

GIYPA GUIDEBOOK



**SUPPORTING
ORGANISATIONS AND
NETWORKS TO SCALE
UP THE MEANINGFUL
INVOLVEMENT OF YOUNG
PEOPLE LIVING WITH HIV**

The Global Network of People Living with HIV (GNP+)

GNP+ is the global network for and by people living with HIV, and 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.

The experience and the range of programming and advocacy expertise that GNP+ offers enhances the Y+ Programme and creates a space where the needs of young people living with HIV (YPLHIV) are incorporated into the broader agenda of the PLHIV community.

For the most up to date information, results and achievements, please visit: www.gnpplus.net

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The Y+ Programme is also pleased to be associated and collaborating with the following agencies, organisations and initiatives: HIV Young Leaders Fund, IPPF, UNAIDS Inter Agency Task-Team on HIV and Young People, UNAIDS, UNESCO, UNICEF and WHO.

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ACRONYMS

| | |
|---------------------|---|
| GIPA | greater involvement of people living with HIV |
| GIYPA | greater involvement of young people living with HIV |
| GNP+ | Global Network of People Living with HIV |
| PHDP | Positive Health, Dignity and Prevention |
| PLHIV | people living with HIV |
| SRH | sexual and reproductive health |
| UNAIDS | Joint United Nations Programme on HIV/AIDS |
| YPLHIV | young people living with HIV |
| Y+ Programme | Young People Living with HIV Programme of GNP+ |

INTRODUCTION

A FEW WORDS ABOUT GIYPA

GIPA – the greater involvement of people living with HIV – is internationally recognised as critical to the success of HIV responses. GIPA cannot be achieved without the active and meaningful participation of young people living with HIV – what we call GIYPA or the ‘greater involvement of young people living with HIV.’

Increasingly, young people represent a high proportion of those who are at risk of HIV, and who are most affected by the epidemic. They also represent a large proportion of people living with HIV (PLHIV). In fact, there are over 12 million people under the age of 24 who are living with HIV. Most of these young people living with HIV (YPLHIV) are aged 15 to 24 (more than 10 million of them), while the rest (2.3 million) are children under 15 years.¹

YPLHIV need space and support to participate in today’s HIV response, and to have their leadership potential nurtured so that they can continue working towards an effective response that protects the rights, meets the needs, and promotes the dignity of all people living with HIV. The Y+ Programme has prepared this guidebook to help youth-focused organisations, networks of PLHIV, networks of key populations², and others involved in HIV responses to scale up GIYPA.

DID YOU KNOW?

What is the Y+ Programme? The Young People Living with HIV Programme (Y+ Programme) is a GNP+ programme for and led by young people living with HIV (YPLHIV). The Global Network of People Living with HIV (GNP+) has established the Y+ Programme to address specific gaps in the HIV response and address the specific needs of young people living with HIV (aged 15–30).

For more information, please consult: www.gnpplus.net/en/programmes/empowerment/young-people-living-with-hiv

This guidebook is informed by the responses from over 300 YPLHIV and almost 175 organisations who participated in our 2010 global survey on GIYPA. It also draws on existing tools that support organisations to practice GIPA and to involve youth. These resources are listed at the end of this document.

DID YOU KNOW?

Between November 2010 and January 2011, the Y+ Programme undertook an exploratory study to better understand the current scope of involvement of YPLHIV in HIV responses around the world and how to increase their meaningful involvement. Over 300 YPLHIV aged 15 to 30 years and almost 175 organisations (including PLHIV networks, key population networks, youth-led organisations, and youth-serving organisations) responded to our online surveys. To the best of our knowledge, this is the first study on the involvement of YPLHIV in the HIV response. The study was able to attract a large sample of YPLHIV compared to many other studies – largely due to the involvement of six YPLHIV from around the world on the research team.

The study and these tools were developed with support from the HIV Young Leaders Fund. Learn more at: www.hivyoungleadersfund.org.

1. UNAIDS, UNICEF, WHO (2007). *Children and AIDS: A Stocktaking Report*. Available at: www.unicef.org/publications/files/ChildrenanAIDSASstocktakingLoResPDF_EN_USLetter_15012007.pdf

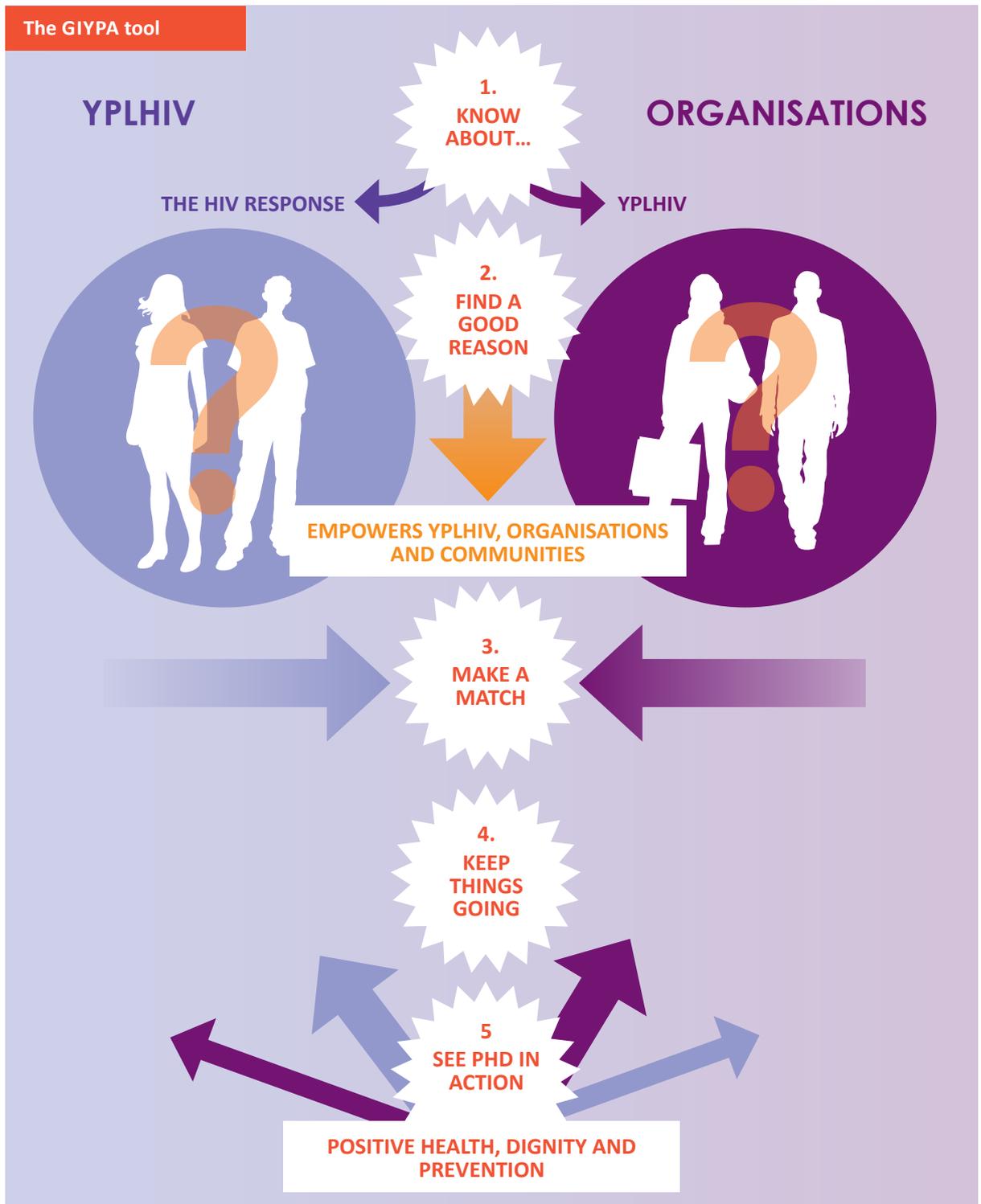
2. ‘Key populations’ is a term often used to describe groups that are most heavily affected by the HIV epidemic. It usually refers to women, young people, men who have sex with men, sex workers, people who inject drugs, prisoners and migrants.

HOW THIS GUIDEBOOK IS ORGANISED

Each chapter in this guidebook outlines one of the five steps to scaling up and sustaining the involvement of YPLHIV in organisations:

1. Understanding what is meant by 'meaningful involvement'
2. Finding good reasons to involve youth living with HIV
3. Linking youth and organisations together
4. Sustaining and growing youth involvement
5. Seeing *Positive Health, Dignity and Prevention* in action

The guidebook provides practical information, tips and tools that can be used by experienced practitioners as well as those who are new to this area to strengthen their capacity to facilitate the meaningful involvement and leadership of YPLHIV.



