

Catalysts for Change:

A blueprint for moving from youth inclusion to youth leadership in HIV responses



Stephen Lewis
Foundation

20
Years



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Meaningful adolescent and youth engagement is an inclusive, intentional, mutually respectful partnership between adolescents, youth, and adults whereby power is shared, respective contributions are valued, and young people’s ideas, perspectives, skills, and strengths are integrated into the design and delivery of programs, strategies, policies, funding mechanisms, and organizations that affect their lives and their communities, countries, and world.

— *Global Consensus Statement on Meaningful Adolescent and Youth Engagement*¹

In July 2023, the Stephen Lewis Foundation (SLF) brought together eight youth leaders from five community-led organizations (CLOs) in Uganda, Kenya, and Zimbabwe to share their priorities and experiences with the SLF and with their CLO counterparts. Having participated in and benefitted from programs and leadership opportunities led by their CLOs, these youth leaders respect and appreciate the depth of support provided by the CLOs, in some cases from the time they were young children. Alongside this appreciation, they have a desire to see CLOs and national HIV and AIDS response systems grow, be responsive to their expressed needs, and evolve just as the young people themselves have. At this meeting, held in Dar es Salaam, Tanzania over three days, the youth leaders thoughtfully discussed the changes and investments that are needed to evolve the HIV response to one that is more inclusive, participatory, and responsive to the needs of young people living with or affected by HIV.

The issues the youth participants raised included:

1 Meaningful involvement



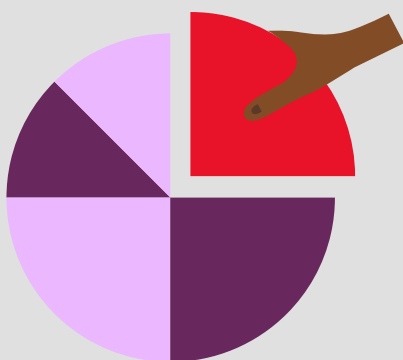
Young people living with HIV are a diverse, dynamic demographic, and HIV impacts their lives in different yet intersecting ways. Young people expressed a need to deepen and extend programming to better support their nuanced experiences. This includes valuing and respecting their perspectives enough to expand organizational systems and grow operational structures in a manner that involves young people living with HIV in all aspects of CLO operations and governance as well as national HIV planning processes. This kind of involvement requires a change in organizational culture and a shift in wider social norms. It also necessitates a willingness to continuously work with young people to learn how best to involve them in youth-centred agendas based on their identified priorities and realities. The benefits to meaningful involvement can be monumental if done respectfully, transparently, and inclusively. For young people, involvement is an avenue for increased self-esteem and responsibility as well as improved community engagement.

2 Scaling up prevention efforts



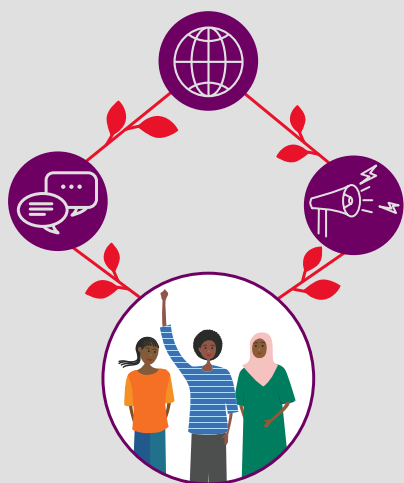
For young people and CLOs, meaningful prevention programming includes more than biomedical interventions and knowledge sharing. It also involves brave conversations and specific initiatives to uproot complex, deeply held ideas and behaviours that are present in wider society. These social norms underpin personal understandings of relationships, love and human connection. Young people at the roundtable expressed deep concern about finding and maintaining loving relationships for people living with HIV. Some young people expressed considerable difficulty in navigating relationship spaces while living with HIV especially in the context of discordant relationships. Part of this difficulty stems from ongoing stigma and the need for more awareness raising around U=U (undetectable=untransmissible). They also identified a need for comprehensive, accessible sexual and reproductive health and rights education for young people. Empowering girls and women through these prevention efforts is paramount. However, in the context of navigating relationships with peers and partners, more comprehensive strategies that intentionally engage boys, young men, and those who are gender non-conforming are also needed. Young people call upon CLOs and gender equality organizations and ministries to work together to reflect on how services for boys, young men and those who are gender non-conforming can be improved to support young people to build healthy, consensual relationships.

