

YOUNG POSITIVES: LIVING THEIR RIGHTS!

CONSIDERATIONS, CHALLENGES AND OPPORTUNITIES TOWARDS UNIVERSAL ACCESS TO TREATMENT, CARE AND SUPPORT.

PURPOSE

The following briefing paper was developed by young people living with HIV. This briefing paper outlines a number of key issues, considerations, challenges and recommendations for policy-makers, NGOs, young people, people living with HIV and other actors in the response to HIV to help us all build a supportive and enabling environment for young people living with HIV to realize their rights.

PARTNERS:

- **Young Positives**
- **Positive Youth Outreach**
- **The Global Network of People Living with HIV (GNP+)**
- **Hope's Voice International**
- **World AIDS Campaign**

INTRODUCTION

Young people (15-24 years old) living with HIV are a vital force to reversing the spread of HIV. As central figures in the HIV epidemic, they live their day-to-day lives with the virus, giving them first-hand experiences of the complexities of being both a young person and living with HIV. In most cases, young people living with HIV are just like other people their age with desires and dreams to live a fulfilled life.

In the global HIV response, young people living with HIV should be recognized as being self-determined agents, but this does not take responsibility away from governments, organisations and others to play a proactive role in supporting and engaging this diverse group. Actively engaging and supporting young people living with HIV in the global, regional and country HIV responses is the key to ensuring that we reverse the spread of the virus, realize human rights and achieve universal access targets.



BACKGROUND: WHO ARE YOUNG PEOPLE LIVING WITH HIV?

There are 5.4 million people worldwide between the ages of 15 and 24 living with HIV, with 59% of them female and about 41% are male¹. Globally about 45% of new HIV infections are among young people².

There are 3.2 million young people living with HIV in sub-Saharan Africa, 76% of whom are female, three young women are infected with HIV for each young man who contracts that virus³.

In Latin America and the Caribbean there are around 420 000 young people living with HIV, with three men being infected for every woman and where the primary mode of infection is among men having sex with men⁴.

Southeast Asia and the Pacific have the second highest HIV prevalence with about 1.27 million youth living with HIV, 70 per cent of whom are male and the primary mode of infection is through injection drug use⁵.

In Central and Eastern Europe there are around 340 000 young people living with HIV⁶, the Russian Federation and Ukraine have the fastest growing epidemics in the world, and young people account for a large proportion of the number of people living with HIV, and the primary mode of infection is through injection drug use⁷.

It must be highlighted when looking at global statistics that there is no one homogenous group of 'youth' and not all young people face the same HIV vulnerabilities⁸. Young people living with HIV are members of multiple social and cultural groups simultaneously. This can compound and increase the vulnerabilities faced by young people due to their age, as well as specific vulnerabilities faced by the other social and cultural groups they may be members of, including people who use drugs, young women, young gay men and other men who have sex with men, young sex workers and young transgendered peoples. There is a need

for specific interventions and policies that address the multiple vulnerabilities faced by diverse groups of young people living with HIV that are also regionally and culturally relevant.

CALL TO ACTION:

Ensure that policies and interventions recognize the diverse experiences of young people living with HIV, and that young people are meaningfully engaged at all levels. Including, ensuring that interventions are tailored and specific for various unique populations of young people living with HIV with an emphasis on the leadership of these groups.

YOUNG PEOPLE BORN HIV-POSITIVE

There are 2 million children under 15 years old living with HIV, 90% of whom acquired the virus through vertical transmission (also known as mother-to-child transmission). As a result, in resource-constrained settings there are more than 1400 children infected with HIV every day⁹. While most countries in the Global North have almost eradicated vertical transmission, there is a huge disparity between them and countries in the Global South¹⁰. The number of children living with HIV has been on a steady increase since the 1990s, while deaths among this group are

on the decrease due to a number of factors, including greater access to antiretroviral treatment¹¹. As the life-prolonging effects of antiretroviral therapy increase due to greater access around the world, the amount of prenatally infected children who survive into becoming young people and to lead productive and fulfilled adult lives will rise.

