

Youth at the Centre: Amplifying the voices and needs of young people to strengthen the HIV response

A Learning Report



Stephen Lewis
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Years

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Photo Credit: Kalaz Media, St. Francis Health Care, Uganda

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Acronyms

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| CLOs | Community-led organizations |
| GBV | Gender-based violence |
| ISAL | Internal Savings and Lending Scheme |
| LGBTIQ | Lesbian, Gay, Bisexual, Transgender and gender diverse, Intersex, and Queer and questioning |
| MU-JHU | Makerere University – John Hopkins University Research Collaboration |
| PrEP | Pre-exposure prophylaxis |
| ROM | Reach Out Mbuya |
| SLF | Stephen Lewis Foundation |
| SRHS | Sexual and reproductive health services |
| STI | Sexually transmitted infection |
| UNAIDS | Joint United Nations Programme on HIV/AIDS |
| UNICEF | United Nations Children's Fund |
| VHT | Village health teams |
| YGA | Young Generation Alive |

Urgency in combatting HIV and AIDS among children and young people

In 2022, an estimated 39 million people were living with HIV worldwide. Almost 1.3 million acquired HIV in 2021 and at least 130,000 of them were children. Nearly 630,000 people lost their lives due to AIDS-related complications.¹ Every preventable death is a tragic loss and a step backward from the global goals of zero new HIV acquisitions, access to treatment for everyone living with HIV with the majority virally suppressed, zero stigma, and zero deaths due to AIDS by 2030.²

The Stephen Lewis Foundation (SLF) supports community-led organizations (CLOs) who are working on the frontlines of the HIV and AIDS epidemic in 14 countries in Africa by providing care and support to women, orphans, grandmothers, and people living with HIV. For 20 years, the SLF has challenged traditional power structures in international development and philanthropy by shifting resources to local communities to build a future free from AIDS.

We work with CLOs through relationships built on mutual trust, support, and learning. In responding to the HIV epidemic, CLOs are the backbone of the HIV response. They meet the needs of individuals, strengthen communities, and advance social change.

In East and Southern Africa, home to 65% of all people living with HIV, more people are accessing HIV testing, especially pregnant mothers, so fewer children are being born with HIV. Expanded access to treatment has improved the lives of many, new HIV acquisitions have been reduced by 57% since 2010, and the number of AIDS-related deaths is declining. While this type of data shows that progress is being made year over year, the margins of progress have become much smaller. Some areas of the HIV response have stalled as CLOs continue to face challenges — funding shortfalls, policy and regulatory hurdles, capacity limitations, and government crackdowns on civil society — all of which impede their efforts.³

The response to end HIV in children and young people, for example, is inadequate.⁴ Without continued investments in this area, the response will categorically stagnate, and hard-fought gains will be reversed. CLOs cannot and should not be alone in the uphill and ongoing fight to directly access flexible HIV and AIDS resources to support urgent and ongoing needs.

In 2022, the United Nations Children's Fund (UNICEF) reported that of the estimated 39 million people living with HIV in the world, nearly 3 million were children and young people under 19 years of age. Nearly 14 million children and young people under the age of 18 have lost one or both parents to AIDS-related illnesses. Millions more children and young people have also been affected by the HIV epidemic through the heightened risk of poverty, homelessness, barriers to education, discrimination, and insufficient socio-economic opportunities.

In addition, adolescent girls and young women in many parts of sub-Saharan Africa still confront an alarmingly high risk of acquiring HIV. The UNAIDS Global Report 2023 underscored that around the world, 4000 adolescent girls and young women aged 15–24 years of age contracted HIV every week, and 3100 of those new HIV transmissions were in Africa. In sub-Saharan Africa, women and girls accounted for 63% of all new HIV transmissions, while in other regions over 70% of new HIV acquisitions were among men and boys. The crisis around children, youth, and HIV and AIDS in Africa remains severe, with particularly dire consequences for young girls due to persistent gender inequalities, limited access to resources, and harmful social norms.

¹ UNAIDS Global AIDS Update 2023, https://thepath.unaids.org/wp-content/themes/unaids2023/assets/files/2023_report.pdf Last assessed online on September 19, 2023

² Global AIDS Strategy 2021–2026 – End Inequalities, End AIDS. https://www.unaids.org/sites/default/files/media_asset/global-AIDS-strategy-2021-2026_en.pdf Last accessed online September 19, 2023.

^{3,4} UNICEF – HIV and children

Global solidarity and local mobilization — collaborators on this report

With longstanding support from the Pathy Family Foundation, the *Reaching Children Through Their Communities: Strengthening the Response to Children Living with and Affected by HIV in sub-Saharan Africa* project was implemented by the SLF's community-led partners. The SLF does not implement projects directly, therefore, this grant built on already existing and ongoing work by CLOs in Kenya, Uganda, and Zimbabwe. The goal was two-fold: First, to draw on the expertise of the extensive network of community-led partners to reach children and youth affected by HIV and AIDS with proven, effective approaches. Second, to promote learning from the powerful, transformational work carried out at the community level to a much broader range of actors in the HIV response.