3 Youth involvement in organizational planning and structures



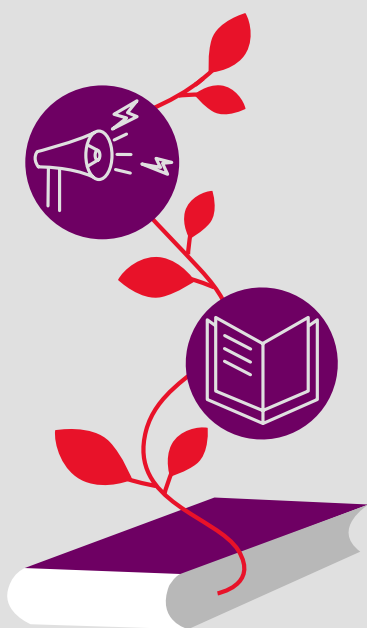
Young people know they can offer value to the CLOs and national HIV partners as a largely untapped and underutilized human resource. However, even after they undertake substantive training and personal development, opportunities for leadership are limited, and older adults often occupy roles well suited to young people who are eager to hone their leadership skills. Additionally, youth programming agendas are usually set by non-youths and tend to focus on the limitations of young people rather than on their initiative and unique insights and perspectives. The youth at the roundtable were clear that organizational cultures, along with wider cultural and societal attitudes toward young people, need to advance. CLOs must recognize the need for youth-centered agendas created by the young people their programs are meant to serve. Furthermore, organizations must have clear strategies on how to involve them in planning, decision-making, budgeting, and governance. Involving young people in meaningful ways within organizational structures needs to be intentional, integrated and transparent. This includes facilitating and operationalizing opportunities for genuine mentorship and collaborating with young people to establish practical avenues for their participation and contributions to the organization.

4 Access to national and international policy agendas



As long as young people's voices continue to be missing from national HIV policy conversations, policies will continue to fall short of adequately addressing youth's needs. Young people emphasized that national policy discussions must be made more accessible and inclusive of young people affected by HIV as well as the CLOs who work with them. They want their voices to be present, heard and counted in policy discussions that affect them. They are best placed and ready to articulate their own issues at all levels — local, regional, national and international. Youth participants requested support in documenting their work and communicating their impact to facilitate their advocacy for inclusion in policy discussions and to provide national policymakers with the evidence required to develop meaningful, effective policy.

5 Advocacy and activism



When young people take on roles as activists, advocates and youth leaders, they frequently share their personal experiences to encourage their peers. This activism often involves talking about their HIV status, past traumas or unresolved family issues. Many have been sharing their stories since they were children, and now as young adults, they wonder how they could tell their stories differently to better reflect the people they are becoming or have already become. They want to share their stories honestly and authentically to help others, but the frequency with which they are expected to share so much of themselves is unsustainable. Youth leaders want more control of their stories and narratives as they undertake advocacy without risk of repercussions for themselves or their organizations such as missing valuable growth and funding opportunities. They want to avoid being narrowly defined by their HIV status or their past. They want more control over their narratives on various platforms and want to work with their CLOs to find ways to do meaningful advocacy while protecting young people and their stories from being exploited. As they redefine their own narratives, these youth leaders can support other young people in owning and defining their own stories from a young age.