In the appendices, there is a self-assessment tool to help organisations assess their current readiness for involving YPLHIV and to identify their priorities for strengthening their capacity. There is also a list of resources that you can consult for further information, strategies, and activities to help you meaningfully engage YPLHIV. Many of the ideas discussed in this guidebook are described in more detail in those resources.

Throughout the guidebook, you will notice that there are different text boxes, providing additional information. These text boxes are explained below.

DID YOU KNOW?

Provides additional background information that helps to explain some of the main content of the document.

SOMETHING TO THINK ABOUT!

Poses some critical questions that you can ask yourself or your organisation.

YOUTH SPEAK OUT!

Lets you hear directly from young people living with HIV through quotes from our study.

GIYPA IN ACTION!

Provides concrete examples of how GIYPA has been realised by other organisations and young people from around the world.

WHAT WE LEARNED!

Highlights some of the findings from our global study that illustrate some of the main content of the document.

TIP!



Provides some practical suggestions on scaling up GIYPA.

Both YPLHIV and organisations have a role in seeing GIYPA realised. The Y+ Programme has prepared a companion guidebook to support YPLHIV to do their part, called *GIYPA Roadmap: Supporting Young People Living with HIV to be Meaningfully Involved in the HIV Response*. This document is available in the Y+ section of the GNP+ website: www.gnpplus.net/en/programmes/empowerment/young-people-living-with-hiv

A FEW WORDS ABOUT POSITIVE HEALTH, DIGNITY AND PREVENTION

Positive Health, Dignity and Prevention (PHDP) recognises and encompasses the full range of health and social justice issues for people living with HIV. From the perspective of people living with HIV, *Positive Health, Dignity and Prevention* involves the following: a supportive legal and policy environment; focusing on holistic health promotion, not only on transmission prevention; tailored to setting, key populations, and to the individual; and, defined by people living with HIV.

PHDP espouses the fundamental principles that responsibility for HIV prevention should be shared, and that policies and programmes for people living with HIV should be designed and implemented with the meaningful involvement of people living with HIV.

Obviously, that means that for policies and programming to be responsive to the needs and realities of young people, they should be designed and implemented with the meaningful involvement of YPLHIV. This guidebook provides a tool to support GIYPA – which is a critical element in reaching the goals of PHDP.

By linking the social, health, and prevention needs of the individual living with HIV within a human-rights framework, PHDP results in a more efficient use of resources and ensures outcomes are not only more responsive to the needs of young people living with HIV, but also more beneficial for their partners, families and communities.

For more information on *Positive Health, Dignity and Prevention*, consult: www.gnpplus.net/en/programmes/positive-health-dignity-and-prevention/positive-health-dignity-and-prevention

1 UNDERSTANDING WHAT IS MEANT BY 'MEANINGFUL INVOLVEMENT'

Understanding is the first step towards any successful action. In the case of GIYPA, this means understanding what involvement is, why it is important and who YPLHIV are.

1.1 UNDERSTANDING 'PARTICIPATION'

Many words are used to describe the idea of participation: engagement, involvement, empowerment. To be meaningfully involved, people must not only be present but also have a say and a role in addressing issues that affect them personally and/or that they believe to be important. In other words, meaningful involvement is defined by people's level of participation and influence. It is achieved by addressing and eradicating the structural barriers which impede meaningful involvement and participation.

Meaningful involvement should benefit the people who are being engaged as well as the organisations that seek to engage them. Those who are engaged should have opportunities to gain knowledge, skills, authority and agency to take control of their lives and contribute to social changes that improve their lives.



Learn more about youth participation in *Inspire* – a resource pack on youth friendly programming and a free web-based resource – developed by the International Planned Parenthood Federation (IPPF). You can find it at: www.ippf.org/en/Resources/Guides-toolkits/Participate+The+voice+of+young+people+in+programmes+and+policies.htm



Simply having more YPLHIV in your organisation does not mean that you have achieved GIYPA. When it comes to involvement, quality is more important than quantity. Seek to engage only as many YPLHIV as your organisation has the capacity to meaningfully involve and adequately support.

1.2 UNDERSTANDING THE IMPORTANCE OF YPLHIV PARTICIPATION IN HIV RESPONSES

Key global documents recognise the need for young people and people living with HIV to take an active role in the HIV response. These include:

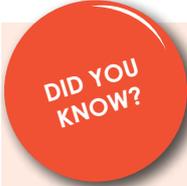
- >> *The Paris AIDS Declaration* (1994)³ – which includes the Principle of Greater Involvement of People Living with HIV (GIPA)
- >> *Declaration of Commitment on HIV/AIDS* (2001). United Nations General Assembly Special Session on HIV/AIDS⁴
- >> *A World Fit for Children* (2004). United Nations Special Session on Children⁵
- >> *Political Declaration on HIV/AIDS* (2006). United Nations High-Level Meeting⁶
- >> *NGO Code of Good Practice*⁷
- >> *Good Practice HIV Programming Standards* (2010). International HIV/AIDS Alliance⁸
- >> *Positive Health, Dignity and Prevention: A Policy Framework* (2011). Global Network of People Living with HIV and UNAIDS⁹
- >> *Political Declaration on HIV/AIDS* (2011). United Nations High-Level Meeting¹⁰

The 1989 *UN Convention of the Rights of the Child*¹¹ further supports the rights of adolescents – including those living with HIV – to participate in matters that affect their lives.



Learn more about GIPA – including what it is, its history and how to practise it – in the *GIPA Good Practice Guide*, a free web-based resource developed by GNP+ and the International HIV/AIDS Alliance. Look for the GIPA Tree, which illustrates the roots that nurture and sustain meaningfully involving of PLHIV, as well as the benefits to communities, organisations and PLHIV themselves.

You can find the guide at: www.gnpplus.net/resources/empowerment-of-people-living-with-hiv-a-their-networks/item/47-good-practice-guide



GNP+ and many other partners around the world now use the *Positive Health, Dignity and Prevention* framework to guide their work in the HIV response. PHDP was developed by GNP+ and UNAIDS through consultation with networks of people living with HIV, civil society, governments, UN co-sponsors and donors globally.

The primary goals of PHDP are to improve the dignity, quality and length of life of people living with HIV; which, if achieved will, in turn, have a beneficial impact on their partners, families, and communities, including reducing the likelihood of new infections. People living with HIV are seen as part of the solution, and their involvement and leadership as the foundation for success.

3. http://data.unaids.org/pub/ExternalDocument/2007/the-paris-declaration_en.pdf

4. www.unaids.org/en/media/unaids/contentassets/dataimport/publications/irc-pub03/aidsdeclaration_en.pdf

5. www.unicef.org/specialsession/wffc/index.html

6. www.unaids.org/en/aboutunaids/unitednationsdeclarationsandgoals/2006politicaldeclarationonhivaids

7. www.hivcode.org

8. <http://stepsinnepal.files.wordpress.com/2011/07/good-practice-standards.pdf>

9. www.gnpplus.net/en/resources/positive-health-dignity-and-prevention/item/109-positive-health-dignity-and-prevention-a-policy-framework

10. www.unaids.org/en/aboutunaids/unitednationsdeclarationsandgoals/2011highlevelmeetingonaids/

11. www.unicef.org/crc

Supporting YPLHIV to get involved in the HIV response is one way that GNP+ is putting PHDP into action. Learn more about PHDP at: www.gnpplus.net/en/resources/positive-health-dignity-and-prevention/item/109-positive-health-dignity-and-prevention-a-policy-framework

The Positive Health, Dignity and Prevention framework

PRINCIPLES

WE
*

WE ARE ALL RESPONSIBLE FOR HIV PREVENTION

WE WILL NOT BE TREATED AS VECTORS OF TRANSMISSION

WE HAVE NEEDS AND DESIRES TO BE FULLFILLED

WE ARE MORE THAN PATIENTS!

