

AIDS-Free Generation Z:

A Call to Action for Improving Youth-Focused HIV Programming



Acknowledgements

The work of EGPAF is made possible by the generous support of the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) through the U.S. Agency for International Development (USAID) and the U.S. Centers for Disease Control and Prevention (CDC), and through the generous support of Unitiad, the Bill & Melinda Gates Foundation, The Children's Investment Fund Foundation, The Hilton Foundation, Johnson & Johnson, United Nations Children's Fund (UNICEF), ELMA Foundation, and ViiV Healthcare.

We wish to thank Michael Isbell and all the EGPAF staff who contributed to the development of this report. We wish to extend our gratitude to the EGPAF Ambassadors, EGPAF Committee of African Youth Advisors (CAYA) Members, the Global Network of Young People Living with HIV (Y+), the Adolescent Treatment Coalition, and all the young people who openly and honestly shared their personal insights and experiences with us, bringing this report to life. The contents are the sole responsibility of EGPAF and do not necessarily reflect the official views of USAID, CDC, the United States government, or other EGPAF donors and partners.



Acronyms

ACT	Accelerating Children's HIV/AIDS Treatment
AYFHS	adolescent- and youth-friendly HIV services
CAYA	Committee of African Youth Advisors
CCABA	Coalition for Children Affected by AIDS
CDC	U.S. Centers for Disease Control and Prevention
DELTA	Delivering Technical Assistance
DRC	Democratic Republic of the Congo
DREAMS	Determined, Resilient, Empowered, AIDS-free, Mentored and Safe
EGPAF	Elizabeth Glaser Pediatric AIDS Foundation
IMPAACT	International Maternal Pediatric Adolescent AIDS Clinical Trials Network
NGO	nongovernmental organization
PEP	postexposure prophylaxis
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PrEP	preexposure antiretroviral prophylaxis
RHITES	Regional Health Integration to Enhance Services
SDGs	Sustainable Development Goals
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
USAID	U.S. Agency for International Development
WHO	World Health Organization

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Introduction

For more than three decades, the work of the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) has been inspired by the vision of a world in which children, youth and families live free of HIV and AIDS. Created in 1988 by three mothers around a kitchen table, EGPAF has grown to become a proven leader in the global fight to end HIV and AIDS, and a leading voice for children, youth and families to live long, healthy lives.

In its early years, EGPAF focused on spurring urgent research on preventing and treating pediatric HIV and AIDS, motivated by the growing number of infants, toddlers and young children who had acquired HIV during gestation, delivery or breastfeeding. Over time, of course, those young children grew into adolescents and young adults. With a deep and abiding commitment to the health and well-being of this generation, EGPAF's work evolved as well, extending across every stage of development, including infancy, young childhood, adolescence and adulthood. EGPAF provides comprehensive HIV services, including prevention and treatment of tuberculosis and related health services, to people at all stages of life.

Today, EGPAF is one of the world's leading providers of HIV prevention, treatment, care and support for adolescents and young people living with or at risk of HIV.' Just as EGPAF's approaches have evolved to address the needs of children as they age into adolescence and adulthood, EGPAF's knowledge, expertise and programs have expanded to address everevolving needs and challenges and to respond to the still-changing science of preventing and treating HIV among young people. Above all, EGPAF has learned from young people themselves, who continue to provide essential guidance to EGPAF about their own needs and preferences and about how best to reach and effectively serve this diverse population.

This report describes EGPAF's work toward ending HIV and AIDS among Generation Z. Generation Z refers to the generation of people born in the late 1990s and early 2000s. The report summarizes EGPAF's approach and the impact of its work on this population; describes key lessons from EGPAF's experience about how best to reach and effectively serve young people; traces the evolution of EGPAF's work with and for young people, with a particular focus on how the input and guidance of young leaders themselves have shaped EGPAF's approach; and notes the continuing challenges that efforts to end HIV and AIDS among young people confront and recommendations from EGPAF on how to overcome these challenges.

As this report explains, much has been accomplished in the struggle against HIV among young people. But this fight is far from over, especially for young people who account for a disproportionate share of new HIV infections, and who experience worse outcomes than adults with key HIV treatment measures. However, it is equally clear that we have the means to end HIV/ AIDS among young people – if we listen to and meaningfully engage young people, let scientific evidence be our guide, and maintain commitment to see this fight through to the end.



^{*} EGPAF defines the population of adolescents as encompassing ages 10 through 19 years and youth as encompassing ages 15 through 24 years.

² Elizabeth Glaser Pediatric AIDS Foundation

One woman's legacy

EGPAF was born from the most powerful force on earth – a mother's love for her children.

Elizabeth Glaser acquired HIV through a blood transfusion she received at the time she gave birth to her daughter, Ariel. Elizabeth and her husband Paul would later learn that Elizabeth had unknowingly passed the virus to Ariel through breastfeeding and to their son Jake, who contracted HIV in utero.

Ariel was lost to AIDS in 1988. Fearing for Jake's life, Elizabeth turned to her close friends, Susie Zeegen and Susan DeLaurentis, to help create the Pediatric AIDS Foundation to raise funding for pediatric HIV research at time when not a single drug had been tested or approved for children living with HIV. "I felt like I had no choice in what I was doing," Elizabeth later said. "I was following a mother's instinct to try and save her child."

The wife of Hollywood celebrity Paul Michael Glaser, Elizabeth knew she had unique entrée into the doors of wealthy individuals and the offices of decision-makers in Washington, D.C. Early fundraisers generated millions of dollars for the Foundation's mission to jump-start essential research on pediatric HIV treatment and prevention. Elizabeth's address at the Democratic National Convention in 1992 (coupled with an address by Mary Fisher, another woman living with HIV, at that year's Republican convention) focused the nation's attention on the urgent need for action to fight AIDS.

Elizabeth lost her own battle with AIDS in 1994, the very year that the National Institutes of Health initiated the groundbreaking study on preventing mother-to-child transmission (ACTG 076) that the Foundation had urged. That study—the first to show that antiretroviral medicines could sharply reduce the risk of mother-to-child transmission—launched the world on its current quest toward ending new HIV infections among children.

In 1996, the foundation was renamed the Elizabeth Glaser Pediatric AIDS Foundation. Reflecting the humanity, hope, and determination of its founder, EGPAF awarded tens of millions of dollars to support groundbreaking clinical research that improved treatment prospects for children living with HIV, undertook advocacy that persuaded decision makers to require drug companies to test their products in children as well as adults, and in 2000 launched its own first clinical programs in sub-Saharan Africa. As an early implementing partner of the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), EGPAF soon expanded to provide care and treatment in resource-limited settings. To date, EGPAF has supported more than 15,000 sites to offer HIV counseling, prevention, diagnosis, and treatment services alongside high-quality family health care.¹

Although Elizabeth and Ariel lost their battles with AIDS, Jake Glaser today is a healthy young adult living with HIV who continues to work with EGPAF to carry on his mother's legacy. "Life can always be counted on to give you the unexpected," Jake says. "It's up to us as individuals to decide what to do with the cards we are dealt. More than anyone I know, my mom understood this."



Elizabeth and Ariel Glaser (Photo: EGPAF)

HIV and young people: A status report

Important progress has been made in the global response to HIV. Since the global epidemic peaked in 1997, the annual number of new HIV infections has fallen by 40%.² Since 2010, the number of children (ages 0–14 years) newly acquiring HIV has declined by 41%,² with prevention efforts averting an estimated 200,000 new infections among children in 2018 alone.³ Steady improvements in HIV treatment regimens and expanding access to treatment services have cut the annual number of AIDS-related deaths by 56% since worldwide HIV mortality peaked in 2004.³

However, the world's young people are not benefiting equally from the advances made in the response to HIV. For example, the decline in AIDS-related deaths in recent years has been more than twice as great for adults older than 20 as among adolescents.⁴ AIDS remains among the 10 leading causes of death among adolescents globally and among the 5 leading causes of death among adolescent girls between ages 10 and 14 years.⁵ Compared with older adults, young people living with HIV are less likely to know their HIV status, to receive HIV treatment, or to achieve viral suppression.^{6,7} Nearly 10,000 young people are newly infected every week,³ and around 100 adolescents die every day of AIDS-related causes.⁸

In 2018, an estimated 4 million young people were living with HIV worldwide, accounting for 1 in 9 people living with HIV (11%). This number includes an estimated 610,000 younger adolescents between ages 10 and 14, 1 million older adolescents (15–19 years old), and 2.4 million young adults (20–24 years old). Sub-Saharan Africa is home to 89% of all adolescents (10–19 years old) living with HIV.

In 2018, more than 500,000 young people were newly infected with HIV, including an estimated 190,000 older adolescents and 320,000 young adults. Altogether, young people accounted for nearly one-third of all new HIV infections in 2018. Adolescent girls and young women confront especially high risks of becoming infected, with the number of girls who acquire HIV during adolescence more than twice the number of adolescent boys who become infected. These gender disparities stem from a confluence of factors, including physiological differences, gender inequalities, intergenerational violence, and gender-based violence. Every

week, 7,000 young women between 15 and 24 years old are newly infected with HIV.⁵ Although adolescent boys are less likely adolescent girls to acquire HIV, adolescence is a time when young men often internalize gender norms and values that can increase their own HIV-related risks and those of their future sexual partners.¹² Young people who belong to marginalized populations—including men who have sex with men, people who use drugs, sex workers, and transgender people—are at exceptionally high risk of acquiring HIV.¹³

Although extensive evidence and hands-on clinical experience demonstrate that children and young people can thrive on antiretroviral therapy, perinatal exposure to HIV is associated with long-term health consequences. Because many children with perinatally acquired HIV infection experience neurological and cognitive deficits, various interventions (clinical, community-based, school-based, peer-based) are needed to support adolescents and young adults who have lived with HIV and/or been exposed to antiretroviral therapy over many years. On average, children who have perinatal exposure to HIV but do not become infected have poorer health outcomes than children born to HIV-uninfected mothers, underscoring the importance of ongoing health monitoring of all children born to mothers living with HIV.

