

Supporting community action on AIDS in developing countries

Greater involvement of people living with HIV (GIPA)

GOOD PRACTICE GUIDE



Good Practice Guide series

This guide is one in a series of *Good Practice Guides* produced by the International HIV/AIDS Alliance (the Alliance). This series brings together expertise from our global community-level HIV programming to define and guide good practice in a range of technical areas, including:

- Human rights and GIPA
- Research, evaluation and documentation
- HIV prevention
- Integration of sexual and reproductive health, HIV and rights
- HIV and tuberculosis
- HIV programming for children
- HIV and drug use
- Programme cycle management

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- targeting HIV programmers working in community settings in developing and transitional countries
- helping to define what is good practice for community-level HIV programmes.

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Alliance good practice HIV programming standards – Greater involvement of people living with HIV (GIPA)

ALLIANCE GOOD PRACTICE HIV PROGRAMMING STANDARDS FOR GIPA

Good practice standard 1

Our organisation is committed to ensure equal and full participation of all stakeholders, especially potential programme beneficiaries, at all stages of the programme cycle

Good practice standard 2

Our organisation is committed to the effective implementation of the GIPA principle throughout all areas of our organisation.

Good practice standard 3

Our programmes promote and provide an enabling and protected environment to facilitate the participation of people living with HIV.

Each guide in the Alliance good practice series is accompanied by a set of programming standards. Implementing these is one of the ways that the Alliance, our partners and other organisations can define and promote a unified and quality-driven approach to HIV programming.

This *Good Practice Guide* contains information, strategies and resources to help programme officers meet the good practice standards and translate the GIPA principle into practice at programme level.

The full programming standards for GIPA can be found in Appendix 3 at the back of this guide.



KEY RESOURCE

The full Alliance good practice HIV programming standards for a range of technical areas can be found at:

[www.aidsalliance.org/
Publicationsdetails.
aspx?Id=451](http://www.aidsalliance.org/Publicationsdetails.aspx?Id=451)

French version
[www.aidsalliance.org/
Publicationsdetails.
aspx?Id=452](http://www.aidsalliance.org/Publicationsdetails.aspx?Id=452)

Spanish version
[www.aidsalliance.org/
Publicationsdetails.
aspx?Id=453](http://www.aidsalliance.org/Publicationsdetails.aspx?Id=453)

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This guide is intended to:

- be easy to use and read
- provide practical information for programme level staff in organisations responding to HIV
- help define good practice for the meaningful involvement of people living with HIV.

Introduction

What is the purpose of this guide?

Many acronyms are used in the HIV response, but none with more potential for creating positive change than GIPA – the greater involvement of people living with HIV.¹ Translating principles into practice, and making them work within your organisation and programmes, can be challenging but needs to be at the centre of responses to HIV.

The guide offers support for translating the GIPA principle into practice at the programme level. It provides background information and practical strategies to help programme officers meaningfully involve people living with HIV in new and existing programmes.

It is also a reference to get you started, but how you meaningfully involve people living with HIV in your organisation will happen in different ways. While the guide is focused on the programme level, the information contained here may also be useful

This guide was developed for programme officers and other people who develop or deliver HIV programmes globally, and especially in the global South. It is intended as a reference guide to support your ongoing work.

for enhancing the involvement of people living with HIV in policy processes and research, and can be applied to many different contexts.

The guide is also relevant to programme officers working on other global health issues, particularly tuberculosis (TB). Depending on where you are in the world, many people living with HIV also have TB. The responses to HIV and TB are becoming increasingly integrated in regions with high HIV prevalence, as these regions tend to have high rates of TB co-infection. Organisations responding to TB can learn from the GIPA principle and apply a similar principle of participation in developing appropriate responses to TB.

How is this guide organised?

There is a wide range of experience of practising the GIPA principle among programme officers and within their organisations. Some are accustomed to practising the GIPA principle and are looking for information around specific issues, while others may be completely new to GIPA and are looking for a comprehensive introduction to the principle and implementation strategies.

1. The Greater Involvement of People Living with HIV/AIDS (GIPA) Declaration was signed in 1994. This guide uses the umbrella term 'people living with HIV' and for historical reasons continues to use the acronym GIPA.

The guide is organised with these different needs in mind. It is intended as a reference that can be used in your ongoing work. You are encouraged to read the sections that are most relevant to your needs. You will find the following chapters in the guide:

- **Chapter 1** *Why involve people living with HIV* explores the basics of the GIPA principle, its history and the benefits for programmes and organisations.
- **Chapter 2** *How to involve people living with HIV in your programmes* provides good practice and guidance on how to integrate the involvement of people living with HIV throughout the programme cycle, strategies for achieving representation of diverse people living with HIV, and how to monitor your efforts to practise the GIPA principle in your work.
- **Chapter 3** *How to involve people living with HIV in your organisation* provides strategies for assessing your organisation to enable a supportive environment for people living with HIV, strategies for working with organisations of people living with HIV, and ways to ensure representation.
- **Chapter 4** *Strategies for building the capacity of people living with HIV* offers strategies for supporting the development of skills and resources for people living with HIV to ensure meaningful participation.

How we developed this guide

- An initial planning meeting was held in India in 2009 with key stakeholders and experts, including people living with HIV. This meeting helped to conceptualise and provide guidance on content for this guide.
- We reviewed a wide range of existing documents, tools and resources on the GIPA principle and the meaningful participation of people living with HIV. See Appendix 2 for the list of documents.
- We held an international consultation with organisations and individuals to gather their experience and insights on working with the GIPA principle. We consulted with international non-governmental organisations (INGOs) and networks, country networks of people living with HIV and Alliance Linking Organisations. We also spoke to programme officers living with HIV, as well as programme officers with limited experience of working with people living with HIV. A total of 11 interviews were held with people from China, India, Kenya, the Netherlands, Switzerland, Thailand, Ukraine and the United States.
- We held a wide international review of the guide. A team of experts and stakeholders on the involvement of people living with HIV participated in the review and provided technical expertise. The review team included people living with HIV, programme officers and technical experts on the involvement of key populations.

Throughout this guide you will notice icons that highlight different types of information:



Key message summarises the important messages.



GIPA in practice provides case studies and examples to illustrate key points about involving people living with HIV at the programme level.



Strategies provides practical guidance on how to involve people living with HIV in your organisation and programmes.



Key resource highlights additional resources for those who want to learn more about specific aspects of the GIPA principle.



Good Practice Standards highlights chapters which will help you to meet the Good Practice Standards.

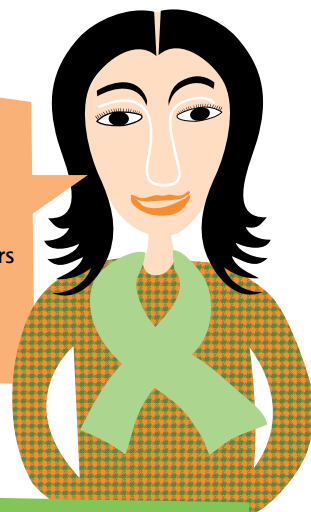
Jambo! My name is Rahid. I am a married 34-year-old man and I work with the Kenyan National Network of People Living with HIV as a volunteer. I have been living with HIV for three years and I now sit on the National AIDS Control Council with government ministers and very experienced staff from NGOs.



Hola! Jambo! B TAYO!! Hello! 你好

Throughout the guide a number of fictional characters will help you with a range of perspectives. They were developed to showcase examples of the involvement of people living with HIV, from those who are highly experienced to those with no experience. They will provide insight, give tips and ask and answer important questions that programme officers need to know.

B TAYO!!
My name is Oksana, and I am an HIV-positive woman from Ukraine. I am 27 years old, a former injecting drug user and have been incarcerated many times. I work as a programme officer in a community-based network for people who use drugs, many of whom are living with HIV. Our network partners with many other NGOs and international development organisations who ask for our expertise on working with people who use drugs and who are living with HIV.



Hola! My name is Francisco. I am a gay man from Bolivia. I am 41 years old and I work as a programme officer in an international development NGO. Many of my programmes are focused on the needs of key populations, including people living with HIV, gay men and other men who have sex with men, sex workers and transgenders.



你好 My name is Ming, and I am young woman from China. I have been living with HIV for five years. I teach other women in the clinic in my region about the benefits of taking antiretroviral treatment for HIV.

Hello! My name is Sam, and I am from the UK. I am 32 years old and I work in Zambia as a programme officer for an international development organisation. I have never worked with people living with HIV, but I am very interested in making sure my programmes are relevant and reflect the needs of those we are trying to reach.



1 Why involve people living with HIV?

In this chapter:

- What is the GIPA principle?
- What is the history of the GIPA principle?
- The GIPA Tree of Involvement
- The benefits of involving people living with HIV in programmes



KEY MESSAGE

GIPA is a commitment to work in a participatory manner with people living with HIV in all aspects of the HIV response.



KEY RESOURCES

Joint United Nations Programme on HIV/AIDS (2007), *'UNAIDS policy brief: the greater involvement of people living with HIV (GIPA)'*. Available at: http://data.unaids.org/pub/Report/2007/JC1299-PolicyBrief-GIPA_en.pdf

Jürgens, R. and Cohen, J. (2006), *'Human rights and HIV/AIDS: now more than ever. 10 reasons why human rights should occupy the centre of the global AIDS struggle'*, Open Society Institute. Available at: www.soros.org/initiatives/health/focus/law/articles_publications/publications/human_20071017

There are many benefits to working in a participatory way with people living with HIV. This chapter provides a brief overview and history of the GIPA principle and the importance of rights-based approaches. To better understand why practising the GIPA principle is vital, this chapter showcases the benefits for communities, individuals and organisations of involving people living with HIV.

What is the GIPA principle?

The greater involvement of people living with HIV (GIPA) is a guiding principle that calls for the active and meaningful participation of people living with HIV in the inception, development, implementation, monitoring and evaluation of policies and programmes. To be successful, the involvement of people living with HIV should be mainstreamed across all aspects of the HIV response, including prevention, treatment, care and support. This participatory way of working breaks down simplistic and false assumptions of 'service providers' as those who are living without HIV and 'clients' as those who are living with HIV.

The GIPA principle is a rights-based approach, which is recognised as good practice in programming and policy. It acknowledges the universal rights of people living with HIV to self-determination and participation in decisions that affect their lives. Violating people's rights to self-determination and participation has serious consequences for them, their communities, organisations seeking to serve them and the countries they are citizens of. Rights violations can impact on people in many ways and result in social isolation, alienation and depression. Services seeking to reach people living with HIV then become irrelevant and policies ineffective. This can greatly increase existing vulnerabilities and impact on the health of people and communities.

The participation of populations in programmes and policy development is not new. Participation of those who will be affected by decisions is widely regarded as good practice by international development practitioners, community development workers and health promotion specialists. These stakeholders recognise that participation leads to ownership, which is essential for sustainable social change. The GIPA principle is a recognition of the value of participation specifically in the context of the HIV response.



STRATEGY: UNDERSTANDING YOUR HUMAN RIGHTS SITUATION

Scanning the human rights environment for people living with HIV is the first step towards taking a rights-based approach. This will help you to determine how successful you will be at involving people living with HIV. For example, is the confidentiality of people living with HIV protected in your organisation and country? Is there anti-discrimination legislation in place in your country? Are rights violations against key populations of people living with HIV, including those who use drugs, sex workers, or gay men and other sexual minorities, common in your country? Answering these questions will help you to begin understanding the barriers to participation for people living with HIV. Learn more about assessing your rights environment in Chapter 3.

It is only by listening to those most affected that we can bring about real change.



This is a shift from a welfare programming model to a rights-based model. We can't be talking at people; we need to be talking with people.



GIPA is a mindset – a way of thinking and a commitment. Once you have this, the creative ways that GIPA can be practised are limitless.



What is the history of the GIPA principle?

Since the early years of the HIV epidemic, HIV responses have been sparked and propelled by social movements of people living with HIV and populations most affected by HIV, such as gay men, women, sex workers, young people, people who use drugs, migrants and people living in poverty.



These advocacy statements were written on banners carried by people living with HIV in 1983 at an American health conference in Denver, Colorado. The activists developed the Denver Principles, which are considered the first act of activist self-determination by people living with HIV.

KEY MESSAGE

Communities living with and affected by HIV have been leaders in the response to HIV. Their advocacy has made it a global health imperative to involve and acknowledge the rights of those most affected by HIV.



KEY MESSAGE

The commitment to the GIPA principle forms part of international declarations on human rights and is highlighted in numerous international declarations and guidelines including the 1994 Paris Declaration, the 2001 UNGASS Declaration of Commitment, and the Code of Good Practice for NGOs Responding to HIV.

The call for active and meaningful involvement of people living with HIV was formally recognised in 1994 when 42 countries signed the Paris Declaration. This declaration formalised and declared: “The Greater Involvement of People Living with, or affected by HIV/AIDS is critical to ethical and effective national responses to the epidemic”, and they 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.”²

Today there are numerous international guidelines and commitments that acknowledge and support the involvement of those living with HIV and other health conditions, including:

- **The 1983 Denver Principles**
www.actupny.org/documents/Denver.html
- **The 1986 Ottawa Charter for Health Promotion**
www.who.int/healthpromotion/conferences/previous/ottawa/en
- **The 1994 Paris Declaration**
www.ecpp.co.uk/parisdeclaration.htm
- **The 2001 United Nations General Assembly Special Session on HIV/AIDS Declaration of Commitment**
www.un.org/ga/aids/docs/aress262.pdf
- **The 2006 United Nations High-Level Meeting Political Declaration**
www.un.org/ga/aidsmeeting2006
- **Code of Good Practice for NGOs Responding to HIV: Renewing Our Voice**
www.hivcode.org

The GIPA Tree of Involvement

The GIPA Tree of Involvement (on the next page) illustrates how practising the GIPA principle contributes to strong and empowered communities and the achievement of universal access to HIV prevention, treatment, care and support. The leaves of the tree illustrate the benefits of involving people living with HIV in programmes; the trunk shows the many ways of practising the GIPA principle; and the roots indicate what is needed to make GIPA grow.

The information in this tree diagram is explained throughout the rest of this chapter.