Existing policies and programmes often ignore the needs of young people who were born HIV-positive, primarily because until recently this group were not expected to survive to adolescence¹². Despite the rising number of young people infected during births that are growing-up, there is an absence of the voices of these young people in the HIV response as their needs and issues are often overlooked¹³. Guidelines, policies and programmes need

to be revised and reviewed to ensure they specifically address the situation of young people who were born with HIV, as well as those who were infected at a later stage¹⁴.

CALL TO ACTION FOR POLICY MAKERS:

Ensure that relevant policies and interventions recognize the unique needs of the growing population of young people who are born HIV-positive.



STIGMA, DISCRIMINATION, CONFIDENTIALITY AND ACCESS TO EDUCATION AND HEALTH

The realities and fears of HIV-related stigma and discrimination are felt intensely by young people living with HIV. Many countries, young people living with HIV face confidentiality breaches and discriminatory attitudes when accessing health care and support services¹⁵.

Confidentiality is a critical issue for young people living with HIV¹⁶. To feel comfortable accessing services they need to know that their HIV status will remain private, and may need support in deciding how to disclose their status to families and partners. Parental consent is often required in many countries for accessing age-appropriate information, health, sexual and reproductive health, treatment, and care and support services. However, even if they are under the age of majority, young people have the right to confidentiality and should not need parental permission for these services¹⁷. Laws must be reformed towards the greater protection of young people's right to confidentiality and right to access services.

To ensure their right to health and support greater access to health services it is critical that young people are permitted to access sexual and reproductive health services, even if they are below the age of consent for sex. Also, it is vital that health care providers receive adequate training and understand their duty to protect young people's right to confidentiality and HIV-related stigma and discrimination when accessing all health and support services.

Young people living with HIV have the right to comprehensive sexuality education¹⁸. Around the world, young people both HIV-negative and HIV-positive have the highest rates of sexually transmitted infections not including HIV, with over 500,000 infections daily¹⁹. Sexually transmitted infections tend to hit people living with HIV more aggressively, making them harder to treat²⁰. Young people living with HIV are at increased vulnerability for sexually transmitted infections and if not treated this can increase their ability to pass on HIV to other sexual partners through unsafe sex. Comprehensive sexuality education is vital to ensuring that young people living with HIV can protect themselves and their partners. Sexuality education is not only a right, it is also effective. Curriculum-based interventions based on defined quality evidence-based criteria, have been shown to have an impact on knowledge, skills and behaviours and support overall sexual health of young people²¹.

In many cases, national education institutions and curriculum need to do more to address the sexual and reproductive health concerns of young people who are already living with HIV, including providing information on starting relationships and dating, practicing safe, pleasurable sex, disclosure issues and includes teacher training²².

CALL TO ACTION FOR POLICY MAKERS:

Ensure that national education institutions and curriculum address the sexual and reproductive health concerns of young people who are living with HIV, including providing information on starting relationships and dating, practicing safe, pleasurable sex, disclosure

issues and includes teacher training.

Work to reform laws and policies towards the greater protection of young people's right to confidentiality and right to access health services regardless of age and without parental permission.

Work to reform policies and laws to ensure that young people living with HIV are permitted to access sexual and reproductive health services, even if they are below the age of consent for sex in their countries.

CALL TO ACTION FOR SERVICE PROVIDERS:

Ensure that health care providers receive adequate training to care for young people living with HIV, including addresses HIV-related stigma and discrimination issues and understanding their duty to protect young people's right to confidentiality.



FALLING THROUGH THE GAP? THE YOUTH MOVEMENT AND THE PEOPLE LIVING WITH HIV MOVEMENT

Young people living with HIV are not adequately supported, engaged or recognized by both global networks and movements of young people respond-

ing to HIV, or by global networks of people living with HIV²³. While both movements have done some work with and around young people living with HIV, more needs to be done. The youth movement often assumes that people living with HIV networks are engaging and working with young people living with HIV, while the people living with HIV movement assumes that young people living with HIV are involved in the youth movement. There is gap which results in neither of these potentially important groups for young people living with HIV in recognizing their needs and engaging with them appropriately. Open dialogue between these movements with the aims of creating supportive sustainable spaces for young people living with HIV will help to ensure that the HIV response is truly effective and that universal access targets to HIV prevention, treatment, care and support are realized.