PROGRAMMATIC COMPONENTS

NEED
*

SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS

PREVENTION OF NEW INFECTIONS

EMPOWERMENT

SOCIAL AND ECONOMIC SUPPORT

GENDER EQUALITY

MEASURING IMPACT

HUMAN RIGHTS

HEALTH PROMOTION AND ACCESS

OUTCOME

**POSITIVE HEALTH,
DIGNITY AND PREVENTION**
*

1.3 UNDERSTANDING HIV-POSITIVE YOUNG PEOPLE

YPLHIV are a diverse group in terms of age, developmental stage, life experiences and social identities. While YPLHIV have some common needs and challenges, they often are united only by their HIV status.

YPLHIV include people who have been growing up with the virus since infancy as well as those who contracted HIV at a young age, either through drug use or sex. They may be students in secondary and post-secondary institutions, or may not attend school at all. They may work in the formal and informal sector, or be unemployed. They may live in stable countries or amidst a humanitarian crisis.

YPLHIV may be part of the general population in their country or belong to groups that face social and economic exclusion – such as sex workers, people who use drugs, men who have sex with men, transgender people, migrants, and indigenous people. In many countries, more young women than men are living with HIV due to biological, sociological, and cultural factors.

Many YPLHIV face stigma and discrimination on a daily basis. They may be discriminated against in schools, workplaces or community groups. They may be forced to drop out of school as a result of bullying, social exclusion or requests from parents of other students who fear the virus in their body. They might lose their jobs because their HIV status became known. They may be pressured by family members to keep their status secret – thinking that the young person will be safer if others do not know they are living with HIV; or they may have learned through past negative experiences to keep their status secret. They may be kicked out their home or rejected by family, friends, or romantic partners. Many YPLHIV do not have access to important health and social services needed to live healthy lives.

Whatever the context, YPLHIV are the experts on their own lives. GIYPA is a critical component of ensuring that policies and programming meet the needs and reflect the realities of young people living with HIV.

DID YOU KNOW?

Just as **'knowing your epidemic'** is important to design effective HIV responses, so too is it important to **'know your YPLHIV'** to effectively engage YPLHIV in your community. Here are some questions to help:

- >> Which groups of young people in your community are vulnerable to HIV?
- >> How are the YPLHIV in your community similar to older PLHIV? Different?
- >> How are the YPLHIV in your community similar to other young people? Different?
- >> How are the needs of YPLHIV similar to other PLHIV? Different?
- >> What is common among the different groups of YPLHIV in your community? What is different?

2 FINDING GOOD REASONS TO INVOLVE YOUNG PEOPLE LIVING WITH HIV

The YPLHIV and organisations involved in HIV responses who participated in our survey told us that being involved not only benefits those who are engaged but also benefits organisations and HIV responses.



2.1 GIYPA EMPOWERS YPLHIV TO LIVE POSITIVELY AND BUILDS A FOUNDATION FOR FULL PARTICIPATION IN SOCIETY

- >> **Healing and hope.** YPLHIV come to terms with their HIV diagnosis, see that there is life after HIV, and focus on their goals and desires.
- >> **Living positively.** Involvement supports YPLHIV to cope effectively with treatment adherence, to disclose their status, and to access to up-to-date information and services to take care of their health – all of which contribute to Positive Health, Dignity and Prevention.
- >> **Social networks and a sense of belonging.** YPLHIV have opportunities to meet new people, find mentors, make friends, and develop connections within the government, civil society and UN agencies. Supportive relationships and acceptance contribute to a sense of belonging.
- >> **Confidence and self-esteem.** YPLHIV gain an optimistic view of themselves and their abilities. The perspective gained from working with other people on HIV-related issues can strengthen young people’s self-awareness and empowerment, which can significantly reduce self-stigma.
- >> **Learning knowledge and skills.** YPLHIV have opportunities to gain transferable knowledge and skills in leadership, program management, and organisational management.
- >> **Employment and livelihood.** YPLHIV gain knowledge and skills they can use to get a job or start their own enterprise.

“I got to learn that I am not alone. I have learnt to live life to the fullest. That is life without worries, and I have managed to live positively despite the fact that I have HIV. I now know that the sky is the limit. Nothing can turn me down. I have to live till I achieve my goals in the future.”



SANDRINE MATAFFEU, CAMEROON

Treatment activist, dreamer, changemaker

Sandrine was a student when she found out she was living with HIV. Sandrine worried that her parents would feel disappointed in her for having contracted HIV after everything they had given to her. Determined to show her family that nothing was lost for her, Sandrine began volunteering with the national PLHIV network during her free time. When Sandrine finished her studies, the Central Africa Treatment Action Group hired her as their Executive Assistant. Being involved not only opened doors for Sandrine to do something she loves and earn a living, it also has provide her with opportunities to gain knowledge and skills and to see that she can have much bigger dreams for her future.

2.2. GIYPA PROVIDES ORGANISATIONS WITH ACCESS TO KNOWLEDGE, SKILLS AND CAPACITY TO BE MORE RESPONSIVE AND EFFECTIVE

- >> **New ideas, strategies, and programmes.** YPLHIV bring new ideas and strategies that can invigorate an organisation's work and lead to the development of innovative programmes that are evidence informed.
- >> **Relevant, accessible and high quality services.** YPLHIV can help organisations understand the needs and realities of their peers, and ensure that their services are relevant, accessible and high quality.
- >> **Connect with other young people.** YPLHIV can easily relate to other young people and encourage them to access programmes and services and to get involved.
- >> **Political influence.** YPLHIV can reach out to and influence decision-makers in ways that adult staff are unable to.
- >> **Human resources.** YPLHIV can help organisations reach large numbers of people.
- >> **Increased capacity to involve youth.** YPLHIV can help organisations strengthen their capacity to work with other youth, including YPLHIV.



GIYPA = Better programmes = Better HIV responses. GIYPA also helps organisations hold themselves accountable to the constituency that they are working with.

YOUTH
SPEAK
OUT!

“Involving young people living with HIV not only makes your organisation look sexier but also more effective. Young people have newer agendas... so you will get new projects and new ways of working as well.”

“Involvement yields hope after an HIV-positive diagnosis. It is a strong weapon for fighting stigma and discrimination among communities and it is a strong model of preventing HIV among young people.”

PLHIV NETWORK

YOUTH
SPEAK
OUT!

2.3 GIYPA SUPPORTS AND STRENGTHENS COMMUNITIES

GIYPA helps communities to better respond to:

- >> **Reducing HIV stigma and discrimination.** The visibility of YPLHIV can normalise an HIV-positive status among young people and help communities to challenge and overcome HIV stigma and discrimination.
- >> **Uptake of services.** YPLHIV encourage other young people to access information and services around HIV and sexual and reproductive health. This drives up demand.
- >> **Behaviour change.** YPLHIV encourage youth and adults to adopt behaviours that help to reduce the onward transmission of HIV.
- >> **Increasing access to treatment, care and support among young people living with HIV.** YPLHIV can reach their peers and increase their access to treatment, care and support.

TIP!



Fully realising the **benefits** of GIYPA in your organisation and community requires that you work with YPLHIV from diverse backgrounds and experiences.

GIYPA IN ACTION!

SHAFEEQ REHMAN, PAKISTAN

Stigma fighter, civil servant, changemaker

Shafeeq was in the Pakistan Air Force a few years ago. He tested HIV-positive while donating blood at a military hospital. After stigma and discrimination forced him to change careers several times, Shafeeq convinced Pakistan's National AIDS Control Programme (NCAP) that they needed a staff member to represent PLHIV and to hire him for this role. He's now the first person openly living with HIV to work in NCAP. Shafeeq is working hard to create a more supportive environment for PLHIV and ensure their participation in Pakistan's national response. In his role with NCAP, Shafeeq helps policy-makers better understand the realities of PLHIV and ensures that PLHIV and the organisations that represent them are involved in Pakistan's national response. Shafeeq knows there are obstacles to involving more YPLHIV in government ministries, but he's not one to let obstacles get in his way of making change!

3 LINKING YOUTH AND ORGANISATIONS TOGETHER

This section provides information about the different ways organisations can involve HIV-positive young people, as well as tips on how organisations can attract YPLHIV and sustain their involvement.

3.1 WAYS TO INVOLVE YPLHIV IN ORGANISATIONS

There are many ways that YPLHIV can be involved in HIV responses. The involvement spectrum (see Table 1) includes a range of progressively more challenging roles YPLHIV can take on in organisations. YPLHIV have different levels of participation and influence at each of part of the spectrum.

The ultimate aim of GIYPA is to provide options for involvement that are responsive to the diverse interests and needs of YPLHIV, and to empower and support interested YPLHIV to move up the spectrum towards more meaningful and challenging roles in the HIV response. At the same time, none of the types of involvement should be seen as 'better' than others. What is 'right' varies depending on the interest and capacity of each young person, as well as the capacity of organisations to facilitate their involvement.