This learning report is based on the experiences and work of Ripples International (Ripples) in Kenya, Chiedza Child Care Centre (Chiedza) in Zimbabwe, and MU-JHU Care Limited (MU-JHU), Reach Out Mbuya (ROM), and St. Francis Health Care Services (St. Francis) in Uganda. The report also focusses on information shared through narrative-style reporting, ongoing conversations, and discussions from a roundtable held in Dar es Salaam, Tanzania, in June 2023. The roundtable was a space for eight young people and five staff from the five participating CLOs to share what they have learned, reflect on successes and challenges, and collectively plan for future programming and advocacy to strengthen the HIV response for children and young people.



Photo Credit: Neema Ngelime, Tanzania

The vital role of community-led organizations

The CLOs in this report were founded by dedicated groups of individuals who were responding to the devastating impact AIDS had wrought in their own lives and their neighbours' lives. Through continued hard work, sacrifice, and both personal and capital investment, these groups have evolved into trusted local institutions that are deeply rooted in their communities, striving to meet the needs of the most vulnerable. Most importantly, they have the confidence of their community members and consistently provide a range of responsive, life-saving, and life-enhancing programs and services.

CLOs have played a crucial role in increasing access to HIV care, treatment, and prevention services, which improves health outcomes, particularly for marginalized populations. Despite the significant impact of their work, CLOs often remain inadequately acknowledged for their contributions to national public health. They also lack representation in global and national HIV arenas and struggle with insufficient funding and resources.

The disparity between the impact CLOs have locally and nationally, and the resources made available to them, creates an unnecessary contradiction in the current HIV response. While some CLOs receive formal recognition from national governments, this recognition rarely translates into tangible or sustained investments in their work. These organizations advocate for human rights, offer legal services, protect child rights, and provide essential services tailored to meet the needs of the most vulnerable populations.⁵ They mobilize critical resources to sustain their work and to assist community members who are in urgent need of support.

Through their efforts, CLOs make a significant difference in the lives of adolescent girls, young women, vulnerable children, grandmothers, and LGBTIQ individuals. They restore hope, defend rights, fight injustice, and save lives.

Collaborating and working in partnerships with CLOs over the long-term in a consistent and flexible way is critical for their ability to adapt, find new solutions, and remain sustainable. As expressed during the roundtable, CLOs have a deep desire to skill-up to better adapt to shifting contexts, and to invest in youth leadership within their organizational structures to inject new energy and ideas into programs and operations.

Staff and young people alike shared that the continued evolution of the HIV response requires more than increased external funding and national acknowledgment of the important role played by CLOs. It also needs an internal culture shift to engage young people as equals in practice, to value their contributions in all areas of the response, maintain transparency in decision-making, and respect their distinct perspectives and experiences.



Meaningful involvement of young people living with and affected by HIV

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.⁶

— Global Consensus Statement on Meaningful Adolescent and Youth Engagement

The global HIV response has a unique history of fighting for meaningful involvement and representation for people most affected by HIV and AIDS. It is anchored in strategies and policies that remain relevant points of reference for national HIV and AIDS responses. For example, the Meaningful Involvement of People Living with HIV and AIDS (MIPA) was first articulated in the Denver Principles⁷ in the early 1980s and was the foundation of the Greater Involvement of People Living with HIV (GIPA)⁸ which UNAIDS endorsed.

Today GIPA is about making sure populations most affected by HIV are actively involved in decision-making at every level of the response. This principle is important when considering the involvement of young people in all of their diversity. Young people living with and affected by HIV and AIDS must be involved in programmatic, strategic, and organizational decision-making by CLOs, yet youth leaders who were consulted in the roundtable said they felt removed from critical decision-making spaces.

Young people living with HIV cannot be defined solely by age and HIV status. They are part of a diverse demographic. HIV affects their lives in different and intersecting ways, particularly when coupled with variables like race, gender identity, sexual orientation, religious identity, and access to financial resources. These realities shape their experiences and influence how they cope with HIV through different stages of their life and development. CLOs have built expertise over time to identify the most effective and age-appropriate strategies for young people. Their approach involves creating opportunities for young leaders to engage in meaningful organizational leadership as well as decision-making.

Community-led organizations, particularly in regions like sub-Saharan Africa, have embraced a fundamental principle: holistic care is vital for young people living with HIV. This approach goes beyond medical treatment, and recognizes that youth need comprehensive support, including leadership development, to thrive. This holistic model encompasses a wide range of services, which address physical, emotional, educational, and leadership needs to nurture young people and empower them to take charge of their health, their lives, and their futures.