CALL TO ACTION FOR NETWORKS OF YOUNG PEOPLE AND PEOPLE LIVING WITH HIV:

Actively engage and create supports for young people living with HIV in all levels of governance, programming and implementation of activities.

YOUNG PEOPLE LIVING WITH HIV: POSITIVE HEALTH, DIGNITY AND PREVENTION

Young people living with HIV enter into relationships, have sex, and bear children. They have unique sexual and reproductive health needs and hopes. Additionally, the specific prevention, treatment and care needs of young people living with HIV, including psychosocial support and sexuality counselling, must be recognized through youth-friendly, health services which are accessible, affordable, respectful, and informative²⁴. Interventions should be provided through a Positive, Dignity, Health and Prevention framework, which is a right-based approach to supporting the health and wellbeing of people living with HIV²⁵. Within

this framework, preventing HIV transmission is a shared responsibility of all individuals irrespective of their HIV status.

Positive Health, Dignity and Prevention promotes a holistic approach to prevention, including equitable access to voluntary HIV testing, treatment, care and support services and addressing psychosocial, economic, educational and socio-cultural vulnerabilities, as well as gender and sexuality. This is vital to ensuring the success of effective interventions for young people living with HIV and wider communities. Protective laws that ensure non-discrimination to reduce stigma, and change harmful gender norms are central to Positive Health, Dignity and Prevention. Legislation must enable HIV-positive individuals to protect themselves and others; not through fear, but through empowerment and with dignity.

This approach recognizes the need to tailor specific interventions for various unique populations of young people living with HIV around the world and emphasises the leadership of young people living with HIV in this process.

CALL TO ACTION FOR POLICY MAKERS AND SERVICE PROVIDERS:

Scale-up youth-friendly and population specific prevention, treatment and care interventions, including psychosocial supports and sexuality counselling, delivered through a Positive, Dignity, Health and Prevention framework, a right-based approach that supports the health and wellbeing of and leadership of people living with HIV.



THE PROBLEM WITH STATISTICS

A major gap in the response to HIV is the disconnect that occurs between what statistics are saying and how programmes and services are designed. For example, the UNAIDS statistic that approximately 45% of new infections occur between young people aged 15-24 years old is often used to advocate solely for primary prevention for HIV-negative young people²⁶. But what about all the young people who contracted HIV and become part of this statistic? The multiple meanings behind statistics are often ignored, when they could be used in a meaningful way to support programmes and services addressing the complexities of the HIV epidemic. There is a need for further evidence-based research focusing on young people living with HIV as the target population. There is currently a severe shortage of reliable data on young people living with HIV. Few countries follow the United Nations General Assembly Special Session (UNGASS)

Declaration of Commitment on HIV/AIDS Core Indicators²⁷ under which they are required to disaggregate data (collect separate data) according to gender and age. While some countries have started to ensure comprehensive reporting on young people's data in 2009 there is still an overall gap in knowledge on this group. Gathering better data on young people living with HIV will help us to better understand the current trends and situation and what creates barriers to designing, developing and implementing comprehensive, relevant and sustainable programmes and interventions for this group²⁸.

To better understand the complexities of the epidemic we also need to compliment statistics with quantitative measures. Instead of collecting quantitative information solely on the sex patterns of young people, information should be complimented with qualitative data (measured through on why they are having sex and why they may not be having sex, including collecting information on the motivations behind safe or unsafe sex. Greater collection of qualitative

data on young people living with HIV can provide us with insight into the emotional and cultural reasons young people are able to or unable to make healthy sexual choices.

CALL TO ACTION FOR POLICY MAKERS:

Encourage the collection of comprehensive data on diverse groups of young people living with HIV, which includes both quantitative and qualitative data to provide a more complete picture of the needs, gaps and facilitators of physical and emotional health for these groups.

