



**Elizabeth Glaser  
Pediatric AIDS Foundation**  
Fighting for an AIDS-free generation

# Lead the Way to an **AIDS-Free** Generation Z




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by using  
**#AIDSFreeGenZ**



## Acknowledgements

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# Foreword

By Jake Glaser and Josephine Nabukenya

All of us, living with HIV or not, need someone to look up to. Whether we are leaning on supportive family or reaching out to close friends, having people in our lives to whom we can turn for understanding, advice, and guidance makes all the difference in the world.

Along our respective paths toward adulthood, the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) proved to be a pillar of support. We are both active global HIV/AIDS advocates. One of us is the son of the EGPAF founder after whom the organization is named, an EGPAF spokesperson, and an entrepreneur. The other leads EGPAF-founded Ariel Clubs in Uganda and now is the first African woman living with HIV to serve on EGPAF's board of directors.

Having other HIV-positive young people in our lives helped get us to where we are today. When we were young, we certainly depended on adults—our teachers, health care providers, and mentors. While those adults were and are essential in the implementation of programs, research, and more, the greatest truth for adolescents is that our peers play a unique role in supporting one another. No one can understand what a young person needs or is feeling better than another young person who has similar life experiences, and no one influences youth more than each other. That is why EGPAF's programs incorporate peer support and active youth engagement—to improve retention in care and viral suppression, help young people make tough decisions and overcome challenges, and ensure that EGPAF's programs meet the needs of the young people they serve.

This brief report is written specifically for young people living with or affected by HIV. The message, in short, is, “Speak up! Get involved! Be a leader!”

Young people can't wait on others to take care of the problems they face. You and your fellow young people

need to take action to create the change you want to see and define the road you want to walk down. That means talking with other youth about HIV, sex, and treatment adherence, seeking and providing peer support, getting involved and showing leadership in your own community, taking responsibility for your own health and well-being, and most of all, exploring and innovating new ways to show your peers and community a reality of HIV that is not defined by stigma. By taking action, you can create a new narrative around HIV that is most meaningful to your generation and be a role model to whom others in your community will look for guidance and inspiration.

The COVID-19 pandemic has reminded all of us how precious life is. As people living with HIV, we are part of a community that celebrates and fights for life. We in the HIV community have long demanded that no one be left behind, that no life is expendable or less important than any other. In the midst of the uncertainty associated with this new pandemic, we have so much to teach and important perspectives to impart.

We wish we could confirm that we are on the road to conquering HIV, but we are not. Hundreds of thousands of children and adolescents become infected with HIV every year. And because they are less likely than adults to know their HIV status or to stay on HIV treatment, AIDS remains a leading cause of death among young people. We have the scientific tools and strategies we need to have an AIDS-free Generation Z, but we haven't done what is necessary to ensure that every young person has the services and support they need to live and thrive. Action is needed right now.

We can't wait for others to end the AIDS pandemic. Thirty years ago we knew very little about the virus and its impact on children like us. Thanks to many courageous people making their voices heard—often challenging the status quo and demanding action from governments set on inaction—we now have the opportunity to end HIV in our lifetimes. As the world changes, we look to the next generation to take up the challenge and lead the fight through innovation, connectivity, and community. In fact you—the world's young generation—undoubtedly possess the solutions you've been waiting for.

**Go out there and make the AIDS-free future you want to see.**

## If we hope to end HIV, young people will need to lead the way.

We know the power of young people in the fight against AIDS—from their own words and experiences.