Under the Sustainable Development Goals (SDGs), the world has committed to end the HIV epidemic by 2030.† By definition, this target cannot be reached if we fail to end HIV among young people. However, the world is not on track to end the epidemic, with especially concerning gaps in meeting the HIV-related needs of young people.

In the 2016 Political Declaration on Ending AIDS, United Nations member states embraced a series of interim "Fast-Track" targets as a step toward the ultimate goal of ending the epidemic. When it comes to young people, the world is far off pace for reaching these interim targets. For example, the 24% decline in new HIV infections among young people from 2010 to 2018 is well short of the 75% reduction envisioned for 2020 by the Fast-Track targets. In 2018, 310,000 adolescent girls and young women acquired HIV—a number more than three times higher than the global Fast-Track target of 100,000.9

^{*} UNAIDS estimates (M. Mahy, personal communication, June 20, 2020).

[†] UNAIDS estimates (M. Mahy, personal communication, June 20, 2020).

[‡] See especially SDG 3, Good Health and Well-Being (https://www.un.org/sustainabledevelopment/health/).

[§] UNAIDS estimates (M. Mahy, personal communication, June 20, 2020).

Unless current trends are reversed, it is projected that the annual number of new HIV infections among adolescents could actually *increase* by 2030, leading to 3.5 million new infections among adolescents from 2018 through 2030.¹⁶

Efforts to put the world on track to end HIV among young people must be grounded in an understanding of young people themselves, which cannot occur without their active involvement and leadership. Youth is a time when human bodies and brains are rapidly developing; a time of experimentation, personal exploration, and new experiences; and a period when many young people take risks. Youth is also a time of considerable vulnerabilities for young people, as many live in poverty, are affected by humanitarian emergencies, and far too frequently experience violence or abuse.

Although it is common to speak of young people living with HIV as a single, undifferentiated group, they are in reality quite diverse. For example, the young people whom EGPAF serves include those who acquired HIV perinatally as well as those who became infected during adolescence or young adulthood.

Moreover, the age range of 10–24 years encompasses a spectrum of needs and perspectives that change as young people age. Younger adolescents typically begin puberty, while sexual debut typically occurs during older adolescence (with a median age of sexual debut in sub-Saharan Africa of 16 for females and 17 for males). Late adolescence and young adulthood is a time of considerable life transition and a common time for starting families, with many women in sub-Saharan Africa giving birth before their 20th birthday. The diversity of young people underscores the need to tailor programs and approaches to each stage of life and to the unique needs of each young person.

The world is experiencing a major demographic wave as the largest-ever generation of young people comes of age. This is particularly relevant for Africa, which accounts for 19 of the 20 countries with the lowest median age. Unless HIV incidence rates come down, the world risks a resurgence of the HIV epidemic. The ability of this generation to transition toward safe, healthy, productive adulthood will largely determine the future of our world, including our success in meeting the SDGs.

In 2018, more than 500,000 young people were newly infected with HIV, including an estimated 190,000 older adolescents and 320,000 young adults.



HIV among young people in the United States

EGPAF's earliest work primarily focused on the United States, and EGPAF remains engaged in efforts to end the HIV epidemic in the U.S. The American record in fighting AIDS not only shows what can be achieved through national commitment and solidarity, but also offers important warnings regarding the consequences of complacency in the HIV response and a resurgence of the epidemic in young people.

One of the most important accomplishments in the response to HIV in the United States has been the country's success in nearly eliminating mother-to-child HIV transmission. Over approximately 25 years, the annual number of children acquiring HIV during pregnancy, labor, delivery, or breastfeeding in the United States has fallen by almost 96%—from a peak of 1,650 in 1991¹⁹ to 73 in 2017.²⁰

Yet at the same time that prevention efforts in the United States have averted thousands of cases of mother-to-child transmission, far too many Americans are acquiring HIV during their youth. In 2018, 21% of new HIV diagnoses in the United States were among young people ages 13–24 years.²⁰ Among young people in the United States newly diagnosed in 2018, 92% were young gay or bisexual men, including 78% who were black or Hispanic/Latino.²¹ As a sign of the need to strengthen prevention efforts for young people, the annual number of new HIV diagnoses among young people in the United States declined by only 6% from 2010 to 2017, with especially concerning increases in new infections among young Latino gay/bisexual men.²¹Children who grow up with HIV or acquire HIV during adolescence often find it challenging to manage their HIV treatment and care. Of the more than 7,000 youth newly diagnosed with HIV in 2017, 21% were ages 15–19 and 79% were ages 20-24, "representing substantial needs for adolescent-focused services and multidisciplinary comprehensive navigation while transitioning from pediatric care to adult settings."22

EGPAF's predecessor, the Pediatric AIDS Foundation, played an important role in developing the architecture for America's AIDS response, persuading the U.S. Congress to include focused projects for

pregnant women and children in the Ryan White CARE Act that continue to serve as a vital safety net for people living with HIV in the United States. Commonly known as Part D of the Ryan White HIV/AIDS Program, these family-focused grants support case management, transportation, child care, and HIV treatment services. Part D programs are a large part of why mother-to-child transmission rates remain so low in the United States.

EGPAF continues to advocate on HIV-related issues in the United States to ensure that the national HIV response addresses maternal, perinatal, and pediatric issues. EGPAF is committed to galvanizing support for high-quality Part D programs, including pushing for continuous evaluation and improvements to perinatal transmission and pediatric/adolescent service delivery implemented under that law. In 2019, EGPAF provided funding to the Bipartisan Policy Center to ensure that its review of key policy and program insights for ending HIV in the United States reflected the experience of programs focused on the needs of mothers, children, and families.²² EGPAF is also a leading voice on the need to incentivize timely study of new HIV medicines to ensure they can be used safely and effectively by children and adolescents, and EGPAF advocates for the inclusion of pregnant and lactating women, as well as children, in research.

EGPAF utilizes its extensive technical expertise to support state and local efforts in the United States to refine and improve HIV strategies around children and young people. For example, EGPAF is currently working on a citywide effort with the District of Columbia to scale up access to pre-exposure prophylaxis (PrEP), particularly for young people. EGPAF staff also serve on a number of expert panels and working groups that establish best practices and standards of care for HIV practitioners in the United States, including the American Academy of Pediatrics Committee on Pediatric AIDS and the U.S. Panel on Antiretroviral Therapy and Medical Management of Children Living with HIV.

EGPAF and young people: An overview

During its first decade, EGPAF focused on laying the foundation for better treatments and health outcomes for children living with HIV, through catalytic funding for cutting-edge research and through advocacy that led to the creation of HIV services for low-income families affected by HIV. EGPAF's programmatic work began in earnest in 1999, when the organization began implementing HIV prevention programs in six high-burden African countries. With PEPFAR funding, EGPAF soon became an important provider of HIV treatment and care in sub-Saharan Africa. In 2014, EGPAF made an organizational commitment to mobilize new resources to expand its services for adolescents.

In 2020, EGPAF works in 13 African countries to address the HIV-related needs of adolescents and young adults. The countries where EGPAF serves young people have among the heaviest HIV burdens in the world.

In 2019, through PEPFAR support, EGPAF provided HIV testing services to nearly 2 million young people ages 10–24. EGPAF provides antiretroviral therapy to more than 125,000 adolescents and young adults. Among 10- to 24-year-olds on HIV treatment who received a viral load test through EGPAF, on average 82% were virally suppressed in 2019, with project results ranging from a high of 95% suppressed in Eswatini (the former Swaziland) to a low of 67% in Côte d'Ivoire. EGPAF's programs prioritize psychosocial support, primarily through peer-driven methods that enable young people to learn from each other and leverage mutual support and resilience. Currently, EGPAF programs are home to more than 500 peer-led psychosocial support groups.

EGPAF provides extensive services to prevent new HIV infections among young people. In 2019, 579,000 young people received modern contraceptive methods through EGPAF programs. EGPAF also provided pre-exposure antiretroviral prophylaxis (PrEP) to 7,388 young people as well as post-exposure prophylaxis (PEP) to 1,121 youth.

EGPAF works in both urban and rural settings. EGPAF's work ranges from the Integrated HIV/AIDS Project in Kinshasa, the large capital city of the Democratic Republic of the Congo (DRC),²³ to programming across rural southwest Uganda, where EGPAF supports even the smallest public health facility. EGPAF is committed to ensuring that all of its programs for young people respond to the social norms, customs, and realities of the young people EGPAF serves.

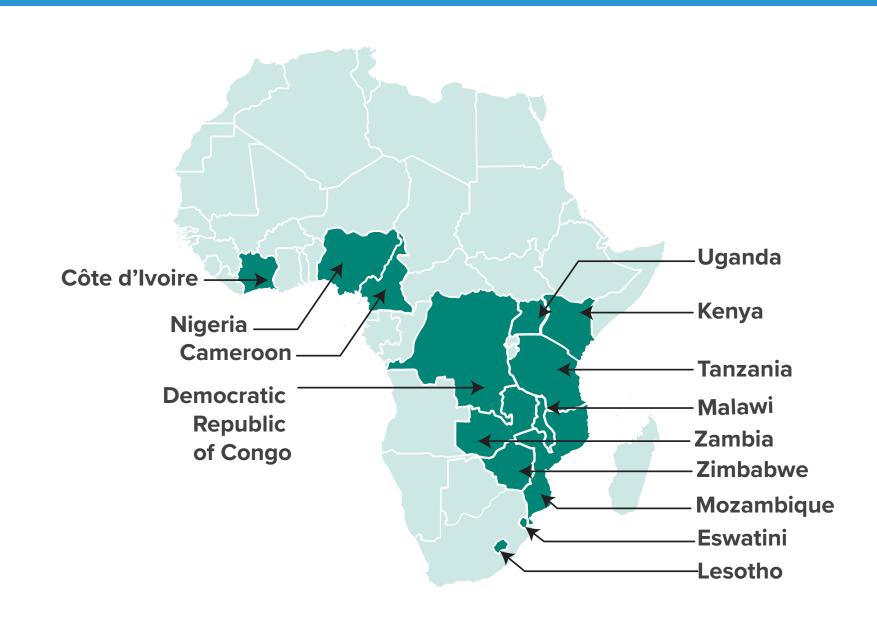
In all the countries where it has programs, EGPAF operates as a trusted and collaborative partner with national stakeholders, including national Ministries of Health and local communities. EGPAF supports national partners in developing and implementing technical guidance that reflects the very best scientific evidence of what works for young people. In Tanzania, for example, EGPAF supported national authorities and UNICEF in revising the country's strategy for adolescent sexual and reproductive health and in developing technical guidance for adolescent HIV services. Likewise, advocacy and technical support by EGPAF, with financial support from PEPFAR, aided the decision by Lesotho to adopt a test-and-treat approach for HIV in 2014.