HIV TESTING COMPLEXITIES AND STIGMA

A vast majority of young people living with HIV do not know their HIV status²⁹. Some of the factors that have attributed to this situation include the lack of information or education on HIV, lack of access to sexual and reproductive health services and supports among young people, lack of testing sites or clinics for young people that are youth-friendly particularly in most rural areas, and the stigma and discrimination associated with HIV that hinders young people to get tested.³⁰

The lack of young people getting tested is an issue even in resource-rich settings, which highlights that there are obstacles to testing beyond accessible information, education, services and supportive legislation. Stigma is highly complex and even when services and information are in place in resource-rich setting, such as Western European countries, stigma can still acts as an obstacle. For example, there are mounting concerns that some young people are opting out of getting tested so that they intentionally will not know their status due to the fear of criminal prosecution in countries where HIV transmission and exposure are being criminalized³¹ although there is limited evidence to support this.

The factors that facilitate supportive environments that enable young people to know their HIV status need to be further investigated. There are many

unknowns in this area, but addressing HIV-related stigma is more complex than ensuring accessible information, education, services and supportive legislation.

CALL TO ACTION FOR POLICY MAKERS:

Reverse laws criminalising HIV transmission and non-disclosure which heavily stigmatize HIV and work against best available public health practice.



SPECIFIC INTERVENTIONS BALANCED WITH NORMALIZING HIV

Young people living with HIV want to know and feel that essentially they are like any of their peers, who want to live productive lives, get a job, start family as they desire and realize their dreams by maximizing their skills and potential³². But at the same time, young people living with HIV are an exceptional group, with specific needs, who need specific services. One of the challenges facing the development of policies and programmes for populations of young people living with HIV is

the need for specific interventions that will address their unique needs, balanced with the need to normalize and mainstream the experience of being HIV positive. The unique needs of young people living with HIV are the need for accessible and specific information youth-friendly health and support services, safe and supportive environments and skills to address their issue of being both young and HIV-positive, which also includes specific information and supports for the many other groups that young people may also be part of, such as young women, people who use drugs, or young gay men or other men have sex with men and young sex workers³³. This is a complexity that is hard to overcome and one that must be recognized when working with young people living with HIV.

HIV prevention messages and campaigns that are designed to warn people about HIV and encourage them to have safe sex or not share needles often result in sending stigmatizing messages to young

people who are already living with HIV. Creating balanced messages that are designed to prevent new HIV infections, but also normalize the lived experience of young people living with HIV is a real challenge in every day practice. Involving young people living with HIV in all aspects of HIV prevention campaign design that are aimed at young people will help to ensure that messages are supportive, relevant and not stigmatizing.

CALL TO ACTION:

Consult with and meaningfully involve young people living with HIV in all aspects of HIV prevention campaign design to ensure appropriate and non-stigmatizing messages.

THE MEANINGFUL PARTICIPATION OF YOUNG PEOPLE LIVING WITH HIV

Often young people living with HIV are overlooked, tokenized, not taken seriously or are simply the targets of policies, programmes and services. But, young people living with HIV have the right to self-determination and to be meaningfully engaged

to participate in all levels of programme decision-making, and policy processes that affect their lives³⁴. This right is called the principle of 'Greater Involvement of People Living with HIV' (GIPA)³⁵ and is often referred to as "nothing about us, without us!" GIPA aims to enhance the quality and effectiveness of the HIV response through the personal experiences and knowledge of people living with HIV³⁶.

Meaningfully engaging young people living with HIV has multiple benefits, including improving self-esteem, decreasing isolation and depression, and improving health through greater access to better information about care and prevention. Engaging young people living with HIV in HIV responses can challenge fear, prejudices and stigmatizing and discriminatory attitudes as well

as provide valuable experiences and invaluable knowledge that can support ensuring that responses to HIV are relevant, realistic, sustainable and cost-effective (ensuring that resources are not wasted with less relevant interventions). The need for relevant and realistic programmes and policies is urgent as countries scale-up their national HIV responses toward the goals of universal access to prevention, treatment, care and support.

While many young people living with HIV are involved in the response to HIV, others do not want to be. It must be recognized that just being HIV-positive doesn't mean that a person will be involved in the response to HIV. There are young people living with HIV who just want to live their lives, go to school, get a job, build relationships and families, and they have the right to do so.