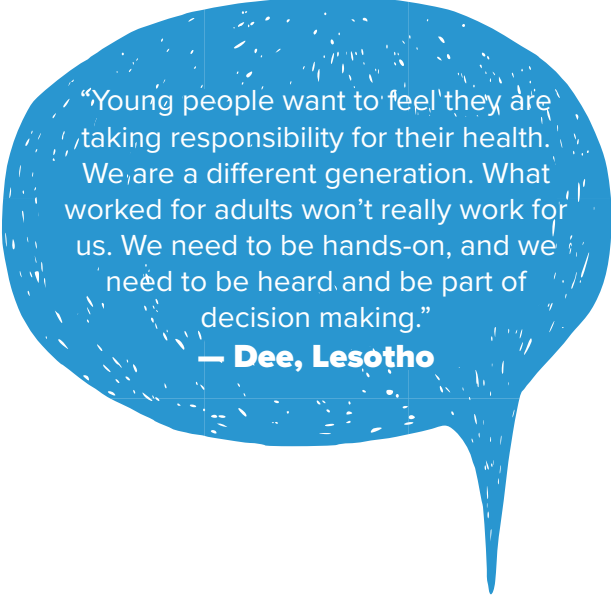
Many of these experiences come from programs sponsored by the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF). Across all of its efforts, EGPAF works to promote the leadership and decision making of young people and to ensure that all of its programs are designed to empower youth and to meet their needs and preferences.

Right now, we have everything we need to make Generation Z (the group of people born in the late 1990s and early 2000s) an AIDS-free generation. But we aren't getting the job done. Thousands of young people become infected with HIV every day, and many adolescents and youth living with HIV aren't benefiting from the medicines, services, and support that can save their lives.

As COVID-19 disrupts service systems and closes off options for many face-to-face encounters, there is a real risk that even more young people could be left behind in the fight against HIV.

Young people can't wait for others to solve the AIDS problem!

This is a **call to action** for young people across the world. The time is now to take action—to take responsibility for your own health and well-being, support other youth, and shape the fight against HIV in your own communities.



“Young people want to feel they are taking responsibility for their health. We are a different generation. What worked for adults won't really work for us. We need to be hands-on, and we need to be heard and be part of decision making.”

— **Dee, Lesotho**

## HIV threatens the health and well-being of young people, but it can be prevented and effectively treated.

We have made important progress in reducing the number of new HIV infections and AIDS-related deaths. But many adolescents and young people are being left behind. Many aren't benefiting from the programs that may work for adults.

Across the world, 4 million young people between the ages of 10 and 24 years are living with HIV.

In 2019, 1,260 young people between 10 and 24 years of age became infected with HIV *every day*.

The world has committed to [end the HIV epidemic by 2030](#), but we are not on track to reach that target. For example, the number of adolescent girls and young women who became infected with HIV in 2019 (280,000) was nearly three times higher than the global target of less than 100,000 new infections by 2020.

Especially in sub-Saharan Africa, young women are especially vulnerable. Every week, 7,000 adolescent girls and young women in Africa between the ages of 15 and 24 become infected with HIV. In sub-Saharan Africa, this group accounts for 10% of the population but for 24% of new HIV infections.

We know that HIV treatment works for young people and that it is possible to live a happy, healthy, and productive life with HIV. But we need to do a better job of making sure that all adolescents and youth living with HIV receive the services, care, and support they need. Compared to adults living with HIV, young people living with HIV are less likely to know their HIV status, less likely to receive HIV treatment, and less likely to have suppressed viral load.

Young people, of course, are not all the same. A 12-year-old has different needs from a young adult. Young women face different challenges than young men do. Those who grow up in poverty have needs that differ



from those whose families are wealthier. Young people living in the countryside have lives that are often different from those who live in cities. Some young people have loving and supportive families, while some others don't. And some belong to communities that are marginalized or stigmatized. Every young person affected by HIV has the right to services and support that match their particular needs and circumstances.

We need immediate action to end HIV among Generation Z. Yours is the largest generation of young people in human history, and the one coming after you will be even larger. Unless we do a better job of preventing adolescents and youth from becoming infected, the annual number of new infections among young people could actually increase during this decade. And unless we do a better job of linking young people living with HIV with testing and treatment services, more will die of AIDS.

**The time for action is now!**



## Youth leadership toward an AIDS-free generation

“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 hope to end the HIV epidemic, it is clear that youth must lead the way. “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.