2. From the Paris Declaration

Strong healthy and empowered communities
 Universal access to HIV treatment, prevention, care and support



People living with HIV (PLHIV) are:

- Governance body representatives • Staff • Volunteers
- Partners • Campaigners • Policy makers • Educators
- Decision-makers • Speakers • Committee members • Trainers
- Consultants • Advisors • Programme evaluators • Researchers
- Supported in organisations and networks of PLHIV

WAYS OF PRACTISING GIPA

Organisational assessment

Recognition of competencies as well as credentials

Capacity-building activities

Training and skills development

Supportive HIV workplace policies

Remuneration for PLHIV

Organisational commitment to the GIPA principle

Barriers to participation are identified and addressed

Supporting organisations of PLHIV

Commitment to change by political and community leaders

Psychosocial support

Key populations of PLHIV are engaged

Peer support

Dedicated resources

Rights-based approaches

Non-judgemental approaches

WHAT MAKES GIPA GROW

See Chapter 2 for more information on how to involve people living with HIV in the programme cycle.



KEY RESOURCES

Cornu, C. and Attawell, K. (2003), *'The involvement of people living with HIV/AIDS in community-based prevention, care and support programmes in developing countries'*, International HIV/AIDS Alliance and Horizons. This study details some of the benefits for people living with HIV when they are engaged! Available at: www.aidsalliance.org/publicationsdetails.aspx?id=132

de Goei, T. and Groverman, V. (2009), *'A world to involve: report of the exploratory study on the GIPA principle'*, STOP AIDS NOW Available at: www.stopaidsnow.org/documents/GIPA_A-World-to-Involve.pdf

The benefits of involving people living with HIV in programmes

There are many practical reasons to involve people living with HIV in your programmes and organisation, including:

Programmes and policies are tailored and responsive

Practicing the GIPA principle enhances the effectiveness of policies, programmes, and services. Involving people living with HIV makes sure that your policies, programmes and services are grounded in their lived realities. Policies, programmes and services that are based on the experiences of people living with HIV are more likely to:

- respond to the needs and priorities of other people living with HIV
- become more open and non-judgemental
- be seen as acceptable and credible
- increase access to programmes and services
- make sure that your organisation's human and financial resources are directed towards the most relevant and realistic interventions
- sustain funding and resources.



GIPA IN PRACTICE: PEOPLE LIVING WITH HIV LEAD TREATMENT LITERACY PROGRAMME IN BOTSWANA

In 2007 the Botswana Network on Ethics, Law and HIV/AIDS (BONELA) developed a partnership with South Africa's Treatment Action Campaign (TAC) and the AIDS and Rights Alliance of Southern Africa (ARASA) to establish an HIV treatment literacy initiative for people living with HIV who were newly on antiretroviral treatment.³ The project trained people living with HIV to become experts on their own health, and included a curriculum to develop a scientific knowledge base among treatment literacy focal points across the country.

The project successfully enabled people living with HIV to become active partners in their own health and enabled them to be advocates for service delivery in their own communities. It also raised awareness nationally about treatment literacy to over 3,500 people living with HIV and established a campaign to raise awareness about HIV and TB.

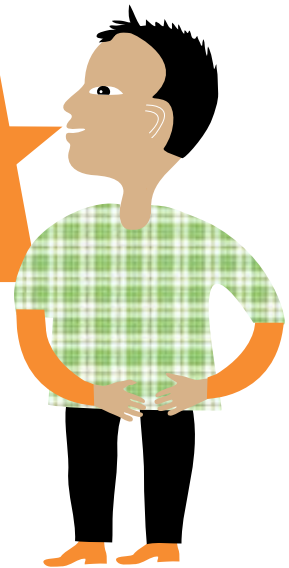
For more information on BONELA: www.bonela.org

3. HIV treatment literacy refers to developing capacity on scientifically sound knowledge, skills and attitudes regarding HIV antiretroviral treatments. Treatment literacy describes a person living with HIV's ability to understand and articulate their own health needs and potential decisions in relation to the essential package of HIV treatment and care services. Individual health literacy has been shown to contribute to maintaining the well-being and health of people living with HIV.



Often people living with HIV face the risk of stigma and discrimination when accessing services. Involving people living with HIV in service delivery may make others feel more comfortable to come to your organisation.


When an organisation practises the GIPA principle, the quality of programming is higher and it is validated by personal and professional experiences. When it is evident that people living with HIV have been involved, this acts as a quality indicator.



Stronger community systems and better local responses to HIV

Practising the GIPA principle by working with people living with HIV and organisations of people living with HIV strengthens community systems and results in better local responses to HIV by:

- ensuring that policies, programmes and services are tailored to the local context and key populations
- creating peer support networks in communities
- challenging negative attitudes about people living with HIV by signalling that they have something to contribute and are valued members of the community
- increasing demand for services
- building capacity within the community to provide an increased range and quality of services, including improved access to physical infrastructure (such as office space, bank accounts and communications technology) and opportunities to learn skills and tools that support organisational systems (such as financial management, strategic planning, monitoring and evaluation, and information management capacities)
- mainstreaming HIV in other sectors and building partnerships at the local level to improve coordination, enhance impact and avoid duplication of service delivery.



KEY RESOURCE

Global Fund to Fight AIDS, TB and Malaria (2010), *‘Community systems strengthening framework’*. Available at: www.theglobalfund.org/documents/civilsociety/CSS_Framework.pdf



GIPA IN PRACTICE: BETTER LOCAL RESPONSES TO HIV THROUGH PRACTISING GIPA

Increasingly, funders, governments and NGOs are investing in organisations and networks run by people living with HIV. Supporting these networks and organisations through partnership, financial investment, training and other support has been shown to dramatically increase access to healthcare services by people living with HIV and progress towards universal access targets.⁴ In the box on the following page, there are some examples from around the world.

4. International HIV/AIDS Alliance (2009), *‘Expanding the role of networks of people living with HIV/AIDS in Uganda’*, USAID and International HIV/AIDS Alliance. Available at: www.aidsalliance.org/publicationsdetails.aspx?id=414



KENEPOTE and INERELA+ decreasing HIV-related stigma

Organisations of people living with HIV are increasingly putting HIV on the agenda of other sectors. For example, the Kenya Network of HIV-Positive Teachers (KENEPOTE) are working within the education sector to challenge HIV-related stigma and build community capacity to respond to HIV,⁵ and the International Network of Religious Leaders Living with or Affected by HIV and AIDS (INERELA+) are working to build awareness and challenge HIV-related stigma in faith communities.

For more information on KENEPOTE: www.healthpolicyinitiative.com/Publications/Documents/839_1_Education_sector_FINAL_acc.pdf

For more information on INERELA+: www.inerela.org

Expanding the role of networks of people living with HIV in Uganda

This three-year project in Uganda, implemented by the Alliance in 2007, found that strategic partnership and capacity-building of networks of people living with HIV can increase access to HIV and health services. The project put people living with HIV and communities at the heart of project delivery, and as a result achieved rapid scale-up and national impact on universal access targets. The project dramatically increased access to prevention, care, treatment and support services for people living with HIV. Over 1.3 million people accessed HIV services through the project. It referred over 19,800 orphans and vulnerable children for health services, and more than 2,200 orphans and vulnerable children were identified and registered through the project for direct food, education, care and psychosocial support.

For more information on the project: www.aidsalliance.org/publicationsdetails.aspx?id=414

Parliamentarians learn from women living with HIV and commit to reform policy and law: Parliamentarians for Women's Health Project⁶

The International Community of Women Living with HIV/AIDS (ICW), Centre for the Study of AIDS (CSA), International Center for Research on Women (ICRW) and Realizing Rights: The Ethical Globalization Initiative (EGI) worked with parliamentarians to improve women's access to healthcare in Botswana, Namibia, Kenya and Tanzania. Through linking women living with HIV with politicians, the project improved parliamentarians' understanding of the health issues that women – especially HIV-positive women – face, including barriers to accessing treatment and sexual and reproductive health services. “The assessments I attended exposed me to the real needs of people on the ground; I had read the statistics but I hadn't been in touch with the real human feeling surrounding it beforehand,” said the Honourable Peya Mushelenga after visiting women living with HIV in her community.

For more information on the project: www.icw.org/node/297

5. USAID (2009), *Rising to the challenge: health policy initiative helps HIV-positive teachers tackle stigma and discrimination in Kenya*.

6. Adapted from: www.icw.org/node/297



Community systems strengthening in Peru: the role of people living with HIV ⁷

In March 2008 the Global Fund approved grants for Peru that went directly to CARE Peru as the Principal Recipient to oversee and implement funding. No government ministry is involved. The Country Coordinating Mechanism and the government openly signalled their backing for such a decentralised strategy by selecting a civil society recipient.

Community systems strengthening is an integral part of the Global Fund grant-supported programmes in Peru, with a specific focus on groups run by people living with or directly affected by HIV and AIDS. For example, each programme objective outlined in the HIV grants is tackled by a consortium of NGOs working together. The funding went towards:

- improving basic management skills, including helping to legalise groups of people living with HIV as NGOs
- training groups of people living with HIV and advocates on how to work effectively and advocate within the public health system
- training gay men and other men who have sex with men, and sex workers to serve as peer educators and counsellors on all issues related to HIV prevention and treatment. Particular attention is paid to giving them the skills and confidence to promote the use of condoms, sexually transmitted infection screening, and care and treatment adherence. The educators also help their peers navigate care systems
- helping networks of people living with HIV to set up income-generating micro enterprises as part of an effort to improve the livelihoods of HIV-positive people.

Increased self-determination and personal development for people living with HIV

Practising the GIPA principle recognises the rights of people living with HIV to self-determination and participation in decisions that affect their lives. It respects their knowledge and abilities to address their own needs.

The GIPA principle supports the personal development of people living with HIV by:

- reducing social isolation, depression, and self-stigma
- building self-esteem
- promoting confidence and overall health and well-being
- creating support networks through peer connections
- increasing employability.

It is important to remember, just because someone is living with HIV does not mean they want to participate in the HIV response. Many people living with HIV lead productive lives outside of contributing to the HIV response and this is their right too.



7. Adapted from: Global Fund, International HIV/AIDS Alliance (2008), 'Civil society success on the ground. Community systems strengthening and dual-track financing: nine illustrative case studies'. Available at: www.theglobalfund.org/documents/publications/progressreports/Dual-Track_Report_en.pdf



Zhang Lin's story: from a training participant to a community leader

In 2004 Zhang Lin started a peer-led support organisation for people living with HIV. After attending a training workshop on antiretroviral treatment for HIV held by Alliance partners in China, Zhang Lin was inspired to share the information with others and start her own organisation.

“I am an ordinary woman living in the countryside in Ruili province, China,” says Zhang Lin. “In November 2003 I tested HIV-positive, my CD4 count was under 200 and by Chinese government standards I was eligible for antiretroviral treatment. I was one of the first groups of people living with HIV in China to get free antiretroviral treatment from the government. As part of this I was asked to participate in training about antiretroviral treatment adherence, conducted by Alliance China. In this training I met other HIV-positive people and they made me feel that I was not alone in this world. This training was a good experience for me.”

“Through the training, I also learnt why antiretroviral treatment adherence is important and about side effects of treatment. The information I learnt was important for others to learn about so they could improve their lives too. After the training my confidence improved significantly. If others could know this information then their lives could also be improved.”

Following the training, Zhang Lin started a peer-led Red Ribbon Centre in her community for other people living with HIV that is connected to the local hospital. The centre is a partnering organisation of AIDS Care China and the Alliance. It has five staff, four of whom are living with HIV. Zhang Lin and her staff support people living with HIV in sharing information on treatment adherence, side effects, home care, counselling and hospital visits. The work of Red Ribbon Centres (there are 28 across China) has dramatically improved the quality of life of people living with HIV.

Karla's story: from service user to representative of people living with HIV in El Salvador

Karla is 32 years old and lives in El Salvador with her two sons. She found out that she was infected with HIV during her pregnancy and her husband later died of HIV-related complications. She joined Asociación Atlacatl Vivo Positivo – an organisation that provides support and information on HIV and addresses stigma and discrimination towards people living with HIV – to find mutual support from other women who had lived through similar situations.

Karla became increasingly involved with Asociación Atlacatl Vivo Positivo and the HIV response. Eventually they hired her to provide services to other people living with HIV, and now she is the country contact for the Central American Network of People living with HIV, coordinator of the Alliance of People Living with HIV and the movement of women living with HIV in El Salvador, and regularly participates in advocacy meetings with members of El Salvador's Legislative Assembly.

Learn more about Asociación Atlacatl Vivo Positivo: www.atlacatl.org.sv

Ways of practising GIPA

There are many ways to involve people living with HIV in your programmes and organisation, including: ⁸

Organisational policy-making	People living with HIV can participate in the development and monitoring of HIV-related policies at all levels within organisations; for example, employment and confidentiality policies. This can be done by making sure that people living with HIV are involved in strategic planning processes and are represented on programme development committees and governing bodies such as boards and executive committees.
Programming and research	People living with HIV can be involved in the choice, design, implementation, monitoring and evaluation of prevention, treatment, care and support programmes and research.
Educators	People living with HIV act as vital sources of information as trainers, consultants, capacity-building experts and advisors to NGOs, civil society groups and governments.
Peer support	People living with HIV can play a vital role by becoming peer educators for others living in similar situations. They provide them with support and can help develop networks that decrease isolation and reduce stigma.
Campaigns and public speaking	People living with HIV can be spokespeople in campaigns or speakers at public events and in arenas outside of the HIV response. People living with HIV bring technical as well as personal experience as public speakers and campaigners.
Advocacy	People living with HIV can advocate for law reform, inclusion in the research agenda, increased access to services, and resource mobilisation. They can participate in advocacy as representatives on committees and the governance bodies of government ministries, including national HIV and AIDS coordinating committees and in global and regional institutions such as the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the Global Fund to Fight AIDS, Tuberculosis and Malaria.
Working with organisations of people living with HIV	People living with HIV run their own organisations and networks, which provide them with a voice on advocacy platforms and with external partners. These organisations and networks are vital and credible partners in HIV treatment, prevention, care and support policies, programmes and services. They bring a lot of knowledge on HIV issues and expertise in advocacy, and can play a key role in mainstreaming issues specific to the situation of people living with HIV in your organisation.

8. Adapted from: UNAIDS (2007), 'UNAIDS policy brief: the greater involvement of people living with HIV (GIPA)'. Available at: http://data.unaids.org/pub/Report/2007/JC1299-PolicyBrief-GIPA_en.pdf



KEY RESOURCES

Networks of people living with HIV

Almost every country will have a network or organisation of people living with HIV.