MAKING ENGAGEMENT AND PARTICIPATION TRULY MEANINGFUL

There are many ways to engage young people living with HIV, including through policy or programme development processes; on committees; as staff people; as speakers and spokespeople; as engaged participants in conferences, meetings, consultations; as part of participatory research project teams, evaluation participants or as research subjects. But, whichever way young people are engaged, there are real costs for engagement that fall on both the young people and those working with them.

Often young people living with HIV are used as tokens³⁷. This means they are used to fill seats on committees and make programmes and interventions 'look good', though their voices are not heard and accepted or their expertise is overlooked. In many instances young people living with HIV are used to 'tell their story' as examples of what others are 'not supposed to be' to support prevention efforts. Mentorship, financial and psychosocial supports need to be in place to fully support the participation of young people living with HIV. Current structures and support mechanisms are not able to provide the unique supports that are needed to truly engage meaningfully this group³⁸.

When young people are engaged to 'tell their story' as speakers at conferences or as part of a educational programme or workshop they are often opening up wounds and sharing traumatic experiences with those they are speaking to. When the presentation is over the young person is still living with HIV and their trauma doesn't go away, they go home and live with it. Greater support for

the psychosocial needs of young people living with HIV who are speaking at events is needed. It must also be recognized that when a young person who is not living with HIV gets involved in the global response to HIV that it is often good for their career and educational goals. But the reverse can be said for young people living with HIV, who often experience hardships, discrimination and are expected to do work on a solely volunteer basis. This is an issue that needs to be better addressed by the global HIV movement if young people living with HIV are to be truly engaged. It must also be recognized that when young people living with HIV are taking part in the HIV response they are often taking time away from their daily lives which includes being in school, spending time with their families, and working in jobs to make money and build a career. Young people living with HIV specific expertise must be rewarded for their efforts and need to be compensated for their work.

A CALL TO ACTION:

When engaging young people living with HIV ensure the following:

- **Assess your capacity:** Do a self-assessment whether your organisation has the capacity and support in place to truly support meaningful participation (Use the NGO Code of Good Practice for NGOs Responding to HIV/AIDS Self-Assessment tools: <http://www.hivcode.org/>).
- **Invite more than one young person:** Two young people should always be invited to meetings where they are to act as representatives so they can support each other; this also

ensures that multiple young people's capacities are developed.

- **Build in time for preparation and capacity building:** Ensure there is time and supports for preparation, capacity and skills building. Young people need time and support to build skills to effectively participate.
- **Supports are in place:** Ensure there are mentorship supports in place including social and peer support and that young people living with HIV are aware of psychosocial supports and resources.
- **Compensate appropriately:** Make sure that young people are compensated for their time, and are aware of all possible costs. Do not assume they have access to credit and make sure their childcare costs are covered as many young people living with HIV are also parents.
- **Hire young people living with HIV:** Young people living with HIV have skills and are experts, hiring them in decision-making positions will build capacity, reduce stigma and create new leadership.



The active and meaningful engagement of young people living with HIV is central to achieving universal access targets and realising human rights. Young people living with HIV are no longer a group to be targeted by interventions, but a group to engage with in what many are already doing to reverse the impacts of the HIV epidemic. Take forward these calls to action to support young people living with HIV claim their rights!

RESOURCES

Living Positively Resources from the Global Youth Coalition on HIV/AIDS (GYCA):

<http://www.youthaidscoalition.org/page/LPresources>

Hope's Voice International:

An international group that challenges HIV-related stigma through the production and presentation of innovative educational lectures, events. <http://hopesvoice.org/>

Live Positive/ Vie Positive:

A Canadian website where young people living with HIV can go for interactive information, games, message boards and more. <http://www.livepositive.ca>

Verdict on a Virus:

A guide from International Planned Parenthood Federation (IPPF) about the criminalization of HIV transmission or exposure and the related health, human rights and legal implications. <http://www.ippf.org/en/Resources/Guides-toolkits/Verdict+on+a+virus.htm>

UNAIDS Inter-agency Task Team on HIV and Young People (IATT/YP) web-page:

Includes useful guidance briefs on HIV interventions for young people. <http://www.unfpa.org/public/iattyp>