Youth leadership in the fight against HIV comes in different forms. By speaking up when services aren’t meeting your needs, you are showing leadership. By pushing back when someone tries to stigmatize you or someone else, you are showing leadership. By joining with other young people to raise awareness about HIV and demand that decision makers pay attention to your needs, you are being an HIV leader.

If you are receiving services at a clinic that doesn’t provide a regular way for young people to make their voice heard, you can speak up. Even better, you can join hands with other young people to insist that your program provide a way for adolescents and youth to be heard.

“Leadership may start by taking that one small first step,” says Josephine Nabukenya, a youth program coordinator in Uganda who now sits on EGPAF’s board of directors. “For example, it may start with an individual conversation about stigma. But the ideas in that one conversation begin to spread to others. Before you know it, your class at school or the local community where you live won’t stigmatize anyone because they know better.”

## Making HIV and other health services youth-friendly

Too often, health services fail to take into account the unique needs and perspectives of adolescents and youth. To be youth-friendly, services need to be tailored specifically for young people. This may mean that clinics offer weekend hours for in-school youth or one-stop models that enable young people to receive all the services they need at a single site. Perhaps above all, youth-friendly services need to have health care providers who understand young people's needs and treat them with respect and protect their confidentiality.

“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.”

The best way to make services youth-friendly is to make sure that programs are informed by the active, meaningful, and ongoing involvement of young people. In addition, having peers involved in the delivery of HIV services—as peer educators, support group leaders, mentors, or ambassadors—is another proven way to make services more youth-friendly.

For young people living with HIV, youth-friendly services recognize that HIV is merely one part of a person's life. Youth living with HIV need additional services and support to thrive, including psychosocial support, mental health care, proper food and nutrition, violence prevention, educational and other life opportunities, and support to avoid unhealthy behaviors, such as alcohol or drug abuse.

Young people who are of childbearing age, pregnant, or breastfeeding need particular services that are tailored to their needs. Young people have a right to ensure that their pregnancies are planned and wanted,

but too many young people don't have access to modern contraception. During pregnancy or after birth, young women are at very high risk of becoming infected with HIV through sex, underscoring the importance of focused HIV prevention programs. Young pregnant and breastfeeding women living with HIV need access to HIV treatment to protect their own health and to guard against the risk of passing the virus to their newborn.

Unfortunately, not all service providers are prepared to meet young people's needs. Speaking up—whether by filling out an anonymous survey or by talking confidentially with a trusted health care provider—when services are inconvenient, inadequate, inappropriate, or disrespectful is an important step toward being a youth leader on HIV.

“Youth-friendly services ensure that young people can speak freely, without judgment, and that they can access the services they need. Youth-friendly services accept young people without discrimination and provide peer education that allows young people to be more open, especially when talking about sex.”

— **Tanya, Zimbabwe**

## Speaking up for youth-friendly health services

Josephine Nabukenya is an EGPAF ambassador who completed her degree in social work from Makerere University in Uganda prior to registering a youth-led nongovernmental organization and authoring a book on growing up with HIV. In 2020, she was elected to EGPAF's board of directors, making her the first young African woman to serve in this capacity.

Although today Josephine is a recognized leader in the fight against HIV, it was not that long ago that she was a young HIV-positive girl whose doctors wanted her to take a medication that was intolerable. "I was taking a syrup and I didn't like it," Josephine recalls. "Everybody thinks doctors always know what is best for us, but I spoke up. I told them that if they did not change my regimen so I won't have to take syrup, I will never take it again! I was honest, and my doctor listened to me. We got a solution by breaking tablets into pieces that I could take.

**"It is important to be open with your doctors about your treatment. By speaking up, young people are able to initiate the change they want to see."**



Josephine Nabukenya (Photo: Eric Bond/EGPAF, 2017)

## Sparking Conversations

After his family moves to a new city, Jacob starts attending a new health facility. This clinic is only open during weekdays, making it hard for Jacob to balance school and visits to the clinic. The doctors and nurses are all significantly older than Jacob and he feels uncomfortable speaking openly with them. He also rarely sees other teens at the clinic. During a counseling session he meets a peer expert client with whom he wants to share his concerns and ideas to make the clinic more accessible for adolescents.