The Global Network of People Living with HIV (GNP+) has links to regional networks of people living with HIV on their website. Through the regional networks you can get connected to your country's network.

Check here for more information:
www.gnpplus.net

The International Community of Women Living with HIV/AIDS (ICW) has contacts all over the world that can help connect you to regional and country networks or organisations of women living with HIV.

Check here for more information:
www.icwglobal.org/en/contact.php



GIPA IN PRACTICE: PRACTISING THE GIPA PRINCIPLE AT MULTIPLE LEVELS

Strengthening the national HIV response through advocacy and investing in the capacity of organisations of people living with HIV

The HIV Leadership through Accountability programme is a practical example of implementing the GIPA principle in different ways, including through capacity-building, organisational development, advocacy, policy development and research. Research led by three national networks of people living with HIV has been completed in Kenya, Nigeria and Zambia, and is helping to strengthen the networks as leaders in HIV research and programming.

National networks of people living with HIV engage people living with HIV as programme coordinators, financial administrators, researchers, campaigners and representatives, with the aim of building evidence-based advocacy campaigns led by and for people living with HIV and civil society. These national networks have developed technical skills, such as planning, research, operational and programme management, accountability and governance. They have also developed partnerships with stakeholders who are directly involved in national response programming and policy.

The national networks have implemented the five research tools – Global Criminalisation Scan, GIPA Report Card, Human Rights Count!, People Living with HIV Stigma Index and SRHR Guidance Package. They are now taking a central role in advocacy platforms that will inform national-level policies and priorities and highlight the important role of civil society – in particular networks of people living with HIV – in working with governments to push forward universal access to HIV treatment, prevention, care and support.

Learn more about the HIV Leadership through Accountability programme:
www.gnpplus.net/programmes/empowerment/hiv-leadership-through-accountability

What makes GIPA grow?

There needs to be a foundation of resources, support and commitment to enable the meaningful participation of people living with HIV. Successful implementation of the GIPA principle requires leadership and strategic planning within organisations. This includes a commitment to ensuring that the involvement of people living with HIV is sustainable by addressing barriers to participation, including discriminatory policies and procedures; ensuring the availability of financial, technical and human resources to facilitate participation; and building capacity for meaningful participation among people and organisations of people living with HIV.

For guidance on how to achieve meaningful participation of people living with HIV throughout your organisation and programmes, go to:

- **Chapter 2** for strategies on involving diverse groups of people living with HIV throughout the programme cycle
- **Chapter 3** for information on making an organisational commitment to GIPA and getting your organisation ready for involving people living with HIV
- **Chapter 4** for information on building the capacity of people living with HIV.



When you talk about GIPA you talk about different ways of involving people living with HIV. One way could be at the workplace, another way could be ensuring a role for organisations of people living with HIV, and another at the governance level.

2 How to involve people living with HIV in your programmes

In this chapter:

- Involving people living with HIV throughout the programme cycle
- Good practices for involving people living with HIV in programmes
- Strategies for achieving representation of diverse people living with HIV
- Monitoring your work on GIPA

Good practice programming standards:



There are many ways to involve people living with HIV in your work. This chapter outlines some of the most common ways to implement the GIPA principle and provides strategies on how to overcome common challenges when working in a participatory way with diverse groups.

Involving people living with HIV throughout the programme cycle

People living with HIV can be involved in all stages of the programme cycle, from assessment through to monitoring and evaluation.

Assessment

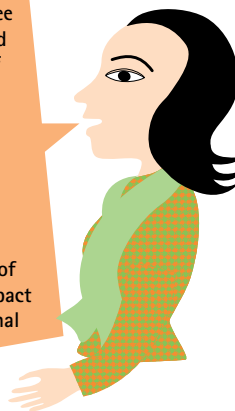
Assessment is the process of gathering and analysing information, experience and evidence in order to identify needs for developing programmes and building on community assets. Effective assessments make sure that programmes are relevant and address a gap or need. For example, understanding the scope of and key trends in the HIV epidemic in your local community will help you to focus your efforts and decide which groups of people living with HIV to engage.

Involving people living with HIV in the assessment phase has many benefits for programmes. It becomes more likely that the assessment and your programme will focus on the issues that are most important and relevant to the affected community. Your data collection methods ask the right questions in a way that your target audience understands. You also collect accurate data and interpret it in a way that helps you address the needs of your target audience. Involvement at the assessment stage increases the likelihood that the target audience will have a sense of ownership over the results and will buy into the solutions. This will increase the sustainability of your programme and the involvement of people living with HIV in it.



But why is it important to do an assessment?

It is important to understand the current response to HIV in your country. Then you can see any gaps in current policy and programming. For example, if you live in a country with a generalised HIV epidemic, the government and civil society actors may not be adequately addressing key populations, including gay men and other men who have sex with men, or people who use drugs. All of these factors will have an impact on the effectiveness of national programmes.



KEY RESOURCES



Tapia, M., Brasington, A., and Van Lith, L. (2007), *'Participation guide: involving those directly affected in health and development communication programs'*, Baltimore: Health Communication Partnership based at the Johns Hopkins Bloomberg School of Public Health/ Center for Communication Programs. The participation guide presents a simple set of guidelines to design and implement participatory health and development communication programmes. Available at: www.aidsalliance.org/includes/Publication/participation_guide.pdf

International HIV/AIDS Alliance (2006), *'All together now! Community mobilisation for HIV/AIDS'*, a toolkit on how to mobilise communities for HIV/AIDS prevention, care, support, and treatment and impact mitigation. Available at: www.aidsalliance.org/Publicationsdetails.aspx?id=228



STRATEGIES FOR INVOLVING PEOPLE LIVING WITH HIV IN ASSESSMENTS

- Work with organisations of people living with HIV by doing the assessment together.
- Ensure relevant representatives of key populations are involved throughout the process.
- Involve people living with HIV as peer researchers.
- Provide research training sessions for people living with HIV.
- Involve people living with HIV as participants in focus groups or surveys.
- Include people living with HIV in the design of data collection tools.
- Bring together in consultation those partners that do not practise the GIPA principle with those that do.



KEY MESSAGE

Involving people living with HIV at this stage will make sure that your programmes are accurate, relevant and appropriate.

When people living with HIV are volunteers it's important to ensure appropriate compensation for food, travel, childcare costs and for time. It is common practice to pay an honorarium when people are engaged in focus groups or consultations.



Planning and design

Planning and design means identifying your goals and objectives, the populations you hope to reach, the strategies you will use to achieve your goals and objectives, and developing your work plan and monitoring and evaluation framework. The work invested in this stage of the programme cycle helps to make sure that your interventions are well thought out and have the best chance of creating positive change.

By involving diverse groups of people living with HIV in designing your programme, you increase the likelihood that it will meet the needs of your target audience, be seen as credible and accessible by your target audience, and help to reduce the stigmatisation of people living with HIV in your community. This, in turn, makes it more likely that your resources will be used effectively, that your programme will achieve its results, and that the community will be more actively engaged in the HIV response.



STRATEGIES FOR INVOLVING PEOPLE LIVING WITH HIV IN THE PLANNING AND DESIGN STAGE

- Involve people living with HIV in all planning meetings.
- Include representatives from diverse groups of people living with HIV on advisory groups and steering committees, and have them guide the planning stage.
- Encourage staff living with HIV to facilitate planning meetings and workshops, and to develop programmes.
- Pilot ideas arising from community consultations and focus group discussions with organisations of people living with HIV.
- Include people living with HIV as representatives of your organisation at meetings with external partners.



KEY RESOURCES

The following initiatives were developed by people living with HIV to measure the application of the GIPA principle, together with programmes and policies to address human rights, stigma and discrimination, and sexual and reproductive health and rights in their countries.

GIPA Report Card: www.gnpplus.net/programmes/empowerment/gipa-report-card

Rapid Assessment Tool: www.gnpplus.net/programmes/sexual-and-reproductive-health-and-human-rights/policy-guidance/1413-rapid-assessment-tool-for-srh-and-hiv-linkages

Global Criminalisation Scan: www.criminalisation.gnpplus.net

Human Rights Count!: www.gnpplus.net/programmes/human-rights/human-rights-count

People Living with HIV Stigma Index: www.stigmaindex.org

NGO Code of Good Practice Self-Assessment Checklists: www.hivcode.org

Sexual and Reproductive Health and Rights Guidance Package: www.gnpplus.net/resources/sexual-and-reproductive-health-and-rights

Positive Women Monitoring Change Tool: www.icw.org/files/monitoringchangetool-designed%2009%2008%20final_0.pdf

In the antenatal clinic in my community, women living with HIV provide information and peer support to new mothers living with HIV. This service is non-judgemental and supportive, resulting in greater uptake of the service and healthier mothers and babies.



Remember, peer workers living with HIV need appropriate training and psychosocial support to do their jobs effectively and to have a meaningful role.



KEY MESSAGE

Involving people living with HIV in the implementation of a programme will help to build trust and break down barriers to accessing services.

Implementation

Implementation means putting the ideas you identified in the planning and design stage into action. Practising the GIPA principle during programme implementation increases the likelihood that your approaches will be non-judgemental and your messages will be appropriate. This builds trust with the people you want to reach and increases access to your services. This is particularly important if those you are working with are people who face other forms of discrimination and stigmatisation, such as young people, people who use drugs, sex workers, migrants, transgendered people, women, and gay men or other men who have sex with men, who may be wary of accessing organisations for fear of discrimination.



STRATEGIES FOR INVOLVING PEOPLE LIVING WITH HIV IN THE IMPLEMENTATION STAGE

- Hire people living with HIV as staff.
- Include representatives from diverse groups of people living with HIV on advisory groups and steering committees, and have them guide the implementation of your programme.
- Involve peer outreach educators in the implementation of your programme.
- Work collaboratively with organisations and networks of people living with HIV to partner on programme implementation.

I have never worked with people living with HIV before. I am new to working in a participatory way with populations. The last organisation I worked for saw populations as recipients of services and was not focused on a community development model.



Monitoring and evaluation

Monitoring and evaluation is a programme management tool. It provides a systematic way of assessing progress towards your desired outcomes, identifying what is contributing to your successes and where adjustments are required. This information can be used to improve your programme, demonstrate its effectiveness, generate the evidence you need to secure future funds, and plan new programmes.

Involving people living with HIV in monitoring and evaluation makes sure that you are measuring things that matter to your beneficiary population in a way that is most relevant to them. Having people living with HIV develop data collection tools, conduct evaluations, review and analyse evaluation data can result in more relevant and nuanced understandings because of their lived experience. This helps to make sure that programmes are continually informed by a strong and relevant evidence base that is grounded in the reality of those you are hoping to benefit.



STRATEGIES FOR INVOLVING PEOPLE LIVING WITH HIV IN THE MONITORING AND EVALUATION STAGE

- Ensure representatives of key populations are involved in monitoring and evaluating your programme.
- Involve people living with HIV as participants in focus groups or surveys.
- Involve people living with HIV in the design of data collection tools.
- Train and work with peer researchers who are living with HIV.
- Work with organisations and networks of people living with HIV by doing the evaluation together.

Good practices for involving people living with HIV in programmes

Putting the GIPA principle into practice is not always easy. This section highlights some examples of good practice in successfully implementing the GIPA principle to help you work towards overcoming common challenges.

Build capacity among organisations and programme officers to practise GIPA

Many people working in community-based organisations have limited knowledge or understanding of the GIPA principle. Usually it is only those at the top level of organisations who have some experience of it, not those at other levels, such as programme officers. Even when

organisations do want to practise the GIPA principle, they may not understand how to or have the capacity to involve people living with HIV. As a result, activities that promote the involvement of people living with HIV at a programme level are often missing or inadequately resourced or supported. If an organisation is not prepared to work effectively with people living with HIV, their work may result in tokenism or could be damaging to people living with HIV.⁹ See Chapter 3 for more strategies on building organisational capacity.

Address HIV stigma and discrimination¹⁰

People living with HIV experience complex forms of stigma related to both their HIV status and other issues like drug use, sexual orientation, sex work, being young and being poor. They may not want to be involved in HIV-related initiatives because they fear stigmatisation or discrimination. Self-stigma – such as feelings of shame, embarrassment and low self-esteem related to your HIV-positive status – can also prevent people living with HIV from being actively involved in HIV-related programmes. Stigma and discrimination are also related to the various key populations that a person living with HIV may belong to. For example, a woman living with HIV who uses drugs may not feel comfortable in a local women’s support group due to judgemental attitudes towards drug use from the other members. See Chapter 3 for strategies for addressing stigma and discrimination and pages 29-31 for strategies for addressing discriminatory barriers for diverse key populations of people living with HIV.

Recognise the competencies of people living with HIV

The life experience of people living with HIV is often devalued or not recognised. They may be excluded from staff or volunteer positions because they do not have the formal education or experiences recognised by NGOs. While living with HIV is not in itself a qualification for working in the HIV response, many people living with HIV do have valuable competencies and skills. See page 42 for information on GIPA in human resource management.

Build capacity among people living with HIV for effective involvement

People living with HIV are often asked to take on a lot of work as volunteers with no financial compensation, even though other committee representatives hold paid positions. This limits the amount of time and resources people are able to devote to their role, for they must do other work to support themselves. Many people living with HIV may not have formal education and may have limited experience of working with civil society organisations and NGOs. See page 48 for ideas on how to build capacities.

KEY RESOURCE

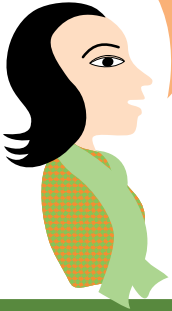
International HIV/AIDS Alliance, ICRW, AED, PACT Tanzania (2007), *‘Understanding and challenging HIV stigma: toolkit for action’*. Available at: www.aidsalliance.org/publicationsdetails.aspx?id=255

It is important to make sure that you take gender into consideration when involving people living with HIV. Understanding how issues like poverty are experienced differently by women, men and transgendered people, will make sure that you have a more complete picture of the barriers facing people living with HIV.

A stylized illustration of a woman with dark hair, wearing a green patterned top. A green speech bubble originates from her mouth, containing text about gender considerations in HIV involvement.