In its country-level work, EGPAF combines adherence to international standards with recognition of the importance of tailoring approaches to the country context. All of EGPAF's programs are aligned with national technical guidelines, and EGPAF works to ensure continuous quality improvement of its programs through staff training, site support, and mentorship. Across the countries where it works, EGPAF programs comprise a community of practice that facilitates sharing of information and best practices.

In addition to administering its own programs, EGPAF works to build broader national capacity through such means as training programs for health care workers and investments in national health infrastructure. Using standardized guidelines, site-level support, and job aids, EGPAF has scaled up trainings for professional and lay cadres for adolescent- and youth-friendly HIV services (AYFHS). In 2017, EGPAF trained 3,291 providers in AYFHS from projects serving young people in eight countries (Cameroon, DRC, Kenya, Lesotho, Malawi, Swaziland, Tanzania, and Zimbabwe).¹

EGPAF's work with young people in Africa is made possible through funding from PEPFAR—through the U.S. Centers for Disease Control and Prevention (CDC), the U.S. Department of Defense, and the U.S. Agency for International Development (USAID)—as well as from philanthropic funders such as the Children's Investment Fund Foundation, ELMA Philanthropies, Elton John AIDS Foundation, Johnson & Johnson, and ViiV Healthcare, and bilateral funders such as Unitaid and the United Nations Children's Fund (UNICEF).

Where EGPAF is working with adolescents in 2020





Youth engagement and leadership

"Youth leadership is important," says a 17-year-old from Namibia. "We are the future, so it's up to us to take a stand and make the change that we want to see."

If we are to end the HIV epidemic by 2030, there is growing recognition that young people must lead the way.²⁵ Across EGPAF programs, young people are supported and promoted to shape and inform local programs and to drive local HIV responses. "Young people have a better understanding of what young people actually need, and can speak in a language that young people understand," notes an HIV-positive 24-year-old from Nigeria.

Not only do young people best know their own needs and preferences, but empowering young people enables them to serve as essential partners in their own health and well-being. "Youth leadership gives young people a chance to solve their problems among themselves," says a HIV-positive 24-year-old who lives in Tanzania.

Where it has youth programming, EGPAF endeavors to move beyond token engagement of young people and ensure that young people have an active say and play a vital role in local programs. As Kananelo, a 25-year-old youth staff person from Lesotho, advises, "Nothing should be done for young people without their consent." That is why many EGPAF programs include youth staff and also routinely include young people in annual programmatic planning processes.

EGPAF engages young people to help develop meaningful and effective approaches and activities. In local programs, young people provide input to improve the ability of their local services to meet their needs. Young people are actively involved in the delivery of services at local EGPAF sites, especially as peer mentors and leaders of peer psychosocial support groups. Through these peer education and support clubs, young people use their own life experiences to inspire people their own age to start and stay on treatment.

A key component of EGPAF's goal of building broad awareness and leadership among young people is its Ambassador program. Current EGPAF Ambassadors include young people from the United States and Africa who share their stories and perspectives with external audiences, including media, political leaders, donors, and stakeholders. Their faces and voices represent the numbers reached by EGPAF programs and bring life to the

"Young people in Africa want to take responsibility for our own health. If someone older who doesn't really understand how we live comes in with their own opinions, it won't really work. We live in a different generation. Right now, we need to be hands-on and we need to be heard and take part in decision making." — Dee **CAYA** member, Lesotho

fight for an AIDS-free generation. Furthermore, Ambassadors are able to produce more personally informed, nuanced responses, pulled from their individual experiences, to questions that, at times, cannot be answered by EGPAF staff.

At the global level, EGPAF draws on the guidance and recommendations of its Committee of African Youth Advisors (CAYA). CAYA plays a pivotal role in ensuring that all of EGPAF's programs reflect the input and meet the diverse needs of young people.

The Committee of African Youth Advisors (CAYA)

CAYA is a key mechanism that EGPAF uses to ensure that young people help guide, inform, and strengthen the organization's work for adolescents and young adults. CAYA members sign two-year voluntary agreements and attend virtual trainings and orientation sessions. Representing 10 countries, CAYA members meet monthly and work alongside EGPAF country staff focal points and global team representatives. CAYA members participate in webinars and global technical forums to learn about the most recent advances in HIV treatment and emerging dynamics in the epidemic. CAYA members play an active role in important global forums, including conferences, workshops, and webinars, making oral and poster presentations that reflect the perspectives and experiences of young people.

CAYA provides broad feedback on EGPAF's programs and approaches, and makes detailed contributions to key EGPAF guidelines and materials. For example, CAYA has provided critical input into the tools that guide and support the work of peer groups in EGPAF programs. In 2019, CAYA provided concrete recommendations on ways that EGPAF could improve access to family planning services, including mainstreaming family planning across all EGPAF services, supporting youth-led organizations, sponsoring dedicated service days for young people to receive HIV and family planning services, and providing refresher trainings on family planning services for providers.

CAYA members have improved EGPAF's understanding of the real-world needs of young people, its ability to effectively engage and reach young men, and its capacity to address the needs of young people who are transitioning to adult care.

From their global-level work, CAYA members have gained knowledge, skills, and perspectives that have informed their advocacy work in their own countries and communities. CAYA members frequently draw on their global-level experience to work on improving responses in their own countries and communities. For example, Rosa and Tanya, CAYA

members in Zimbabwe, played an active role in advocating for national adoption of a globally developed, tool kit—driven approach to disclosure of HIV status to young people living with HIV (many of whom, if infected prenatally, may not know they are HIV-positive). In addition, CAYA enables members to share experiences and to learn from one another.

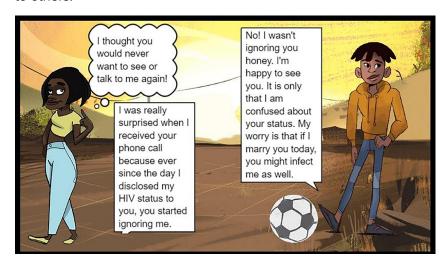
"CAYA gives me the motivation to support my peers, and it has impacted the lives of adolescents and young people living with HIV," says Tanya. "CAYA increases access to services, and it helps address stigma and discrimination by enabling access to information and advocacy for the rights of young people. CAYA helps me participate in the creation of different tools that can help young people to live a better life. By being a part of CAYA, I can help give voice to the voiceless."



CAYA Member, Rosa in Zimbabwe (Photo: Eric Bond/EGPAF, 2018)

The active engagement and empowerment of young people has provided EGPAF essential insights into the importance of talking about sex with young people, including the need to support young people in having these conversations among themselves. In 2018, CAYA members created a series of cartoons, written in language designed to be accessible and compelling for young people, to be used by peer support clubs. Developed using Young Voices, a platform created by the UK-based HIV/AIDS nonprofit Avert, the cartoons—which address sensitive topics such as stigma, shame, and disclosure—are read aloud in groups that are facilitated by adolescents or young people. Accompanying guides help the facilitator use the cartoons to evoke discussions that allow young people to work through difficult issues together.

In one cartoon created by the CAYA team in Zimbabwe, a serodiscordant young couple (Lineo and Dario, one HIV-positive and the other HIV-negative) explores relationship challenges associated with the negative partner's fears that he might become infected were he to marry his HIV-positive sweetheart. By exploring fears an HIV-positive young person might have about disclosing HIV status to a romantic partner, the facilitation session aims to equip young people living with HIV with the courage and skills to disclose their HIV status to others.



Young people are best able to exert leadership when the communities in which they live are educated, mobilized, and supported. EGPAF engages local communities to help spread knowledge about HIV prevention and treatment, support early HIV testing and immediate treatment initiation for those who test HIV-positive, increase understanding of the importance of careful treatment adherence, and encourage service utilization among

"CAYA has made me strong and it motivates me. Now that I represent thousands of adolescents and young people in Kenya, I have to take my medication just as prescribed. I have to act as a role model. And I have to build networks, which has forced me to learn more about communications technology! By being a part of CAYA, I have been able to raise issues or concerns on behalf of young people and adolescents." — Joshua **CAYA** member, Kenya

populations who often struggle to obtain appropriate care and support, including young people and men of all ages.²⁶

In addition to helping ensure that EGPAF's programs are as relevant and youth-centered as they can be, youth leaders also obtain benefits from their engagement that can last a lifetime. For example, Brian Ahimbisibwe, an EGPAF Ambassador from Uganda, is now an inspiring leader working toward a world without AIDS, serving as a Global Health Corps fellow, a board member of a local hospital foundation, and an active leader of a USAIDfunded initiative to improve health integration in the region where he lives. Another EGPAF Ambassador, Josephine Nabukenya, completed her degree in social work from Makerere University in Uganda prior to registering a youth-led nongovernmental organization (NGO) in 2019 and authoring a book on growing up with HIV. She received the Queen's Young Leader 2016 award for her advocacy work and has spoken at various high-level events, including Women Deliver and the International AIDS Society conference. In 2020, she was elected to EGPAF's Board of Directors, making her the first young African woman to serve in this capacity.

