

STOP

AIDS

NOW!

Greater involvement of people living with HIV **A world to involve**

GIPA is a principle that aims to realise the rights and responsibilities of people living with HIV, including their right to participation in decision-making processes that affect their lives. In these efforts, GIPA aims to enhance the quality and effectiveness of the AIDS response and is critical to halting and reversing the epidemic. The idea that personal experiences should shape the AIDS response was first voiced by PLHIV in Denver in 1983. The GIPA principle was formalised at the 1994 Paris AIDS Summit.

“There is a lack of understanding among stakeholders at national and provincial levels regarding the GIPA principle. In many cases PLHIV are only involved at basic levels of programming. They don’t have any meaningful involvement in designing and decision making processes, even though the programmes are supposed to meet their needs.”

Tip

Read the in-depth studies of Indonesia, Kenya, Zambia, Nicaragua and Costa Rica in annex XI, 1 to 4



STOP AIDS NOW! requested an exploratory study on the opportunities to improve the incorporation of the GIPA principle in STOP AIDS NOW! partner programmes and STOP AIDS NOW! development projects.

Organisations and networks of people living with HIV play a key role when it comes to implementing the GIPA principle. They are the ones who represent the interests of PLHIV and give them a voice. With this study STOP AIDS NOW! aimed to gain more insight in how exactly these networks and organisations contribute to achieving GIPA.

The outcomes show that GIPA is far from being a common practice. This factsheet summarises the main challenges of the implementation of GIPA. With each challenge a recommendation is provided.

“Involvement of PLHIV often does not go further than inviting PLHIV to participate in seminars and workshops.”

Challenges to achieving GIPA

Stigma and discrimination

Fear of stigma and discrimination are considered the most important barriers for PLHIV to make their voices heard.

Recommendation: The most important impact of the work of PLHIV organisations and networks is that the situation of PLHIV has been made known and put on the agenda. Participation of PLHIV provides a human face to the virus, breaking down fear and prejudice. These organisations and networks should be supported and empowered.

Lack of awareness and visibility

- Government institutions and all kinds of development organisations show low level of understanding of GIPA.
- Although in all countries included in the study national AIDS policies have been developed, GIPA is seldom practiced or applied, due to lack of resources and skills and lack of understanding at different governmental levels concerning what GIPA is about.
- Often staff members of PLHIV organisations are not aware of the GIPA principle, do not understand what it is and how it could be applied.

Recommendation: GIPA needs to be promoted, it has to become a living and practised concept within organisations. Skills building and tools should be provided to all stakeholders, in particular donors, HIV/AIDS service delivery organisations, NGOs working with HIV projects and organisations and networks of PLHIV.

For more information:

Please visit our website for more information about GIPA:

http://www.stopaidsnow.org/related_topics_article/gipa

For many downloadable resources on HIV and AIDS and other related issues, visit:

<http://www.stopaidsnow.org/downloads>

Resources & capacity of organisations and networks of People living with HIV

- Involvement of PLHIV is often hindered by funding constraints, low skill levels of PLHIV, poverty and lack of workplace policies as enabling environment.
- Most organisations/networks heavily draw on volunteers and staff is overloaded, lacking time and capacity to improve GIPA.
- There is a lack of attention among PLHIV organisations/networks to the diversity among people living with HIV.
- PLHIV organisations/networks have limited contacts with development organisations and vice versa which hampers opportunities to address broader developmental needs and rights of PLHIV, including the implementation of GIPA.

Recommendation: Provide support for institutional and organisational development of PLHIV organisations based on a needs assessment. Tailor-made capacity building will improve participation, such as inclusion of minorities and attention to gender issues. The study suggests to support organisations of PLHIV to join forces when it comes to advocacy at national level.

Measuring involvement of PLHIV

- Measuring involvement of PLHIV within projects supported by STOP AIDS NOW! partners is limited, since reports coming from the South do not always include clear indicators about participation of target groups.

Recommendation: The study recommends STOP AIDS NOW! partners to review their HIV policy to ensure GIPA is addressed in programmes and their commitment to the GIPA principle is translated into practice. Based on this study, STOP AIDS NOW! should invest in the development of clear GIPA indicators to provide visibility in the future about the involvement of PLHIV within the programmes of STOP AIDS NOW! partners.