⁶ The Global Consensus Statement in Meaningful Adolescent and Youth Engagement, PMNCH, August 2020. <https://pmnch.who.int/resources/publications/m/item/global-consensus-statement-on-meaningful-adolescent-and-youth-engagement> Last accessed online September 19, 2023

⁷ Meaningful Involvement of People Living with HIV and AIDS (MIPA) – The Denver Principles of 1983/ The Denver Principle Manifesto. https://actupny.org/documents/denver_principles.pdf

⁸ GIPA Policy Brief – UNAIDS. https://data.unaids.org/pub/briefingnote/2007/jc1299_policy_brief_gipa.pdf Last accessed online on September 19, 2023



Photo Credit: Siyano Photography/Chiedza Child Care Centre, Zimbabwe

Chiedza, for example, supports children living with and affected by HIV through a holistic approach. They acknowledge that a child requires more than one intervention to thrive. The organization works with other stakeholders so that children can receive comprehensive services. Chiedza, like many CLOs, provides children with nutritional, educational, and psychosocial support, while ensuring caregivers, often grandmothers, have the parenting skills, nutrition knowledge, and economic empowerment to support the children in their care.

The provision of wrap-around services to accompany anti-retroviral therapy ensures that children grow into thriving young people who have a sense of agency about their futures. Marisa's (not her real name) story is a testament to this restoration of hope: *"My first day at Chiedza is a day that I will never forget. The day was a turning point of my life. Considering my poor family, I never thought I was going to be back in school and sit for examinations. I am glad that Chiedza assisted me during the most difficult time, and I am now the first child in a family of four to be enrolled at university. I am now a role model for other family, colleagues, and children who are supported by Chiedza. I am confident that I will sail through and empower other adolescent girls."*

CLOs support and work alongside young people living with HIV as they navigate the distinct challenges of this stage of their lives.

ROM staff also use different strategies depending on the young person's age. In early childhood, children are supported through play. The organization has several play centres equipped with books and toys, staff, and volunteers. As children get older, they are referred to age-appropriate groups and receive support through storytelling and therapy. Nutritional support is offered on all clinic days where families can be assessed to determine whether additional support is needed.

At Young Generation Alive (YGA), MUJHU's children and youth psychosocial program, children, adolescents, and young adults affected by HIV and AIDS are supported to develop skills in self-expression, self-awareness, and self-actualization through the provision of holistic psychosocial activities. Young people engage in regular support groups and sports and are provided with further counselling and treatment adherence support as needed. Through these interactions, young people build self-esteem and learn to deal with stigma and discrimination while strengthening their life skills. Young people often build on their experience and skills to become peer educators and youth leaders.

The greatest power of the programmatic approach of these CLOs is that as young people grow and evolve, they also become more invested in their own futures. They are driven to exercise the leadership skills they have cultivated. During the roundtable, CLO staff and young people expressed a need to deepen and extend programming to better support the young people they serve, beyond providing access to services and offering them roles as peer educators.

This includes expanding organizational systems and structures in a manner that involves young people who are living with HIV and AIDS in all aspects of CLO operations and governance. It will require change in organizational culture, willingness to learn how best to involve young people, and a youth-centred agenda based on their priorities and realities. The benefits can be monumental if done respectfully, transparently, and inclusively.⁹ For young people, involvement can build self-esteem, increase their sense of responsibility, and improve community engagement.

At an organizational level, youth involvement can enhance and innovate care, quality of services, and program processes and outcomes. At the community level, meaningful involvement of young people affected by HIV in key decision-making spaces can reduce HIV-related stigma and discrimination and expand safe spaces to reach marginalized communities. When young people see peers in positions of power, they are better able to envision themselves taking on leadership roles. The idea is that if they can see it, they can be it.

The Shadow Idol Youth Club, a project at St. Francis, focusses on mentoring youth to achieve their life goals and to stay safe and healthy. Young people take technical training to learn to make documentaries and films, using media and themes that are most relevant to them. Girls also have access to three-month leadership courses and upon completion, they are able to run youth clubs with minimal staff supervision. The clubs conduct school outreach using educational entertainment that taps into the lived experiences of young people living with HIV. Through ongoing support from St. Francis, young people grow their confidence and are now using their voices to advocate for themselves and their peers at regional, national, and international levels.

At MU-JHU, the youth mentored through the YGA initiative are engaged in a range of age-appropriate activities, from sports and group exercise to planning activities for YGA's more than 300 members. The young people continue to expand their social and mutual support networks in safe and structured ways, including through peer-to-peer learning.

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People think young people are empty tins that need to be filled. We are told about avenues to engage but we are not given a chance to exercise what we learned. We have seen spaces meant for young people and older people come in and occupy them. That leaves young people with one avenue — social media.