**What could Jacob suggest to make the clinic more youth-friendly? What are some actions he can take to raise awareness and advocate for these changes? Who can he seek out to support him in his goals?**

## Young people supporting each other


One of the most important things you can do in response to HIV is to talk to other young people—about HIV, about sex, and about the challenges you and your peers are facing.

It is always good to have adults in your life who are looking out for your best interests. But no one can relate to young people the way other young people can.

Peer support groups can help young people living with HIV—to take their medications on time, to cope with stigma and discrimination, and to deal with family problems. By educating and supporting each other, young people living with HIV are better able to take control of their lives, set goals, and achieve their potential. Peer support builds people’s resilience, helps young people to have healthy relationships, and enables young people to cope with life’s challenges. With the support of other young people, HIV-positive youth are able to understand HIV as just one facet of their lives—one that can be managed and one that is fully compatible with a long, healthy, happy, and productive life.

As Hajarrah, 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 peer support group] 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.”

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



“Young people need to be able to talk to their peers about the challenges they are facing.”

— **HIV-positive 25-year-old in Kenya**

## Why peer support matters: The story of Joseph\*

The story of Joseph, an HIV-positive young person who is an EGPAF client in Uganda, shows the special power of peer support. Having grown up in an orphanage after losing both his parents to AIDS, Joseph started 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 about 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 in getting 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.”**

