



Position paper

Greater Involvement of Persons Living with or Affected by HIV/AIDS (GIPA)

involvement, participation, discrimination, stigma, representation, HIV-positive, seropositive.

Definitions

GIPA: The original term used in the 1994 Paris Declaration, “greater involvement of persons living with HIV/AIDS”, has since been widened to “persons living with *or affected by HIV/AIDS*,” thus encompassing HIV-negative people who have been personally affected by HIV infection in partners, parents, children, other relatives, and friends.

Note: The acronyms PWHA or PLWHA are often used to avoid repetition of the complete term (earlier in the epidemic, PWA - “People With AIDS” - was the most widely used acronym). However, UNAIDS staff are urged to avoid such acronyms whenever possible, since their over-use becomes de-humanizing, reducing people to categories.

Key Messages

1. Where they have the political space and resources to get involved, people living with or affected by HIV/AIDS are probably the greatest resource in the global response to the epidemic.
2. Involvement goes beyond being given “a place at the table” (representation only) – it means being able to make a meaningful contribution (participation) at all levels and all aspects of the response, from the individual and community level to the highest levels of national and international policy and decision making.
3. Putting GIPA into practice may require organizations to adapt normal employment practices or assign new resources in order to accommodate and support the involvement of persons living with or affected by HIV/AIDS.

Position Statement

As noted in the UNAIDS 2002 Global Report, persons living with or affected by HIV/AIDS “are probably the greatest resource in the global response to the epidemic, as has been proven repeatedly in countries where such individuals/groups have had the political space and resources to get involved” (see below). This has always been UNAIDS’ view, and underpins its support of GIPA (UNAIDS, 2002b). The June 2001 [Special Session of the UN General Assembly \(UNGASS\)](#) adopted a Declaration of Commitment which reaffirms the GIPA principle by:

... acknowledging the particular role and significant contribution of people living with HIV/AIDS... in addressing the problem of HIV/AIDS in all its aspects, and recognizing that their full involvement and participation in the design, planning, implementation and evaluation of programmes is crucial to the development of effective responses to the HIV/AIDS epidemic.

Having signed on to the Declaration, countries can be held to account if they do not fulfil these goals.

At its most basic, GIPA means two things:

- (a) recognizing the important contribution persons infected or affected by HIV/AIDS can make in the response to the epidemic
- (b) creating a human rights-based enabling environment within all levels of society for their active and increasing participation in all aspects of that response

Involvement must be at all levels and all aspects of the response, from the individual and community level to the highest level of national and international policy and decision making.

Sustained support for people doing GIPA work. The motivation of individual persons or groups is not enough to sustain GIPA. Persons living with or affected by HIV/AIDS who are actively involved in GIPA work must be supported in practical ways. The level of support will depend to a great extent on the type of post or involvement – a greater level of support will be necessary for a full-time salaried post than for occasional participation in a local volunteer-based committee, for example. Support may include:

- access to treatment and care, including counselling and emotional support, and benefits such as insurance. This is a priority for people doing GIPA work, since their continued health is key to their effective participation.
- reasonable accommodation to their needs and abilities (e.g., adapting the work environment, hours of work, transportation, etc.)

While these arrangements may be developed specifically to accommodate GIPA-related jobs (i.e., those occupied by or designated for persons living with or affected by HIV/AIDS), they should be institutionalized through HIV/AIDS workplace policies developed in consultation with employees (see the [ILO Code of Practice on HIV/AIDS](#) and the world of work (ILO, 2001).

Skills and capacity building. In many cases, effective GIPA activities will require strengthening the capacity of individuals to participate through training and skills-building. While this may include training for a specific job, training for people in GIPA posts may include:

- personal empowerment, communication and presentation skills, training of trainers
- knowledge about HIV/AIDS (medical, legal and social aspects) and counselling skills
- skills for organizing and conducting policy dialogue, negotiating, institutional strengthening, and networking
- If the employee is to take on any administrative responsibility for GIPA activities, training should also include the basics of programme planning and monitoring.

Preparing the organization. It is equally important that organizations – including top executives as well as supervisory staff – receive training about GIPA's aims and implementation in order for it to be effective. Again, the [ILO Code of Practice](#) is a useful resource, giving guidance on training and workplace collaboration through social dialogue. The Code is now complemented by an education and training manual to guide its implementation (ILO, 2002).

Background

The early 1980s witnessed the emergence of a movement by persons living with HIV/AIDS demanding their human rights, and offering their contributions to prevention and care (e.g., the [Denver Principles](#) of 1983). They have been crucial to the response. In North America and Europe, most notably, they not only successfully raised awareness, but also achieved representation on committees or institutional boards that deal with HIV/AIDS policy at national and local levels.