— Youth leader

⁹ Organisation for Economic Co-operation and Development (OECD) – Evidence-based policy-making for youth well-being. <https://www.oecd.org/dev/evidence-based-policy-making-for-youth-well-being-9789264283923-en.htm> Last accessed online on September 19, 2023

Scaling up HIV prevention efforts to protect young people

In sub-Saharan Africa, HIV prevalence among adolescent girls and young women is more than 3 times as high as it is among their male peers.¹⁰ The 2022 World AIDS Day report by UNAIDS, *Dangerous Inequalities*¹¹ explained how gender inequalities remain a key driver of the HIV and AIDS epidemic especially in sub-Saharan Africa. The report also outlined how the impact of unequal power dynamics and harmful gender norms not only keeps young girls and women vulnerable, but affects their ability to access adequate and appropriate services and therefore their ability to protect themselves from acquiring HIV.¹²

St. Francis works in rural eastern Uganda with Village Health Teams (VHTs) to mobilize pregnant women to access low-cost delivery services at the St. Francis Health Centre. The program aims to eliminate vertical transmission, to monitor clients who are on life-long antiretroviral therapy, and to ensure they go to their clinic appointments. The VHTs encourage all mothers to immunize their children and attend health talks about parenting and childcare. With adolescents, they support a peer-to-peer approach regarding HIV prevention and adherence support for those on treatment.



Photo Credit: Kalaz Media, St. Francis Health Care, Uganda

^{10, 12} UNAIDS Global AIDS Update 2023, https://thepath.unaids.org/wp-content/themes/unaids2023/assets/files/2023_report.pdf Last assessed online on September 19, 2023

¹¹ *Dangerous Inequalities: World AIDS Day report 2022*. Geneva: Joint United Nations Programme on HIV/AIDS; 2022.



I am 20 years old ... I started taking ARVs in 2014 from ROM. I used to fall sick all the time, vomiting, losing weight, and had no appetite. But now I am normal like any other person who is negative and looking healthy so that no one can tell whether I have HIV. I grew up with my mother who is also on medication at ROM, but I have no clear information about my father because he left my mother when she was pregnant. Before I was diagnosed, I was at home one day and a doctor from ROM came to our community, sensitizing the community on HIV and AIDS. My mother took me for HIV testing because she was fed up of me falling sick all the time and spending a lot of money to treat me in the clinic. I got tested and I was HIV positive. After joining ROM, I started receiving HIV treatment and enrolled in the Children's Friends Forum. I realized that there were many children on HIV treatment like me. I have learned how to encourage myself and others who are taking medication like me to adhere to their treatment regimes.

— Montana K., a peer educator at ROM

HIV prevention campaigns continue to incorporate the empowerment of women through various efforts, including increased access to health education, HIV testing for pregnant mothers, access to pre-exposure prophylaxis (PrEP) as well as support for mothers to share their own, and their children's, HIV status with them. That said, prevention is about more than biomedical intervention and knowledge sharing. It also involves complex and deeply rooted behaviours and individuals' personal understandings of relationships, love, and human connection.

Many of the young people at the roundtable expressed deep concern over constructs of love and relationships for people living with HIV. There is a deep desire to find love and maintain healthy, respectful relationships with partners. Some young people expressed difficulty in navigating this space while living with HIV. Part of this difficulty stems from ongoing stigma and the need for comprehensive sexual and reproductive health and rights education.

Another challenge is related to navigating cultural and gendered expectations of relationships, including how power manifests. What love and intimate connections should look and feel like is deeply entrenched and reinforced in popular culture: music, art, and media. Young people spoke about trying to find love with a partner who was not HIV positive, and how challenging it can be due, in part, to gendered power dynamics and societal expectations. They shared examples of how, in discordant relationships, their HIV status was at times weaponized to suggest that they should feel grateful to be in the relationship. These early experiences can lead to mistrust, and shape how young people feel about future relationships.

Gender inequality and harmful social norms remain significant challenges that continue to fuel the HIV epidemic. To mitigate disastrous impact, CLOs continue to invest resources in girls' education and training and skills development for women to promote financial independence and bridge the gender gap. The aspiration is to work toward equality and equity for people of all genders to have equal rights and access to resources, leading to a more stable, peaceful, prosperous, and sustainable world.

Resources must be directed to women and girls because gender inequalities have the most direct and tangible consequences in their lives, particularly at the intersection of other inequities and variables of risk. When women thrive, communities thrive. However, decades of initiatives intended to shift harmful gender norms through the empowerment and resocialization of girls and women has fallen short in creating gender-equal spaces. There is an absence of adequate programming to target the effect of harmful gender norms on boys, men and those outside the gender binary. Programs must dig deeper than knowledge-sharing if they are to succeed in uprooting entrenched beliefs and behaviours. CLOs require more resources to create truly transformative spaces that are inclusive of all marginalized gender identities.

