

6. GREATER INVOLVEMENT OF PEOPLE LIVING WITH HIV AND AIDS (GIPA)

The GIPA principle is now accepted as central to addressing HIV and AIDS effectively, yet involvement can still be tokenistic. Women and girls living with HIV and AIDS may find it particularly difficult to be involved. The challenge is to move from theory to meaningful practice, in particular by recognising the vital contribution made by people living with HIV and AIDS, and supporting and strengthening bodies that reflect the needs and rights of people living with HIV and AIDS.

VSO is striving to gain the involvement of people living with HIV and AIDS in all programmes and activities and to ensure their experience is valued equally.



WHY IS IT IMPORTANT?

The principle of greater involvement of people with HIV and AIDS (or GIPA) derives from the Paris AIDS Summit Declaration of 1994. In 1999, UNAIDS published the first guidelines on GIPA and expanded its meaning to include all people directly affected by HIV and AIDS.¹

When people incorporate the GIPA principle into their work, it means people living with HIV and AIDS are consulted and fully involved in decision-making processes, strategic discussions, policy-making and programme implementation. This results in responses that are appropriate and challenge the stigma and discrimination that surround individuals affected by HIV and AIDS.

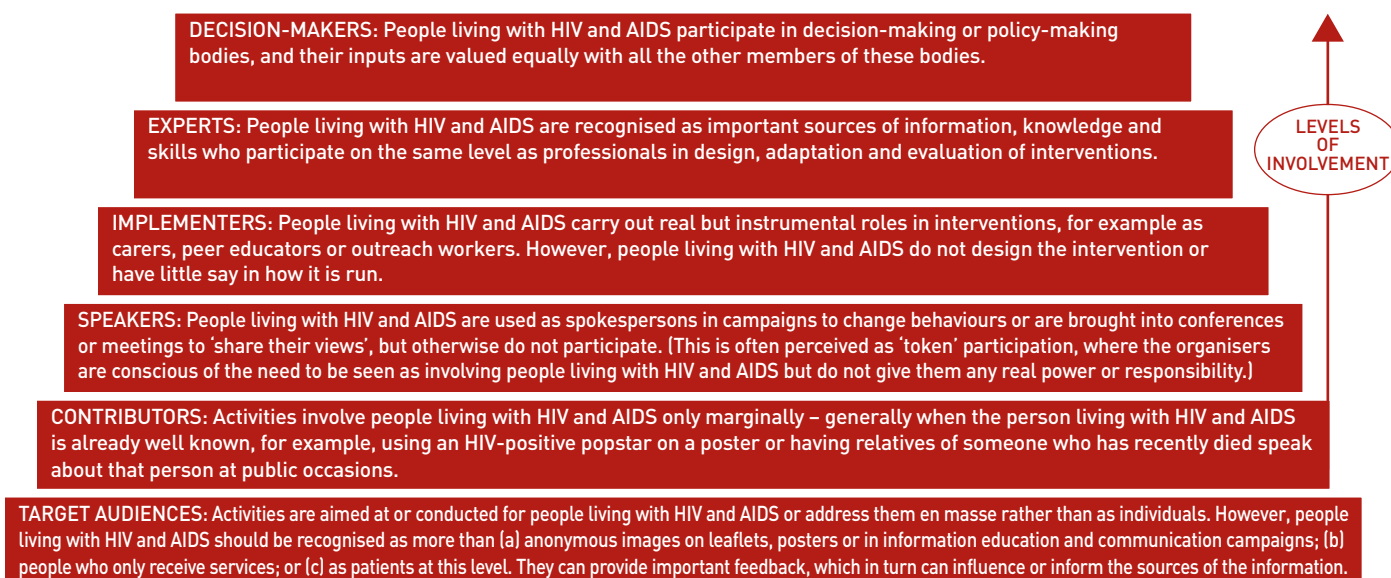
KEY DEBATES

The involvement of people living with HIV and AIDS is now widely accepted. The challenge is to put the theory into meaningful practice. One major concern raised is around the tokenistic or tick-box use of people living with HIV and AIDS – that they be used to warn others of the dangers or be used as negative examples, rather than as equal partners in developing programmes and interventions.