SOMETHING TO THINK ABOUT!

Many YPLHIV are involved in **more than one** of these ways – even in the same organisation.

SOMETHING TO THINK ABOUT!

YPLHIV come into organisations at different points on the spectrum and have their own desires and goals for their participation in HIV responses. HIV is only one part of their lives; they have other aspirations and interests beyond HIV, and may be busy with family, friends, school, and earning an income. Some YPLHIV may want to take on increasingly active roles within the HIV response and others may not.

GIYPA IN ACTION!

JOSÉ ANTONIO MALDONADO RODRÍGUEZ, MEXICO
Volunteer, advocate, network builder, changemaker

Antonio got involved in the HIV response when he was 16 to overcome loneliness and to find a place where he would not face discrimination or questions about how he contracted HIV. At first, he got involved in prevention and care as a volunteer in a local organisation. Being involved helped Antonio feel useful and instilled a sense of responsibility to continue helping others. When Antonio discovered that many adults don't take youth seriously, he decided to work with other young people to change things. Antonio started the Centre for Youth Development and Research through which he advocates for treatment access, stigma reduction, the rights of YPLHIV, and HIV education. He is also building a network of YPLHIV in Mexico called Jóvenes Positiv@s. Being involved gave Antonio the chance to make friends and to learn how to confidently speak about his sexuality and health and stand up for other YPLHIV.

Table 1: The involvement spectrum¹²

| LEVEL | DESCRIPTION | EXAMPLES |
|--|---|--|
| Participant or service user | YPLHIV participate in programmes and services offered by organisations. They use these programmes and services to live positively, improve their life, upgrade skills, have fun, or gain self-confidence. | <ul style="list-style-type: none"> Participant in a post-test club or YPLHIV social group. |
| Structured consultation | YPLHIV are consulted in a structured way in order to identify the issues that affect them and their solutions. The information gathered is used to influence the organisation's policies, programmes and strategies. | <ul style="list-style-type: none"> Focus group participant. Survey participant. E-consultation participant. |
| Programme or organisational assistance | YPLHIV take on specific roles or tasks within the organisation and its programmes. They may contribute ideas through informal discussions and be responsible for programme delivery, but they are not responsible for programme planning and evaluation, or decision-making. | <p>Front-line staff or volunteers involved in:</p> <ul style="list-style-type: none"> Preparing condom packages. Doing outreach. Facilitating workshops. Acting as volunteer testing and counselling or support group peer counsellors. Conducting research. Mentoring other YPLHIV. |
| Informal influence in organisations and programme development | YPLHIV provide input and advice in the design and delivery of programmes and activities, but do not have decision-making power. They act as advocates on issues selected by the organisation. | <ul style="list-style-type: none"> Advisory group member. Youth spokesperson at meetings or in media. |
| Policy-making involvement | YPLHIV are recognised as important resources in the organisation and are involved for the benefit of the organisation as well as for their own development. They are included on formal decision-making bodies such as boards and committees, and can vote and are respected as equals. They are in staff positions with decision-making authority. | <ul style="list-style-type: none"> Member of board of directors. Coordinator or senior staff. |
| Youth-Adult and/or YPLHIV-non-YPLHIV | YPLHIV are integrated into the organisation's structure and have equal influence in decision-making. YPLHIV are recognised as full partners, sharing responsibility, authority and accountability. | <ul style="list-style-type: none"> YPLHIV work as full partners with adults and/or non-positive youth to plan, deliver and evaluate programmes. |
| YPLHIV-driven | All decision-making and responsibilities are carried out by YPLHIV. If adults and/or non-positive youth are present, they serve only as resource people or advisors. | <ul style="list-style-type: none"> YPLHIV-governed organisation or programme |



- >> Are YPLHIV currently involved in your organisation? If so, at which level(s) on the involvement spectrum?
- >> Are any groups of YPLHIV missing or underrepresented?

12. Adapted from International Institute for Child Rights and Development, 2010

3.2 DRAWING YPLHIV INTO YOUR ORGANISATION

The strategies organisations use to attract YPLHIV will differ depending on the type of role (e.g., volunteer, staff, board member), their ability to support and build the capacity of the young people who get involved, and whether YPLHIV feel safe being open about their HIV status in the community.



While it is often easier to find and engage more privileged YPLHIV, these youth may have limited understanding of the challenges faced by their marginalised peers. Marginalised YPLHIV often live with multiple challenges that can make it hard for them to get involved and leave them feeling hurt and resentful. Engaging marginalised YPLHIV requires an ongoing commitment and additional supports.



Don't get discouraged if you are having difficulties engaging YPLHIV. All organisations have to start somewhere. Through our study, YPLHIV shared two strategies for engaging their peers: 1) find a charismatic YPLHIV who can draw others into your organisation and 2) reach out to YPLHIV in the real world and virtual spaces where they hang out. Consider posting your involvement opportunity on the Y+ Leadership Initiative – a web-based one-stop shop for YPLHIV involved in the HIV response. Learn more about the Y+ Leadership Initiative at the Y+ section of the GNP+ website: www.gnpplus.net/en/programmes/empowerment/young-people-living-with-hiv

Here are some tips organisations can use to recruit YPLHIV for involvement opportunities:

- >> **Reach out to YPLHIV through programmes and services for youth and/or people living with HIV.** Many YPLHIV join part the HIV response by using services or taking part in existing groups and programmes, and then move into leadership roles. Reach out to support groups, networks of PLHIV, clinic services, post-test clubs, teen clubs, youth centres, and others to ask for help to encourage YPLHIV to get involved. Organisations may also want to set up their own programmes and services for YPLHIV.
- >> **Look for potential and then build capacity.** Get clear on which qualities, knowledge, skills and credentials can be developed once the YPLHIV are involved and which are a necessary foundation for the role. While some positions may require specific qualities, knowledge, skills or credentials, many others only require potential, a willingness to get involved and to learn, and the passion that comes from a personal connection to the issues.
- >> **Provide a variety of roles that appeal to different YPLHIV.** Some YPLHIV want roles in which their HIV-status is known and others want to be involved without making their status known. Some YPLHIV want a career in the HIV response and others only have a few hours a month to dedicate. Some YPLHIV may be looking for their first involvement opportunity and others may be experienced and looking for new challenges. Some YPLHIV are only available in the evenings and weekends, and others during business hours. A variety of roles can appeal to these different needs.
- >> **Understand why YPLHIV get involved in HIV responses and stay involved as well as the barriers that keep them from getting and staying involved.** We asked HIV-positive young people and organisations about the factors that affect the involvement of YPLHIV in HIV responses. Organisations can use their responses (see Table 2 on page 17) to develop a recruitment and retention strategy. We have also offered a few strategies to get started.

TIP!



The factors that affect participation can be gendered.

Consider how these factors may be similar and different for young women, young men and transgender youth in your community.

SOMETHING
TO THINK
ABOUT!

- >> What are the main barriers to the participation of YPLHIV in your organisation? What can you do to overcome these barriers?
- >> How can you build or strengthen referral networks with organisations that work with YPLHIV, such as schools, youth centres, and youth groups?
- >> How can you reduce HIV stigma and normalise an HIV-positive status among young people?

GIYPA IN
ACTION!

MAKING YPLHIV VISIBLE IN THE HIV RESPONSE THROUGH PARTICIPATORY RESEARCH

Until recently, the PLHIV movement in Tanzania was primarily the domain of adults. The National Council for People Living with HIV and AIDS (NACOPHA) was determined to increase the visibility and leadership of YPLHIV in the national response. To do this, NACOPHA engaged HIV-positive young people as peer researcher in a study on positive health, dignity, and prevention that will be used by YPLHIV to influence policies and programmes. Even though the project is still in its early stages, NACOPHA has already witnessed the potential of GIYPA. The opportunity to be involved in a concrete project and to gain research skills appealed to YPLHIV. Where there once was silence, YPLHIV are now stepping forward, joining together in YPLHIV organisations, and showing themselves to be capable, strong advocates. NACOPHA hopes that other adults will be inspired to make space for YPLHIV leadership and participation when they see what these peer researchers can achieve.