At the 1994 Paris AIDS Summit, 42 national governments declared GIPA critical to ethical and effective national responses to the epidemic. This is, therefore, the official position of these governments, which have committed themselves to supporting full involvement of persons living with or affected by HIV/AIDS in the “common response to the pandemic at all – national, regional and global – levels” (UNAIDS, 1999).

Since its creation in 1995, UNAIDS has reserved five seats on its overall policy making body (the Programme Coordinating Board) for NGOs, including associations of people living with HIV/AIDS. At country level, many National AIDS Committees designate a number of seats for such NGOs or for people living with or affected by HIV/AIDS.

In recent years, the Global Fund has recently provided additional impetus to GIPA, as the Country Coordination Mechanisms (CCM) set up to administer the Global Fund’s activities in countries are designed to include organizations representing persons living with or affected by HIV/AIDS. A recent multi-country study of the involvement of HIV-positive people in CCMs found solid contributions by representatives of persons living with HIV/AIDS in the work of many CCMS, but also obstacles to their participation which the Global Fund is working to overcome (GNP+, 2004).

In Uganda, the newly formed Uganda HIV/AIDS Partnership - an innovative coordination mechanism led by the Ugandan AIDS Commission - is expressly structured to ensure the influence of persons living with HIV/AIDS (called PHA in Uganda) at the highest policy level. All of the country’s relevant networks and associations work together in a “PHA Forum” which is represented in the Partnership along with relevant ministries, the Uganda AIDS Commission, donors, etc. The Forum co-manages a Treatment Fund for HIV/AIDS Advocates in Uganda which currently provides six advocates with ARV treatment, using funds from Rotary International and its Belgian and Ugandan branches (Uganda AIDS Commission/UNAIDS, 2003)

In recent years, the movement of HIV-positive people has become stronger and more influential in the CIS countries. For example, in Ukraine, the All-Ukrainian Network of Persons Living with HIV/AIDS has helped shape the National AIDS Prevention Programme, and is increasingly involved in providing HIV-related care services (UNDP, 2003).

Despite such progress, the September 2003 International Conference of People Living with HIV/AIDS (entitled the Dawn of New Positive Leadership) stated in its final Declaration that “Our communities and organizations are still starved of the resources they need to effectively fulfil their potential and perform the role that is being demanded of us”. The Declaration demanded “That we are supported in our efforts to build capacity to effectively contribute as equal partners in the response” (GNP+, 2003)

Evidence in support of the position

GIPA activities must be tailored to the specific conditions of the epidemic in a given country or region.

In Africa, with its high HIV prevalence in many adult populations, a particular focus has been GIPA in the workplace. A pilot project in South Africa, the GIPA Workplace Model, was

created with the support of UNDP and WHO in the late 1990s (UNAIDS, 2002a). It placed trained fieldworkers, living openly with HIV/AIDS, in companies and organizations in different sectors so that they could set up, review or enrich workplace policies and programmes. Their experiences showed that persons living with or affected by HIV/AIDS can add considerable value to workplace HIV/AIDS programmes. Among other benefits, GIPA fieldworkers have:

- provided role models to de-stigmatize the disease
- helped develop or improve workplace HIV/AIDS policies and communicated policies to employees
- improving the effectiveness of peer education
- provided formal pre- and post-test counselling; and extended the process to surrounding communities.

In Asia, most GIPA activities focus on building relationships between government and groups representing or working with persons living with or affected by HIV/AIDS (UNDP, 2001). In Cambodia, for example, the United Nations Volunteers (UNV), in cooperation with UNDP and UNAIDS, has hired GIPA “provincial animators” to work with the Provincial AIDS Committees and Secretariats in three provinces. Their duties include working with leaders and groups to orient them about GIPA, helping to initiate GIPA activities, facilitating provision of training and assistance, and assisting such groups to strengthen coordination among themselves and with other agencies in the province.

Issues to be aware of

Uptake of GIPA: Despite the examples given above, not enough has been done so far to make this principle a reality, even in countries with high prevalence of HIV. GIPA is rarely reflected in national policies and programmes in any concerted or large-scale way.

Exploitation of HIV-positive people. HIV-positive people who take on activist roles often face enormous challenges with minimal support. For example, HIV-positive women in Africa have expressed frustration about pressures to disclose their status as part of prevention campaigns, while their own financial, medical and emotional needs are ignored. The commitment and volunteerism of people living with HIV has been exploited by NGOs and government programmes that use this cheap or free labour in place of health-care services (Manchester, 2003). It is more essential than ever to provide more funds for capacity-building, financial compensation for work performed, and treatment and psychological support for HIV-positive people involved in such work.

