures.<sup>10</sup> Energy spent on basic survival, including fighting for access to treatment for HIV and opportunistic infections,

care and support as well as financial insecurity can also be critical barriers to the participation of people living with HIV in their own organizations and networks.

There are also many societal barriers to the effective implementation of GIPA, some of which are rooted in poverty, gender inequality, homophobia and other forms of prejudice. People living with HIV often face stigma and discrimination, and this prevents them from accessing services, earning livelihoods and becoming involved, especially in organizations for people living with HIV or in high visibility roles. This burden is greater for those who belong to marginalized populations. Rejection by family, friends and the community, and discrimination by health service providers and in workplaces and schools is common. There are regular incidents of violence against people living with HIV. In some countries, traditional inheritance laws place an extra burden on women after the death of a partner as they have to leave their land and their homes. In many countries, anti-discrimination laws to protect people living with HIV and HIV workplace policies either do not exist or there is a failure to enforce them.

*The participation and contribution of people living with HIV is one of the best examples of global progress in public health. We have come from a place where people openly living with HIV were stoned to death, to a place where we have been invited to stand among the leaders of the world to shape international policies. There is still a long way to walk but we have made historical changes and gains of which we can be proud.*

Gracia Violeta Ross, National Chair, Bolivian Network of People Living with HIV/AIDS

<sup>8</sup> Positive prevention involves helping people living with HIV to protect their sexual and physical health, to avoid new sexually transmitted infections, to delay HIV disease progression and to avoid transmitting HIV.

<sup>9</sup> For some, MIPA—the meaningful involvement of people living with HIV—is a preferred term to GIPA because it the fact that people living with HIV are active and equal agents of change, not passive recipients of services.

<sup>10</sup> POLICY, GNP+ and GTZ (2004). Challenging, Changing and Mobilizing: A Guide to PLHIV Involvement in Country Coordinating Mechanisms. See also: Think Tank Meeting (2005). Revitalizing the Global Movement of People Living with HIV. Nairobi, Kenya, 28–30 November 2005.

## Policy position

No single agency can provide for the full spectrum of needs of people living with HIV: partnerships between actors are therefore needed. To enable the active engagement of people living with HIV, UNAIDS urges all actors to ensure that people living with HIV have the space and the practical support for their greater and more meaningful involvement.

Governments, international agencies and civil society must:

- set, implement and monitor minimum targets for the participation of people living with HIV, including women, young people and marginalized populations,<sup>11</sup> in decision-making bodies. Selection processes should be inclusive, transparent and democratic; and
- involve people living with HIV in developing funding priorities and in the choice, design, implementation, monitoring and evaluation of HIV programmes from their inception.

Additionally, UNAIDS recommends the following actions.

### Actions for governments

- Include GIPA in the National AIDS Plan; undertake a baseline survey for measuring GIPA and stigma and discrimination<sup>12</sup> and include GIPA within the national monitoring and evaluation system.
- Enable people living with HIV to claim their rights<sup>13</sup> and meet their responsibilities by creating a supportive legal and policy environment that also protects them from discrimination and violence.<sup>14</sup>
- Strengthen public policy dialogue on HIV; create and promote educational<sup>15</sup> and employment or income-generating opportunities; and promote the adoption of workplace policies in the formal and informal sectors, following the International Labour Organization recommendations.<sup>16</sup>
- Support the creation and strengthening of organizations of people living with HIV in addressing infra-

structure, governance, management, resource mobilization, accountability and staff skill building needs.

- Strengthen the capacity of people living with HIV who volunteer for leadership in public speaking and communication skills, in organizing and conducting policy advocacy, dialogue and negotiation, in programme design, and in monitoring and evaluation at the international, regional, national and local levels.
- Provide resources to train, and engage or employ people living with HIV in self-care, in HIV prevention—particularly positive prevention—and in being a knowledgeable participant in personal treatment decisions (treatment literacy); as home-based care and community health-care workers; in the practicalities and legal and social aspects of HIV and counselling; and in anti-stigma campaigns. Ensure that reasonable measures to facilitate employment of people living with HIV are taken.<sup>17</sup>
- Ensure psycho-social support for persons living with HIV who, in revealing their status, may experience discrimination against themselves or their dependants.
- Promote better understanding of HIV-related vulnerabilities and the needs of people living with HIV in the community and the workplace.

### Actions for organizations of people living with HIV

- Organize and establish common ground with other organizations and networks of people living with HIV, and demand a place at decision-making tables.
- Ensure that the GIPA Principle is a living and practised concept within organizations and that new, inclusive and diverse leadership, such as female, young people and other vulnerable population leadership, is nurtured.
- Encourage professionals, particularly people living with HIV, to become involved by offering their skills and services to organizations and networks of people living with HIV.

<sup>11</sup> Depending on the context, these may include men who have sex with men, injecting and other drug users, sex workers, people living in poverty, prisoners, migrant labourers, people in conflict and post-conflict situations, refugees and internally displaced persons.

<sup>12</sup> USAID, APN+ and Policy (2005). Baseline survey of GIPA and stigma and discrimination in the Greater Mekong Region. Report on qualitative surveys in Lao PDR, Thailand, Viet Nam, and Guangxi and Yunnan Provinces, China. Annexes 1–3.