9, 10. de Goei, T. and V. Groverman (2009), *‘Greater Involvement of People Living with HIV: A world to involve’*, STOP AIDS NOW! Available at: www.stopaidsnow.org/documents/GIPA_A-World-to-Involve.pdf

I am a representative on the steering committee, but all these policies and big language sometimes make it hard for me to know what is going on. I know what is best for my community, but the other committee members don't listen to me because I don't speak their policy language.



I am representing people living with HIV in my country on a national level, but as a heterosexual man I do not have the unique perspectives of women, men who have sex with men, or drug users. This means that I have limited capacity to give a real voice to all people living with HIV in my country.



Build capacity among organisations of people living with HIV for effective involvement

Many organisations and networks of people living with HIV have capacity challenges that make it hard for them to be an equal partner with larger, more established, better-funded NGOs. Capacity challenges include inadequate financial resources; reliance primarily on volunteers; lack of rigorous policies and operational procedures; and limited contact with development organisations, which hamper opportunities to address broader developmental needs and rights of people living with HIV. A recent study found that organisations of people living with HIV in the global South often lack diversity. Many do not have appropriate gender policies and are unwelcoming to sexual minorities, including gay men.¹¹ See Chapter 4 for ideas on how to partner.

Promote representation and accountability

Not all people living with HIV are the same. They belong to many different social and cultural groups, including women, men, transgendered people; old and young people; rich and poor people. Sometimes the only thing a group of people living with HIV may have in common is their HIV-positive status.

It is impossible for one person living with HIV to represent all the issues facing the diverse range of people living with HIV in our communities. Often there are no processes in place for representatives to report back to communities or to make sure there is two-way communication between representatives and those they represent. Sometimes representatives do not represent any constituency at all, or only the voices of a select few are heard. Because there can be many benefits to being a representative of people living with HIV, such as opportunities to travel and to be known by high-level leaders, some representatives and well-known activists refuse to make room for younger and more diverse emerging leaders. See page 40 for strategies on ensuring representation and accountability in governance and page 28 for strategies on ensuring diverse representation of people living with HIV.

Plan to overcome barriers to involving key populations

Some people living with HIV also belong to key populations that are more vulnerable to HIV infection than the population as a whole, such as people who use drugs, gay men and other men who have sex with men, transgendered people, sex workers, young people, women, prisoners and migrants. HIV is often only one issue among many that they are facing.

11. de Goei, T. and V. Groverman (2009), 'Greater Involvement of People Living with HIV: A world to involve', STOP AIDS NOW! Available at: www.stopaidsnow.org/documents/GIPA_A-World-to-involve.pdf

People from key populations may be reluctant to participate in HIV-related programmes because they fear exposure to laws that limit their freedoms or criminalise their behaviours and make it difficult for them to exercise their human rights. Participation may also make certain people vulnerable to other forms of stigma and discrimination, such as homophobia. People from key populations may not have or be able to get the things they need to live comfortably, like an education, a job, decent housing, and healthy food. This makes it hard for them to participate in civil society.

Some organisations are apprehensive about working with key populations, fearing that it may expose them to similar forms of stigma and discrimination. Whether these fears are perceived or real, it is vital to challenge stigmatising and discriminatory attitudes rather than succumb to them. See pages 29-31 for strategies on overcoming barriers to the participation of key populations of people living with HIV.

Some organisations find it challenging to implement the GIPA principle because they do not have contact with anyone who is living openly with HIV. Sam, Rahid and Ming discuss common good practice for overcoming this challenge:



Strategies for achieving representation of diverse people living with HIV

The diversity of the HIV epidemic can make it challenging to represent the full range of perspectives and needs. Often it may be easier for programme officers to engage people living with HIV who have high levels of knowledge, competencies and technical skills. But the GIPA principle will not be achieved without the active and meaningful involvement of diverse groups of people living with HIV, particularly those from socially marginalised groups.

The way to begin engaging with the populations you are planning to work with is to start small and be open-minded, sensitive and responsive to their specific issues and needs. Until you understand these you will not be able to support or work adequately with them.

Keep in mind that people often hold more than one social identity. This can compound the issues they face. For example, a young woman living with HIV who migrates to another country and becomes a sex worker holds the identities of woman, young person, migrant and sex worker simultaneously and the vulnerabilities that come with each identity.

PEOPLE LIVING WITH HIV HAVE DIVERSE LIVES AND FACE DIVERSE CHALLENGES

“I got HIV from my husband, who is now dead. His family took our property and all our possessions. They blame me for his HIV. They told the whole community about what happened. I am all alone now.” – Woman living with HIV

“I have HIV and at 16 years old I still live with my mother and father ... it is hard for me to get involved. My parents are embarrassed; they are scared of what others will say if they find out, so we don't talk about it.” – Young woman living with HIV

“I moved here for work. It is hard and I am lonely. I had to make money using sex work. I tested HIV-positive at the anonymous clinic, but now I know my status there are no services for me ... since I am not a citizen I cannot access health services or treatment” – Migrant woman living with HIV

“My country criminalises homosexuality. I have a boyfriend who I love, but we cannot be open, we have to live our lives in secret. Living with HIV is hard and we get no information about how to protect ourselves. The treatment centre is not friendly to us. I go to a support group, but the other members are very homophobic and I cannot be open about who I really am.” – Gay man living with HIV

“I got HIV from using drugs. The local health centre won't treat people like me, police attack us and I have been to jail five times ... now I have nowhere to live.” – Man who injects drugs and is living with HIV

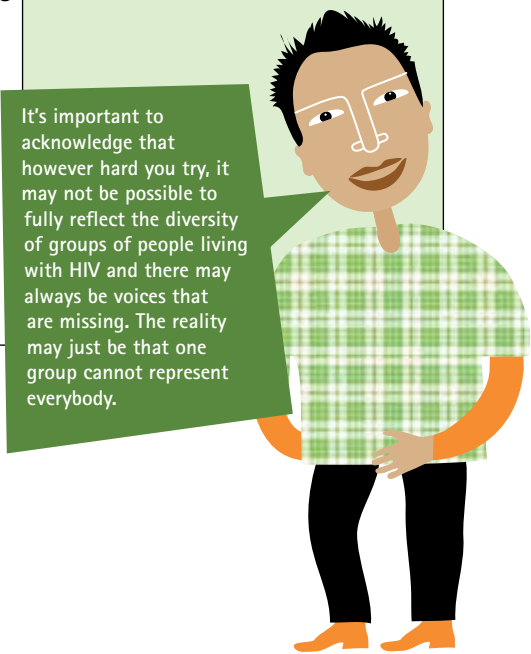
The table below helps to explain some of the barriers to participation experienced by people from different populations that can affect the representation of people living with HIV. It also highlights approaches and strategies to overcoming these barriers. Many of these approaches and strategies are similar, although the barriers may not be.

POPULATION	KEY BARRIERS TO PARTICIPATION	STRATEGIES
<p>Children (aged 14 and younger)</p>	<ul style="list-style-type: none"> ■ Lack of recognition of decision-making power and self-determination ■ Requirements for parental consent and reliance on adults ■ Lack of child-friendly services ■ Voices not valued by adults ■ Hours they are available ■ Ability to travel on their own; paternalistic attitudes ■ Child protection policies and legislation 	<p>Increase your awareness and understanding of the realities of the key population(s) you want to work with and the barriers they face to realising their rights.</p> <p>Be aware of your own values and beliefs and how they help or harm your ability to work with key populations. Work to overcome your own prejudices.</p>
<p>Young people ¹² (15–30 years old)</p>	<ul style="list-style-type: none"> ■ Age minimums on accessing services; parental consent excludes those considered minors ■ Ageism and lack of capacity among service providers to communicate with young people ■ Economic exclusion ■ Lack of relevant ‘youth-friendly’ services and information ■ Lack of recognition of decision-making power and self-determination; requirements for parental consent and reliance on adults ■ Not often available during daytime ■ Lack of relevant services ■ Voices not valued by adults ■ Child protection policies and legislation for minors 	<p>Recognise and acknowledge power and disparities between staff and key populations throughout all aspects of partnership development, participation and collaboration.</p> <p>Analyse and reduce access barriers in your organisation’s policies and practices, such as parental consent and identification requirements.</p> <p>Make sure that your work hours coincide with the availability of those you want to engage (for example, if you want young people to become involved, do not hold a meeting during school hours).</p>
<p>Women</p>	<ul style="list-style-type: none"> ■ Gender inequity ■ Lack of recognition of self-determination in many cultures ■ Cultural norms and traditions that position women as inferior to men ■ Gender-based violence 	<p>Continually advocate for the voices of diverse key populations to be included in decision-making on governance bodies such as boards and committees.</p>

12. Definitions of ‘young people’ vary around the world. UNFPA and UNICEF define young people as those aged between 15 and 24 years old. For global youth networks and organisations of young people living with HIV, young people are usually defined as aged between 15 and 30 years old. In many sub-Saharan African and southern Asian countries, young people are defined beyond the age of 30 and in some cases up to 35.

POPULATION	KEY BARRIERS TO PARTICIPATION	STRATEGIES
Women (continued)	<ul style="list-style-type: none"> ■ Economic exclusion ■ Responsibilities at home ■ Lack of childcare support 	<p>Go where those you want to reach are. Do not wait for them to come to your organisation. Technologies like Facebook, blogs, Twitter and Skype could be used as targeted communication strategies for recruiting people.</p> <p>Identify one or two more confident members and learn from them the safest way to reach their peers; for example, by word of mouth.</p> <p>Encourage people to come to see you privately if they want to learn more. This enables stigmatised people to link up with your organisation but not have to disclose their status at meetings and risk stigma or violence.</p> <p>Think about the different identities we all possess. We all select which identity to express and keep others hidden. It is the task of an organisation to find ways to enable people to keep a stigmatising identity hidden if they wish but still be involved in discussion and decision-making and get the support they need.</p> <p>Ensure appropriate compensation for time. Provide food at meetings.</p> <p>Make sure that your organisation has comprehensive confidentiality policies in place and that they are communicated to all and enforced.</p>
Heterosexual men	<ul style="list-style-type: none"> ■ Cultural norms and traditions that position men as strong, powerful, self-sufficient and dominant over women ■ No targeted services; often left out of interventions and ignored 	
Gay men and other men who have sex with men	<ul style="list-style-type: none"> ■ Homophobia ■ Social marginalisation affects ability to be open about sexuality ■ Punitive laws criminalising homosexuality; violence ■ Lack of experienced health professionals to support needs 	
Transgendered people	<ul style="list-style-type: none"> ■ Social and economic marginalisation; poverty ■ Cultural and social gender norms that do not recognise transgendered identities; punitive laws criminalising “homosexuality”; gender-based violence ■ Limited employment opportunities ■ Isolation ■ Lack of experienced health professionals to support needs 	
People who use drugs	<ul style="list-style-type: none"> ■ Stigmatisation due to drug use ■ Social and economic marginalisation; poverty ■ Punitive laws criminalising drug use ■ Lack of harm reduction services ■ Unease in formal settings ■ Limited employment opportunities ■ Lack of experienced health professionals to support needs 	

POPULATION	KEY BARRIERS TO PARTICIPATION	STRATEGIES
Migrants	<ul style="list-style-type: none"> ■ Lack of citizenship or registration can act as barriers to accessing services ■ Isolation ■ Language barriers ■ Unease in formal settings ■ Limited employment opportunities ■ Punitive laws and fear of deportation for those who are not legally migrating 	<p>Stigma and discrimination and lack of support mean that there may not be local groups in communities run by key populations such as people who use drugs, gay men or men who have sex with men, or sex workers.</p>
Sex workers	<ul style="list-style-type: none"> ■ Stigmatisation and discrimination due to social and cultural norms ■ Violence ■ Lack of relevant services ■ Isolation ■ Punitive laws criminalising sex work ■ Unease in formal settings 	<p>There are regional or international groups run by these key populations. Getting connected to these organisations may help you identify more strategies and also leaders who may be able to connect you to people in your community.</p> <p>Global Network of Sex Work Projects: www.nswp.org</p>
Currently and formerly incarcerated people	<ul style="list-style-type: none"> ■ Limited access to services, including healthcare, HIV prevention technologies and harm reduction services ■ Not physically able to participate externally ■ Limited employment opportunities ■ Violence 	<p>Global Youth Coalition on HIV/AIDS: www.youthaidscoalition.org</p> <p>Global Forum on MSM & HIV: www.msngf.org</p> <p>International Harm Reduction Association: www.ihra.net</p>
Indigenous peoples	<ul style="list-style-type: none"> ■ Historical and present-day experiences of colonisation and racism ■ Systemic poverty ■ Inter-generational trauma associated with loss of territories and traditional culture ■ Distrust of institutions ■ Lack of cultural safety in mainstream health and social service agencies 	<p>It's important to acknowledge that however hard you try, it may not be possible to fully reflect the diversity of groups of people living with HIV and there may always be voices that are missing. The reality may just be that one group cannot represent everybody.</p>



In many communities, women living with HIV are not well served or represented. This can mean that the unique issues faced by women living with HIV are excluded from policy and programming development initiatives. One step you can take to change this is to develop partnerships with organisations of women living with HIV.



KEY MESSAGE

Monitoring the implementation of the GIPA principle will make sure that successes are demonstrated and replicated. Tracking the involvement of people living with HIV can help measure the impact that people living with HIV have on the response and can monitor those responsible for implementing the GIPA principle.

KEY RESOURCES



Use these resources to plan for the involvement of diverse populations:

International HIV/AIDS Alliance, '*Code of good practice for NGOs responding to HIV/AIDS: key populations self-assessment tool*'. Available at: www.hivcode.org/silo/files/final-key-populations-.pdf

International HIV/AIDS Alliance, Canadian HIV/AIDS Legal Network, Open Society Institute, International Network of People who Use Drugs (2008), '*Nothing about us without us: greater, meaningful involvement of people who use illegal drugs*'. Available at: www.aidsalliance.org/publicationsdetails.aspx?id=310

International HIV/AIDS Alliance, '*Children's participation in HIV/AIDS programming*'. Available at: www.aidsalliance.org/includes/Publication/ovcnl02_childrens_participation.pdf

Shookner, M., Population Health Research Unit, Dalhousie University (2002), '*An inclusion lens: workbook for looking at social and economic exclusion and inclusion*'. Population and Public Health Branch, Atlantic Regional Office, Health Canada. Available at: www.phac-aspc.gc.ca/canada/regions/atlantic/pdf/inclusion_lens-E.pdf

International HIV/AIDS Alliance (2010), '*Alliance good practice guide on HIV and drug use*'. Available at: www.aidsalliance.org/Publicationsdetails.aspx?Id=454

Monitoring your work on GIPA

Putting the GIPA principle into practice can have a great impact. You can help build the evidence base for involving people living with HIV by monitoring and evaluating your work. Evaluating how you apply the GIPA principle in your work also ensures that you are responsive, accountable and rigorous.