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¹ (UNAIDS, 2007)

² (UNAIDS, 2008)

³ (UNAIDS, 2007)

⁴ (UNAIDS, 2007)

⁵ (United Nations Interagency Task Team on HIV and Young People, 2008)

⁶ (UNAIDS, 2007)

⁷ (United Nations Interagency Task Team on HIV and Young People, 2008)

⁸ (Fransen-dos Santos, 2009)

⁹ (United Nations Interagency Task Team on Prevention of Mother-to-Child Transmission of HIV, 2007)

¹⁰ (United Nations Interagency Task Team on Prevention of Mother-to-Child Transmission of HIV, 2007)

¹¹ (UNAIDS, 2007)

¹² (WHO, 2006)

¹³ (WHO, 2006) and (Global Youth Coalition on HIV/AIDS (GYCA), September 2008)

¹⁴ (aids 2031, 2009)

¹⁵ (WHO, 2006)

¹⁶ (WHO, 2006) and (Global Youth Coalition on HIV/AIDS (GYCA), September 2008)

¹⁷ (GNP+, ICW, Young Positives, EngenderHealth, IPPF, UNAIDS, May 2009)

¹⁸ Comprehensive sexuality education is defined as being accurate and age appropriate, including information on family planning (access to family planning measures, condoms etc.), the dangers of early pregnancy, and HIV and STI prevention, symptoms, sexual

²⁴ (WHO, 2006)

self-esteem and management of the disease. (GNP+, ICW, Young Positives, EngenderHealth, IPPF, UNAIDS, May 2009)

¹⁹ UNFPA web-page on young people and HIV:

<http://www.unfpa.org/hiv/people.htm>

²⁰ (GNP+, ICW, Young Positives, EngenderHealth, IPPF, UNAIDS, May 2009)

²¹ (WHO, UNICEF, UNFPA, UNAIDS, LSHTM, 2006)

²² (GNP+, ICW, Young Positives, EngenderHealth, IPPF, UNAIDS, May 2009) and (WHO, 2006)

²³ (WHO, 2006)

²⁴ (Global Youth Coalition on HIV/AIDS (GYCA), September 2008)

²⁵ (The Global Network of People living with HIV (GNP+), September 2009)

²⁶ Primary prevention is defined as prevention campaigns and messages that are aimed at preventing HIV-infection among those who are HIV negative. Primary prevention messages assume that the target audience of their message is people living HIV negative and with unknown status.

²⁷ In 2001, 189 governments committed to the UNGASS Declaration of Commitment on HIV/AIDS, which, among other stipulations, laid out specific targets and indicators by which to reduce the spread of HIV and AIDS. These are to be reported on every two years to the Secretary General of the United Nations. (The Joint United Nations Programme on HIV/AIDS (UNAIDS), 2007)

²⁸ (Global Youth Coalition on HIV/AIDS (GYCA), September 2008)

²⁹ (WHO, 2006)

³⁰ (WHO, 2006)

³¹ (Verdict on a virus, IPPF, GNP+ and ICW, 2008)

³² (Global Youth Coalition on HIV/AIDS (GYCA), September 2008); (WHO, 2006) and (Fransen-dos Santos, 2009)

³³ (Global Youth Coalition on HIV/AIDS (GYCA), September 2008) and (WHO, 2006)

³⁴ This right is also enshrined in the UNAGSS declaration of Commitment on HIV/AIDS. In 2001, 189 United Nations member countries endorsed the GIPA Principle as part of the Declaration of Commitment on HIV/AIDS. The 2006 Political Declaration on HIV/AIDS unanimously adopted by 192 Member States at the 2006 High Level Meeting on AIDS also advocated the greater involvement of people living with HIV. (The Joint United Nations Programme on HIV/AIDS (UNAIDS), 2007)

³⁵ The GIPA Principle was formalized at the 1994 Paris AIDS Summit when 42 countries 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" (The Joint United Nations Programme on HIV/AIDS (UNAIDS), 2007)

³⁶ (The Joint United Nations Programme on HIV/AIDS (UNAIDS), 2007)

³⁷ (WHO, 2006)

³⁸ (WHO, 2006)