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

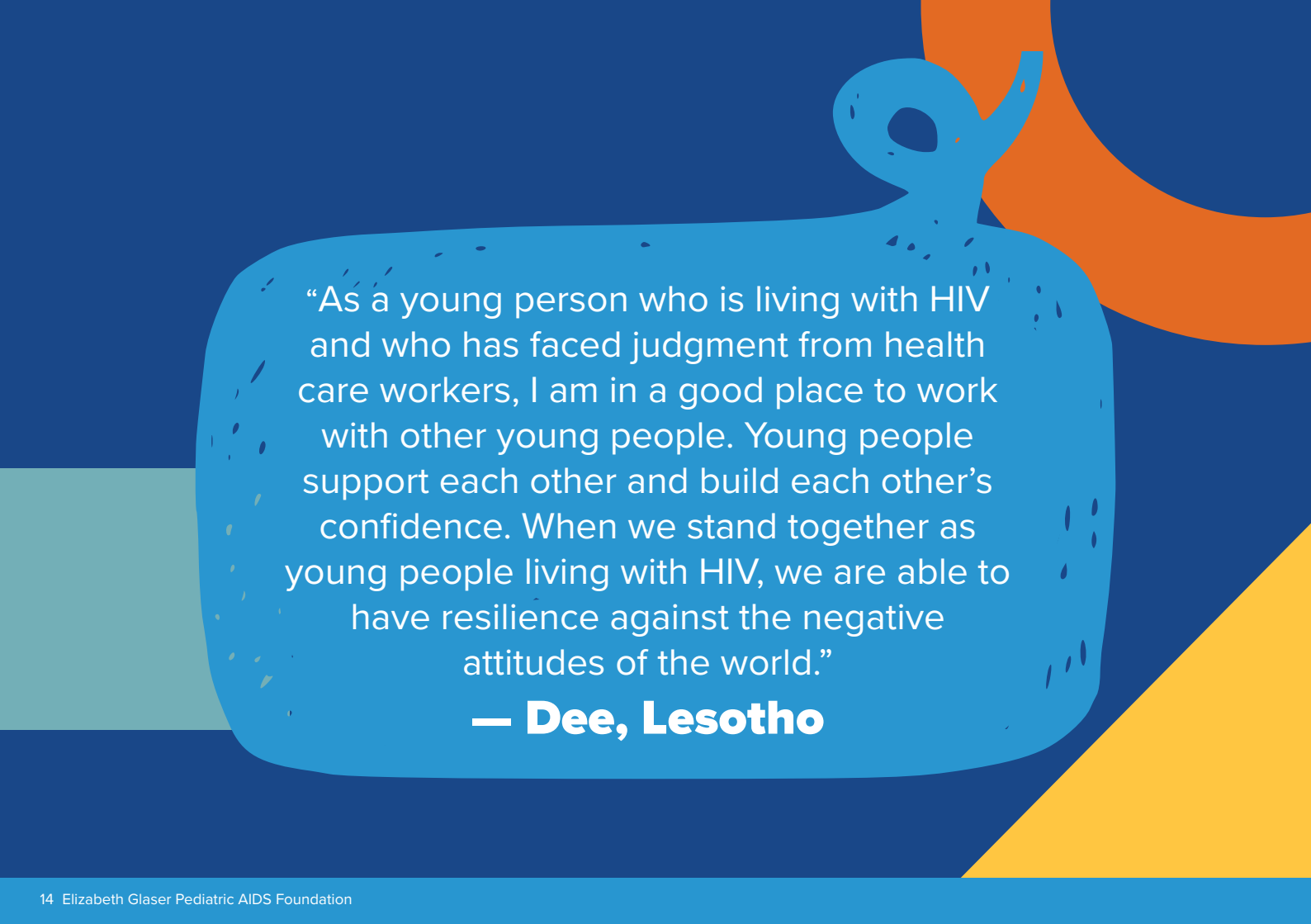




Young people's support for one another comes in many forms. It can be informal, such as day-to-day conversations with your friends. Support can be face to face, or, especially in the age of COVID-19, virtual, through telephone calls, SMS and WhatsApp messages, online support groups, and other virtual platforms. Some programs use teen mentors, who help other young people cope with difficult feelings, make important decisions, negotiate sexual safety, and stand up against gender-based violence. Others are more formal, such as EGPAF's Ariel Clubs, with monthly, facilitated meetings that focus on the individual needs of HIV-positive young people.

For most young people living with HIV, deciding when and how to disclose one's HIV status to others is among the most difficult challenges they face. HIV-positive youth who have faced and overcome this challenge offer a unique source of support and advice for other young people who are struggling with disclosure. "Most adolescents living with HIV experience stigma and discrimination, and it is hard for them to disclose," notes Tanya, 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 [learn] how to live a positive life during this time."

For adolescents and youth living with HIV, it's a smart move to actively look for other HIV-positive young people with whom you can connect and share experiences. If your local clinic or community doesn't offer a peer-led psychosocial support group for young people, you might consider speaking up and recommending that they do so or try seeking out a larger local network. Or you might just organize a support group on your own.



“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, Lesotho**

## Sparking Conversations

Your friend Elizabeth, who is living with HIV, tells you that she has been feeling isolated and that no one understands what she is going through. She does not know many people her age who are living with HIV and worries about disclosing her status. She confesses that she often feels hopeless.

**What can you do to help support your friend? What other sources of support could be available for Elizabeth at her facility or in her community?**

## Taking responsibility for your own health

Health care settings, especially those that haven't been designed specifically to meet young people's needs, don't always make it easy for youth living with HIV to stay engaged in care. Particularly when services are inconvenient, inaccessible, or disrespectful, young people may stop visiting the clinic or quit getting their medicines refilled.

For some young people living with HIV, their HIV status is a source of anxiety and something they would rather forget. For some, it is simpler to stop taking one's medications than it is to confront the difficult feelings that being HIV-positive can sometimes cause. And many young people living with HIV face other significant challenges that can make it difficult to take their pills at the same time every day.

Even though available treatments for HIV are highly effective and enable people living with HIV to live long and productive lives, AIDS remains one of the leading causes of death among adolescents and young adults.

Service providers should empower young people living with HIV to participate as partners in their own health care. Ultimately, each of us is responsible for taking the needed steps to protect our own health. But taking that responsibility is much easier when you are empowered and have a strong support network. Peer-led support groups educate young people about the importance of staying in care and taking their medications as prescribed. Such support groups help young people “unpack” and address the issues or anxieties that make staying in care or adhering to medication regimens difficult.