Civil society groups, organisations and governments are now developing GIPA indicators to evaluate effectively the implementation and practice of meaningfully involving people living with HIV. The Alliance GIPA Good Practice Standards in Appendix 3 are an example of GIPA indicators. We recommend that organisations adopt these standards and make them relevant to their context. This will help you monitor your work and progress on implementing the GIPA principle and make sure that organisations are following a similar quality standard of GIPA practice.

To help you develop your own GIPA indicators and evaluate your work, here are some key questions to continually ask yourself:

- Is our work supporting people living with HIV?
- If so, what is the quality of that work? Has it been respectful? Has it been responsive?

- Has our work been in close coordination with networks or organisations of people living with HIV?
- Do our programmes reflect the priorities and issues of people living with HIV as articulated by people living with HIV?

One key resource for monitoring the application of the GIPA principle is the GIPA Report Card, an advocacy tool developed by GNP+. This gathers information about how countries are applying the GIPA principle at national level. The GIPA Report Card is a tool that holds governments, NGOs, United Nations agencies, donors, organisations of people living with HIV and other stakeholders accountable to their commitments to the GIPA principle. It also increases and improves the meaningful participation of people living with HIV within the broader national response. To learn more about the GIPA Report Card see: www.gnpplus.net/programmes/empowerment/gipa-report-card.


KEY RESOURCE

Use the Alliance GIPA Good Practice Standards in Appendix 3 to help you develop GIPA indicators for your organisation.



GIPA IN PRACTICE: NATIONAL GUIDELINES AND INDICATORS FOR MONITORING GIPA

National GIPA guidelines in Kenya

Kenya is one of a few countries that have national GIPA guidelines. These include indicators for government, civil society, the private sector and people living with HIV to support the implementation of meaningful involvement of people living with HIV across the country's response.¹³ The Kenya National AIDS Strategic Plan 2005/2010 (KNASP) aims to fully operationalise the GIPA principle throughout the strategy. The process of implementing the GIPA principle and translating policies into action is being spearheaded by the National AIDS Control Council (NACC), which has developed guidelines for different stakeholders engaged in the national HIV response. There is a representative from the National Empowerment Network of People Living with HIV/AIDS in Kenya (NEPHAK) on the NACC.

The guidelines are intended to increase and improve the meaningful participation of people living with HIV by all actors in Kenya's national response, including government, civil society, faith communities, networks of people living with HIV, and the private sector. The Kenyan guidelines for civil society include:

- Mainstream HIV within organisations, including the development and implementation of specific HIV workplace policies that incorporate the GIPA principle
- Create procedures for implementing GIPA at all levels in the workplace, including recruitment of skilled people living with HIV to boards and senior management positions
- Commit and devote financial resources to organisational development, including leadership, management and governance, and capacity-building for people living with HIV, organisations and networks.

13. Summarised from NEPHAK and GNP+, Kenya GIPA Report Card, December 2009.

3

How to involve people living with HIV in your organisation

In this chapter:

- What is an organisational commitment?
- Creating an enabling organisational environment for involving people living with HIV
- GIPA in organisational governance
- GIPA in human resource management
- Getting partners ready for involving people living with HIV

Good practice programming standards:



STANDARD 2



STANDARD 3

Whether your organisation has lots of experience involving people living with HIV or you are just starting out, this chapter will help you to establish or review your institutional commitment to meaningfully involve people living with HIV. This is to make sure that the meaningful participation of people living with HIV is sustainable in your organisation.



We have a person living with HIV on our board; we have done our work on GIPA.

This is a common misconception, Sam. GIPA all depends on leadership and can be practiced at all levels of organisations. To ensure accountability it is important to refresh the organisation's understanding of implementing the GIPA principle.



What is an organisational commitment?

Effectively implementing the GIPA principle at the programme level will work best when the entire organisation is committed to involving people living with HIV. An organisational commitment can take different forms, such as:

- including the involvement of people living with HIV as a measurable goal in your strategic plan or work plan
- creating a plan to implement and mainstream the GIPA principle in your organisation
- hiring a staff person who is dedicated to the involvement of people living with HIV
- working in a participatory way with beneficiary populations.

KEY MESSAGE

These practical steps can help you to involve people living with HIV in your organisation:¹⁴

- Secure a commitment across the whole organisation.
- Critically assess how people living with HIV are currently involved in your organisation and how supportive your organisational environment is for people living with HIV.
- Identify strategies for enhancing your organisation's ability to engage and sustain the participation of people living with HIV.
- Create a GIPA action plan that includes the next steps for your organisation.

14. Adapted from: Asia Pacific Network of People Living with HIV/AIDS (APN+) and the Asia-Pacific Council of AIDS Service Organisations (APCASO) (2005), 'Valued voices: GIPA toolkit: a manual for the greater involvement of people living with HIV', Module 3: Analyzing your organisations and making a GIPA plan.



STRATEGIES FOR DEVELOPING AND SUSTAINING A COMMITMENT TO GIPA

Some strategies to develop and sustain your organisation's commitment to the GIPA principle include:

- Ask an organisation of people living with HIV to conduct a GIPA commitment workshop with senior management and the board of directors to establish a common vision and organisational commitment to the GIPA principle.
- Be reflective in your work. Start by being honest about what involvement people living with HIV currently have in your organisation and move forward with realistic and measurable goals.
- Develop a GIPA mainstreaming policy or programme. Make sure that women living with HIV and key populations living with HIV have equal opportunities to be meaningfully involved in all areas of the organisation. Use this guide and the *Code of Good Practice for NGOs Responding to HIV/AIDS* (www.hivcode.org) as guidance for your GIPA policy and/or programme development.
- Use ongoing monitoring and evaluation, consultation with partners and continual feedback and advice from people living with HIV to track your progress towards your commitment.
- Actively involve a diverse group of people living with HIV in developing, implementing and assessing your organisational commitment. Consider asking your country or regional organisation of people living with HIV to help your organisation with these strategies.



GIPA IN PRACTICE

Organisational leadership leads to involvement of women living with HIV at the World YWCA

Every four years the World YWCA holds a World Council where women come together from around the world and develop strategic directions for the organisation. The 26th World Council was held in July 2007 in Nairobi, Kenya, with the focus on women's leadership in HIV. Dr Musimbi Kanyoro, the general secretary of the organisation, has had a strong commitment to HIV and had been addressing the epidemic since the 1990s.

For every World Council meeting, YWCA country organisations are financially supported to bring three delegates. But for the Nairobi meeting, Dr Musimbi Kanyoro decided that organisations would be supported only if they brought a young woman living with HIV. "There were lots of ripple effects – many partnerships developed between positive women, positive women's networks and the YWCA," says Sophie Dilmitis, World YWCA HIV coordinator. "But what we did realise afterwards is that if it is not sustained from a leadership level, this kind of meaningful involvement could fall away. Once GIPA is working you still need to maintain the political will."

Learn more here: www.worldywca.org

Creating an enabling organisational environment for involving people living with HIV

Your organisational environment plays a key role in your ability to successfully engage and sustain the meaningful participation of people living with HIV. You may have barriers to involvement that are not obvious to those people who are not living with HIV.

The chart below highlights elements that create an enabling environment.

WHAT IS NEEDED	WHY IT IS NEEDED	RESULTS WHEN IT IS THERE	RESULT WHEN IT IS NOT THERE
Organisational commitment	Without commitment, none of the other pieces can be in place	Meaningful participation will flourish in various creative ways and become part of the organisation's culture	Poorly resourced efforts for participation, tokenism and lack of credible and relevant programmes and services
Resources and financial support	To ensure work is valued and people are appropriately compensated, and to overcome barriers to participation, such as expenses related to childcare and transportation	Meaningful participation is financed and resourced, therefore fully supported and sustainable	Poorly resourced efforts for participation will not be meaningful, thoughtful or planned effectively
Supporting all your staff and building knowledge of and sensitisation to HIV	To ensure all staff are supported to challenge their attitudes and build their knowledge of HIV and working with people living with HIV	Safe work environments that are free of stigma and discrimination are created and sustained	Stigma and discrimination may exist in the workplace, staff may have limited knowledge of people living with HIV and may act in discriminatory ways
Recognition of competencies as well as credentials	To ensure that life experience is valued and that programmes reflect the realities of people's lives. People living with HIV are seen as partners, not just as clients	A wide range of expertise and knowledge informs programmes; barriers to participation of those without credentials are reduced	Programmes lack relevancy for target audience; the organisation is not able to reach those who are most vulnerable

WHAT IS NEEDED	WHY IT IS NEEDED	RESULTS WHEN IT IS THERE	RESULT WHEN IT IS NOT THERE
Training and skills building	To ensure people living with HIV have relevant skills to enable effective participation	People living with HIV feel comfortable and confident to participate	People may be tokenised, not heard and devalued
Supportive HIV workplace policies to enable participation (including sick leave, work day length, etc.)	Policies help create an enabling environment and provide guidance on good practice	An enabling environment is institutionalised in policy and barriers to participation are removed	People living with HIV are not truly supported to participate; people living with HIV do not seek employment at the organisation. People living with HIV who do seek employment feel devalued, disengaged and may leave
Expectations and limitations are communicated, including clear roles and responsibilities	To ensure mutual understanding is created and everyone understands expectations, limits and constraints	Everyone understands his or her role and can be effective in that role	People do not understand their roles and purpose; confusion and increased conflict can occur
Psychosocial support, including peer support	Living with HIV can be stressful and contribute to depression, fear of the future and anxiety. People living with HIV have experienced discrimination and stigma	Meaningful participation is sustainable and the burnout of people living with HIV can be reduced	Burnout can increase; turnover will increase



STRATEGY: KEY STEPS

Key steps to assess and prepare your organisation for the involvement of people living with HIV

1. Engage the people in your organisation who champion the GIPA principle, or those who are willing to work in a participatory way with people living with HIV or who have done so in the past. Establishing a GIPA working group can help to prepare your organisation for involving people living with HIV.
2. Assess your organisation to identify its current strengths and weaknesses and what is needed to involve people living with HIV meaningfully and successfully. Seek the advice of a diverse group of people living with HIV when doing an organisational assessment and ask them for practical advice and guidance. For example, if your organisation is planning to work with young people living with HIV, have a group of young people living with HIV do a walk-through assessment of your office and ask them what they like or do not like about the space and what changes would make the place more welcoming to young people.
3. Establish organisational values, practices and policies that provide a solid foundation for involving people living with HIV. Participation works best in environments that are open, inclusive, non-judgemental, respectful of diversity, and value various types of competencies and skills. Take practical steps to make people living with HIV feel comfortable in your organisation's work environment, such as those provided in this chapter.
4. Communicate GIPA policies, programmes, successes and ongoing benefits within your organisation and externally to partners. Ensure your organisation's HIV workplace policy is implemented and communicated throughout the organisation.
5. Reflect on your work and continually get feedback from people living with HIV and partners. These five steps should be continually renewed and practiced within your organisation to ensure that your work is relevant and that the experiences of people living with HIV guide your work.



KEY RESOURCES

The following resources were developed by people living with HIV to help organisations assess their readiness to engage with people living with HIV in a meaningful way:

Gray, G. and Chong, S. (2005), '*Valued voices: GIPA toolkit: a manual for the greater involvement of people living with HIV*', module 3: analyzing your organisations and making a GIPA plan, Asia Pacific Network of People Living with HIV/AIDS and the Asia-Pacific Council of AIDS Service Organisations. Available at: www.gnpplus.net/cms-downloads/files/2005%20Valued%20Voices%20-%20A%20GIPA%20Toolkit.pdf

Global Network of People Living with HIV/AIDS (GNP+) and the Asia Pacific Network of People Living with HIV/AIDS (APN+), '*Code of good practice for NGOs responding to HIV/AIDS. Self-assessment checklist: meaningful involvement of PLHIV and affected communities (MIPA)*'. Available at: www.hivcode.org/silo/files/final-mipa-.pdf

International HIV/AIDS Alliance in India (2006), '*Enhancing the greater involvement of people living with HIV (GIPA) in NGOs/ CBOs in India*'. Available at: www.aidsalliance.org/publicationsdetails.aspx?id=227

Organisations should develop policies to involve people living with HIV meaningfully in governance, policy and decision-making structures in your organisation. Policies should include setting minimum targets for participation of appropriately qualified and experienced people living with HIV.



GIPA in organisational governance

One of the most common ways that organisations currently practice the GIPA principle is by having one or more designated seats for people living with HIV, or, a representative from an organisation of people living with HIV, on their governance committee or board. This can ensure that your organisation is continually informed by the voices of people living with HIV.

As representatives on governance structures, people living with HIV are often asked to take on a lot of work for no financial compensation. This limits the amount of time and resources they can devote to their role if they must also do other work to support themselves. As a programme officer, these are issues that you may have no control over. But you can at least create opportunities for people living with HIV who are representatives to reflect critically on the challenges and limitations of their role. Momentum and leadership cannot be sustained unless there is space for engaging those who are not as involved and those who are newly engaged.



STRATEGIES FOR ACTIVE AND MEANINGFUL INVOLVEMENT IN GOVERNANCE BODIES

Representatives of people living with HIV need to be supported and their participation needs to be more than tokenistic. All board members, regardless of HIV status, should be subject to the same key principles. The following is a list of effective governance procedures:

- Provide comprehensive board orientation and training that clearly communicates expectations, responsibilities and required tasks.
- Encourage representatives to do a capacity self-assessment and address areas for personal development.
- Allow for the mentoring of new representatives by more experienced board members.
- Reimburse or cover expenses for food, internet, board, travel and childcare.
- Include more than one representative living with HIV to avoid tokenism and elitism, and to ensure diverse perspectives, mentoring and ongoing capacity development.
- Ensure that decision-making is democratic and that all representatives are encouraged to share their point of view.
- Provide board members with sensitivity training that includes the importance of the GIPA principle.
- Ensure that the workload for volunteers is realistic and respectful of its volunteer position.