Making HIV services youth-friendly

Compared with adults and young children, adolescents have distinctively different lifestyles, circumstances, and psychosocial needs. Young people have been shown to thrive both in youth-focused and in mainstream service settings. However, in all cases, service approaches need to be carefully tailored to young people's needs and preferences, and informed by the active, meaningful, and ongoing involvement and leadership of young people. Youth-friendly services increase young people's health literacy, generate and draw from strong community support, ensure that providers have the competencies needed to meet young people's needs, prohibit discrimination or mistreatment, provide service packages that are appropriate for young people, and ensure young people's ongoing participation.²⁷ Youth-friendly services also treat young people with respect and protect their confidentiality.²⁸

"Youth-friendly services entail having doctors and nurses who are willing to work with the young people they treat and listen to them without making assumptions or overreacting," says a 19-year-old living in the United States. In the words of a 22-year-old from Kenya, "Youth-friendly services empower adolescents and young people."

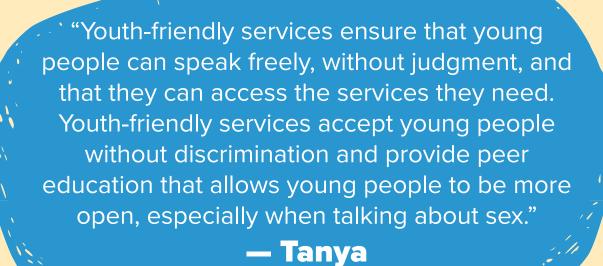
Youth-friendly approaches adapt or reconfigure service delivery in response to the needs and preferences of young people. EGPAF has established school-based mobile testing, used mobile services near schools to deliver sexual and reproductive health services to adolescent girls and boys, adapted clinic hours to make them convenient for young people (such as offering weekend hours for in-school youth), created one-stop models that allow young people to receive diverse services in a single setting, and engaged young people in the development and oversight of service programs. In partnership with PEPFAR and the Lesotho Ministry of Health, EGPAF established eight adolescent-friendly centers that provide a comprehensive array of youth-focused services.²⁹ In western Kenya, EGPAF's implementation of "Red Carpet" services increased the share of newly diagnosed adolescents who were linked to care in a six-month period, from 61.6% to 94.0%.30

EGPAF trains health care providers (including facility-based workers, community health workers, and youth experts and peer counselors) to increase their ability to provide youth-friendly services. As part of PEPFAR's DREAMS" initiative, EGPAF established youth-friendly services in 52 health facilities in Mozambique, training providers in how to respond to young people's sexual and reproductive health needs in an open and thoughtful manner.²⁹ Through the Accelerating Children's HIV/AIDS Treatment (ACT) Adolescent Project, supported by CIFF, in Tanzania, EGPAF and the Ariel Glaser Pediatric AIDS Healthcare Initiative, a local EGPAF affiliate organization, trained 250 health care workers on adolescent-friendly services and established 50 teen clubs (one at each participating facility).²⁹ In Lesotho, EGPAF developed a seven-module training course on youth-friendly services that was rolled out to 118 PEPFAR-supported sites.²⁹ In Malawi, EGPAF uses an intensive, three-day training program to build providers' capacity to address the needs of adolescents living with HIV. EGPAF has helped galvanize health worker training and clinic adaptation across Tanzania by supporting the country's Ministry of Health, Community Development, Gender, Elderly and Children to develop and disseminate a guide for health care workers regarding adolescent-friendly HIV services.31

Integrating peers into HIV services for young people is a proven strategy for making these services youth-friendly. For example, teen expert clients, also called peer educators, mentors, or Ambassadors, use their own life experiences to inspire young people to remain on treatment and to set and attain their own personal goals. In Lesotho, EGPAF trained 40 youth Ambassadors who work to increase demand for utilization of health services around facility communities, conduct HIV testing, serve as a peer cadre on the HIV treatment team, and facilitate support groups.²⁹

^{**} Developed through extensive local stakeholder engagement and with support from ViiV, EGPAF's Red Carpet model involved a package of services at boarding schools for young people living with HIV (such as counseling on HIV and sexually transmitted infections, adherence support, storage of HIV medicines, anti-stigma education and advocacy, and linkage to youth-friendly health care sites), interventions in health facilities (such as health worker training in Red Carpet services, VIP express services for project participants, peer counseling and psychosocial support, and implementation of adolescent-friendly approaches), and youth involvement (such as a peer advisory group, involvement in the design of the Red Carpet model, feedback on Red Carpet components, and design of the VIP express service).

^{††} Determined, Resilient, Empowered, AIDS-free, Mentored, and Safe.



CAYA member, Zimbabwe

Addressing the treatment needs of young people living with HIV

Recognizing that scaled-up, optimized antiretroviral therapy is a pillar of hope for ending the HIV epidemic, the global community in 2014 embraced the 90-90-90 targets set by the Joint United Nations Programme on HIV/ AIDS (UNAIDS).32# In response to the urgent need to accelerate progress for young people, the global "Start Free, Stay Free, AIDS Free" initiative called for rapid action to reach 95% of all adolescents living with HIV with antiretroviral therapy.³³ Although evidence from many countries is limited on adolescents' outcomes across the treatment cascade (especially among older adolescents), it is clear that the world is falling far short of reaching these ambitious treatment targets for young people, with younger people having consistently poorer outcomes than older adults at each stage of the cascade.³⁴ In Malawi, Zambia, and Zimbabwe, for example, less than 50% of young people living with HIV are aware of their HIV status, compared with 74%–80% of adults living with HIV.

Studies undertaken by EGPAF have identified aspects of health care services that deter young people living with HIV from seeking the care they need. These include unfriendly attitudes of health care workers, long wait times at clinics, the long distances that many young people must travel to reach a clinic, unaffordable out-of-pocket costs associated with health care services, and the frequent absence of "edutainment" specifically geared for young people.35

EGPAF is actively working in the following ways to close these testing and treatment gaps to ensure that young people living with HIV lead the way toward ending the HIV epidemic.

Helping young people gain knowledge of their HIV status:

Providing testing services to nearly 2 million young people annually, EGPAF uses diverse means to reach young people at risk of HIV with testing services that enable them to learn their HIV status and, if positive, access lifesaving treatment. In Eswatini, EGPAF leveraged ELMA Foundation support to collaborate with the Ministry of Health to implement an innovative schoolbased initiative that linked 1,124 adolescents with HIV testing services²⁹ and also provided HIV testing to more than 40,000 adolescent girls and

young women through DREAMS-on-wheels vans in 2019. EGPAF has trained professional and lay health providers on strategies for promoting and scaling up HIV self-testing among young people who might not access facility-based testing services. Mobile testing services have proven effective in reaching young people. With support from the ELMA Foundation, EGPAF rolled out a "smart testing" screening tool to identify and provide testing services to adolescents at high risk.²⁹

Family and partner testing is a current focus of EGPAF's efforts to minimize undiagnosed infection among young people. Under this approach, all clients receiving antiretroviral therapy are supported to ensure that their children and teens have access to HIV testing and, if positive, start treatment as quickly as possible. Psychosocial support helps clients consider the health of their family and, if desired, disclosure. In addition, men with younger female partners and young people who test HIV-positive are counseled and asked to provide their sexual contacts, who are then offered HIV testing in a confidential way. This approach, called index case testing, has enabled EGPAF to improve the diagnostic yield of its testing efforts. Testing is conducted in a manner that protects the privacy and safety of everyone involved. EGPAF is also supporting classroom training, webinars, and other means to increase uptake of index testing across its programs.

Linking to HIV treatment:

EGPAF has a demonstrated ability to support newly diagnosed young people to access treatment services. In western Kenya, EGPAF in two years increased the number of adolescents receiving antiretroviral therapy by a multiplier of 7.5.36 With funding from the Elton John AIDS Foundation, EGPAF provided HIV testing services to more than 28,000 adolescents over two years, linking 97% of the 1,492 adolescents who were newly diagnosed to HIV treatment services.³⁶ In 2019 alone, EGPAF, with PEPFAR support, initiated 36,000 adolescents on treatment.

To support rapid linkage to care for people who test HIV-positive, some EGPAF programs use the Red Carpet approach, which focuses on removing service barriers and facilitating the earliest possible initiation of HIV treatment

^{##} The 90-90-90 approach envisions that by 2020, (1) 90% of all people living with HIV will know their HIV status, (2) 90% of all people with an HIV diagnosis will receive antiretroviral therapy, and (3) 90% of all people receiving antiretroviral therapy will achieve viral suppression.

following a positive test result. In Kenya, with funding from ViiV Healthcare, EGPAF's peer-navigated Red Carpet program increased the proportion of newly diagnosed young people who were linked to care from 56.5% to 97.0% in 2016.30 EGPAF's Red Carpet model also increased the proportion of HIV-positive adolescents who remained engaged in care at six months from 54.4% to 98.6% in 2016.30

EGPAF continually innovates to improve treatment outcomes for the young people living with HIV whom it serves. With support from the Children's Investment Fund Foundation, EGPAF, working in 20 health facilities in Homabay County, Kenya, aimed to keep HIV-positive young people engaged in care and adhering to HIV treatment through providing non-conditional incentives (such as underwear, sanitary pads, and watches) and by hosting "fun days" in which health sessions were interspersed with youth-oriented recreational opportunities. Over two years, the program successfully linked 427 adolescents to antiretroviral therapy (87% of those who tested HIVpositive when provided HIV testing).37

Tailoring treatment services to young people's needs and circumstances:

Because young people living with HIV have diverse needs, EGPAF uses differentiated treatment delivery approaches that tailor services to young people's individual circumstances. This enables EGPAF to provide intensive, focused support for young people who are failing on treatment or to reengage those who have fallen out of care. For HIV-positive young people who are stable, with suppressed viral load results, EGPAF makes multi-month prescriptions for antiretroviral medicines, thus preventing treatment-adherent young people from having to return to the clinic just to obtain a refill. To ensure that social needs are addressed for adolescents who depend on community HIV treatment delivery, EGPAF deploys social workers to conduct home visits.²⁹ In Mozambique, mobile clinics deliver HIV treatment services to young people, while in some EGPAF treatment facilities youth-specific rooms have been created to ensure that treatment services are youth-friendly and youth-focused. An EGPAF feasibility study in Zimbabwe identified key elements needed to make differentiated service delivery effective for young people, including community outreach, peer-based support groups, multimonth dispensing, and distribution of HIV prevention commodities in schools and colleges.35

Expanding and optimizing treatment regimens:

To inform and accelerate efforts to develop antiretroviral drugs and formulations suitable for children and young people of all ages, EGPAF joined in 2018 with the World Health Organization (WHO), Unitaid, the International Maternal Pediatric Adolescent AIDS Clinical Trials Network (IMPAACT), and other experts to develop a tool kit for drug manufacturers, researchers, and other stakeholders and partners.³⁸ This tool kit aims to enable robust research and development to ensure that young people have the array of treatment regimens and formulations needed to achieve and sustain excellent treatment outcomes.