Table 2: Factors that affect the involvement of YPLHIV in HIV responses

| | WHAT SURVEY RESPONDENTS TOLD US | | WHAT THIS MEANS FOR INVOLVING YPLHIV |
|--|--|---|---|
| | INTERNAL FACTORS | EXTERNAL FACTORS | |
| Enablers  | <ul style="list-style-type: none"> • HIV-positive status • Getting support from other YPLHIV • Making a difference in the HIV epidemic • Gaining new skills • Making new friends | <ul style="list-style-type: none"> • Being encouraged by people in their lives, such as teachers, support groups, and parents/guardians | <ul style="list-style-type: none"> • Involve currently engaged YPLHIV in recruiting their peers. • Emphasise in recruitment materials the opportunities to meet new people, gain skills, get support from other YPLHIV, and make a difference. • Partner with school counsellors, support group leaders, youth workers, and testing sites to encourage YPLHIV to get involved. |
| Sustainers  | <ul style="list-style-type: none"> • Feeling supported to live positively • Knowledge and skills that contribute to one's goals • Feeling like one is making a difference • Meeting mentors and role models • Making friends • Getting support from their peers | <ul style="list-style-type: none"> • Being around other people living with HIV and/or young people living with HIV • Feeling comfortable at the organisation's office • Having one's work recognised | <ul style="list-style-type: none"> • Provide YPLHIV with trainings and mentoring. • Recognise the contributions of YPLHIV. • Focus on building relationships as well as on getting work done. • Make your organisation welcoming and comfortable for YPLHIV. |
| Barriers  | <ul style="list-style-type: none"> • HIV is only one of aspect of life • Not enough time • Need to earn money • Fear of HIV-status being disclosed • Not knowing anyone at the organisation • Not knowing how to find organisations working on HIV • Not feeling comfortable going into HIV organisations | <ul style="list-style-type: none"> • HIV stigma in the community • No youth programmes at the HIV organisation • Only unpaid positions available | <ul style="list-style-type: none"> • Hire YPLHIV as staff whenever possible. • Provide honoraria for volunteers. • Work to reduce HIV stigma and normalise an HIV-positive status among youth, in the community and particularly in schools. |

4 SUSTAINING AND GROWING YOUTH INVOLVEMENT

Getting HIV-positive young people involved is one thing; keeping them involved is another! Organisations have the best chance of sustaining GIYPAs if they create a supportive organisational environment and if their staff learns how to work effectively with YPLHIV.

4.1 MAKING YOUR ORGANISATION MORE SUPPORTIVE TO THE NEEDS OF YPLHIV

WHAT WE LEARNED!

YPLHIV told us that the first step for organisations that want to engage their peers is to build their capacity to work with HIV-positive young people.

WHAT WE LEARNED!

Networks of PLHIV and of key populations told us that they know how to engage PLHIV but have less experience engaging young people, while youth-focused organisations told us that they know how to engage youth but have less experience engaging HIV-positive youth.

The meaningful involvement of YPLHIV works best when the whole organisation is committed to creating a friendly and supportive environment. Being 'YPLHIV-friendly' means understanding what will create a warm, welcoming and inclusive environment for young people living with HIV. Some characteristics of YPLHIV-friendly organisations include:

Friendly and accessible environment

- >> A designated staff person is responsible for recruiting, coordinating and supporting YPLHIV.
- >> All staff members are trained and sensitised to the issues and concerns of YPLHIV.
- >> Open when YPLHIV are available (often evenings and weekends for those who are in school or working).
- >> Located in a place that is convenient and accessible for YPLHIV.
- >> Transportation and other participation supports (e.g., child care) are available if needed.
- >> Office space is clean and hygienic. Safe drinking water and sanitation systems are available.
- >> Policies and procedures are in place to ensure YPLHIVs' rights to privacy and confidentiality are respected.
- >> An HIV workplace policy is in place to support YPLHIV to take care of their health (e.g., time off when sick or to go to doctors' appointments).
- >> A commitment to working with YPLHIV is integrated in key documents like the strategic plan, policies and job descriptions.

Friendly and accessible processes

- >> A sense of shared ownership and collective responsibility is fostered.
- >> Activities are used to build relationships among YPLHIV and between adults and PLHIV as well as between HIV-positive young people and their HIV-negative peers. Getting to know each other on a more personal level makes it easier for people to connect across differences and to feel comfortable participating.
- >> ‘Scaffolding’ is provided to ensure success by balancing structure and guidance with freedom, creativity and ownership. This balance needs to be tailored to fit the experience and capacity of individual YPLHIV.
- >> Staff and organisations are adaptable and flexible.
- >> Organisational decision-making processes are engaging and encourage YPLHIV to speak up. Alternative formats are used, such as interactive activities, small group work, etc.
- >> Participatory processes are used to encourage dialogue, reflection, and critical thinking.
- >> YPLHIV are provided with formal and informal opportunities to build the necessary knowledge and skills.
- >> YPLHIV are encouraged to learn from their experiences, including failures.
- >> Successes are celebrated and contributions recognised.

Recognising different capacities as valuable

- >> YPLHIV are respected for the unique knowledge, skills and perspectives they bring to the organisation based on their age and HIV-status.
- >> YPLHIV are accepted as they are rather than being expected to conform to adult standards or to be like their HIV-negative peers.
- >> YPLHIV are selected using inclusive criteria, such as passion, potential, willingness and representation.
- >> Emphasis is placed on the strengths that each YPLHIV brings to the organisation.

Respectful relationships

- >> Diversity among YPLHIV is recognised.
- >> Communication processes are open, positive and respectful.
- >> YPLHIV are protected from stigma and discrimination. Our research indicates that YPLHIV also want to be protected from unwanted sexual attention.
- >> Opportunities are provided for staff and volunteers to learn about and transform attitudes, mindsets and practices that exclude people based on their age, gender, ethnicity or race, sexual orientation, HIV status or other aspects of their social identity.
- >> YPLHIV decide if, when and to whom to disclose their HIV status.

Sharing of power

- >> YPLHIV are involved in governance and throughout the programme cycle and not just in programme delivery.
- >> YPLHIV are encouraged to share ideas and perspectives, including critical feedback.
- >> Expectations, roles and responsibilities are clearly articulated.
- >> YPLHIV are involved in decisions about policies and procedures.

SOMETHING TO THINK ABOUT!

- >> How YPLHIV-friendly is your organisation?
- >> What are you already doing well? How can you build upon this?
- >> What are some gaps or areas of weakness? What can be done to address these gaps and weaknesses?
- >> The organisational checklist in Appendix 1 can help you assess your organisation’s current readiness for involving YPLHIV and to figure out what you would like to do to strengthen its capacity.

GIYPA IN ACTION!

WORKING WITH TEENS TO SUPPORT THEIR PEERS

Improved treatment for children with perinatally-acquired HIV means that the number of HIV-positive teens is growing rapidly. Botswana-Baylor Children's Clinical Center of Excellence (Baylor COE) launched its Teen Club in 2005 to meet the needs of these YPLHIV. Linking positive youth development principles with the call from PLHIV of 'nothing for us, without us', Baylor COE runs the Teen Club in partnership with YPLHIV. Each year, Teen Club members elect five boys and five girls to be Teen Leaders who help make decisions about activities and operations, act as peer counsellors and mentors, solicit feedback from other members, and take an active role in outreach, fundraising, advocacy, and even hiring staff. The Teen Club is regularly featured as a best practice for supporting YPLHIV and is being replicated in other areas of Africa. The success of the Teen Clubs shows that when HIV-positive teens are given a voice and supported to overcome obstacles to good health, their strength, creativity and passion can engender hope, even in the most desperate situations.

4.2 DEVELOPING AN YPLHIV INVOLVEMENT STRATEGY

WHAT WE LEARNED!

Two-thirds of organisations said they do not have a formal strategy to support GIYPA or specific roles for YPLHIV, even though the majority actively encourage YPLHIV to get involved in their organisations.

Strategies help organisations succeed. A strategy sets out a big picture vision and the plans for realising it. A strategy says what is important to an organisation and helps people work independently toward a common goal. An YPLHIV involvement strategy should outline the following elements.

The purpose of YPLHIV involvement in the organisation

It is important for organisations to articulate the ideal role of YPLHIV in the organisation and how their involvement will contribute to the organisation's work.

Guiding principles for effective YPLHIV involvement

GIYPA is more of an art rather than a science. Organisations and people seeking to engage YPLHIV cannot use cookie-cutter approaches, but rather must be innovative and able to respond to the needs and dynamics of different individuals and groups. Guiding principles can provide useful reference points or sign posts to ensure that one's practice and decisions stay on-track amid complexity, unpredictability, and change. See the box of tips on page 22 for some ideas.

