The Greater Involvement of People Living with HIV (GIPA)

Context

Nearly 40 million people in the world are living with HIV. In countries such as Botswana, Swaziland, and Lesotho 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, self-determination and participation in decisions affecting their quality of life, and freedom from discrimination.

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 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. 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”.

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 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

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3. Discrimination can occur in many areas—even after death through refusal to handle the body.
4. 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.
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

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8 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.

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

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, 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 and include GIPA within the national monitoring and evaluation system.
- Enable people living with HIV to claim their rights and meet their responsibilities by creating a supportive legal and policy environment that also protects them from discrimination and violence.
- Strengthen public policy dialogue on HIV; create and promote educational 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.
- 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, engage and 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.

- 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.
Actions for wider civil society and the private sector

- Mainstream HIV within organizations 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 Mn’g’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.

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.