

# 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.

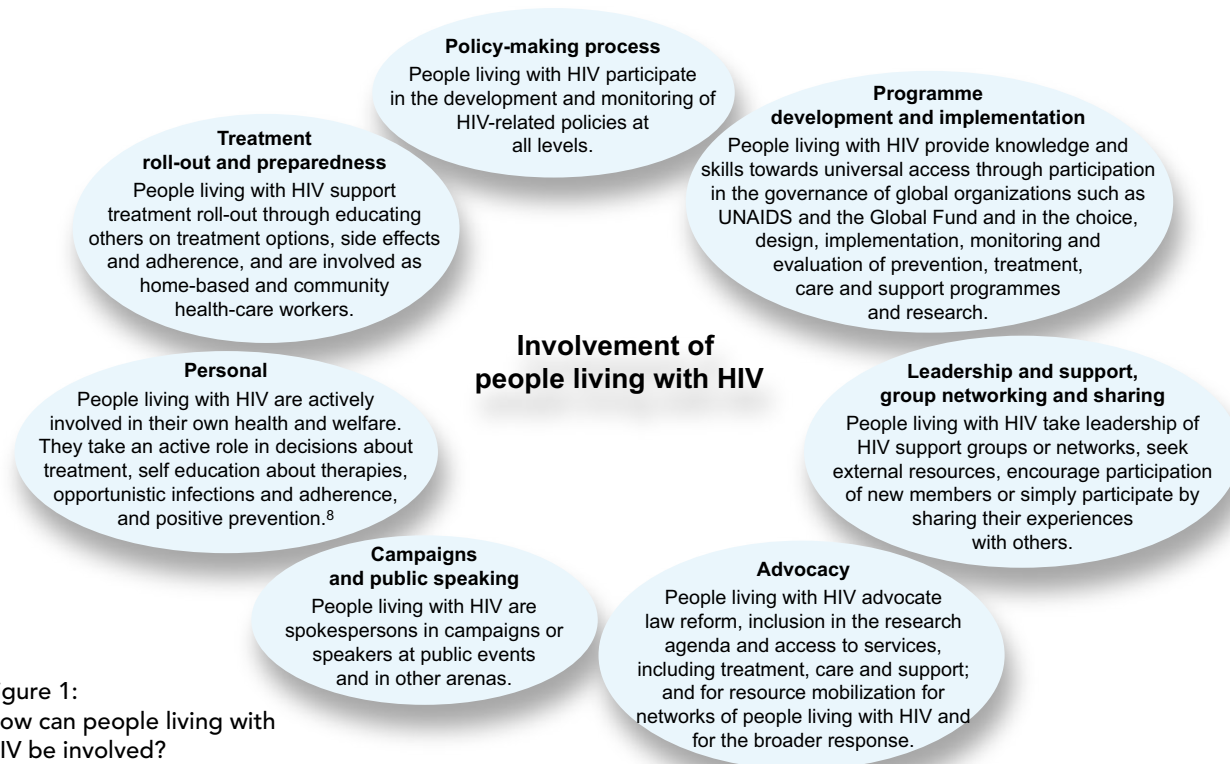


Figure 1:  
How can people living with HIV be involved?

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.