A model of shared decision-making with YPLHIV

Clarity about how decisions get made and the level of influence YPLHIV have in decisions is extremely important. There are many models for adults working with youth. Three common models are: youth-led – in which young people have the authority and responsibility for decisions, with adults only providing support as requested; adult-led – in which adults have the authority and responsibility for decisions; and youth-adult partnerships – in which youth and adults share authority and responsibility for decisions. These models can also be used by youth-led organisations to define how decision-making will be shared among young people who are HIV-positive and HIV-negative.



Here are some guiding principles that organisation can build upon:

- >> **Recognise YPLHIV as agents of change.** HIV-positive young people not only have the potential and energy to positively influence HIV responses, they already are actively shaping their lives and communities.
- >> **Start from strengths.** All people and communities have assets such as skills, knowledge, and opportunities. Look for what is already working well and build upon it.
- >> **Value diversity.** Diversity leads to more relevant solutions when differences are embraced and inclusion nurtured. Involve YPLHIV with diverse social identities and life experiences.
- >> **Encourage learning by doing.** Keep YPLHIV engaged and motivated by responding to their desire for action and immediate results. Incorporate reflection with action to promote learning and capacity development.
- >> **Foster critical awareness by focusing on underlying causes.** Promote healing, empowerment and long-term change by shifting the focus from individuals and their behaviours to the social, cultural, historical, economic, and political factors that shape and constrain people's lives and fuel HIV epidemics.
- >> **Take a rights-based approach.** Rights-based approaches are recognised as a good practice in HIV programming and policies. Understanding one's rights is a critical foundation for empowered participation. The rights literacy of YPLHIV and the organisations that seek to engage them should be nurtured.
- >> **Normalise an HIV-positive status among young people.** GIYPA should not be limited to the HIV response. Space is needed for YPLHIV to participate fully in their communities and countries with the same rights and opportunities as other citizens.
- >> **Make the invisible visible through dialogue and knowledge exchange.** Take time out to step back and reflect on the big picture vision, tensions and commonalities in your goals, and your group dynamic; celebrate triumphs and learn from tribulations; share ideas and lessons learned, and find solutions to challenges. Engage older young people living with HIV and those who have transitioned out of their youth in sharing their knowledge and mentoring younger leaders.
- >> **Safe disclosure.** The continuing ownership and leadership of the HIV response by HIV-positive people can only be achieved if YPLHIV feel safe to disclose their HIV status. YPLHIV grapple with complex and difficult questions around disclosure. Decisions about if, when, and to whom to disclose should be a matter of personal choice; disclosure should not be a prerequisite for participation. The right of YPLHIV to privacy and confidentiality should be of utmost concern to the organisations that seek to engage them.

It is important that organisations choose a model that works best for them and the YPLHIV they engage. What works depends on a number of factors, including the readiness and capacity of your organisation and staff to work with YPLHIV, and the capacity of the involved YPLHIV. Many organisations find that their model for working with YPLHIV evolves over time as commitment and capacity for GIYPA grows.

A plan for increasing YPLHIV involvement

Identify what actions are needed to increase the involvement of YPLHIV and the meaningfulness of their involvement. Some actions include:

- >> **Develop policies that promote and facilitate involvement.** Consider policies on HIV workplace issues (and especially concerning disclosure, confidential and privacy), gender equality, prevention of sexual harassment, volunteer recruitment and retention, and on being youth-friendly.
- >> **Develop structures and processes to support involvement.** Consider a designated staff person with the requisite time and capacity to engage YPLHIV, position descriptions for volunteers and staff, capacity development opportunities such as training and mentorship, and participation incentives. Integrate the ability to work with YPLHIV into the position descriptions of any staff who will be working with them.
- >> **Train staff, board members, and volunteers.** Foster mindsets and practices that support social inclusion and promote GIYPA through trainings to overcome adultism, HIV stigma, homophobia, gender inequalities, and other forms of stigma.
- >> **Identify a recruitment and retention plan.** Develop outreach and engagement plans for YPLHIV, sustaining the participation of those who are engaged, and overcoming barriers to involving YPLHIV.
- >> **Identify the resources you will need to support meaningful involvement, and make a plan for getting them.** Meaningful engagement requires an investment of staff time and additional resources such as trainings and participation incentives. Take time to document the human and financial resources needed, and include these items in funding proposals and discussions with donors. Be prepared to make a case for the importance and benefits of GIYPA in HIV responses.

TIP!



Compensating YPLHIV for their participation shows that you value their contributions and can also remove barriers to participation. Organisations that are not able to hire YPLHIV should consider other forms of compensation and recognition such as honoraria or stipends, transportation supports, food, trainings, certificates of participation, and special opportunities such as being a representative at a high-level meeting or in a media story. Avoid an unhealthy dependence on external incentives by also nurturing values and motives that support active citizenship.

WHAT WE LEARNED!

Organisations told us that a key barrier to involving YPLHIV in HIV responses is that there are **limited financial resources to support youth programmes in general** and to facilitate the involvement of YPLHIV in the HIV response.

Help us overcome this barrier by sharing the many benefits of GIYPA for young people themselves and for HIV responses with National AIDS Commissions, UNAIDS, the Global Fund, and other donors, and by advocating for policies and resources to support organisations to meaningfully engage YPLHIV.

INSTITUTIONALISING THE INVOLVEMENT OF HIV-POSITIVE YOUTH

YPLHIV have been part of Dance4Life's work since the organisation was founded in 2003. Initially, they shared their stories during school tours to inspire youth to get involved with Dance4Life and in their communities. In 2009, Dance4Life decided to take the involvement of YPLHIV even further. With funding from the Ford Foundation, Dance4Life hired a YPLHIV Officer to work on key issues identified in a research report prepared by a young woman living with HIV. It took a while to find the right person for the job, but there is now a YPLHIV on staff who is reviewing current systems and practices and will develop an action plan to guide structural and programmatic changes. Dance4Life is committed to sustaining funding for the YPLHIV Officer and investing in strengthening its capacity to meaningfully engage and provide a supportive environment for HIV-positive young people, and to support their leadership in HIV responses. Working with GNP+ has helped Dance4Life move their vision forward, while establishing a staff position to institutionalise GIYPA has made a positive impression among other organisations and in communities.

4.3 BEING AN EFFECTIVE FACILITATOR AND ALLY TO HIV-POSITIVE YOUTH

GIYPA is a process that takes time and is built on relationships and trust. Adults and HIV-negative youth need to be allies and effective facilitators to successfully engage YPLHIV. Allies stand by and stand up for people who face stigma and discrimination, whether or not they too are affected. Facilitators support groups to come together and work towards a common purpose by setting the tone, fostering positive relationships among group members, providing structures for discussions and making decisions, and refocusing the group when needed.

Here are some tips for working effectively as an ally and facilitator with YPLHIV:

- >> **Get to know YPLHIV as individuals.** Find out each person's existing capacities, strengths, areas for growth, and needs.
- >> **Level power differentials.** Things like how a room is set up, the types of activities used and how one dresses can send messages about who has power and who does not. Encourage participation by sitting in a circle, using interactive activities that encourage dialogue and learning among group members, and dressing casually.
- >> **Create a safe and inclusive environment.** Develop group guidelines with YPLHIV. Emphasise the importance of acceptance and mutual respect. Encourage group members to express their opinions, experiences, and feelings. Listen carefully. Be open-minded and respectful. Create opportunities but do not force group members to participate in discussions and activities.
- >> **Meet YPLHIV on their level.** Use everyday language rather than jargon. Ground discussions of theory and strategy in the YPLHIV's lived experiences, while avoiding being intrusive. Recognise that YPLHIV are a diverse community of individuals with shared and varying experiences. Treat everyone with respect and equally. Ask questions that build an understanding of how they see their lives and community. Make sure that everyone understands instructions.
- >> **Develop participatory activities that encourage expression and critical thinking.** Look for creative activities that encourage YPLHIV to reflect on and critically analyse their lives and communities. Use a variety of means such as games, photography, mapping, drawing, and small group discussions.
- >> **Pay attention to the group and its dynamic.** Look for verbal and non-verbal clues from your group to make sure they understand and to intervene early if they are bored, confused, upset, etc.