STRATEGIES FOR ACTIVE AND MEANINGFUL INVOLVEMENT IN GOVERNANCE BODIES (CONTINUED)

- Ensure that language considerations are supported and that representatives who do not speak the primary language of the board or committee are able to participate through translation.
- Select representatives who demonstrate that they have some form of constituency that they can draw upon and encourage them to be honest and open about the limitations of their representation.
- Create a policy that involves limits on the length of service of representative positions in order to balance perspectives and ensure inclusiveness and accountability.
- Recognise that not all representatives have the capacity and resources to communicate with their constituencies. Be open and honest about the limitations of representatives and provide support when necessary. If needed, provide representatives with staff resources to support them in reporting to their constituencies on an ongoing basis.



GIPA IN PRACTICE

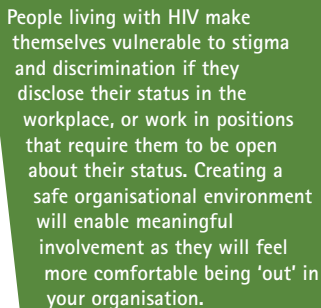
A policy to ensure the capacity development of younger representatives

The International Community of Women Living with HIV/AIDS (ICW) mandates that 50% of their Global Steering Committee is made up of women under 29 years old. All committee members must be living with HIV. This makes sure that the organisation is institutionally mentoring young women living with HIV, who are provided leadership skills and capacity development through their participation on the committee. This also helps to avoid 'founder's syndrome', where those who have been involved for a long time do not give up their role to others.



KEY MESSAGE

People living with HIV have a wide range of skills and competencies. Recognising potential over credentials is one of the keys to achieving the meaningful involvement of people living with HIV as staff in your organisation.



People living with HIV make themselves vulnerable to stigma and discrimination if they disclose their status in the workplace, or work in positions that require them to be open about their status. Creating a safe organisational environment will enable meaningful involvement as they will feel more comfortable being 'out' in your organisation.



GIPA in human resource management

Hiring people living with HIV as managers, programme officers, peer educators, consultants, and technical advisors is one way to practise the GIPA principle. An HIV in the workplace policy can help to:¹⁵

- create a safe and supportive environment by making sure that the rights of people living with HIV are respected and protected in your organisation
- eliminate stigma and discrimination in the workplace on the basis of real or perceived HIV status, or vulnerability to HIV infection
- manage and mitigate the impact of HIV on the work of the organisation.



STRATEGIES TO ENABLE A SUPPORTIVE ENVIRONMENT

Organisations and staff need to take a number of issues into consideration to create a supportive workplace for involving people living with HIV. These include:

Create supportive recruitment and promotion policies and procedures

Organisations should develop and implement human resource policies that support the meaningful involvement of people living with HIV at all levels of the organisation. This includes:

- ensuring hiring processes actively recruit and are explicitly targeted at diverse groups of people living with HIV
- ensuring that hiring processes are not biased towards those with formal education. Recognising other types of experience and skills, such as leadership potential, volunteer training, community-based training, and volunteer and community-based experience, will help to ensure people living with HIV without formal education are not systematically excluded from job opportunities.

Support the health and well-being of staff living with HIV

Ensuring that staff living with HIV are supported to take care of their health will ensure that an environment is created where meaningful involvement is achieved. This is called 'reasonable accommodation'. It means that your organisation understands that there will be times when staff living with health conditions are not able to perform their duties and that they will not be penalised for this.

15. Adapted from: Asia Pacific Network of People Living with HIV/AIDS (APN+) and the Asia-Pacific Council of AIDS Service Organisations (APCASO) (2005), 'Valued voices: GIPA toolkit: a manual for the greater involvement of people living with HIV'.



STRATEGIES (CONTINUED)

'Reasonable accommodation' for people living with HIV includes:

- ensuring extra support for their health and well-being, such as consideration for regular sick days, doctor visits and accommodation for hospital stays. Medical appointments may take a few hours or they may take a few days depending on your geographical location
- ensuring staff living with HIV have access to medical benefits, including access to antiretroviral treatment, if they are not available locally
- ensuring the provision of psychosocial support such as counselling and time off when needed. This is one way to mitigate burnout and make sure that staff are adequately supported. Such considerations should be given not only to those living with HIV but to all staff with health conditions.

Ensure awareness of the complexities of disclosure and develop policies to safeguard confidentiality

Staff living with HIV should not be required to disclose their HIV status to everyone they work with or to the public. They should not be told that, 'no visibility equals no involvement'.¹⁶ A person's HIV status is their personal information. It is not appropriate to share their HIV status without their consent. Staff must also be provided with information to make informed decisions and understand the consequences of whether to share their status. This includes:

- making sure that managers are sensitised to the issues of working with staff living with HIV so that they can provide appropriate managerial support
- ensuring that people living with HIV are supported to feel comfortable to disclose their status by having confidentiality policies in place. This is one way to support disclosure and protect the right to confidentiality of people living with HIV
- ensuring that those who are involved are aware of the consequences of disclosure and are comfortable enough with their HIV status to be open. This is the key to making sure that the benefits of involvement are realised. It is important to recognise the transformative potential for people, organisations and communities of having people involved who are open about living with HIV in the workplace. This can help to challenge misconceptions and reduce HIV-related stigma, but can also come at a social cost to those who are open.

16. Adapted from: Asia Pacific Network of People Living with HIV/AIDS (APN+) and the Asia-Pacific Council of AIDS Service Organisations (APCASO) (2005), 'Valued voices: GIPA toolkit: a manual for the greater involvement of people living with HIV'.



KEY RESOURCES

These resources include excellent practical guidance on developing an organisational HIV workplace policy:

UK Consortium on AIDS and International Development (2003), '*Working positively: a guide for NGOs managing HIV/AIDS in the workplace*'. Available at: www.aidsportal.org/store/551.pdf

STOP AIDS NOW! (2009), '*Addressing HIV and AIDS in the workplace: lessons learnt from civil society organisations and donors*'. Available at: www.stopaidsnow.org/documents/WPP_LessonsLearnt_July09.pdf

International HIV/AIDS Alliance (2004), '*Developing workplace medical benefits policies to support staff with HIV: draft summary*'. Available at: www.aidsalliance.org/includes/Publication/csd1203_Medical_benefits.pdf



The valuable experience of staff living with HIV: Anandi Yuvraj – a woman living with HIV and former Alliance India programme officer

“At the programme officer level in 2002 I was the only person living openly with HIV in the Alliance in India. The staff had an open view and really accepted me. Other programme officers had credentials, project management experience or degrees in social work, which I didn’t. But my understanding of health and HIV issues was often much better than the rest of my colleagues. My analysis of the programmes and critical analysis of statistics was better as I knew the real life experiences. I could see there was value for me to be there.

“They found my inputs very helpful, and they created space for me to take leadership. This included having me lead strategic information discussions at national level and represent the organisation externally. It was a win-win situation. I got benefits and developed my leadership, and for the organisation it was a great way of promoting the Alliance, building credibility and promoting the organisation’s community principles.”

HIV-positive staff in the United Nations – UN Plus and living with HIV in the workplace

UN Plus is the United Nations system-wide advocacy group of staff living with HIV. It was established in 2005 and seeks to create an enabling environment for all HIV-positive staff members of the United Nations. UN Plus works to challenge stigma and discrimination and also works on the development of and improvement of existing policies on HIV and AIDS at United Nations agencies. UN Plus also provides support and advice for HIV in the workplace-related issues to United Nations staff and external partners.

UN Plus regularly meets with United Nations Secretary General Ban Ki-Moon to raise awareness about the issues faced by people living with HIV who work as employees. UN Plus members have very real concerns about stigma towards those living with HIV.

For more on UN Plus go to: www.unplus.org

Organisational internships for people living with HIV

As part of the World YWCA and ICW’s longstanding partnership, there was an internship programme and both organisations had a swap arrangement on interns. An intern living with HIV would go to the World YWCA head office for a year and a YCWA intern from a developing country would go to ICW’s international support office for a year. This process sensitised staff and built personal and organisational capacity. The Alliance has also instituted an internship programme for people living with HIV. The internship is a paid position for a six-month term. It is hosted in the international secretariat and provides training opportunities, mentoring and support. This initiative supports the ongoing personal and professional development of people living with HIV.

Getting partners ready for involving people living with HIV

Many programmes work in partnership with other organisations. It is possible that your partners may not see involving people living with HIV as a priority or they may have a limited understanding of how to facilitate meaningful involvement. Sharing your practices, experiences, and lessons learned can help other organisations understand the importance of the GIPA principle and strengthen their capacity to practise GIPA.



STRATEGIES FOR BUILDING SUPPORT FOR PEOPLE LIVING WITH HIV

- Include information about your GIPA policies in your organisation's newsletter, annual report or in a flyer.
- Make sure that a qualified staff member, board director or volunteer living with HIV represents your organisation externally at events with partners.
- If you are a funding organisation, before providing grants ask that your recipients have HIV workplace policies, dedicated governance positions for people living with HIV and hiring policies that favour people living with HIV.
- Conduct GIPA workshops at partnering organisations in collaboration with people living with HIV.

4 Strategies for building the capacity of people living with HIV

In this chapter:

- How does capacity-building support people living with HIV to participate actively and meaningfully?
- Strategies for building capacity among people living with HIV and organisations of people living with HIV

Good practice programming standards:



STANDARD 2



STANDARD 3

In order to practise the GIPA principle effectively, people living with HIV must not only be present but be able to participate actively and meaningfully. This chapter outlines ideas and strategies that will strengthen the capacity of people living with HIV, including volunteers and staff, to make appropriate and relevant contributions.



An enabling organisational environment is an important foundation for building and supporting the capacity of people living with HIV. There is more about this in chapter 3.



The first step to capacity building is recognising the capacities that people living with HIV already have.

How does capacity-building support people living with HIV to participate actively and meaningfully?

It can be difficult for people living with HIV to be equal partners with programme staff and other representatives on governance structures and in programmes. For example, many people living with HIV are from key populations who may be marginalised in society and may have limited education or work experiences. Also, organisations of people living with HIV are often under-resourced and may have limited capacity to participate in partnerships.

To make sure that the participation of people living with HIV is meaningful and does not result in tokenism, individuals and organisations of people living with HIV need to be supported to develop their capacity to participate effectively. Capacity development also helps to make sure that leadership in the HIV response is sustainable and that skills are shared across communities rather than held by a select few. Capacity-building is important to sustain leadership in the response to HIV.

Capacity refers to skills and knowledge as well as opportunities and resources. Some capacities that need to be developed include:

- knowledge about how NGOs work, such as aspects of funding, programme design, planning, implementation, monitoring and evaluation
- information about health, HIV and antiretroviral treatment
- understanding of government systems, advocacy and campaigning.

KEY MESSAGE

Capacity-building means that people living with HIV are provided with opportunities and all the technical information they need to deal effectively with issues affecting their lives and the lives of those they represent.

Strategies for building capacity among people living with HIV and organisations of people living with HIV

Building capacity begins from the moment you start to involve people living with HIV and continues throughout the programme cycle. To be most effective, it should happen at a number of levels, from personal capacity to organisational and community capacity.

Building capacity is a two-way process in which everyone is both a learner and a teacher.



Step 1: Understand what capacities support active participation in your programmes and organisation

It is important to understand and know what capacities need to be supported and developed for people living with HIV and organisations of people living with HIV to participate in your programmes and organisation. Conduct a capacity analysis by answering the following questions:

- What competencies do different people need in order to carry out their tasks well or to support the programme?
- What competencies do they already have? What competencies are lacking?
- What strategies can we use to build competencies now and regularly throughout the programme?

Step 2: Recognising and building on existing assets

All people, communities and organisations have assets. Capacity-building works best when the assets of individuals, communities and organisations are recognised, understood and mobilised.

Individual assets include knowledge, experience, skills, relationships and connections. The assets of people living with HIV may include first-hand knowledge of the key issues underlying HIV epidemics; passion and commitment; knowledge of social networks and support systems of those living with HIV; and skills needed for mobilising communities to respond to HIV.

Community and organisational assets include networks and associations, experience, funding, institutions and partnerships. The assets of organisations of people living with HIV may include advocacy and mobilisation experience; partnerships with government ministries, support groups and peer support networks; treatment expertise; experienced spokespeople; and credibility with their constituencies.

Use the table on the next page to map individual and community assets to better understand the skills that already exist among participating populations:

LEVEL	TYPES OF ASSETS	ASSESSMENT QUESTIONS
Individual	<ul style="list-style-type: none"> ■ Knowledge ■ Experience ■ Skills ■ Relationships and connections 	<ul style="list-style-type: none"> ■ What things do you know a lot about? ■ What things are you good at doing? ■ What things do you care deeply about? ■ What existing connections, partnerships and networks are you part of?
Community and organisation	<ul style="list-style-type: none"> ■ Networks and associations ■ Experience ■ Funding ■ Institutions ■ Partnerships 	<ul style="list-style-type: none"> ■ What are the values of your organisation? ■ What existing networks and partnerships is the organisation part of?

Step 3: Practical ways to build capacity

Capacity-building can be hard work and takes time and investment. Planning for capacity-building in your organisation and programmes ahead of time will help to minimise any burden. People learn in different ways. Some will learn by ‘doing’, while others may need more structured learning activities. Developing learning activities for new and ongoing participants will allow people living with HIV to develop and apply their knowledge in your programmes. Often when someone is first involved in an organisation or programme there is initial training or orientation. Training should always be followed by ongoing monitoring, support and supervision. Here are some ideas on how to build capacity. But, do not feel overwhelmed if you do not do all of these.

- Develop or enrol people living with HIV in relevant training and curriculum-based learning programmes.
- Open up all your organisational training to members of organisations of people living with HIV.
- Ensure ongoing orientation and training for volunteers living with HIV.
- Develop an internship programme for people living with HIV in your organisation and other opportunities to build skills through learning ‘on the job’.
- Develop a staff or internship swap programme with an organisation of people living with HIV.
- Provide operational support to programmes of organisations of people living with HIV.
- Make space for staff and volunteers living with HIV to represent your organisation externally with partners.
- Put capable people living with HIV in leadership positions, including as facilitators of meetings, workshops and events.