Many young people living with HIV, especially those who have taken antiretroviral therapy for extended periods, experience treatment failure and require access to second- and third-line regimens. This is a particular need among adolescents and young people with perinatally acquired HIV, many of whom have been on HIV treatment for 15 years or more and have exposure to earlier, inferior treatment regimens. In 2014, EGPAF joined with Johnson & Johnson and the Partnership for Supply Chain Management to launch the New Horizons Collaborative.§§ A major focus of the initiative has been collaboration to drive uptake of donated darunavir/etravirine to increase access to third-line regimens among young people who are failing on second-line treatment. In support of the initiative, EGPAF provides technical support to countries to facilitate timely regulatory approvals for the donated drugs, enable resolution of supply chain issues, and build clinical capacity for optimal sequencing of treatment regimens for young people. With its New Horizons partners, EGPAF has developed an algorithm and tool kit to support health care workers, lay counselors, and multidisciplinary teams in managing treatment failure for pediatric and adolescent patients.³⁹

Responding to cases of advanced HIV disease:

EGPAF is prioritizing efforts to identify and address cases of advanced HIV disease in young people. Through training and technical support, EGPAF is working with clinics to ensure that all clients newly initiating antiretroviral therapy have a baseline CD4 count measure. Tools have been developed to quide clinicians in conducting routine monitoring of advanced HIV disease and in intervening appropriately for young people at an advanced stage of HIV disease, who in Tanzania, for instance, account for 40% of new adolescent clients.40

^{§§} Since the launch, additional partners have joined the New Horizons Collaborative, including Right to Care, The Relevance Network, and the International AIDS Society's Collaborative Initiative for Paediatric HIV Education and Research.

Increasing viral suppression:

EGPAF has scaled up routine viral load testing to optimize health outcomes for young people living with HIV and ensure timely intervention if and when a patient's viral load begins to increase. In Eswatini, Kenya, and Uganda, coverage of viral load testing approaches 100% for young people enrolled in EGPAF treatment programs. In Malawi, an EGPAF audit found that 85% of the 957 HIV-positive adolescents who were eligible for a viral load test received one, and that 80% of the young people who received the test were virally suppressed.²⁸ These viral load audits are increasingly used across EGPAF's treatment programs to drive program quality, identify areas where improvement may be needed, and maximize EGPAF's ability to help young people attain sustained viral suppression. In Malawi, for example, the viral load audit highlighted the need to ensure timely identification of eligible adolescents and to provide adolescent-focused adherence counseling through specially trained health care workers.⁴¹

Keeping people engaged in care and supporting strong treatment adherence are critical to improving rates of viral suppression. In Tanzania, EGPAF has leveraged funding from the Children's Investment Fund Foundation to establish Victory Clubs, which sponsor workshops for adolescents with high viral loads and their caregivers. In many of its service sites for young people, EGPAF has trained and mobilized young people to serve as peer mentors to bolster treatment adherence.

Building capacity for self-care:

EGPAF's treatment services aim to empower young people to participate as partners in their own health care. EGPAF's peer-led support groups educate young people living with HIV about their potential to live a long and healthy life with HIV, the importance of remaining engaged in care and adhering to prescribed regimens, why sustained viral suppression is so important, how to seek help for other health issues (such as mental health care), and other things young people can do to stay healthy. In 2018, EGPAF Kenya published a detailed treatment literacy guide for support groups of adolescents living with HIV.

Supporting disclosure of their HIV status to young people living with HIV:

Because many young people with perinatally acquired HIV are not aware of their HIV status, effective care and treatment requires appropriate support for disclosure of HIV status to the young person. Disclosure is not a one-time event but rather something that should happen as a process over time.⁴² National guidelines on when full disclosure should occur vary among African countries, ranging from any time after age 7 in Zambia to 12–13 years old in Cameroon and 11–14 years old in Rwanda.⁴² As part of the New Horizons Collaborative, EGPAF created a tool kit to help health care workers make successful and informed disclosure of HIV status to adolescents living with HIV.42

Enabling successful transitions:

Learning of one's HIV status is only one of the many transitions that young people living with HIV must make. At some point, young people transition from pediatric to adult care systems, and many young people transition between providers, change schools, or in the case of pregnant adolescents, begin to obtain care in antenatal settings. To support successful and healthy transitions for young people living with HIV, EGPAF joined with its New Horizons Collaborative partners and leveraged the input of CAYA members to develop detailed, stepwise guidelines for health care workers and multidisciplinary teams to use in working with their young clients who are making these transitions. For example, to support successful transitions between pediatric, adolescent, and adult care systems, EGPAF guidelines identify key steps for successful transition, including early engagement with the young person and her or his household, support from a multidisciplinary clinic team, meaningful inclusion of young people in the process, an individualized assessment, bidirectional communication between providers involved in the transition, involvement of peers, and tracking of outcomes of the transition.

In Eswatini, Kenya, and Uganda, coverage of viral load testing approaches 100% for young people enrolled in EGPAF treatment programs.

Preserving HIV services in the era of COVID-19

The COVID-19 pandemic has had a swift, profound effect on EGPAF's work. In Cameroon, for example, community HIV testing initiatives as well as Ariel Club meetings were halted as part of the national COVID-19 control lockdown. Many EGPAF facilities in Cameroon and elsewhere have been assigned as frontline providers of services for COVID-19 cases. As a result, many adolescents living with HIV are not eager to visit a health facility, especially because immune-compromised individuals are at heightened risk of severe illness due to COVID-19,⁴³ and even community-based activities have been restricted in the name of COVID-19 control. There are reports that some people have been coerced by authorities into disclosing their HIV status as part of public health measures to minimize COVID-19—related illness and death. Slowdowns in international commercial exchange and in-country transportation pose the risk of shortages of essential health commodities.

EGPAF has taken concerted steps to mitigate the negative effects of the pandemic on access to HIV services. EGPAF programs are using telemedicine and other digital communications tools to reach clients, encourage continued treatment adherence, and provide psychosocial support. Virtual learning and telemedicine platforms have been leveraged to enhance infection control efforts in the health facilities supported by EGPAF. In response to COVID-19, EGPAF is further accelerating its use of non-facility-based, differentiated service delivery models for antiretroviral therapy. In Uganda, for example, community- or home-based antiretroviral therapy services have been scaled up to ensure continued treatment access.

While working to preserve and strengthen HIV services in the midst of quarantines and other COVID-19 control measures, EGPAF is also supporting its country-level partners to contribute to their national and local COVID-19 responses. In Lesotho, for example, EGPAF is supporting local partners to integrate COVID-19 screening with HIV treatment distribution. EGPAF has developed media trainings to raise awareness of the importance of physical distancing; trained laboratory technicians

and health workers on the safe collection, packaging, and transport of COVID-19 samples; and supported COVID-19 surveillance activities. EGPAF-supported youth peer counselors, such as Peter and Ismail at Kabale Regional Referral Hospital in southwest Uganda, are working with young people to reduce the stigma associated with COVID-19.⁴⁴

telemedicine and other digital communications tools to reach clients, encourage continued treatment adherence, and provide psychosocial support.

Preventing new HIV infections among young people

Preventing HIV among young people is challenging. Many young people feel invulnerable and have little awareness that they might be at risk of acquiring HIV. Youth is a time for experimentation and risk taking for many people, and young people are exposed to a plethora of influences, including their peers, the broader youth culture, older individuals, and the media, as well as their parents, teachers, and community leaders. The shortage of accessible, welcoming, youth-friendly service options can make reaching young people with prevention messages and services especially difficult, and prevention messaging developed by adults may not resonate with young people.

Consistent with international recommendations, EGPAF uses a "combination prevention" approach in its efforts to prevent new HIV infections among young people. This approach recognizes that no single prevention method is 100% effective, that different young people need different prevention strategies, and that combining effective approaches maximizes public health impact. In working to prevent HIV acquisition among young people, EGPAF leverages its proven ability to reach, engage, empower, and listen to young people.

HIV prevention education:

As a foundation for effective HIV prevention, young people need accurate information on how HIV is transmitted and how it can be prevented. In sub-Saharan Africa, only 36% of young men and 30% of young women have accurate and comprehensive knowledge about HIV.8 To help close this serious knowledge gap among young people, EGPAF programs provide young people with essential, youth-tailored messages on HIV and sexual and reproductive health. In Kisumu, Kenya, for example, prevention messaging reached more than 152,000 young people over a two-year period.36 EGPAF has established youth corners in secondary schools to deliver information about HIV and sexual and reproductive health.

Condoms and other contraceptive services:

Although condoms remain a pillar of effective HIV prevention, their availability and use remains inadequate, especially among young people.⁴⁵ In 31 of 41 countries with survey data on young men and women (ages 15–24), less than half of young women reported using a condom the last time they had sex.¹¹ EGPAF is working to close the condom and contraceptive gap

for young people and to deliver youth-targeted prevention programming that can instill lifelong healthy sexual norms, in large part by integrating HIV prevention with broader, youth-focused sexual and reproductive health services. Close integration of HIV with sexual and reproductive health services enables young people to receive as many quality services as possible at the same time and in the same place.