- >> **Be open to trying new ideas and ways of doing things.** YPLHIV can bring new ways of thinking and new strategies to organisations. They may also have different ways of working and getting things done. This can be uncomfortable for organisations and staff. Shared decision-making, however, means being willing to explore and try out new ideas and ways of doing things. Taking such a leap of faith can pay off!
- >> **Be patient and persistent.** Involving YPLHIV who are marginalised can be a slow process. With time, trust is built, and barriers overcome.
- >> **Be an advocate and a mentor.** Some YPLHIV will need one-on-one follow up or help connecting with further support.

TIP!



Keep in mind that there is a wide range of capacities among YPLHIV. The strategies that work with one group of YPLHIV may not work with another. For example, the strategies that work with an adolescent living with HIV are different from those that work with a young adult living with HIV who has completed post-graduate training. Tailor your approach to the interests and capacities of each YPLHIV.

SOMETHING TO THINK ABOUT!

- >> How would you rate your current ability to work with YPLHIV as an ally and facilitator?
- >> What are you already doing well? How can you build upon this?
- >> What are some gaps or areas of weakness? What can be done to address these gaps and weaknesses?

4.4 NURTURING LEADERSHIP AMONG YPLHIV AND BUILDING THEIR CAPACITY FOR MEANINGFUL INVOLVEMENT

WHAT WE LEARNED!

YPLHIV told us that organisations should look for HIV-positive young people with potential and then build their capacity. Capacity development should focus not only on technical areas, but on the whole person, including empowerment and building life skills.

Opportunities for personal and professional development support YPLHIV to make meaningful and relevant contributions in organisations, and sustain their leadership in HIV responses. Such opportunities also empower YPLHIV, support them with healing, and help them to achieve their own goals and aspirations.

Some capacities that YPLHIV need for effective participation in HIV responses include:

- >> **Evidenced-based knowledge** about HIV, sexuality, sexual and reproductive health and rights, substance use, harm reduction, positive prevention, treatment literacy, and HIV responses.
- >> **Critical awareness** of underlying causes such as gender inequalities, poverty, homophobia, and misguided laws and policies.
- >> **Opportunities to heal and be empowered** through the development of critical awareness. This requires opportunities to reflect on their own lived experiences with HIV, to see commonalities in their own experiences and those of other YPLHIV, and to explore how broader systems affect their lives.
- >> **Leadership skills**, including self-awareness and skills for communication, decision-making, problem-solving, conflict resolution and group facilitation.

- >> **Skills for fostering personal and social change**, including behaviour change communication, advocacy, social mobilisation, and social media and new technologies.
- >> **Skills to design, plan, implement**, coordinate and monitor and evaluate programmes and activities.

There are many ways to nurture leadership and build capacity amongst involved YPLHIV. It is best to use a mix of upfront trainings (in anticipation of skills that may be needed later), just-in-time trainings (for skills needed for immediate use), and ongoing supports for 'learning through doing' such as facilitative supervision, mentors and regular reflection.



Link experienced YPLHIV who are 'aging out' with YPLHIV who are newly involved in the HIV response to facilitate knowledge exchange and ensure the continuity of the movement.

Keep in mind that good leadership needs investment to develop and that sometimes good leaders have to fail before they develop. Organisations can encourage YPLHIV's ongoing growth by linking them with progressively more challenging positions and supporting access to educational opportunities, training, mentoring, and job opportunities.

There are two critical things that need to be avoided in order to effectively and more meaningfully involve HIV-positive young people in your organisation:

1. **Burn-out is all too common among YPLHIV who are engaged in the HIV response.**
Burnout happens when people give too much of their time and energy, and end up feeling worn out or even used. Some of the factors that contribute to burnout are inadequate support within the organisation; undue feelings of responsibility to be involved; and disillusionment about the effectiveness and impact of GIYPA. Organisations can help YPLHIV avoid burnout by supporting them to find a good balance between their life and work in the HIV response and encouraging them to be realistic about how much they can do and how much change to expect.
2. **Tokenism is the inclusion or reference to a person or issue for the sake of appearances** and, in many cases, to meet a minimum requirement of law. It is often considered to be a symbolic gesture in place of meaningful involvement. This means that tokenism is the complete opposite of GIYPA. Organisations can avoid tokenising YPLHIV by ensuring that they know the value that GIYPA will bring to their work and have planned properly how the contributions of YPLHIV will be well integrated into their work and/or governance structures.



- >> How can you make sure that the YPLHIV involved in your organisations are supported to maintain a healthy work-life balance and to avoid burnout?
- >> How do you ensure that YPLHIV are being engaged and involved in your organisation for the right reasons?

4.5 WORKING WITH YPLHIV TO EXPLORE KEY ISSUES AND IDENTIFYING OPPORTUNITIES FOR CHANGES

A sense of ownership is an important component of meaningful involvement. Ownership can be facilitated by engaging YPLHIV in participatory activities. Such activities help people explore, think critically, and better understand the complex and multi-dimensional issues that fuel HIV epidemics, and which prepare them to identify opportunities and strategies to catalyse change. Some other common features of participatory activities are that they enhance people's understanding of abstract concepts through connection to personal experiences, encourage dialogue among group members, and develop skills and tools that can be used to engage others in creating social change.

There are many fun and participatory approaches to exploring issues, some of which are described in the resources listed in Appendix 2.

4.6 SUPPORTING THE DREAMS AND ASPIRATIONS OF YPLHIV

YPLHIV will not be young forever. Many active members of youth movements have found that when they transition out of being a 'youth', they no longer are invited to high-level meetings and do not have the skills needed to easily step into other roles and opportunities. Organisations can support YPLHIV to successfully make the transition by encouraging them to identify and to develop the skills needed to realise their dreams and aspirations for their careers and ongoing involvement in the HIV response and community. Organisations can also support YPLHIV to learn how to write their curriculum vitae and to document the transferable skills gained through their involvement in the HIV response, and provide letters of recognition and appreciation that can be used by YPLHIV when applying for post-secondary programmes, scholarships and bursaries, and jobs.

GIYPA IN ACTION!

PRINCESS NURU NUBUMBU, UGANDA

Peer counselor, writer, policy advocate, changemaker

Princess discovered she had been born with HIV when she was 20 years old, after falling into a coma. Even though her father passed away when she was 10 years old and she experienced many HIV-related illnesses, no one had told Princess about her status. Since learning her status, Princess has been standing up against HIV stigma and standing up for the rights for YPLHIV – including their sexual and reproductive rights. Princess first got involved in the HIV response after meeting some Straight Talk* members while waiting at a clinic for counselling and drugs. Soon after, she agreed to be featured in their magazine. This led to her becoming a volunteer writer and then a staff working with YPLHIV. Now, Princess is a UNAIDS Special Youth Fellow, influencing policy-makers at the national level and supporting youth organisations involved in the HIV response. Because of her work, YPLHIV are now included in Uganda's prevention strategies and their rights are more visible.

**Straight Talk is a Ugandan community-based organisation that have been providing information for young people and adults through a number of media for over 15 years – one of the key areas of information provided is around sexual and reproductive health and HIV. For more information please go to their website: www.straighttalkfoundation.org*

5 SEEING POSITIVE HEALTH, DIGNITY AND PREVENTION IN ACTION

The vision of *Positive Health, Dignity and Prevention* cannot be achieved if the needs and priorities of YPLHIV are not understood and addressed. When organisations bring the voices, ideas, experience and skills of YPLHIV into their work, it becomes more likely that efforts to improve the dignity, quality, and length of life of people living with HIV will be relevant for YPLHIV.

GIYPA IN ACTION!

PUTTING YPLHIV ON THE NATION'S AGENDA

Young Positives of Uganda knew they had to increase attention given to YPLHIV in the national response. They decided the best way was to get on the national bodies that make decisions about the priorities, funding allocations, and policies. When invited in 2002 to participate in consultations on a multi-sectoral response policy, YPLHIV seized the opportunity to advocate for a seat on the Uganda AIDS Partnership Committee. This opened doors to get on the Country Coordinating Mechanism of the Global Fund and the Civil Society Fund Steering Committee, and then the Health Policy and Advocacy Committee.

Young Positives of Uganda has achieved many successes through their involvement in these bodies; for example, having the age of consent for HIV testing lowered to 12 years and ensuring a focus on YPLHIV in all HIV projects. Young Positive of Uganda has learned that their ability to influence decision-making bodies is affected by the chair of the committee, as well as the confidence and skill of representatives and their ability to meet with the young people they represent.