HIV-related stigma, masculinity norms, toxic and otherwise, costs associated with accessing health care, and the way services are delivered are all factors that can contribute to lower health-seeking behaviours and lower access rates of HIV services by men than women. Globally, among people living with HIV aged 15 years and older, knowledge of HIV status, treatment coverage, and viral suppression is considerably lower for men than women.¹³ The growing imbalance in services and care for boys and men can be seen across various regions and epidemic settings.

According to the young people at the roundtable, there remain narrow and heteronormative definitions of what it means to be a boy or a young man, and many societal and patriarchal expectations of men in relationships. The young people expressed that a prevalent and problematic attitude they have encountered is that boys should innately know “what it means to be a young man.” This idea assumes that there are still culturally agreed and specific ways a man should be. The question that remains is: How are these outdated norms and ideas being perpetuated?

Shame associated with archaic attitudes — that boys must be strong, brave, and not cry — can prevent boys and young men from reaching out for help when they need it. When young men enter relationships, they are often ill-equipped to manage their emotions, express vulnerability, and communicate challenges they experience. As a result, they do not internalize or actualize the essential elements of healthy respectful relationships.



*We think we are grown up but we are not. We are young and need guidance.
We need [parents' and guardians'] care and help.*

— Youth leader

Empowering girls and women through prevention efforts remains imperative and urgent. What is also needed are more comprehensive strategies that engage boys and young men, and to strengthen and diversify gender equality programming. There is a need for CLOs to reflect on how services for boys and young men can be improved.

¹³ UNAIDS Global AIDS Update 2023, https://thepath.unaids.org/wp-content/themes/unaids2023/assets/files/2023_report.pdf Last assessed online on September 19, 2023

Youth involvement in organizational planning and structure

Young people who participated in the roundtable shared immense gratitude to CLOs for making life-changing investments in them. They also said they felt like they can now offer value to the CLOs. Taking into consideration their age and abilities with the leadership training CLOs provide, the meaningful participation of young people is a largely untapped and underutilized human resource. They added that another challenge is that opportunities are limited, and adults often occupy roles better suited to young people who are eager to hone their leadership skills.

For mentoring schemes to be more effective, they need to be as diverse as young people's lived experiences and ambitions. Agendas are usually set by adults and tend to focus on youth limitations rather than on their initiative and unique insights and perspectives.

Organizational cultures, along with wider cultural and societal attitudes toward young people, need to advance. CLOs must recognize the need for youth-centred agendas created by the young people their programs are meant to serve. 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 collaborating with young people to establish practical avenues for their participation and contributions to the organization.



Photo Credit: Neema Ngelime, Tanzania

Young people are demanding transformational leadership. It is not about tweaking a few aspects here and there to fit them in to check a box. They have made clear that they do not want to be “talked at.” They want to be respected and connected with mentoring and leadership opportunities. They are a diverse group who want access to training on a range of skills, so they can have impact in their areas of interest and experience.

CLO representatives at the roundtable committed to reporting these requests to their organizations. They agreed to reflect and review their organizational policies with an aim to co-create more youth-specific strategies with young people. They also intend to explore practical opportunities, including shadowing staff at work and sitting on the board of trustees for their organizations.

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Young people’s concerns are not being prioritized at the decision-making level. We need to learn to listen to them and not dismiss them. Voices of young people matter.

— CLO staff member

Access to national and international policy agendas

HIV and AIDS policy work is a specialized area that necessitates both community and youth involvement. HIV policies are guiding documents that help to set out the actions that a country or the international community should undertake to address HIV care, treatment, and support outcomes. They are key to the structure of national HIV programs and the populations they serve. Policies are evolving reference documents that provide guidance for properly planned, implemented, and evaluated programs.

Policy work requires sustained investments in training and knowledge sharing. In the HIV response, contexts are constantly shifting, so it is also necessary to establish current and relevant pathways for continuous policy engagement. Some CLOs have a dedicated policy arm, but the organizations involved in this report work with constrained human and financial resources and therefore must prioritize providing critical frontline services for their communities. They may be left with limited time and opportunity to connect and contribute to local or national HIV policy discussions, let alone access global policy platforms, all of which are critical to shaping the trajectory of the HIV response.

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We need to inform ourselves on the global and national policies that affect our workWe have to interest ourselves in these policies and we all have a contribution to make.... Then we need to disseminate the policies.

— CLO staff member

Among the CLO staff, there were mixed levels of awareness of the link between HIV policies and their day-to-day work. A key concern was, however, a notable lack of access to policy spaces.



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We have good themes and policies, but they are not followed.... Are the platforms accessible to young people? If you talk about young people, you need to hear from young people themselves.