KEY RESOURCES

Gray, G. and Chong, S. (2005), '*Valued voices: GIPA toolkit: a manual for the greater involvement of people living with HIV*', module 3.3: developing PLHWA capacity and network, Asia Pacific Network of People Living with HIV/AIDS and the Asia-Pacific Council of AIDS Service Organisations. Available at: www.gnppplus.net/cms-downloads/files/2005%20Valued%20Voices%20-%20A%20GIPA%20Toolkit.pdf

Asset-Based Community Development Institute (2005), '*Discovering community power: a guide to mobilizing local assets and your organization's capacity*'. Available at: www.abcdinstitute.org/docs/kelloggabcd.pdf

International HIV/AIDS Alliance (2004), '*NGO capacity analysis: A toolkit for assessing and building capacities for high quality responses to HIV/AIDS*'. Available at: www.aidsalliance.org/includes/Publication/cat0704_Capacity_analysis_toolkit_eng.pdf

International HIV/AIDS Alliance (2003), '*Developing HIV/AIDS work with drug users: a guide to participatory assessment and response*'. Available at: www.aidsalliance.org/includes/Publication/idu0803_idu_guide.pdf

- Make sure that there is always more than one person living with HIV, and all members of the network's coordination council are HIV-positive.
- Invest in organisations of people living with HIV, including those that represent people living with HIV from key populations. This can happen through financial support, partnership development, collaborative projects, staff secondments and training and mentorship support.
- Support people living with HIV to participate in country, regional and international conferences.
- Establish links with other organisations for training, mentoring and internships.



GIPA IN PRACTICE: BUILDING CAPACITY THROUGH INVESTMENT IN PEOPLE AND ORGANISATIONS

Building capacity to address stigma and discrimination in the Philippines

The People Living with HIV Stigma Index is a research initiative that is measuring and detecting changing trends relating to stigma and discrimination experienced by people living with HIV. It is a tool that was conceptualised and is driven by people living with HIV as the primary project implementers and researchers. In 2008 the regional training for researchers took place in Bangkok. Lumier, one of the training participants, went on to work on implementing the stigma index in the Philippines. Lumier is 22 years old and living with HIV. "I've learnt a lot; before we started the interviewing we were all trained. I gained knowledge and skills. I learnt the importance of confidentiality and how to be an effective interviewer. Learning to interview people gave me a sense of professionalism."

The benefits of the index for those conducting it go further than collecting much-needed evidence. Lumier says, "It made me more aware of my rights and how to lessen stigma and discrimination among people living with HIV". The process of personal development of people living with HIV, their networks and communities is crucial for the stigma index, which is aiming to become a catalyst for change in the communities in which it is used.

Learn more about the stigma index: www.stigmaindex.org

Building capacity through investment: the changing role of the All-Ukrainian Network of People Living with HIV/AIDS

The All-Ukrainian Network of People Living with HIV/AIDS was founded in 1999 by HIV-positive activists, who joined to protect



GIPA IN PRACTICE: BUILDING CAPACITY THROUGH INVESTMENT IN PEOPLE AND ORGANISATIONS (CONT.)

their legal rights, lobby access to treatment, and improve quality of life of HIV-positive people in Ukraine. In 2000 the Network received a multimillion grant from the Global Fund to Fight AIDS, Tuberculosis and Malaria and has gone on to implement it successfully. The network is an organisation governed by people living with HIV, and all members of the network's coordination council are HIV-positive.

The network has successfully developed from an initial group of HIV-positive people to become a powerful organisation of activists and professionals that is represented in all 25 regions of Ukraine and unites over 500 HIV-positive activists in more than 100 cities in Ukraine. The organisation has found certain stages of its development challenging; for example, becoming the Global Fund Principal Recipient in Ukraine with ambitious commitments was very demanding for a community organisation of people living with HIV. The network continues to do everything it can to secure resources to ensure full access to treatment, care and support for people living with HIV.

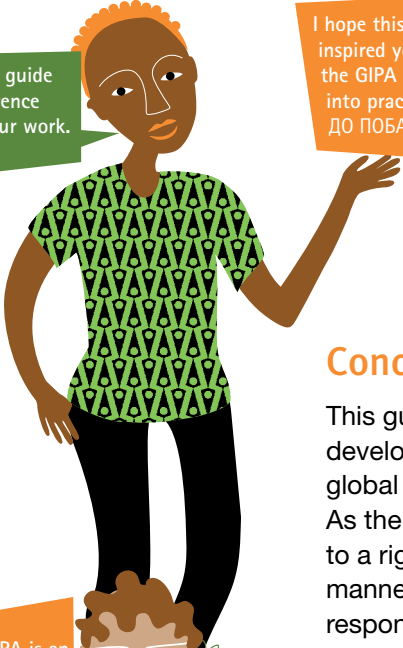
Learn more about the network: www.network.org.ua

Leadership through Accountability programme in Zambia


The Leadership through Accountability programme has been systematically working to invest in and build the capacity of organisations of people living with HIV in the global South. Over five years and in 15 countries, GNP+ and the World AIDS Campaign have been supporting country-level organisations of people living with HIV to strengthen evidence-based advocacy, policy, programming and participation in national processes.

In Zambia, the programme is driven by the Network of Zambian People Living with HIV/AIDS (NZP+), which is implementing a number of projects. Kenly Sikwese, the Zambian Leadership through Accountability programme coordinator, acknowledges the value of capacity-building for people living with HIV and the success of their activities. "We empower people through skills-building, through the various activities of the programmes, and provide them with the freedom to use their skills and creativity. It is not just about allowing people living with HIV a voice; it is about enabling them to use their skills and expertise," says Kenly.

Find out more about the Leadership through Accountability programme: www.gnpplus.net/programmes/empowerment/hiv-leadership-through-accountability



Keep this guide as a reference for all your work. Kawheri!




I hope this guide has inspired you to put the GIPA principle into practice. ДО ПОБАЧЕННЯ!

Check out all the great resources listed in the guide for more information to strengthen your GIPA work. 再见

Conclusion

This guide is for programme officers and other people who develop or deliver HIV programmes globally, and especially in the global South, to support their efforts to practise the GIPA principle. As the guide has outlined, the GIPA principle is a commitment to a rights-based approach and to working in a participatory manner with people living with HIV in all aspects of the HIV response. The commitment to the GIPA principle is highlighted in numerous international declarations and guidelines. Implementing the principle in your work may be challenging at times, but it is important to remember that practising GIPA is a journey. You may not be able to accomplish everything in this guide. But through the process of meaningfully involving people living with HIV in your work, you will learn to be creative in promoting the GIPA principle.



Practising GIPA is an ongoing rewarding, learning experience. Keep up the great work! Good bye.



Adiós!

The guide recognises that people living with HIV have been leaders in the response to HIV and are vital partners in strengthening community systems and achieving universal access to HIV prevention, treatment, care and support. Involving people living with HIV throughout the programme cycle makes sure that your programmes are responsive, relevant and sustainable. But doing this work requires commitment, planning and dedicated resources. You can continually enhance your ability to practise GIPA by using the tools provided to assess critically how people living with HIV are currently engaged in your organisation, and identify strategies to enhance your organisation's ability to engage and sustain the participation of diverse groups of people living with HIV.

People living with HIV have a wide range of skills and competencies. This guide has illustrated how to recognise competencies and also how to build the capacity of people living with HIV. This means that they are provided with opportunities and the technical information they need to deal effectively with the issues affecting their lives and the lives of those they represent.

We hope this guide has been helpful and we hope that you use it as an ongoing reference in your work when designing, implementing, evaluating and monitoring programmes.

Appendix 1:

Glossary

Advocacy: a process aimed at changing the attitudes, policies, laws and practices of influential individuals, groups and institutions for the betterment of people affected by the issue.

Community: a group of people linked and interacting in some way; for example, by location (living in a village), kinship (family and tribe), occupation (peer educators) or by having a common problem (HIV). People may belong to several different communities at any one stage of their lives.

Culture: culture describes what we learn, think, feel and do as individuals and what our society considers important. Our culture reflects our history and is based on our social, economic and environmental situation. It is learned from our family and society, which provide us with guidelines on how to behave as men and women, how to raise children and how to live. Messages from different sources also influence our culture. All societies change to take account of new knowledge and situations. We can belong to many different sub-cultures.

Development: the process and mission aimed at raising the standards of living and quality of life of people around the world.

Discrimination: discrimination is when, in the absence of objective justification, a distinction is made against a person that results in them being treated unfairly or unjustly on the basis of belonging, or being perceived to belong, to a particular group.

Evaluation: the periodic assessment of the relevance, performance, efficiency, results and impact of work in relation to its stated objectives.

Gender: the socially constructed roles, behaviours, activities and attributes that a society considers appropriate for men and women. It dictates the status of men and women and who has more power. Gender varies from place to place and can change over time and between generations.

Human rights: the universal legal guarantees for all human beings, set out in international standards, protecting human dignity and fundamental freedoms and privileges. Human rights cannot be waived or taken away.

Impact: the longer-term effects produced by a development intervention, directly or indirectly. For example, it may refer to a rise or fall in incidence and/or prevalence of HIV.

Indicators: the markers used to measure the results of an intervention, project or programme.

Key populations: populations that may be at a higher risk of acquiring HIV because of increased vulnerability. For example, where same sex practice is illegal, men who have sex with men have limited access to information or services on safer sex. The involvement of key populations is vital to the response to these problems.

Monitoring: the systematic and continuous assessment of the progress of an activity or programme over time, which checks that things are going to plan and enables us to make adjustments in a well-thought-out way.

Outcomes: the results of an intervention. Outcomes may include increased service coverage and use or behavioural changes.

Participation and participatory approaches: the active involvement of people affected by a problem, together with those who are concerned about it, in assessing, planning, implementing and evaluating programmes. They help to empower marginalised groups within the wider society. They also contribute to projects tailored to local needs and resources, and a sense of ownership that increases their chance of success.

Poverty: the condition of lacking basic human needs. These include lack of access to food, water, nutrition, healthcare and clothing. The World Bank defines extreme poverty as a person subsisting on less than US\$1 a day.

Programme: an overarching national or sub-national systematic response to a health problem. It may include a number of projects and interventions.

Programme cycle: the stages that a project goes through while it is active. The cycle includes assessment, planning, implementation, monitoring, evaluation and adjustment and/or scaling up.

Project: a particular endeavour with a beginning and an end. It is aimed at achieving specific measurable objectives that are part of an overall programme objective.

Public health: aims to address the factors that make people vulnerable to poor health and prioritises approaches that help to improve the health of communities as well as individuals. Public health research provides evidence on which interventions work so that we can plan our programmes based on science rather than opinion.

Sensitisation: efforts to change attitudes within a society by providing information designed to increase people's understanding of a problem.

Stakeholders: the groups and individuals with an interest in an organisation and/or project. They include those who will be affected by a project, work on it and fund it.

Stigma: the identification that a social group creates of a person (or group of people) based on a physical, behavioural or social trait perceived as diverging from group norms.

Strategy: a planned and systematic approach to responding to a particular need.

Appendix 2: References and consulted documents

- African Network of Religious Leaders Living with or Personally Affected by HIV and AIDS** (2005), 'Positive voices: religious leaders living with or personally affected by HIV and AIDS', ANERELA+.
- Asia Pacific Network of People Living with HIV** (2004), 'APN+ position paper 2: GIPA', Bangkok: APN+.
- Asia Pacific Network of People Living with HIV/AIDS and the Asia-Pacific Council of AIDS Service Organisations** (2005), 'Valued voices. GIPA toolkit: a manual for the greater involvement of people living with HIV'.
- Cain, R. and Roy, C.M.** (2001), 'The involvement of people living with HIV/AIDS in community-based organizations: contributions and constraints', *AIDS Care*, 13(4): 421–432.
- Chandran, S.** (2004), 'Common ground: the greater involvement of people living with HIV/AIDS in India', Policy Project, Futures Group International.
- The Global Fund to Fight AIDS, Tuberculosis and Malaria (GFFATM) and International HIV/AIDS Alliance (Alliance)** (2008), 'Civil society success on the ground. Community systems strengthening and dualtrack financing: nine illustrative case studies', GFFATM/Alliance.
- Global Network of People Living with HIV** (2005), 'Challenging, changing, and mobilizing: a guide to PLHIV involvement in Country Coordinating Mechanisms', Amsterdam: GNP+.
- Global Network of People Living with HIV** (2009), 'GIPA report card: final pilot report for India, Kenya, Lesotho and Trinidad and Tobago', Amsterdam: GNP+.
- Global Network of People Living with HIV** (2005), 'Revitalising the global movement of people living with HIV', Think Tank meeting, Nairobi, Kenya, 28–30 November.
- de Goei, T. and Groverman, V.** (2009), 'A world to involve: report of the exploratory study on the GIPA principle', STOP AIDS NOW!
- International Community of Women Living with HIV/AIDS** (2005), 'Participation tree', ICW, www.icwglobal.org/files_en/7f9ded7059973f9cf357103cc5c13342icw_poster.jpg
- International HIV/AIDS Alliance** (2009), 'Expanding the role of networks of people living with HIV/AIDS in Uganda', Alliance.
- International HIV/AIDS Alliance in India** (2006), 'Enhancing the greater involvement of people living with HIV (GIPA) in NGOs/CBOs in India', Alliance.
- Odiambo, D. and Lawson, P.** (2007), 'Guidelines for mainstreaming GIPA into the national HIV response in Kenya', National AIDS Control Council.
- Stephens, D.** (2004), 'Out of the shadows: greater involvement of people living with HIV/AIDS (GIPA) in policy', policy working paper series No. 14, Policy Project, USAID.
- The Joint United Nations Programme on HIV/AIDS** (1999), 'From principle to practice: greater involvement of people living with or affected by HIV/AIDS (GIPA)', Geneva: UNAIDS.
- The Joint United Nations Programme on HIV/AIDS** (2007), 'Policy brief: the greater involvement of people living with HIV (GIPA)', Geneva: UNAIDS.
- The Joint United Nations Programme on HIV/AIDS (2004)**, 'Position paper: the greater involvement of people living with or affected by HIV/AIDS (GIPA)', Geneva: UNAIDS.
- UNDP** (2004), 'From involvement to empowerment: people living with HIV in Asia Pacific', UNDP.
- USAID** (2009), 'Rising to the challenge: health policy initiative helps HIV-positive teachers tackle stigma and discrimination in Kenya', USAID.



Appendix 3

Alliance good practice HIV programming standards – GIPA

What are good practice programming standards?