In addition to promoting primary HIV prevention, integration of family planning into HIV services also advances progress toward the goal of eliminating mother-to-child HIV transmission by ensuring that every pregnancy is planned and wanted. Family planning services are integrated in many of EGPAF's programs, especially alongside HIV services. Through EGPAF's Boresha Afya initiative for service integration, the number of young people accessing family planning services increased in 2019 from 78,847 to 106,242 with targeted outreach, youth-friendly service sites, and integration into maternal and HIV departments. In Uganda, RHITES (Regional Health Integration to Enhance Services) Southwest reached 184,094 young people with family planning services in 2019.

"I personally feel like HIV is not even a concern [in my community]. Nobody in power seems to care that these kids are our future."

— 18-year-old living in the United States

Voluntary medical male circumcision:

In high-burden settings, voluntary medical male circumcision is a key component of combination HIV prevention. 45 Not only does voluntary medical male circumcision sharply lower the risk of female-to-male sexual transmission, 46-48 but it also helps protect adolescent girls and young women from acquiring HIV, by reducing the number of men who are capable of transmitting the virus.³³ Over the period 2016–2018, 11 million voluntary male circumcision procedures were performed in high-burden African countries, with young men ages 10–24 accounting for 84% of circumcisions. 11 EGPAF is contributing to the scale-up of voluntary male medical circumcision through programs in three countries (Eswatini, Kenya, and Uganda). In 2019, EGPAF provided these services to 77,435 young men ages 10–14, 45,755 older adolescent boys, and 22,324 young adult men. To promote uptake of voluntary medical male circumcision, EGPAF has implemented door-to-door mobilization, Voluntary Medical Male Circumcision Fridays, and back-toschool circumcision initiatives.

PrEP:

Although PrEP is highly effective, its uptake has been slow—globally and specifically in sub-Saharan Africa.11 Provision of PrEP to adolescents and young adults has been especially meager, due in part to low awareness of PrEP among young people at risk of HIV.⁴⁹ This finding is confirmed by recent focus groups EGPAF conducted among young people (both HIV-positive and HIV-negative, in countries where EGPAF has projects), the majority of whom said their peers were largely unaware of PrEP and how to obtain it. EGPAF is helping close the PrEP access gap by improving PrEP access in the Eswatini, Kenya, Lesotho, and Uganda. In 2020, EGPAF will begin providing access to PrEP in Malawi and Tanzania.

Comprehensive prevention for adolescent girls and young women:

The PEPFAR-funded DREAMS initiative is a public-private partnership that aims to achieve sharp reductions in new HIV infections among adolescent girls and young women. The comprehensive DREAMS package includes both biomedical and social and structural interventions, including HIV testing and counseling, education subsidies, violence prevention and post-violence care, PrEP, condom promotion, youth-friendly sexual and reproductive health, support for parents or caregivers, and community-based mobilization and norms-changing approaches.⁵⁰ In Mozambique and Uganda, EGPAF has worked to support implementation of the full DREAMS package. In Eswatini, Lesotho, and Malawi, EGPAF has been the clinical partner for adolescent girls and young women in DREAMS sites, leading post-violence and rape care, and targeting male partners with HIV services.





Addressing the needs of young pregnant women and mothers

Adolescence and young adulthood is a time when many young people have children. In sub-Saharan Africa, one in five adolescent girls and young women becomes pregnant by age 18.51 In EGPAF-supported regions in 10 countries, 46% of new antenatal care clients were 15-24 years old, including 17% who were ages 15–19 years.

Young people who are of childbearing age, pregnant, breastfeeding, or in early motherhood experience unique challenges that require specific, tailored approaches:

- Family planning: Young people have the right to ensure that their pregnancies are planned and wanted. Unfortunately, an estimated 200 million women and girls living in low- and middle-income countries who want to avoid becoming pregnant do not have access to modern contraceptive methods, and the unmet need for family planning is greater among young women than among older adult women.8
- HIV prevention: During pregnancy and just after giving birth, women are two to four times as likely to acquire HIV through sexual intercourse than in other times of their lives, underscoring the urgency of strengthening primary HIV prevention among women of childbearing age. 52 Young pregnant women need access to antenatal care that includes routine HIV testing, access to condoms and PrEP, and continuous antiretroviral therapy for those who test HIV-positive.
- HIV treatment: Young pregnant and breastfeeding women who are living with HIV require HIV treatment not only to prevent transmission to their newborns but also for their own health. However, many women who start HIV treatment during pregnancy do not continue taking it, inviting treatment failure and worsening long-term health outcomes.⁵³
- Opportunities to engage male partners: Because men living with HIV experience poorer outcomes across the HIV treatment cascade than HIVpositive women, antenatal care offers a critical opportunity to help reduce this disparity by engaging men in HIV testing and treatment services.⁵⁴

EGPAF's support for pregnant and breastfeeding adolescent girls and young women is wide-ranging, including the delivery of essential family planning and primary HIV prevention services, antenatal care, HIV testing, antiretroviral therapy, and community capacity building for home visits for pregnant adolescents.

In 2019, 453,000 young people received antenatal care through EGPAF, including 3,906 who obtained antiretroviral therapy. In support of the Family Planning 2020 partnership, EGPAF has committed to supporting 500 health facilities in Africa to provide at least 500,000 people (at least half of them under age 25) with family planning methods. In response to the heightened risk of sexual HIV acquisition during pregnancy, EGPAF is prioritizing the scale-up of PrEP for HIV-negative pregnant women enrolled in its antenatal care programs. Young women account for 20%-30% of the clients who receive EGPAF services for the prevention of mother-to-child transmission.

Recognizing that young pregnant women and mothers often confront complex, overlapping challenges, EGPAF emphasizes innovative approaches to meet their needs. These include a home-based program in Kenya to link teen mothers to health and social services, as well as school groups and mobile services in Mozambique that address the needs of young women related to pregnancy and early motherhood. With the support of Johnson & Johnson, EGPAF implemented a peer-led project for HIV-positive pregnant or breastfeeding adolescent girls and young women, providing enhanced psychosocial support and opportunities for mutual support. Over six months, the share of women participating in this peer-led project who had viral suppression rose from 78% to 96%.29

To promote more effective action to address the HIV prevention needs of pregnant adolescents and young women, EGPAF in 2019 joined with PEPFAR and UNICEF to convene stakeholders to increase awareness of heightened HIV risks during pregnancy and to identify and share best practices for addressing the needs of young women who are pregnant. This was followed by a webinar hosted by the Coalition for Children Affected by AIDS (CCABA), in partnership with EGPAF and the WHO, to share more widely the emerging evidence regarding the prevention, treatment, and support needs of this unique subpopulation. EGPAF is working with CCABA and other partners to turn the information collected and perspectives shared by young mothers and adolescent-focused service providers into specific recommendations to guide and drive advocacy at the global and national levels.

AIDSFree JUA (Jielimishe Uzazi Na Afrya)

Using best service practices and peer leadership to improve health outcomes for pregnant adolescents and young mothers

In 2017–2019, EGPAF joined with JSI Research & Training Institute and Kenyan civil society partners Make Me Smile, Kagwa, Adventist Centre for Care and Support, and St. John Community Centre to implement the AIDSFree JUA project in Kenya, with funding from USAID. The name of the project derives from a Swahili phrase meaning, "take pride in parenthood and health."

Drawing from an extensive analysis of peer-reviewed and gray literature, the JUA design used a case management model in which trained home visiting teams provided individualized services for adolescents and their households. The home visiting teams focused on ensuring that adolescents received antenatal, postnatal, and/or HIV prevention services; ensuring that infants received services for their health and development; and building adolescents' resilience and empowerment. These teams consisted of mentors who offered peer support for pregnant adolescents and mothers; household facilitators (one female, one male) to work with each young woman's household to address potential barriers to care; and supervisors who ensured that teams worked together as one. While the ultimate aim of JUA was to increase health service utilization and improve health outcomes, a key focus of the program was to address sociocultural and behavioral barriers to service utilization by engaging not only the adolescent herself but also her parents, caregivers, and community members, especially men.

JUA's comprehensive, tailored, multidisciplinary model achieved striking results. Among adolescents participating in JUA, 94% delivered their babies with a skilled birth attendant (compared with the national average in Kenya of 64%). Whereas only 24% of adolescents living with HIV in Kenya typically achieve viral suppression, the rate of viral suppression among JUA participants was 94%.

The adolescent girls, women, and households touched by JUA have testified to the project's life-changing effects. For Brenda, who experienced an especially difficult labor, the timely intervention by the JUA facilitator got her to the health facility just as her blood pressure spiked dangerously. "I only remember waking up and finding my baby lying beside me," says Brenda, whose high medical bills were waived following JUA's intervention. "I have resumed school. I can read and do my homework in the evening with the lantern JUA provided. And my baby is doing well."

Winnie, another JUA client, recalls: "At 17 years, I experienced a difficult delivery to twin babies. I was scared and worried that I would never manage to take care of my twins. The JUA team supported me and my grandmother to manage the babies. I had a strong desire to pursue my education and become a medical doctor. The JUA team negotiated my readmission to school. I was able to finish my school, and now I have joined medical college to pursue a diploma in nutrition and dietetics."



Winnie and her twins (Photo: Gibson Kabugi/EGPAF, 2019)

Ensuring holistic and comprehensive services

EGPAF has found that HIV services for young people work best when they actively address and support all facets of a young person's life. In EGPAF's experience, facilitating support among young people themselves offers a critical avenue for providing essential psychosocial support, which not only promotes holistic health and well-being but specifically improves HIV treatment outcomes.