— Youth leader

If young people’s voices are missing from national HIV policy conversations, policies will be developed without their crucial input and are likely to fall short. Young people and CLO staff emphasized that national policy discussions must be more accessible and inclusive of young people affected by HIV as well as the CLOs who work with them.

The young participants specified that they do not want to get “caught out” by national strategies or policies that do not include their input. They want their voices to be present, heard, and counted in policy discussions that affect them. They are best placed to articulate their own issues at all levels — local, regional, national, and international. To facilitate applications for greater inclusion of CLOs and the youth in their programs, participants requested support in documenting their work and communicating their impact to provide policymakers with the evidence required to develop meaningful, effective policy.

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I was challenged by the session on policy, and I now see the importance of making deliberate efforts to influence policy. I have a better understanding of the connection between HIV policies and what is happening on the ground.

— CLO staff member

Advocacy, activism, and youth leadership

When young people take on roles as activists, advocates, and youth leaders, they frequently share their personal experiences to encourage others to live positively with HIV. Roundtable participants shared that it often involves talking about trauma, including unresolved family issues or the death of one or both parents or loved ones. Some young people at the roundtable expressed a fear of burnout, even though they feel that serving as youth leaders is a rewarding experience. Some said they 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. Others said they feel they do not “have their lives together” and yet they are under pressure to be role models for others. They continue to honestly and authentically share their stories with the aim of helping others. At the roundtable, as these young people spoke about their feelings and experiences, it became apparent that for some, the scale on which they are expected to share so much of themselves is unsustainable.

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If I don't tell my story, people will tell it wrong. They might only want to focus on the negatives.

— Youth leader

There were a number of questions raised at the roundtable in need of further exploration and unpacking. How do young people avoid being narrowly defined by the stories they repeat in service of their peers and communities? How do they get more control over their narratives on various advocacy platforms? What can CLOs do to cultivate activism and encourage advocacy while protecting young people and their stories from being exploited? What balance can be struck?

A few of the youth reported feeling overwhelmed by the stress of upholding leadership positions while balancing their personal responsibilities and managing life events. Many young people get little to no remuneration for the peer education work they do. Some are dealing with multiple traumas and feel as though they are retraumatized through the retelling of their experiences in their peer support work. HIV activism and advocacy, and being a role model for many, is both immensely rewarding but also emotionally taxing and lonely at times. The demands of the work can have a negative impact on mental health and well-being.

As a result of what they heard at the roundtable, CLO staff plan to re-examine systems within their organizations to better accommodate young people's needs and to be mindful of what they ask of them. One idea proposed by young participants was to create dedicated spaces to decompress to avoid burnout and reduce dependencies on their peers for support. This is the beginning of an important and ongoing conversation on mental health and wellness, specific to youth leaders.

Addressing unmet needs for young people

Mental health and sexual and reproductive health are complex and nuanced areas complicated by political, cultural, family, and religious realities. CLOs must continuously navigate these influences in their communities and countries. Mixed messaging and insistent approaches by people in positions of relative authority — health care workers, religious leaders, and teachers — present challenges for young people in accessing youth-friendly and human rights-informed services. Yet, having sexual and reproductive health knowledge and meaningfully applying it when learning to navigate through life is fundamentally important for the health and well-being of young people living with and affected by HIV at all stages of life.

In their partner reports to the SLF, ROM highlighted that they regularly hold sexual and reproductive health sessions for adolescents and young adults. For each group, tailored, age-appropriate information is shared for discussion. The sessions raise awareness of sexually transmitted infections (STIs) and gender-based violence (GBV) and provide access to essential health information and services.

Similarly, MU-JHU holds psychosocial support meetings with young people during which they discuss sexual and reproductive health. According to their reports, they credit their success to young people's leadership of these sessions. They take the lead in connecting peers who are having sexual and reproductive health issues with the support they need. MU-JHU also holds football and netball events, during which young people have opportunities to access information on sexual and reproductive health, HIV treatment adherence, and sharing their HIV status.

For many years, young people living with HIV have been advocating for the consistent evidence-based sexual and reproductive health information they need. As they age, they want to be in healthy, loving, consensual relationships built on trust, honesty, and mutual respect. However, stigma, religious and cultural beliefs, and gendered power dynamics are still major barriers to honest discussions, reliable information, and access to effective services.

Some of the young people talked about parents and guardians who refuse to engage with them honestly about their HIV diagnoses, or simply do not have the tools to have difficult conversations. Many will not discuss sex, sexuality, or contraception. Young people are frustrated by not having access to accurate information — including about their anti-retroviral medications — from the people they are supposed to trust the most, including caregivers entrusted with decisions around their medical health. As a result, young people often turn to their peers, websites and search engines, or social media for information.

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There is a need to package this [SRHS] information so that young people get the right information.