The need for support and training. A study of 17 NGOs providing HIV and AIDS services in four countries (Burkina Faso, Ecuador, India and Zambia) revealed that failure to account for the needs of HIV-positive people reduced the effectiveness of the services provided. Involving people living with HIV in outreach education without giving them the necessary training and ongoing support can have a negative impact on service quality, and can also harm the individuals themselves (Horizons Program, 2002).

Disclosure and confidentiality. It should be stressed that GIPA does not mean necessarily disclosing one’s serostatus. UNAIDS’ GIPA adviser notes, “If a person is hired or appointed to give HIV/AIDS a face and voice, it obviously cannot be a hidden face or a silent voice. However, at country and community level, HIV-positive people may do a variety of activities such as prevention work, home-based care, psychosocial support, etc., without disclosing their serostatus. Although HIV-positive individuals may choose to be open about their serostatus to their colleagues and community, they also have the right to choose to be involved without

making their serostatus public. In other words, GIPA cannot be reduced to 'no visibility = no involvement'."

Inclusion of sero-negative persons: some activist organizations, particularly those from industrialized countries, oppose the inclusion of seronegative persons from GIPA activities. While understanding their focus on HIV-positive persons, UNAIDS' policy of inclusiveness is based on several considerations. First, the parents, spouses and other important people in HIV-positive persons' lives have much knowledge to contribute from their experience of caring and advocating for their loved ones. Second, the exclusive approach tends to reflect an individualistic view of society that is widely characteristic of the industrialized West, but does not reflect family and community organization in many other parts of the world.

Key source documents

UNAIDS (2002) *The faces, voices and skills behind the GIPA Workplace Model in South Africa*. Best Practice case study.

ILO (2002) *Implementing the ILO Code of Practice on HIV/AIDS and the world of work: an education and training manual* and (2001) *The ILO Code of Practice on HIV/AIDS and the World of Work*. Geneva.

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

For details of UNAIDS policy and Cosponsor activities in this field, see the UNAIDS Secretariat Strategic Framework document on GIPA (under development). The Report on the Global HIV/AIDS Epidemic, July 2004 (pages 183-188) contains a [Focus Section](#) devoted to GIPA

References

GNP+ (2003) *Declaration - 11th International Conference for People Living with HIV/AIDS* [webpage] http://www.gnpplus.net/kampala/kampala_declaration.html

GNP+ (2004) *A Multi-Country Study of the Involvement of People Living with HIV/AIDS (PLWHA) in the Country Coordinating Mechanisms (CCM)*. The Global Network of People Living with HIV/AIDS. Amsterdam. http://www.gnpplus.net/files/ccm-reports/multi_country_study.pdf

Horizons Program (2002). Greater involvement of PLHA in NGO service delivery: findings from a four-country study. Washington, Population Council. Available at <http://www.popcouncil.org/pdfs/horizons/plha4cntrysum.pdf>

ILO (2001) *The ILO Code of Practice on HIV/AIDS and the World of Work*. Geneva. <http://www.ilo.org/public/english/protection/trav/aids/code/codemain.htm>

ILO (2002) *Implementing the ILO Code of Practice on HIV/AIDS and the world of work: an education and training manual*, Geneva. <http://www.ilo.org/public/english/protection/trav/aids/code/manualen/index.htm>

Manchester J (2004). Hope, involvement and vision: reflections on positive women's activism around HIV. *Transformation*, South Africa.

Uganda AIDS Commission/UNAIDS (2003) *The Uganda HIV/AIDS Partnership*, Draft Partnership information note 31/07/03, Kampala.

UNAIDS (1999) *From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)*, Best Practice Key Material. At www.unaids.org/html/pub/publications/irc-pub01/jc252-gipa-i_en_pdf.pdf

UNAIDS (2002a) *The faces, voices and skills behind the GIPA Workplace Model in South Africa*. At http://www.unaids.org/html/pub/Publications/IRC-pub01/JC274-GIPA-ii_en_pdf.pdf

UNAIDS (2002b) *Report on the global HIV/AIDS epidemic*. UNAIDS, Geneva. At

- www.unaids.org/html/pub/global-reports/barcelona/brglobal_aids_report_en_pdf.pdf
- UNDP (2001) *Snapshots of GIPA: the Greater Involvement of People Living with HIV/AIDS in South Asia. An Interim Report*. UNDP HIV and Development Programme.
http://www.hivanddevelopment.org/publications/Pdf/GIPA_1.pdf
- UNDP (2003). *Ukraine and HIV/AIDS: time to act*. Ukraine Human Development Report Special Edition. Kiev.

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