APPENDIX 1

ORGANISATIONAL CHECKLIST ON YPLHIV INVOLVEMENT

Below is a tool (a simple checklist) that organisations can use to reflect on their experience of practicing GIYPA. The tool will help organisations assess their current readiness for involving YPLHIV and to figure out what they would like to do to strengthen their capacity. It is important to prioritise those changes that are most important and feasible.

| QUESTIONS | ASSESSMENT OF CURRENT GIYPA SITUATION | DESCRIPTION OF IDEAL GIYPA SITUATION | IDEAS FOR IMPROVEMENT |
|--|---------------------------------------|--------------------------------------|-----------------------|
| 1. How much YPLHIV involvement is there currently in your organisation? | | | |
| 2. What types of roles do YPLHIV hold in your organisation? | | | |
| 3. What is your organisation's approach to YPLHIV involvement? | | | |
| 4. Does your organisation have an HIV policy? | | | |
| 5. Does your organisation have a policy on youth participation? | | | |
| 6. How YPLHIV-friendly is your organisation at this time? (See Section 4.1) | | | |
| 7. Do the leaders of your organisation understand the need for YPLHIV involvement? | | | |
| 8. Are the leaders willing to support the learning and risk associated with YPLHIV involvement, and to adapt the structure of your organisation to accommodate new ways of doing things? | | | |

Fatima works at a PLHIV network. Here's how she assessed how GIYPA is currently practiced in her organisation:

1. We recently started a support group for YPLHIV.
2. YPLHIV attend activities and use services. There are a few older YPLHIV who volunteer in the network.
3. We welcome YPLHIV who approach us, but do not have formal strategies to reach out to young people or designated roles for YPLHIV.
4. Yes, we have an HIV workplace policy.
5. No, we don't have a policy on youth participation.
6. We do offer participation incentives like food and travel vouchers. We are also open in the evenings and on the weekends. Our staff and volunteers have not been formally trained in working with youth.
7. Reaching out to YPLHIV is a priority for our network. Many young people in our community are living with HIV. We need to find ways to meet their needs and support their leadership.
8. We work on a shoestring budget. All the same, the leaders in the network are committed to finding additional funding to set up programmes and services for YPLHIV.

Paulo works at a large youth sexual and reproductive health organisation. Here's how he assessed how GIYPA is currently practiced in his organisation:

1. An increasing number of the youth using our services are living with HIV. This has pushed us to start thinking about how well we are meeting their sexual and reproductive health needs and how we can improve our services.
2. YPLHIV use our services. We have many youth volunteers. It is likely that some are living with HIV, but none have disclosed their status to date.
3. We don't currently have an approach to involving YPLHIV. We want to develop formal strategies and designated roles.
4. Yes, we have an HIV workplace policy.
5. Yes, we have a policy on youth participation. It does not include YPLHIV specifically.
6. Our organisation and services are designed to be youth-friendly. We need to make changes to be friendlier to YPLHIV. We need help from YPLHIV to figure out what changes are needed and how to make them.
7. Our senior management and board members have prioritised enhancing the availability and accessibility of our services to YPLHIV.
8. Our senior management and board members have funded a project to engage YPLHIV in assessing our organisation and are committed to acting on their recommendations.

APPENDIX 2

REFERENCES AND RESOURCES

We referred to many of the following resources when developing this document. These are good places to find further information, strategies, and activities to help you meaningfully engage YPLHIV.

GUIDES AND TOOLKITS

Canadian AIDS Society. *One Foot Forward: A GIPA Training Toolkit*.
www.cdnaids.ca/onefootforwardagipatrainingtoolkit

Global Network of People Living with HIV (GNP+) (2012). *GIYPA Roadmap: Supporting Young People Living with HIV to be Meaningfully Involved in the HIV Response*. (See the Y+ section of the GNP+ website: www.gnpplus.net/en/programmes/empowerment/young-people-living-with-hiv)

Global Network of People Living with HIV (GNP+) (2011). *Young People Living with HIV Advocacy Brief: A Briefing Document to Support the Advocacy Messages Developed for the 2011 High Level Meeting on AIDS*. (See the Y+ section of the GNP+ website: www.gnpplus.net/en/programmes/empowerment/young-people-living-with-hiv)

International HIV/AIDS Alliance (2011). *Good Practice HIV Programming Standards*.
www.aidsalliance.org/Publicationsdetails.aspx?Id=451

International HIV/AIDS Alliance and Global Network of People Living with HIV (GNP+) (2010). *Good Practice Guide: Greater Involvement of People Living with HIV (GIPA)*.
www.gnpplus.net/resources/empowerment-of-people-living-with-hiv-a-their-networks/item/47-good-practice-guide

International Institute for Child Rights and Development (IICRD) (2010). *Changing the Landscape: Involving Youth in Social Change*.
www.issuu.com/youthscape/docs/ys_guidebook_print

International Planned Parenthood Federation (IPPF) (2008). *Inspire: an IPPF resource pack on youth friendly programming*.
www.ippf.org/en/Resources/Guides-toolkits/Participate+The+voice+of+young+people+in+programmes+and+policies.htm

Ontario Public Health Association (2011). *A Project Lead's Guide to Planning, Implementing and Sustaining Youth Engagement Programming*.
www.youthengagement.ca/sites/default/files/YEGuide_Final_Web.pdf

Ontario Public Health Association (2011). *Youth Engagement Toolkit – Working with Middle School Students to Enhance Protective Factors and Resiliency: A Resource for Health Professionals working with Young People*.
www.youthengagement.ca/sites/default/files/OPHAYouthEngagementToolkit-April2011.pdf

Restless Development. *Youth Advocacy Toolkit*.
www.restlessdevelopment.org/file/final-toolkit-pdf

TakingITGlobal. *HIV/AIDS Youth Guide to Action!*
www.tigweb.org/action-tools/guide/hivaids/network.html

ONLINE RESOURCES AND NETWORKS

Advocates for Youth. www.advocatesforyouth.org

HIV Young Leaders Fund. www.hivyoungleadersfund.org

NGO Code of Good Practice. www.hivcode.org

Y+ Leadership Initiative (Young People Living with HIV Leadership Initiative) Global Network of People Living with HIV (GNP+). www.gnpplus.net/en/programmes/empowerment/young-people-living-with-hiv

Y+ Programme (Young People Living with HIV Programme) Global Network of People Living with HIV (GNP+). www.gnpplus.net/en/programmes/empowerment/young-people-living-with-hiv

Young People Living with HIV Facebook Community, Global Network of People Living with HIV (GNP+). www.facebook.com/groups/162631207190708 **Youth Coalition.** www.youthcoalition.org

Youth RISE. www.youthrise.org

Youth, the Arts, HIV and AIDS Network. www.yahanet.org

REPORTS

Global Network of People Living with HIV and UNAIDS (2011). *Positive Health, Dignity and Prevention: A Policy Framework.*

www.gnpplus.net/en/resources/positive-health-dignity-and-prevention/item/109-positive-health-dignity-and-prevention-a-policy-framework

UNAIDS, UNICEF, WHO (2007). *Children and AIDS: A Stocktaking Report.*

www.unicef.org/publications/files/ChildrenanAIDSAStocktakingLoResPDF_EN_USLetter_15012007.pdf

DECLARATIONS

The Paris AIDS Declaration (1994).

http://data.unaids.org/pub/ExternalDocument/2007/theparisdeclaration_en.pdf

United Nations General Assembly Special Session on HIV/AIDS (2001). *Declaration of Commitment on HIV/AIDS.*

www.unaids.org/en/media/unaids/contentassets/dataimport/publications/irc-pub03/aidsdeclaration_en.pdf

United Nations Special Session on Children (2004). *A World Fit for Children.*

www.unicef.org/specialsession/wffc/index.html

United Nations High-Level Meeting (2006). *Political Declaration on HIV/AIDS.*

www.unaids.org/en/aboutunaids/unitednationsdeclarationsandgoals/2006politicaldeclarationonhivaids/

United Nations High-Level Meeting (2011). *Political Declaration on HIV/AIDS.*

www.unaids.org/en/aboutunaids/unitednationsdeclarationsandgoals/2011highlevelmeetingonaids/

GLOBAL AND REGIONAL NETWORKS

Global Forum on MSM and HIV. www.msngf.org

Global Network of Sex Work Projects. www.nswp.org

Global Youth Coalition on HIV/AIDS. www.gyca.org

International Network of People Who Use Drugs. www.inpud.net

Regional Network of PLHIV. Global Network of People Living with HIV (GNP+).
www.gnpplus.net/en/regions



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