EGPAF integrates peer-led psychosocial support across its programs, through more than 500 peer support groups. These approaches use various models that are tailored to local needs, including Ariel Clubs (see page 26), Teen or Adolescent Clubs (such as those in Cameroon, which meet weekly and also plan group outings), and teen mentor programs. Peer support mechanisms help young people living with HIV cope with stigma and discrimination, and build strong collective commitment to remaining engaged in HIV care. To ensure relevance and age-appropriateness, support groups are organized in five-year bands, so that similarly situated young people are able to provide and receive support that matches their own life experiences.

For many young people enrolled in EGPAF programs, access to peerled psychosocial support is life-changing. As Hajarah, a young student in Uganda, notes, "All those things we go through—lying, defaulting on medicine, not caring about life—when you get to share that story with your peers, you no longer feel alone. [Through participating in the local Ariel Club] I began to see a bigger picture. I started to think that it is time to adhere to my medication and suppress my HIV so that I can live healthfully and cannot transmit it. I had hopes of becoming like that person who reached out to [help] me."

Although EGPAF's psychosocial support services primarily aim to improve treatment adherence and rates of viral suppression, they also have the added benefit of building young people's resilience and enhancing their ability to cope with challenges they face. Peer-led support groups at EGPAF service sites work to increase young people's treatment literacy in order to help them take control of their lives, set life goals, and achieve their potential—all while managing a chronic disease. 55 EGPAF's peer support groups are specifically designed to build and reinforce self-awareness. critical thinking, communication skills, and planning for the future, including for key transitions.⁵⁶

Some EGPAF programs use teen mentors to help people identify solutions and learn healthy coping skills in the face of important life challenges and transitions. In Zambia, for example, the Tisamala teen mentors program

focused on coping with difficult feelings, making decisions at difficult stages in life, having healthy relationships, experiencing sexual safety, coping without drugs and alcohol, standing up against gender-based violence. supporting friends, and thinking about and making plans for the future.

"Young people need to see a life beyond antiretroviral therapy," says Joshua, a CAYA member living in Kenya. "People need to make steps in life, and they need each other's support to develop the resilience to do so."

Disclosing their HIV status to their peers and potential romantic partners, and within their home communities, is among the most difficult transitions that young people living with HIV experience. "Most adolescents living with HIV experience stigma and discrimination, and it is hard for them to disclose," notes Tanya, a CAYA member from Zimbabwe. "But when they disclose they become more confident. Through support from peers, young people can learn how to disclose their HIV status. Peer-to-peer counseling helps young people accept their status and cope more effectively. Through sharing success stories, young people increase their confidence and understanding that HIV isn't a death sentence. Peer support has been especially important during the COVID-19 period, in helping young people [know] how to live a positive life during this time."

> "As a young person who is living with HIV /and who has faced judgment from health' care workers, I am in a good place to work with other young people. Young people support each other and build each other's confidence. When we stand together as young people living with HIV, we are able to have resilience against the negative attitudes of the world."

> > - Dee, **CAYA** member, Lesotho

Why peer support matters: The story of Joseph*

The story of Joseph, an HIV-positive young person who is an EGPAF client in Uganda, demonstrates the special power of peer support. Having grown up in an orphanage after losing both his parents to AIDS, Joseph initiated antiretroviral therapy but subsequently dropped out of care, fearing discrimination. Ismail, a youth peer counselor at the local health facility, and other health care providers noticed that Joseph had stopped coming to the clinic. Ismail searched the streets until he found Joseph and accompanied him back to the clinic, where Ismail shared his own journey of overcoming stigma. At Ismail's suggestion, Joseph joined a peer support group for adolescents his own age and reengaged in HIV care. Today, Joseph's health has improved, and he now takes an active role in supporting his peers to get the care they need.

"Joseph is doing well on [HIV treatment], and the support from his peers has made all the difference," Ismail reports. "He doesn't have to worry about hiding. We know how he feels and we make him feel safe."

* Note: Joseph's name has been changed to protect his privacy.



Ariel Clubs

Tailoring psychosocial support to the needs of children and adolescents living with HIV

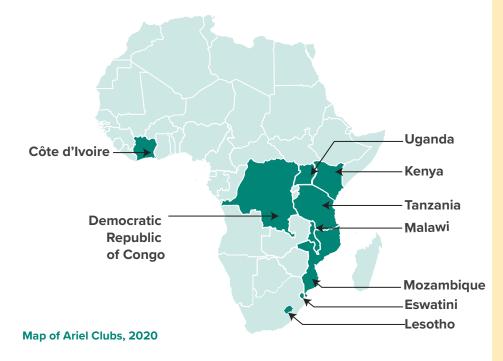
Ariel Clubs provide the focused psychosocial support that HIV-positive young people need to adhere to antiretroviral medication regimens.

Named after the daughter of EGPAF founder Elizabeth Glaser, Ariel Clubs are currently in place in EGPAF programs in nine countries. Designed for HIV-positive children and adolescents ages 5–19, Ariel Clubs are segmented to enable tailored, age-appropriate support for young people in different age bands. In Tanzania alone, Ariel Clubs are operating in more than 100 health facilities in six regions.⁵⁷ To ensure continual quality improvement of Ariel Clubs, EGPAF has issued detailed guidelines to support implementation of the model.⁵⁸

Based in health facilities, Ariel Clubs offer a package of psychosocial services, including individualized counseling sessions by trained service providers, dedicated and age-appropriate facility spaces, and monthly support group meetings where trained providers facilitate discussions on such topics as treatment adherence, stigma reduction, and disclosure of HIV status. Although specifically focused on the individual needs of the HIV-positive young people enrolled in the health facility, Ariel Clubs also actively work to engage local leaders, civil society, and communities, and to respond to the needs of families affected by HIV. The Ariel Club model promotes service integration to ensure that young people receive comprehensive care and support.

The model has proven to generate additional benefits, including increased provider capacity to communicate well with young HIVpositive clients; more successful disclosure of HIV status to young people; opportunities to deliver age-appropriate information on sexuality and sexual health; facilitated channels for medication dispensing that help decongest overburdened health facilities; and provision of a safe, fun, and socially engaging space for children and adolescents living with HIV. Many Ariel Club participants have gone on to play important roles in HIV service delivery and advocacy, including serving as peer workers, CAYA members, and EGPAF Ambassadors.







Addressing vulnerabilities that affect health outcomes

Especially for young people, HIV is much more than a health issue. Because social and structural issues affect young people's vulnerability and their ability to access essential services, EGPAF is committed to ensuring that young people receive social protection interventions that are tailored to their needs. EGPAF provides case management services for young people living with HIV, regularly assessing key environmental factors that influence service uptake and outcomes, including the home, education, sexual activity, security, and other risk factors. In some EGPAF programs, social workers actively work to link young people to needed services, and in others EGPAF provides direct support to cover the costs of transportation or to ensure access to necessities such as food and nutrition.

Mitigating the effects of poverty:

Many young people served by EGPAF live in households that confront vexing choices about how to satisfy the basic needs of life. Once they leave school, many young people face a scarcity of good jobs. As a 25-year-old HIV-positive young person in Kenya advises, "Lack of jobs is the biggest challenge that young people are facing." With few resources, young people often struggle to afford transportation to health services or may avoid services altogether due to out-of-pocket costs.

EGPAF programs often include work to relieve the impoverished conditions in which many young people live. EGPAF provides its services for free and actively advocates for the removal of user fees from health services for young people. EGPAF invests in income-generating activities that enable young men and women to escape poverty by earning a living. In Turkana County, Kenya, for example, EGPAF jump-started a local bakery and a soap-making business, enabling HIV-positive individuals to boost their household income.²⁴

Preventing and responding to violence:

More than one in three women and girls have experienced physical or sexual violence,8 with even higher prevalence in some countries, such as Cameroon, where more than half of women 15 years and older have experienced physical, sexual, or emotional violence.⁵⁷ An experience of violence increases by 50% the odds of acquiring HIV among women and girls in some countries⁸, and intimate-partner violence is associated with poorer retention in HIV care and suboptimal HIV treatment outcomes.⁶⁰

To meet the needs of young people who have disclosed violence, EGPAF provides an array of violence prevention and post-violence support services in seven countries (Cameroon, DRC, Eswatini, Lesotho, Mozambique, Tanzania, and Uganda). With support from the CDC through Project DELTA (Delivering Technical Assistance), EGPAF has supported six sites in Cameroon to provide post-violence care to 235 survivors of sexual and gender-based violence, providing 73% of eligible survivors with PEP to reduce their risk of acquiring HIV.

To build the skills of 26,000 adolescent and young girls in Uganda to prevent rape, EGPAF partnered with No Means No Worldwide to use its IMpower curriculum. In 2020, this rigorously evaluated, evidence-based approach⁶¹ will be expanded to partners targeting young boys and girls receiving support services in Botswana, Lesotho, Malawi, Tanzania, Zambia, and Zimbabwe through 2021 through the DELTA 2 Project supported by CDC.

> Especially for young people, HIV is much more than a health issue.

Advocacy for a robust and effective response to HIV among young people

EGPAF directly undertakes advocacy, cultivates advocacy partners, and supports young people to advocate for themselves, with the aim of creating a political environment that better addresses the needs of adolescents living with or at risk of HIV. Advocacy helps leverage EGPAF's presence in countries to generate more far-reaching change that can affect the lives, health, and well-being of young people who don't live in the communities where EGPAF has a presence.

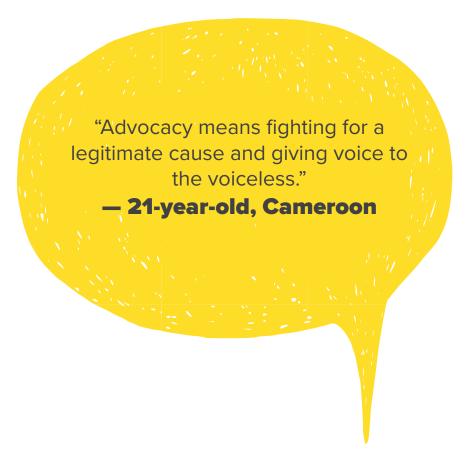
EGPAF advocacy targets laws and policies that reduce young people's access to essential health services or increase their vulnerability to HIV. In particular, EGPAF has worked to roll back laws that limit young people's access to HIV testing. Among 142 countries reporting information on their national HIV response to UNAIDS, 106 had laws in place requiring parental consent before an adolescent may access HIV testing.9 In the DRC, EGPAF has joined with other HIV and TB partners in advocating for a reduction in the age of consent for testing from 18 to 14 years, supporting development of a new law (still not passed) and facilitating meetings with parliamentarians.