<sup>13</sup> This includes the right to free and responsible sexual and reproductive health choices.

<sup>14</sup> Creating a supportive legal and policy environment can be achieved through enacting supportive HIV-specific and anti-discrimination laws; providing for anonymous involvement of people living with HIV, and by protecting the confidentiality of a person's HIV status; public campaigns on tolerance; media trainings; garnering the support of public (political) figures and the media; providing legal aid and redress; training and sensitizing human rights commissions and law enforcement officers, and the judiciary on the rights of people living with HIV.

<sup>15</sup> Besides educating people in basic reading and writing skills, people living with HIV, particularly women in rural communities and marginalized urban areas, require basic education and information about human rights so that they as the rights-holder can both claim their rights and fulfil their responsibilities.

<sup>16</sup> ILO (2001). International Labour Organization Code of Practice on HIV and the World of Work. Available at <http://www.ilo.org>

<sup>17</sup> Ibid. Employers, in consultation with the worker(s) and their representatives, should take measures to reasonably accommodate the worker(s) with AIDS-related illnesses. These could include rearrangement of working time, special equipment, opportunities for rest breaks, time off for medical appointments, flexible sick leave, part-time work and return-to-work arrangements.

## Actions for wider civil society and the private sector

- Mainstream HIV within organizations<sup>18</sup> including the development and implementation of specific HIV workplace policies.
- Create procedures for implementing GIPA at all levels in the workplace including recruitment of skilled people living with HIV to boards and senior management.
- Commit and devote financial resources to organizational development, including leadership, management and governance, and capacity building of organizations and networks of people living with HIV.
- Work in partnership with other nongovernmental and government organizations and networks of people living with HIV on advocacy, service delivery and other relevant actions.

## Policy-makers' voices

*Honourable Lediana Mafuru Mng'ong'o, Member of Parliament, Tanzania; Chair, Coalition of the African Parliamentarians against HIV/AIDS and Chair, Tanzanian Parliamentarians' AIDS Coalition*

People living with HIV must be at the forefront of the response because they are living with HIV each and every day. You cannot plan for them; you have to plan with them! Political leaders have to stand up for the rights of people living with HIV by enacting laws, budgeting for programmes to support them and also by speaking up in ways that will normalize HIV. Today, nearly 80% of Tanzanian Parliamentarians are dues-paying members of an AIDS Coalition (TAPAC) that I chair. One of TAPAC's objectives is to safeguard the rights of people living with HIV and affected families within and outside Parliament. TAPAC wants to ensure that funds allocated to HIV reach the communities in need, and are not lost along the way. TAPAC models what it preaches and constantly engages people living with HIV as advisers and organizes regular roundtable meetings with them to discuss issues. TAPAC members meet people living with HIV in their constituencies and publicly speak up in favour of GIPA. As a result, more and more people in Tanzania are declaring their HIV status publicly. If we want to win the battle against HIV, the full participation of people living with HIV in the AIDS response is necessary. At the same time, people living with HIV need to stand united, they need to strengthen their organizations and they need to speak with one voice in order to influence policy makers and to realize GIPA.

## Actions for international partners

- Prioritize initiatives, supported by enhanced, predictable and continued funding, to build and sustain the capacity of organizations and networks in line with their self-identified needs.
- Promote efforts to fulfil the rights of people living with HIV, particularly women, young people and vulnerable populations.
- Promote good practice, strategic alliances and information exchanges between organizations and networks of people living with HIV within and across countries and particularly promote, fund and document South-South collaboration and mentoring.
- Harmonize, simplify and create more flexibility in donor/partner procedures to facilitate access to technical and financial resources for organizations and networks.
- Ensure that people living with HIV are included in the design of ethical research for new prevention technologies and the development of treatments.

*Dr (Ms) Yerasilova Isidora, Director General, the Republican AIDS Centre (National AIDS Programme), Kazakhstan*

The majority of people living with HIV in Kazakhstan are injecting drug users and sex workers and their sexual partners. As laws and public opinion are not favourable towards these groups, we recognized that these populations would not access HIV and other health services provided by the government. In order to overcome this barrier, partnership and support from people living with HIV was recognized to be critical. Today, our national and local level strategic planning and monitoring and evaluation processes engage people living with HIV. In fact, we are pushing that people living with HIV demand accountability from local authorities. Public attitudes continue to pose challenges. Many people are indignant that public resources are being used to provide services to drug users and sex workers. These misplaced attitudes limit the participation of people living with HIV in the AIDS response. As many people living with HIV are poorly educated, this also hampers their ability to express themselves clearly. Yet, we have managed to identify several partners and have supported them by developing their personal and institutional capacities to become proactive and to make their voices heard. Slowly but surely, we are seeing success. In Temirtau, the city facing the largest HIV epidemic in Central Asia, the consequences of HIV have been mitigated for many families, and more people living with HIV are openly accepting their status, which is improving public understanding and reducing stigma.

<sup>18</sup> IFRC et al. (2004). *Renewing our Voices: NGO HIV/AIDS Code of Good Practice Project*.