Young people living with HIV need to have their health monitored regularly. Where tests indicate that an HIV regimen is no longer working, providers need to proactively switch to an alternative regimen in order to support reaching suppression. To make this work, programs need ready access to second- and third-line treatment regimens.

## Sparking Conversations

A close friend, Thomas, confides that he has stopped taking his HIV medicine. He says that the side effects make him feel sicker than he did before he started taking medication. He also tells you that he doesn't know anyone else who has to take pills every day and doesn't want anyone to see him taking medication.

**What advice would you give to Thomas?**

## Turning the tide against new HIV infections among young people

Youth is a time of exploration, experimentation, and new experiences. The lessons learned during this period last a lifetime.

But while young people are learning key lessons during these important years, they may also encounter serious health risks, including the risk of becoming infected with HIV. The number of young people becoming infected with HIV has fallen somewhat over the last decade, but not fast enough to put us on track to having an AIDS-free generation.

How to prevent HIV among adolescents and youth is not a mystery, as we have many proven prevention tools and strategies. But we haven't taken the steps to ensure that every young person has access to the prevention tools they need.

To take action to avoid exposure to HIV, young people first need to understand what HIV is and how it is prevented. They also need to recognize that they themselves are at risk.

A key first step for effective HIV prevention is for young people to talk to each other about HIV. **Talking about sex—what it means, and when and how to have sex safely and responsibly—is essential.** Talking about HIV with your friends is also an opportunity to correct misinformation about how the virus is transmitted.

Comprehensive sex education and sexual and reproductive health services provide young people with the knowledge, tools, and motivation they need to inform positive prevention practices and behavior. Condoms are highly effective in preventing HIV transmission during sex. Voluntary medical male circumcision reduces the risk that an adolescent boy or young man will acquire HIV during sex with a woman by about 60%. And oral preexposure prophylaxis, or PrEP—the use by HIV-negative people of some of the same drugs used to treat HIV infection— prevents HIV transmission more than 90% of the time if it is taken daily.

When a person living with HIV has an undetectable viral load, it is virtually impossible for them to transmit the virus to a sex partner. This reality has generated a global movement known as U = U, or Undetectable equals Untransmittable. This means that HIV prevention isn't just the job of people who are HIV-negative, but that people living with HIV also have a role to play in ending new HIV infections.

Every young person at risk of HIV has the right to effective prevention services. But, too often, such services are not easily available. And when they are available, many youth are unaware of them. That's another reason why adolescents should talk to each other about HIV and sexual and reproductive health—to spread the word about prevention services that can help young people avoid becoming infected with HIV.



## Speaking up: Advocacy for the change we need to see

Many adults—health care providers, government officials, and academic experts—speak for or about young people. Now is the time for young people to speak for themselves.

Taking action on your own—by talking about HIV with your friends or in your community, or by demanding steps to make services more youth-friendly—is an important first step in creating the kind of change you want to see. But change is most likely to occur when you join with other young people in a unified voice.

At the global level and in many countries, networks or groups of young people living with HIV exist. These networks can offer a way for you to get involved in broader advocacy on behalf of young people living with or affected by HIV. For example, in countries that have laws that prevent young people from accessing HIV testing or sexual and reproductive health services without the consent of their parent or guardian, young people have joined up with other partners to advocate for the repeal of these laws.

EGPAF works with youth to advocate, both globally and in their home countries—young people from the United States and Africa share their stories and perspectives with external audiences, including media, political leaders, donors, and stakeholders. Their faces and voices represent the hundreds of thousands of young people reached by EGPAF programs and bring life to the fight for an AIDS-free generation.

In Zimbabwe, two EGPAF youth leaders, Tanya and Rosa, accompanied the EGPAF technical director in meetings with the Ministry of Health to discuss adoption of a toolkit on HIV disclosure for young people, which they contributed to, as well as a youth-created cartoon guide specifically designed to encourage conversations about HIV acceptance and disclosure among young people. Having participated in the development of these publications, Tanya and Rosa were natural advocates with national decision makers about how best to use them to address young people's HIV-related needs.