Programme standards define quality and good practice. The standards also define our approach to HIV programming and conducting research. They define what users or beneficiaries of our programmes can expect.

At the intervention level, we refer to tools that define good practice for specific intervention types.


These programme standards do not define reach and scope. Targets for reach and scope are set by people closer to the specific programmes, according to local epidemiology and context.


Why develop programming standards?


- To define and promote good practice in community-based HIV programming. Definitions of good practice and quality are based on evidence and programme learning, and are shaped by the Alliance's values.
- To support assessment and evaluation of programme quality.
- To influence programme design.
- To build an evidence base for quality programming.
- To shape the provision of technical support provided through the Alliance's Technical Support Hubs.

Who is involved?

- Alliance Linking Organisations and their implementing partners (community- and faith-based organisations), and Alliance's Technical Support Hubs, their users and beneficiaries, will use programming standards to design, implement and evaluate HIV programmes.
- Users or beneficiaries of Alliance services and programmes can use programming standards to understand what our programmes are for, and to help evaluate Alliance programmes.
- Alliance programme officers and programme managers will use programming standards to assess, design and evaluate programmes (using a self-assessment tool).
- Alliance resource mobilisation staff will use programming standards to develop high quality proposals.
- Funders of Alliance programmes have an interest in programming standards. Alliance standards illustrate that our programmes are shaped by a culture of quality and good practice, are informed by evidence, and are monitored and evaluated according to a set of standards.
- Other civil society organisations are interested in quality standards for their community level programmes. Alliance programming standards can influence and guide good programming in other civil society organisations.


STANDARD	DESCRIPTION	IMPLEMENTATION ACTIONS	MARKERS OF PROGRESS
<p>A standard is an agreed-upon level or benchmark of quality. It is measurable and evidence-based</p> <p>STANDARD 1</p>  <p>Our organisation is committed to ensure equal and full participation of all stakeholders, especially potential programme beneficiaries, at all stages of the programme cycle</p>	<p>Explanation of the standard and evidence</p> <ul style="list-style-type: none"> ■ Participation is not simply understood as a tool to better implement programmes, but as a mechanism to foster community mobilisation that will result in advocacy for the full realisation of the right to health and other related human rights. ■ Our organisation includes all relevant populations in the initial planning of programming and advocacy activities, especially those populations that programmes are directed at. ■ There is commitment within our organisation to understand the diversity within specific population groups, such as within groups of people living with HIV and key populations, with varying needs, experiences and expertise. For example, it is acknowledged that women living with HIV may need different programmes than men who live with HIV, or rural women living with HIV may have different perspectives on advocacy issues than urban women living with HIV. ■ We provide a safe space and respectful environment for diverse groups to participate at each stage of the programme cycle. 	<p>Suggestions for actions to implement the standard</p> <ul style="list-style-type: none"> ■ Develop strategies for the meaningful involvement of target populations at all stages of the project cycle. ■ Develop policies and governing rules that ensure confidentiality and privacy in all aspects of the organisation's work. ■ Develop or support networks and build links with organisations which represent key populations and people living with HIV. 	<ul style="list-style-type: none"> ■ Our organisation has documented strategies in place to ensure the meaningful participation of all stakeholders, with special emphasis on those populations that are intended to benefit from programmes. ■ Memoranda of Understanding have been signed with organisations representing specific sub-populations to ensure cross-fertilisation of programme planning and implementation. ■ Minutes of meetings with stakeholder groups at all stages of the programme cycle are kept and shared with these groups. ■ Our organisation has a workplace policy that ensures confidentiality, privacy and meaningful engagement of people living with HIV and key populations. ■ Programme objectives reflect involvement of key populations in planning, implementation and evaluation of all projects.
<p style="text-align: center;">MATERIALS AND RESOURCES</p> <ul style="list-style-type: none"> ■ International HIV/AIDS Alliance, Canadian HIV/AIDS Legal Network, OSI, International Network of People who Use Drugs (2008), <i>'Nothing about us without us: greater, meaningful involvement of people who use illegal drugs'</i>. Available at: www.aidsalliance.org/Publicationsdetails.aspx?id=310 			

STANDARD	DESCRIPTION	IMPLEMENTATION ACTIONS	MARKERS OF PROGRESS
<p>STANDARD 2</p>  <p>Our organisation is committed to the effective implementation of the GIPA principle throughout all areas of our organisation</p>	<ul style="list-style-type: none"> ■ GIPA is good practice, is a commitment, and is a way of working. GIPA calls for the active and meaningful participation of people living with HIV in the inception, development, implementation, monitoring and evaluation of policies and programmes across all aspects of the HIV response including prevention, treatment, care and support. ■ GIPA aims to ensure that people living with HIV are equal partners and decision-makers in the HIV response. ■ Effective implementation of the GIPA principle improves the credibility, relevance, acceptability and effectiveness of our programmes. ■ We acknowledge the importance of applying GIPA in all areas of our organisation's structure. This commitment cascades down from the governance level to programme design, implementation and evaluation. ■ The full and meaningful engagement of people living with HIV has a direct positive impact on public health. For example, involving women living with HIV in the development of programmes for pregnant women helps to create services that are welcoming and sensitive to the issues faced by women living with HIV and that are based on their needs. This then results in greater uptake of services and the improved health of mothers and children who are living with HIV. [See UNAIDS Policy Brief: <i>The Greater Involvement of People Living with HIV (GIPA)</i>] 	<ul style="list-style-type: none"> ■ Assess organisational policy and practice for GIPA to ascertain current practice, using an approach that acknowledges the specific needs, expertise and experiences of people living with HIV as a diverse group. This assessment includes measuring current levels of involvement and opportunities for people living with HIV to participate meaningfully in the governance, policy and decision-making of the organisation, and includes people living with HIV participating at all stages of the project cycle. ■ Undertake a GIPA commitment workshop to establish the vision and commitment to GIPA, defined with people living with HIV. ■ Develop a GIPA programme and/ or policy, which is: defined with people living with HIV; that ensures women living with HIV and key populations living with HIV are provided with equal opportunities to be involved; is based on the Alliance <i>Good Practice Guide on GIPA</i> and the <i>NGO Code of Good Practice</i>. 	<ul style="list-style-type: none"> ■ An organisational GIPA assessment, including an assessment of government structures, has been carried out and is documented. ■ A vision of and commitment to GIPA has been established by leaders of our organisation. ■ A GIPA policy with a corresponding implementation strategy has been developed, published and disseminated which includes minimum targets for participation of appropriately qualified and experienced people living with HIV in governance, policy and decision-making bodies and at the level of programme implementation. ■ GIPA principles are integrated in strategic plans, annual plans and workplans, including performance appraisal plans. ■ Monitoring and evaluation reports highlight successes and challenges on GIPA, and next steps to address challenges. ■ Documentation of the increased involvement of appropriately qualified and experienced people living with HIV in governance, policy and decision-making structures exists.

STANDARD	DESCRIPTION	IMPLEMENTATION ACTIONS	MARKERS OF PROGRESS
<p>STANDARD 2</p> 		<ul style="list-style-type: none"> ■ Develop a strategy to meaningfully involve appropriately qualified and experienced people living with HIV in governance, policy and decision-making structures, based on the findings of the assessment. ■ Develop a capacity-building programme for people living with HIV to strengthen their capacity to participate in governance, policy and decision-making structures, and to be involved at the programme planning and implementation level. ■ Establish monitoring and evaluation structures to ensure implementation of GIPA, defined with people living with HIV. 	<ul style="list-style-type: none"> ■ The capacity of people living with HIV to participate has been assessed and meaningfully documented. ■ A GIPA capacity-building programme has been established which is funded, promoted and implemented. Minimum targets have been set for the number of people living with HIV who will be trained to strengthen involvement at governance level and at the level of programme planning and implementation. ■ Programme plans demonstrate participation of people living with HIV. ■ Participation of people living with HIV is documented and measured, along with successful programme and public health outcomes resulting from the meaningful implementation of GIPA, as part of the organisation's monitoring and evaluation activities.

MATERIALS AND RESOURCES

- Gray, G. and Chong, S. (2005), '*Valued voices: GIPA toolkit: a manual for the greater involvement of people living with HIV*', Asia Pacific Network of People Living with HIV/AIDS and the Asia-Pacific Council of AIDS Service Organisations. Available at: www.gnpplus.net/cms-downloads/files/2005%20Valued%20Voices%20-%20A%20GIPA%20Toolkit.pdf
- Canadian AIDS Society, '*One foot forward: a GIPA training toolkit*'. Available at: www.cdnaids.ca/web/casmisc.nsf/cl/cas-gen-0169
- Code of good practice for NGOs responding to HIV/AIDS. Available at: www.hivcode.org
- International Community of Women Living with HIV/AIDS (2008), '*The greater involvement of people living with HIV/AIDS: from principle to practice?*', Participatory learning and action series no.58, June. Available at: www.icw.org/files/PLA58_ch11_low.pdf
- International HIV/AIDS Alliance (2007), '*Impact 2010: strategic framework 2008 to 2010*'. Available at: www.aidsalliance.org/Publicationsdetails.aspx?Id=282
- International HIV/AIDS Alliance (2009), '*Expanding the role of networks of people living with HIV/AIDS in Uganda*'. Available at: www.aidsalliance.org/publicationsdetails.aspx?id=414
- International HIV/AIDS Alliance/Horizons (2003), '*The involvement of people living with HIV/AIDS in community-based prevention, care and support programs in developing countries*'. Available at: www.aidsalliance.org/publicationsdetails.aspx?id=132
- International HIV/AIDS Alliance/Canadian HIV/AIDS Legal Network/OSI/International Network of People Who Use Drugs (2008), '*Nothing about us without us: greater, meaningful Involvement of people who use illegal drugs: a public health, ethical, and human rights imperative*'. Available at: www.aidsalliance.org/Publicationsdetails.aspx?Id=310
- International HIV/AIDS Alliance in India (2006), '*Enhancing the greater involvement of people living with HIV (GIPA) in NGOs/CBOs in India*'. Available at: www.aidsalliance.org/publicationsdetails.aspx?id=227
- Global Network of People Living with HIV (GNP+), '*GIPA report card*'. Available at: www.gnpplus.net/programmes/empowerment/gipa-report-card
- The Ontario HIV Treatment Network (2007), '*Living and serving II: 10 years later – the involvement of people living with HIV/AIDS in the community AIDS movement in Ontario*'. Available at: www.health.gov.on.ca/english/providers/pub/aids/reports/living_serving_ii_report_april07.pdf
- The People Living with HIV Stigma Index. Available at: www.stigmaindex.org

STANDARD	DESCRIPTION	IMPLEMENTATION ACTIONS	MARKERS OF PROGRESS
<p>STANDARD 3</p>  <p>Our programmes promote and/or provide an enabling and protected environment to facilitate the participation of people living with HIV</p>	<ul style="list-style-type: none"> ■ We acknowledge that the meaningful involvement of people living with HIV must take place within an enabling and protected environment. This means promoting access to our programmes by overcoming barriers, along with providing protection against stigma and discrimination related to HIV, sex and sexuality, gender and drug use. ■ We demonstrate a commitment to the value of involving people living with HIV by creating a supportive workplace in which people living with HIV are supported and protected from discrimination. 	<ul style="list-style-type: none"> ■ Assess employment, recruitment and retention policies to measure how enabling the workplace environment is for people living with HIV and to identify barriers and/or opportunities for participation. This assessment pays particular attention to the need for capacity building; financial remuneration; mentoring; childcare; and ensuring involvement of women and key populations. ■ Develop a recruitment, employment and retention policy to allow for the meaningful involvement of people living with HIV and key populations at all levels of the organisation, paying particular attention to opportunities for people living with HIV and key populations to be recruited for specific projects. 	<ul style="list-style-type: none"> ■ An assessment of employment, recruitment and retention policies has been undertaken and documented. ■ A minimum target has been set for the number of people living with HIV working at different levels within the organisation and for retaining people living with HIV within it. ■ A documented HIV in the workplace policy has been developed that addresses recruitment, employment, benefits, development, retention and support for/of staff living with HIV. ■ HIV in the workplace policy is implemented and communicated throughout the organisation.

MATERIALS AND RESOURCES

- Gray, G. and Chong, S. (2005), *‘Valued voices: GIPA toolkit: a manual for the greater involvement of people living with HIV’*, Asia Pacific Network of People Living with HIV/AIDS and the Asia-Pacific Council of AIDS Service Organisations. Available at: www.gnpplus.net/cms-downloads/files/2005%20Valued%20Voices%20-%20A%20GIPA%20Toolkit.pdf
- International Labour Organization (2005), *‘ILO code of practice on HIV/AIDS and the world of work’*. Available in five languages at: www.ilo.org/global/What_we_do/Publications/lang--en/docName--KD00015/index.htm
- Stop AIDS Now!, *‘Managing HIV and AIDS in the workplace’*. Available at: www.stopaidsnow.org/documents/WPP_LessonsLearnt_July09.pdf



A global partnership:
International HIV/AIDS Alliance
Supporting community action on AIDS in developing countries

GOOD PRACTICE GUIDE

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Established in 1993, the **International HIV/AIDS Alliance** (the Alliance) is a global alliance of nationally-based organisations working to support community action on AIDS in developing countries. To date we have provided support to organisations from more than 40 developing countries for over 3,000 projects, reaching some of the poorest and most vulnerable communities with HIV prevention, care and support, and improved access to HIV treatment.

The Alliance's national members help local community groups and other NGOs to take action on HIV, and are supported by technical expertise, policy work, knowledge sharing and fundraising carried out across the Alliance. In addition, the Alliance has extensive regional programmes, representative offices in the USA and Brussels, and works on a range of international activities such as support for South-South cooperation, operations research, training and good practice programme development, as well as policy analysis and advocacy.

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GNP+ is the global network for and by people living with HIV. GNP+ advocates to improve the quality of life of people living with HIV. As a network of networks, GNP+ is driven by the needs of people living with HIV worldwide. Based on emancipation and self-determination, GNP+ works with independent and autonomous regional and national networks of people living with HIV in all continents. Under the central theme **Reclaiming Our Lives!**, GNP+ implements an evidence-informed advocacy programme focused on: empowerment; human rights; positive health, dignity and prevention; and sexual and reproductive health and rights of people living with HIV. For the most up to date results and achievements, please visit:

www.gnpplus.net