— Youth leader

There are already existing spaces that can be better utilized to serve youth. Health care facilities can play an important role in promoting sexual and reproductive health. They can improve the quality and range of services through youth-friendly care and information that is professional, non-judgmental, evidence-based and impartial. Creating youth-friendly spaces that are co-created by and linked to youth groups and CLOs can go a long way toward improving services for young people.

In sharing about themselves and their peers, the young participants suggested that young people living with or affected by HIV often lead complex lives from the start. While they are passionate, inspired, smart, and resilient they also are touched by poverty, abuse, unemployment, and difficult family dynamics. Mental health remains a taboo subject, and as a result, mental health issues are often not diagnosed or dealt with sufficiently.

They are supported by CLOs with psychosocial services and may themselves become peer educators and leaders in their communities, but still some gaps remain. In this post-COVID-19 era, screening for mental health may be a crucial starting point for services. To address ongoing and emerging mental health issues, CLOs need 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.



Photo Credit: Museruka Emmanuel, Uganda

The role of economic empowerment

Across sub-Saharan Africa, young people of working age are twice as likely to be unemployed as adults. Young people tend to be employed informally and for short periods of time, which is correlated with a higher risk of HIV acquisition. Young people living with HIV are unlikely to be employed due to self and societal stigma, discriminatory workplace policies, and the sheer lack of employment opportunities available to them.¹⁴

CLOs involved in this grant have been innovative in incorporating economic empowerment and livelihood initiatives into HIV programming by providing savings and loans opportunities, skills building, and start-up capital to enable families and individuals to start generating income and increase their financial resources. Some of these initiatives have also helped in some small ways to begin to address mental health issues for adolescents and youth that are related to economic insecurity.

For instance, Chiedza incorporated income-generating activities for caregivers into their programming. Caregivers who are supported to work toward increasing their household incomes develop resiliency and are more able to meet the needs of children in their care. Chiedza supports an Internal Savings and Lending Scheme (ISAL) for caregivers and trains them in business management, which equips them with skills to select, plan, and manage their small businesses. Participants form ISAL groups. Together they save funds and lend group members capital to start or boost their income-generating projects.

ROM offers apprenticeships and vocational training in tailoring, catering, hairdressing, and agribusinesses, including poultry farming, to adolescent girls and young women in vulnerable situations. Learning these skills equips them to create businesses, earn income, and support themselves and their families. ROM also equips participants with management skills to increase the viability of their small businesses.

Nassanga Shalom joined the apprenticeship training scheme in 2019 at age 19. She was assessed and enrolled in a tailoring class in which she performed well. When she graduated in February 2020, she was given a sewing machine. After graduation she started selling second hand clothes to get some more capital for further developments. She had working capital of 100,000 Ugandan shillings and later joined a local Village Savings and Loan Association group where she accessed a loan of 100,000 shillings. Her group won during the entrepreneurship competition that was organized by ROM at its Kasaala site. The reward was used to start a boutique with three of her friends. After sharing some profits from the shop, Nassanga started her own boutique in a more marketable area (Ngogolo). She is now one of the best Bitengi [clothing] designers and sellers in Ngogolo town. On a good day, She can earn profits of 40,000 shillings. She is also supporting grandmothers with some basic needs using income from her business.

¹⁴ International Labour Organization – www.ilo.org/aids

Despite these programs and successes, the roundtable exposed a communication and ideological disconnect between CLOs and young people in relation to what they want from livelihood opportunities. Young people flagged that proper market research is needed to identify and diversify career opportunities in communities within evolving economies instead of relying on only short-term training and traditional skills like sewing, crafts, and soapmaking. Through traditional income-generating opportunities, trainees end up offering similar goods and services. Finding markets and ways to differentiate their products requires creativity and ingenuity, which fortunately the young people possess in great measure when they are passionate about their work.

Consultation with this group of young people found that they want to be more equipped for success in new and evolving economies, and for employment opportunities to be more relevant to emerging and creative industries. They noted that it is difficult to sustain personal and professional momentum when income generation remains grounded in providing funds to support only their immediate needs, as opposed to facilitating access to long-term growth opportunities.

“

The current business (economic empowerment programs) are money killers.

— Youth leader

Owning, operating, and sustaining a business is markedly different to learning a skill or trade. Unfortunately, many businesses do not survive to see their first anniversary. While young people may be trained in a trade or production-related skills, like sewing, soapmaking, and crafting, they may be insufficiently trained in how to manage and grow a business. They also need financial literacy, marketing, communications, and organizational skills. Moreover, the trade or skill for which training is offered may not connect to a deep interest beyond supporting immediate survival. These obstacles make genuine momentum difficult to sustain.

“

Instead of giving me fish, teach me how to fish.