## Sparking Conversations

Grace is passionate about sexual and reproductive health and making sure that all youth and adolescents can access resources and prevention methods—such as condoms and other forms of contraception—to prevent pregnancy, HIV, and other sexually transmitted infections. However, many of the policies in her country make it difficult for teens to access sexual and reproductive health services. Grace would like to change those policies but doesn't know where to begin.

**What steps do you think Grace could take to advocate for this issue?**

## **A call to action: Adolescents and youth can and should shape their communities and futures to achieve an AIDS-free Generation Z.**

- ▶ Educate yourselves—and other young people—about HIV, how to prevent it, available treatments, and the importance of accessing HIV, sexual and reproductive health, and other health services.
- ▶ Talk to other young people—openly, honestly, and without judgment—about HIV, sex, and the challenges you are facing in your lives. Provide and seek peer support, and become involved as a peer worker. Actively work to fight stigma and misinformation about HIV.
- ▶ Take responsibility for your health and well-being. Know your HIV status! If you are HIV-positive, stay engaged in HIV treatment services and take your medications as prescribed. If you are HIV-negative, actively seek out the prevention services you need, including PrEP. If you are struggling to take the actions needed to protect your health, seek the support of other young people.
- ▶ Speak up if services and the providers who deliver them are not meeting your needs. Actively work in your local clinic and community to ensure that services are youth-friendly and that young people are actively involved in the planning, delivery, and monitoring of services.
- ▶ Network with other young people living with or affected by HIV. Seek out groups of young people living with or affected by HIV in your own community, your country, or across the globe.
- ▶ Join with others to advocate for things you are passionate about, which could include the elimination of age-of-consent laws, effective actions to end child marriage, expansion of educational and economic opportunities for youth, and universal access to comprehensive sex education and sexual and reproductive health and rights.

**Be an advocate for the change your community needs to make an AIDS-free Generation Z a reality.**

# Want to learn more? Here are some sources of information.

## Resources

- [READY to advocate: A guide for young people living with HIV](#)
- [READY to care: Improving health services for young people living with HIV](#)
- [Advocating for Change for Adolescents! A Practical Toolkit for Young People to Advocate for Improved Adolescent Health and Well-being](#)
- [COVID-19: Keeping young people healthy: Practical guides](#)
- [AIDS-Free Generation Z: A Call to Action for Improving Youth-Focused HIV Programming](#)
- [Disclosure of HIV Status Toolkit for Pediatric and Adolescent Populations](#)
- [Adolescent and Youth Transition of Care Toolkit](#)
- [EGPAF Committee of African Youth Advisors \(CAYA\) Rapid Response: Recommendations for Adolescent and Youth Programming Amidst COVID-19](#)

## Networks

### Global

- [Y+](#)
- [LetsStopAIDS](#)
- [Youth Against AIDS](#)

### Region-/Country-Specific

- [YouAct](#) (European Region)
- [AfriYAN](#) (African Youth and Adolescents Network ) (African Region)
- [Sauti Skika](#) (Kenya)
- [UNYPA](#) (Uganda Network of Young People Living with HIV/AIDS) (Uganda)
- [NYP+](#) (Network of Young People Living with HIV and AIDS) (Tanzania)
- [SNYP+](#) (Swaziland Network of Young Positives) (Eswatini)
- Cameroon Network of Positive Youth
- [YPNSRHHA](#) (Young People's Network on Sexual Reproductive Health, HIV, and AIDS) (Zimbabwe)

### Youth-Led Organizations

- [International Youth Alliance for Family Planning](#)
- [YouthLead](#)
- [Youth Rise](#)
- [Teenergizer](#)
- [Y-PEER Youth Peer Education Network](#)
- [Y+](#)
- [HER Voice Fund](#)
- [Youth Force](#)

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