6 Sexual and reproductive health (SRH) services and targeted gender transformative programming



Mixed messaging and partial information about sex and sexuality harms young people. For young people living with HIV, this is even more pronounced due to the persistence of HIV stigma and misinformation about HIV transmission. Yet, political, cultural and religious beliefs about sex and sexuality continue to limit the scope of SRH education many young people receive from parents, teachers and community leaders. Additionally, these societal structures have too often become a barrier to young people's access to sexual and reproductive health services. Young people living with and affected by HIV are advocating for community-led organizations and schools to commit to delivering consistent, evidence-based, age-appropriate sexual and reproductive health information. To be most effective, this education needs to be combined with skills-building on navigating relationships and transforming gendered power dynamics. Key stakeholders like the government and CLOs should work together to ensure there are child and youth friendly services for SHR at health facilities and safe spaces.

7 Economic empowerment



Across sub-Saharan Africa, young people of working age are twice as likely to be unemployed as adults. This is intensified for youth living with HIV who may experience self- and societal stigma and discriminatory workplace policies and attitudes on top of the scarcity of employment opportunities that young people in general face.

Many community-led organizations responding to the impacts of the HIV epidemic already incorporate income-generating activities as an essential part of their programming. However, young people who have been supported by CLOs to complete their education and build their leadership skills want training for and access to employment opportunities in new and emerging economies in addition to or instead of informal and traditional forms of income generation such as training in skilled trades, and the production and selling of goods. Training in practical entrepreneurship and life skills can prepare young people to start and manage their own enterprises.

Young people living with and affected by HIV are asking for a multi-sectoral approach to youth economic empowerment. They recognize that CLOs are often over-stretched and they are ready to collaborate with CLOs to identify opportunities for mutually beneficial partnerships with the private sector and governments to increase training and networking opportunities for youth economic empowerment. Both the public and private sector also need to invest in creating awareness about financial products that benefit young people who often struggle with capital for business start-ups.

8 Mental health support for youth leaders



With the support of community-led organizations and their own passion and commitment, many young people living with or affected by HIV have become leaders among their peers. In many cases, they have received psychosocial support from CLOs over the years and are now peer educators, offering support and guidance to other young people. Their leadership and accomplishments, paired with stigma around mental health issues, can contribute to the assumption that young leaders do not need ongoing access to mental health support and services. Young people living with or affected by HIV are passionate, inspired, smart and resilient and, in many cases, they are also touched by poverty, abuse, unemployment and difficult family dynamics. They are advocating for CLOs to raise resources to develop effective interventions, including strategies for managing stress and anxiety, and for promoting self-care for young people and for their own staff.

Community-led organizations have been instrumental in providing holistic support such as psychosocial services, medical care, education, and food and nutrition to children and adolescents affected by HIV and their caregivers. Now, many of those children from their communities are young adults who have evolving needs as well as the desire and capacity to lead.

These young leaders are deeply grateful for years of support from their CLOs, and they are demanding their rightful seat at the decision-making table in their communities and countries moving forward. They are calling upon CLOs and national HIV partners to center their voices, honour their expertise, and meaningfully include them in decision-making. The international community and national governments also need to honour their own responsibilities to invest in both CLOs and young people as valued partners. Investment in this new generation of young leaders is needed to strengthen their capacity to deliver effective services that can reach the people who need them the most. It will require a global paradigm shift on the inherent value that young people, in all their diversity and lived experiences, bring to decision-making spaces at all levels.

Special thanks to the following organizations for their support to the youth leaders:

- Ripples International (Ripples) in Kenya,
- Chiedza in Zimbabwe
- MU-JHU Care Limited (MU-JHU), Reach Out Mbuya (ROM), and St. Francis Health Care Services (St. Francis) in Uganda.