EGPAF has worked to insert HIV treatment issues in the global youth agenda, encouraging the Committee on the Rights of the Child in 2015 to recognize the unique needs of adolescents living with HIV. In 2016, EGPAF joined with PEPFAR, UNAIDS, the WHO, UNICEF, and others to launch the Start Free, Stay Free, AIDS Free initiative, the first major HIV campaign to expressly prioritize a life-stage approach to meeting the needs of young people affected by HIV.

EGPAF has a long-standing partnership with the Organization of African First Ladies against HIV/AIDS, now known as the Organization of African First Ladies for Development, which raises awareness of key actions needed to prevent new HIV infections among children and address the prevention and treatment needs of young people. To inform and strengthen the advocacy of African First Ladies for more effective HIV responses for children and adolescents living with HIV, EGPAF developed an advocacy tool kit that includes key messages, facts, and background information.⁶²

EGPAF also supports advocacy by young people and by leaders and stakeholders in the communities where EGPAF works. Many of the young

people who are CAYA members or EGPAF Ambassadors have become effective advocates in their home communities and countries. In its support for youth advocacy, EGPAF aligns its work with international recommendations, building young people's ability to advocate in different venues, use diverse advocacy strategies, and mobilize others to take action.63



Building the evidence base to address young people's HIV-related needs

In addition to implementing its own programs, EGPAF tries to drive goodquality programming in non-EGPAF service settings by generating and disseminating evidence of what works for young people. Adolescents are included in roughly half of all EGPAF studies. Over the last five years, EGPAF has contributed to more than 100 articles in peer-reviewed scientific journals, including more than 20 articles focused on adolescents.

EGPAF has led dozens of studies on how best to prevent and treat HIV in children, adolescents, and youth, and how best to care for and support families affected by HIV and AIDS. In 2020, EGPAF has more than 10 active studies involving adolescents, including studies evaluating differentiated service delivery models for children and adolescents, clinical outcomes and retention among children and adolescents receiving antiretroviral therapy, adolescent-focused services and interventions, and pediatric and adolescent HIV risk screening tools in several countries. These studies often use both quantitative and qualitative methods to gather comprehensive data, incorporating the perspectives of adolescents and the health care workers who serve them.

In Kenya, EGPAF recently conducted an evaluation of the implementation, effectiveness, and acceptability of a standardized Early Adherence Counseling package for children and adolescents. Leveraging the New Horizon Collaborative, EGPAF is leading a multi-country research study to collect critically needed data on the demographic and clinical profiles of treatment-experienced children and adolescents, and their clinical outcomes after they switch to selected third-line antiretroviral regimens. EGPAF has conducted evaluations of youth- and/or adolescent-friendly services in Kenya, Tanzania, and Zambia to inform future service delivery planning for adolescents.^{29,64}

EGPAF broadly disseminates its research findings in study reports, at national and international conferences, and through manuscripts in peerreviewed scientific journals. Recent examples include an important study of the feasibility of differentiated HIV service delivery for adolescents and young people, the impact of an adolescent-focused HIV case-finding intervention, 65 and a national household survey of the prevalence of violence among Zimbabwean youth ages 13-24 and the connections between violence and HIV.35





Call to Action

For more than 30 years, the words of Elizabeth Glaser have served as motivation: "People say they care, but actions are what save lives." The world has repeatedly pledged to meet the needs of young people living with or at risk of HIV: launching major global initiatives, setting ambitious targets, and pledging to usher in an AIDS-free generation. However, the inescapable reality is that the global community has utterly failed to translate its rhetoric into meaningful action for youth. It may be a cliché to say that young people are our future, but the threat that HIV and AIDS pose to this generation is real—and the data tell us that action on behalf of young people affected by HIV is falling tragically short.

In its conception, design, and execution, the global HIV response primarily focuses on meeting the HIV-related needs of adults, pretending that young people can be served by approaches that are lightly adapted from those used for older people. In reality, though, we will meet the HIV-related needs of young people only if we listen to and empower young people themselves, design systems and approaches specifically to meet their needs, and hold ourselves accountable to continually improve the relevance of our services and the outcomes they achieve.

EGPAF has learned important lessons that should be taken on board by the broader HIV response. Perhaps above all, the youth beneficiaries have been integral to this charge, and EGPAF has listened to them and made them central partners and agents of change in its work. EGPAF has also endeavored to remain agile, especially in response to epidemiological and programmatic data—using innovative approaches to reach those who aren't being served, identifying and rapidly responding to the factors that undermine good outcomes for young people, and rapidly incorporating the latest scientific learning.

As the lagging progress in meeting the HIV-related needs of young people indicates, there is much more to be done if we hope to end HIV and AIDS in this generation. The lessons that EGPAF has learned through its work with young people offer important guidance for translating rhetoric into reality for young people and for moving from pledges of action to genuine accountability for results.

Drawing from its experience in working with and for Generation Z, EGPAF recommends the following key actions:



► Adopt modern and flexible approaches to HIV and AIDS programming for adolescents and youth

- Recognize that youth-centered service delivery requires continuous
 evaluation and adaption based on ongoing and regular dialogues with
 young people to keep approaches relevant and up-to-date. This is a
 dynamic population that quickly responds to the world around it; therefore
 medical interventions and public health messaging must adapt quickly too.
- Emphasize training of health care workers to provide appropriate, youthfocused services, and gather client feedback to keep them accountable.
 Health care workers are the gatekeepers of youth access to health care
 services, which means even the best youth-centric program will fail if health
 care workers are judgmental and disrespectful. Health care workers must
 be sensitized to issues facing youth, trained on how to provide youthfocused services, and empowered to engage other sectors if young people
 need additional support.
- Collect and proactively analyze age- and gender-disaggregated data to better expose and understand the variations in service delivery needs and health outcomes experienced by subsets of adolescents and youth.
- Treat integration of services as essential when developing programmatic
 youth-centric HIV service delivery models, with particular attention to
 the integration of sexual and reproductive health services and with HIV
 programming. Youth have been clear on this topic; the global HIV response
 community needs to act.
- Respect that youth and adolescents have a multitude of needs that
 extend well beyond their HIV status. HIV programs that do not take into
 consideration the whole person—including the psychological, economic,
 and social needs of youth and adolescents—will not be as successful as
 those that do.
- Advance an innovation agenda that does not solely rely on translating adult-focused programs into adolescent-friendly programs, but rather takes into account all of the information available to develop health technologies and service delivery models created explicitly for adolescents' needs and their needs alone.
- Systematically track and assess funding allocations for adolescent programs by major HIV donor entities and through domestic health budget processes.

► Increase the substantive participation of adolescents and youth in policy development and program implementation

- Invest resources in youth-led local and regional organizations and networks to strengthen advocacy, service delivery design and support, and accountability efforts. Youth know what their peers and communities need, but they cannot bring their inputs forward and affect change without financial support.
- Better involve youth in the generation of evidence to inform HIV services, such as indicators, monitoring and evaluation structures, client satisfaction surveys, and setting of research priorities.
- Create paid staff positions for youth to assist in design and implementation of youth-centered programming within implementing organizations and at research centers.
- Establish, train, and compensate cadres of youth peer counselors.
- Establish and fund opportunities for sustained, meaningful youth leadership within governmental and quasi-governmental HIV-related decision-making forums, such as national AIDS councils.
- Support and respond to youth-led movements to hold the public and private sectors accountable for securing the health and well-being of young people today and helping them create healthy communities in the future.

► Prioritize comprehensive and multi-sectoral prevention, care, and treatment services for all adolescents and youth

- Make prevention of HIV in adolescents and young people of both genders a much higher priority and pressure policy makers to treat HIV prevention as an essential part of all international, regional and national commitments to end AIDS in children and youth.
- Ensure that all adolescents and youth can access sexual and reproductive health services and HIV prevention services without fear, stigma, and discrimination. This includes condoms, PrEP, comprehensive sex education, voluntary medical male circumcision, family planning, and pregnancy care. Furthermore, policy barriers that prevent the scale-up of these prevention services for adolescents and youth must end.
- Invest in the research and development of innovative prevention strategies
 to meet the needs of adolescents and youth, including long acting PrEP
 and dual prevention that combines PrEP and contraceptive options. It is
 vital that the research and development of these commodities include the
 perspective of young pregnant and breastfeeding women to ensure that
 these tools are to all.
- Drastically scale up PrEP access for youth, especially for adolescent girls and young women. Additionally, national guidelines must be amended to ensure that PrEP is available for pregnant and breastfeeding adolescent girls and young women.
- Integrate key prevention services, such as PrEP and re-testing, into antenatal care to keep both young mothers and their babies healthy.
- Improve access to services that bolster adolescent health outcomes along the continuum of care, from self-testing to peer support groups to assistance with disclosure to viral load testing.
- Differentiate between the models of care needed by perinatally infected HIV-positive youth and those infected during the adolescent and youth period.

► Empower adolescents and youth to shape their communities and futures

- Build up programmatic partnerships with adolescents and youth to implement their own solutions to identified challenges, with other actors playing supporting and guiding roles as needed.
- Enhance social protection safety nets to keep vulnerable adolescent girls from engaging in behaviors that put them at risk of contracting HIV or undergoing unwanted pregnancies.
- Remove legal and cultural barriers that prevent youth from engaging in informed health decision making, including restrictive age-of-consent laws, permissive child marriage norms, and other coercive or harmful familial practices.
- Advance a rights-based agenda to ensure that adolescents, young people, and their communities not only survive, but also thrive.



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