

TIP SHEET:

Involving PLWHIV/AIDS in your Advocacy Strategy



PLWHIV/AIDS and affected communities need to be involved in a variety of roles at different levels in NGOs, including as decision-makers on governing boards; as managers, programmers, providers and participants in the design, implementation and evaluation of programs and services; as decision-makers, advocates and campaigners in policy and advocacy; and as planners, speakers and participants in meetings, conferences and other forums.

In fostering meaningful involvement of PLWHIV/AIDS and affected communities within our own organizations and in partnerships with organizations and networks of PLWHIV/AIDS and affected communities, we need to:

- create an organizational environment that fosters non-discrimination and values the contribution of PLHA and affected communities.
- recognize and foster involvement of the diverse range of PLWHIV/AIDS and affected communities
- ensure involvement in a variety of roles at different levels within our organizations.
- define roles and their associated responsibilities; assess what a particular role requires, and the capacity of individuals to fulfill the role; and provide the necessary organizational support, including financial.
- ensure organizational policies and practice provide timely access to information to

enable participation, preparation and input, before programmatic and policy decisions are made.

- ensure workplace policies and practices recognize the health and related needs of PLWHIV/AIDS and affected communities and create an enabling environment that supports their involvement.
- ensure, when seeking PLWHIV/AIDS and affected community representatives, that PLWHIV/AIDS and affected community organizations and networks have strategies for accountability to their members and processes for ensuring that the views put forward represent their members.
- resource and support capacity-building within PLWHIV/AIDS and affected community organizations and networks.
- fund and/or advocate for funding of PLWHIV/AIDS and affected community organizations to ensure they have the resources to build capacity and empower others within their own networks.

1-800-499-1986 • www.cdnaids.ca • www.HIVandPoverty.ca

Advocacy Allies! “Renewing Our Voice”

This Code sets out a number of Guiding Principles, which apply a human rights approach to the range of HIV/AIDS-specific health, development and humanitarian work undertaken by NGOs responding to HIV/AIDS. These principles provide a common framework applicable to all NGOs engaged in responding to HIV/AIDS, and are embodied within good practice principles, which guide both how we work as NGOs and what we do. Chapter 5 includes Key resources such as tool kits and manuals that can assist in putting the principles into practice. It also includes information about the process of ‘signing on’ to the Code and about implementation of the Code. Visit www.ifrc.org for more information.

About the GIPA Principles

Greater involvement of people living with or affected by HIV/AIDS

The idea that the personal experiences of people living with HIV could and should be translated into helping to shape a response to the AIDS epidemic was first voiced in 1983 at a national AIDS conference in the USA. It was formally adopted as a principle at the Paris AIDS Summit in 1994, where 42 countries declared the Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA) to be critical to ethical and effective national responses to the epidemic.

Today the GIPA principle is the backbone of many interventions worldwide. People living with, or affected by, the virus are involved in a wide variety of activities at all levels of the fight against AIDS; from appearing on posters, bearing personal testimony, and supporting and counselling others with HIV, to participating in major decision- and policy-making activities. People living with HIV understand each other’s situation better than anyone and are often best placed to counsel and advise one another and to represent their needs in decision- and policy-making forums.

For more information and tools to help you implement the GIPA principles, visit www.unaids.org and download “From principle to practice: Greater involvement of people living with or affected by HIV/AIDS (GIPA)” from the Best Practices Collection.

About the International Community of Women Living with HIV/AIDS

For information on how to apply the GIPA principles in a way that supports the participation of women, visit the International Community of Women Living with HIV/AIDS. The International Community of Women Living with HIV/AIDS (ICW), a registered UK charity, is the only international network run for and by HIV positive women. ICW was founded in response to the desperate lack of support, information and services available to women living with HIV worldwide and the need for these women to have influence and input on policy development. You can download a vibrant poster called “The Participation Tree” that uses visuals to illustrate how GIPA applies to women living with HIV. Visit www.icw.org for more information.

The most successful programs:

- Involve people living with HIV, and the wider community, in all planning, implementation and evaluation stages. Recognize the realities that people face in their daily lives, and take people's own needs and interests as a starting point (rather than, for example, starting from your own assumptions about people's knowledge, beliefs or attitudes)
- Create open attitudes and accept how people are (rather than being critical or judgmental)
- Use positive images and friendly messages (rather than being frightening or authoritarian)
- Develop skills and knowledge (rather than telling people what to do)
- Win support from people in positions of authority (e.g. teachers, doctors, religious leaders, professional associations, government officials)
- Recognize that even well-planned approaches sometimes fail (and, therefore, review, progress and adjust the program when needed)
- Carry out some form of evaluation, however brief (so the activity can be replicated or improved by the same group or by others in the future)

Figure 1. A pyramid of involvement by PWHAS

This pyramid models the increasing levels of involvement advocated by GIPA, with the highest level representing complete application of the GIPA principle. Ideally, GIPA is applied at all levels of organization.