Our thanks and gratitude to the following youth leaders for their thoughtful participation in the workshop and the development of this report:



Sunday Akullu

My name is Sunday Akullu, a Ugandan born and living with HIV. I was born to a family of four out of which I was the only one who turned out HIV positive. As of today, I have grown up to become a well-equipped and helpful young adult who supports children and adolescents living with HIV. I started supporting adolescents and children in 2016 when I got attached to Reach Out as the Teenage and adolescent supporter in the community. While supporting the children, I look at their adherence toward ARVs and any hindrances present. Most children face the problem of being stigmatized in the community they stay in but with continuous counselling, they become better. I used to support the Friends Forum program funded by the SLF team. The program targeted the adolescents who are HIV positive from the age of 10 to 24. There was a package to unpack which included adherence, disclosure, stigma and discrimination, and life skills among others.

I am currently working as a social worker under the USAID OVC Kampala Activity where I support the children living with HIV to ensure they have good adherence and are able to suppress the virus. We also ensure that they are educated and living in a safe environment.



Winnifred Kasoga

I am Winnifred Kasoga a music, dance and drama coach, dance artist, peer counsellor and youth advocate supporting fellow young people with basic Sexual Reproductive Health and Rights information and HIV information. I support young people in life skills and advocacy skills both in and outside school and create and ensure there is a safe space for young people while accessing services at the facility.

Currently I :

- refer and follow up with those that need services and those that have received them.
- create awareness on the youth friendly services that are available and also mobilise young people to receive services.
- train and create awareness using music and dance.
- provide support during adolescent clinics to disseminate information most especially during the ART clinic to support those on ART to adhere and cope with stigma.
- conduct dialogue meetings as a mode of creating awareness on different issues affecting young people and find possible ways of managing or overcoming them.



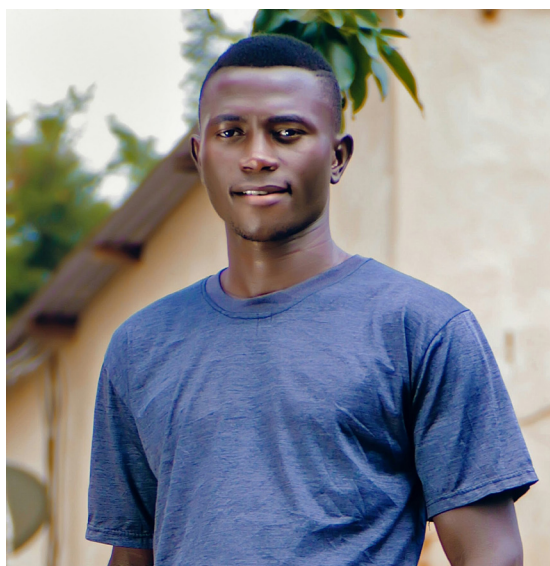
Floridah Kathoni

My Name is Floridah Kathoni, I am a beneficiary of an SLF education program through Ripples International, My mother passed on when I was very young and I was taken by my grandmother who took care of me. Ripples International rescued me from the abuse I was going through at my grandmother's place and I was sheltered at Tumaini center. Later, I joined a high school where I did my Kenya Certificate of Secondary Education. Currently I am a 3rd year student at Meru National Polytechnic where I am pursuing a diploma in agriculture.



Charles Kiganda

I work with Makerere University John Hopkins University Research Collaboration (MU-JHU) as the Youth Trial Board Coordinator. MU-JHU deals in research for various chronic illnesses and also supporting families and communities infected and affected by HIV/AIDS through the psychosocial support division with support from SLF. I support the youth-led activities conducted at MU-JHU to support young people infected and affected by HIV/AIDS through the monthly meetings to address adherence challenges through peer to peer support and also advocating for rights of young people involved in clinical trials and provision of youth friendly services. We also conduct school and community outreach activities to create awareness about HIV/AIDS hence combating stigma and discrimination.



Vicent Kijana

I am a Ugandan male living with HIV since 2014. My grandmother raised me as my parents separated when I was one year old. Today, I am an educated, well-equipped young man who supports children and adolescents living with HIV and AIDS and those not living with HIV and AIDS. I joined ROM in 2017, where I am still working as a Peer Supporter and Educator.