— Youth leader



Photo Credit: Museruka Emmanuel, Uganda

While CLOs aim to address the full range of a young person's needs — physical, mental, social, and financial — through people-centred programs, they are not designed to be one-stop shops. Economic empowerment for young people is one area where collaboration with the private sector or the government could be beneficial. Also requested are networking opportunities, a service for linking young people to apprenticeships, entrepreneurship training, and integration of vocational skills and business development.

Many CLOs are overstretched with little capacity or resources left to fully research what their distinct client groups want and need. The disconnect between what young people want and what CLOs can provide is another key area of exploration. The opportunity exists for conversations and greater youth engagement on balancing income generation to meet immediate needs, like food and shelter, with job relevance for long-term satisfaction. By including young people in this conversation, there is the potential to unearth mutually beneficial solutions that satisfy their expressed needs. Economic empowerment programs need to be relevant to young people's lives, and integrate what is practical as well as what will hold their interest and keep them motivated over time.

This learning report highlights a few key issues: the lack of meaningful involvement by young people in decision-making, especially on issues that directly impact their lives, and a lack of clear pathways within CLOs for young people to have input into program planning and budgeting. Young people need to be heard, and what they say needs to be taken seriously and acted upon.

Partnerships with other CLOs

The CLOs who participated in this grant recognize that their skills, experiences, and programming all contribute to a cause greater than their individual organizational missions. They are part of a CLO community working in-country to achieve wider national-level HIV and AIDS outcomes in prevention, care, treatment, and support, including the UNAIDS 95-95-95 targets. There are both programmatic and strategic advantages to sharing resources and insights with each other. There is hope and power in allyship, in community, and in the knowledge that collaboration can strengthen organizations and multiply impact.

The CLOs have shared their work, learned together, supported each other, and built new partnerships. Once the COVID-19 pandemic subsided and most related restrictions were lifted, MU-JHU and St. Francis collaborated on an exchange visit for older children and adolescents. The main goal was for the children and adolescents to connect and share their experiences to reduce any internalized stigma among the group. Through this visit the young people expanded their networks and were reassured that people can live with HIV and enjoy a positive, fulfilling life. The success of the visit is a small but significant reminder that where global health threats are concerned, partnerships and collaborations are key to reaching as many people in need as possible.



Funding and governments

Considerable work has been done since the beginning of the HIV epidemic to invest in HIV prevention and the expansion of HIV treatment to millions of people around the world. Community systems continue to be strengthened to support the most vulnerable and marginalized communities. Indeed, the world has rarely seen individuals, communities, governments, organizations, businesses, and philanthropists come together to collaborate in the way they have to fund the HIV response.

However, the HIV response is at a critical juncture. The goal is to end new HIV acquisitions to support the reality of an AIDS-free generation by 2030. For this goal to be achieved, special focus must be made on children and young people who represent the hope of ending the HIV epidemic. This requires a new injection of funding and resources to those best positioned to protect the progress already made against HIV and AIDS, and to reach marginalized people who remain lost in national responses.

Due to bureaucratic funding processes and investment in large international non-governmental organizations, the necessary resources are still not getting directly into the hands of CLOs to fund their life-saving work. When CLOs do have access to funding, it is usually considerably constrained by burdensome application processes and restricted operational and programmatic flexibility. National governments need to support CLOs domestically and meaningfully involve them in budget planning and discussions on national HIV policies to feed into global policies.

Conclusion

CLOs have shown leadership and vision within national and global HIV and AIDS responses for decades. They mobilize people, generate hope, and increase impact by building the capacity of individuals and communities to look after themselves and others. There is a lot that can be learned from communities in the way they have kept going with minimal resources. They focus on the person and their needs, not only what ails them. They value each community member and journey together with them to rebuild in the face of the HIV epidemic and the uncertainty caused by the COVID-19 pandemic.¹⁴

The international community and national governments need to honour their responsibilities to continue to invest in both CLOs and young people as valued partners. If we are going to end AIDS, children, adolescents, and young adults need to be front and centre in the HIV response and in ending new transmissions. We need continued investment in this new generation of young leaders, to strengthen their capacity to deliver effective services that can reach the people who need them the most.

We are at a critical point in the HIV response at which the value of CLOs cannot be questioned and must be honoured by investing fully in their visions for their communities, where young leaders are eager to lead. Investing in their leadership is an ethical and strategic imperative. Through investments in young people and their leadership, impact will be sustained well into the future. It assures that the most vulnerable have a part in decisions affecting their future, that lived experience is centralized in planning, and that young people are valued as essential contributors to a more equitable and just future for all.

¹⁴ UNAIDS Global AIDS Update 2022. https://www.unaids.org/sites/default/files/media_asset/2022-global-aids-update_en.pdf Last accessed online on September 19, 2023

Championing health and human rights with community-led partners to end AIDS.



Photo Credit: Kalaz Media, St. Francis Health Care, Uganda

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