The UNAIDS model below provides guidance on how to ensure people living with HIV and AIDS can be meaningfully involved.

Figure 1. A pyramid of involvement by People living with HIV and AIDS (PWHAs)²

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 organisation.



¹ UNAIDS publication, *From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)*, describes the rationale for involving people living with HIV in the response.

² Adapted from UNAIDS (1999) *From Principle to Practice: The Greater Involvement of People Living with or Affected by HIV/AIDS*.

Women living with HIV and AIDS often face different experiences and obstacles to realising their rights under GIPA principles. Women have reported being taken less seriously than men by political leaders and male activists. Their contributions may be undermined by others, and their additional care work in communities or families can limit the time they have to engage in policy development or influence.

VSO'S POSITION

VSO believes the greater involvement of people living with HIV and AIDS is a fundamental part of our response to the HIV and AIDS pandemic. Without the full participation of people living with HIV and AIDS in our programmes and activities, we cannot be assured of the relevance and effectiveness of our work, or legitimacy in our advocacy work.

The views, expertise, needs and rights of people living with HIV and AIDS must be part of our programme and partnership development, our implementation activities and organisational practices at all levels.

As an organisation, VSO is committed to providing an inclusive environment for people living with HIV and AIDS, where staff and volunteers can work without fear of stigma and discrimination. As a result, VSO encourages a supportive work environment in which staff and volunteers can discuss HIV and AIDS openly, including their own experience of living with HIV and AIDS. However, to protect individuals, any disclosure of HIV status will be treated as confidential and any HIV- and AIDS-related information about an individual can only be disclosed with the voluntary and informed consent of the person concerned.

KEY PRINCIPLES

- At VSO we need to recognise the vital contribution people infected or affected by HIV and AIDS make in the response to the HIV and AIDS pandemic. Involvement of people living with HIV and AIDS must be meaningful and must avoid tokenism and using people only for testimonies about their HIV status to raise awareness or to warn people.
- We need to create the spaces and opportunities within all our processes for the involvement and active participation of people living with HIV and AIDS, taking into account the different challenges and experiences faced by women and men living with HIV and AIDS.
- Our programmes should support the development and strengthening of bodies that reflect the needs of people living with HIV and AIDS, such as networks and support groups.
- VSO must create an organisational environment that fosters non-discrimination and values the contribution of people living with HIV and AIDS and affected communities in all countries.
- VSO should ensure workplace policies and practices recognise the health and related needs of people living with HIV and AIDS and affected communities, and create an enabling environment that supports their involvement.
- VSO should support the funding and/or advocate for funding of organisations of people living with HIV and AIDS and ensure they have the resources to build capacity and empower others within their own networks.
- We should always involve people living with HIV and AIDS in the design and implementation of programmes and advocacy work.

RESOURCES

- ILO (2001) *ILO Code of Good Practice on HIV and AIDS and the world of work*
- UNAIDS (2007) *Policy Brief: The Greater Involvement of People Living with HIV*
- UNAIDS(1999) *From Principle to Practice: Greater Involvement of People Living With or Affected by HIV/AIDS*
- VSO (2005) *The international VSO workplace HIV and AIDS policy for staff and volunteers*
- VSO-RAISA (2005) *You don't belong here: Fear, blame and shame around HIV and AIDS*

LANGUAGE

- VSO supports the use of the term '**people living with HIV and AIDS**' rather than 'positive people' or 'HIV+ people'. This is because, unlike the other terms, 'living with' does not imply that their HIV status makes up their whole identity.
- Many new acronyms such as **MIPA** and **FIPA** – 'meaningful involvement' and 'full involvement' of people with HIV and AIDS – have emerged recently, but the principle is the same in that we must ensure people living with HIV and AIDS are involved in all activities at all levels.



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