In 2021, I started a football academy that uses football as a tool to equip young people with comprehensive information on how we can end AIDS. In 2023, I was part of the Pathy roundtable, organized by the SLF, which equipped me with information I am now sharing with youth I work with.

ROBUST MIRAS is a football academy under the ROBUST MIRAS SPORTS PROJECT. The project focuses on improving youth's abilities, skills and understanding through sports.

I am also a football referee, football coach, and journalist.



Jane Faith Mutsatsa

Jane Faith Mutsatsa is a 22-year old young woman currently studying for an Honours Degree in History and International Affairs at the University of Zimbabwe. She joined Chiedza in 2017 after she was accepted into the out-of-school program. She is currently a peer educator, mentor and a member of the Child Advisory Board. She is passionate about advocating for and encouraging fellow peers to reach their full potential. She believes that every young person can make it in life if they have a conducive environment to do so.

Faith is currently impacting about 200 adolescents and youth in her catchment. She brings them enlightening education on how to thrive above pressure from circumstances, discrimination and low self-esteem. The system is designed to educate them as to how they can excel to their full capacity in life on the basis of her lived experiences.

It is her dream to be able to do this at an international level as she fully understands that it is not only the young people in Harare that are affected by life challenges in both their lives and in the HIV movement.



Josephine Nabukenya

I am Josephine Nabukenya Founder of *Miles of Smiles Foundation* in Uganda and a published author "*Beyond your status. Thriving in life in spite of HIV*". Over the years, I have been passionate with the provision of psychosocial support to children, adolescents and young people both infected with and affected by HIV and AIDS. This passion has enabled me to support psychosocial activities in Southwestern Uganda and advocate for better treatment options and psychosocial support services on both national and international platforms under the Elizabeth Glaser Pediatric AIDS Foundation. I am also a national trainer of the Young Adolescent Peer Support (YAPS) model in Uganda supporting the Ministry of Health to design, plan, implement and evaluate a standardised peer-led model with lessons learnt from the Community Adolescent Treatment Supporter (CATS) model in Zimbabwe and other key implementing partners involved in service provision in the country. Recently, I am running informative series

about HIV Cure (**#series of Jojo**) for adolescents and young people to understand what is happening around the Cure so that they dismantle the untrue information in our communities and also work with HIV Cure scientists to simplify the Cure terms used for a lay audience.

I hold a Bachelor's degree in social sciences from Makerere University and have attended life-changing courses such as Leading Change from the University of Cambridge as a Queen's Young Leader where my work was also awarded by Her Majesty the Queen of England for the impact created in the world.

I am privileged to serve on two great international platforms, that is the **International AIDS Society Governing Council** as the first African young person under 30, as well as on the **Elizabeth Glaser Pediatric AIDS Foundation Board of Directors** as the first African woman living with HIV.

In my past work, I worked as a Youth program coordinator for the Stephen Lewis Foundation program at MU-JHU Care limited which gave me the opportunity to serve children, adolescents and young people living with HIV.



Huzairu is a 26-year-old youth coordinator at St. Francis Health Care Services. He is also a youth researcher and active HIV/SRHR advocate where he leverages five years of experience on community mobilization with a focus on young people living with HIV and AIDS, TB and Malaria. He also served as a member of SRHR Alliance Uganda Youth Advisory Committee, where he influenced national programming for adolescents and youth in Eastern Uganda under the Get Up Speak Out (GUSO) project.

He also works closely with National Forum for people living with HIV Networks in Uganda (NAFOPHANU) as a peer mentor/supporter to build and strengthen the capacity of YPLHIV. He also supported research on the 2017/2018 HIV and AIDS stigma index; a framework that analyses the levels of HIV related stigma and discrimination in Uganda and proposes recommendations to implementing partners on how to design youth friendly interventions.

Thank you to the Pathy Family Foundation for their generous support for this work with young people and community-led organizations in their efforts to end AIDS.

Championing health and human rights to end AIDS.



Photo Credit: Neema Ngelime, Tanzania



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