# MEDICAL MENTORSHIP FOR YOUNG PEOPLE LIVING WITH HIV

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## A letter from Toraje Heyward

Youth Activist, Engaging Communities around HIV Organizing (ECHO)

Dear Readers,

My name is Toraje Heyward and I use he/him/his pronouns. I am a part of Advocates for Youth's Engaging Communities around HIV Organizing (ECHO) Youth Council. The purpose of this Toolkit is to provide a map for organizations interested in creating robust and effective mentorship programs that cater to, serve, and, most importantly, center young people living with HIV. As a youth-led project, the Toolkit has been informed and designed by young people living with HIV who hope to inspire the minds of the next generation of leaders.

As a queer Black man living with HIV, it was essential for me to have a mentor to help me cope with my diagnosis. In 2018, when I first entered into care, I met a young man by the name of Lamar, who introduced me to a support group, entitled "Positive Choices." Turns out, Lamar was actually the CEO of a non-profit organization called H.Y.P.E. 2 Empower, which has the sole mission of equipping youth and communities living with HIV with the capacities to be leaders in their communities and promote their communities' interests. Lamar not only showed me that living with HIV was not a death sentence, but that I could still be fulfilled in all aspects of my life—social, emotional, sexual, medical—despite the obstacles that were to come.

Unfortunately, many people, whether they are living with HIV or coming out of the closet, do not have spaces that affirm all of their identities or a network of support. Their families have shunned them. Their churches have excommunicated them. The school administration has turned its back on their concerns and marked them off as "personal issues." Beyond their medical needs, these young people need support, information, and affirmation. And you can give that to them.

This Toolkit recognizes that the transition to adult care is not easy, but with the support and affirmation of a mentor, the process is smoother. When I was first diagnosed, my grandmother was the initial person that guided me through the steps needed to fill out my AIDS Drug Assistance Program (ADAP) paperwork. My grandmother also supported me in identifying a potential provider and health center. When I first arrived at a health center based in Atlanta, I honestly did not know how to interact with staff and the provider. There were so many different kinds of medicines, and I was nervous about how my body would respond to certain HIV medications. While my grandmother reassured me that everything would be alright, I also needed this support from my provider. I needed my provider to reassure me that I wouldn't experience bone damage or kidney failure. But their responses were very clinical and left me confused and scared. "It's a potential side effect." "We will monitor over time and do our best. Some medicines work well for some people, others don't." Without my grandmother, I do not think I would have been mentally capable of managing my HIV care alone. My experience has inspired me to mentor other young people living with HIV. I never want a young person living with HIV to feel alone or afraid.

This Toolkit will serve to close the gaps between service providers and the transition of young people living with HIV into adult care. While I was privileged by having multiple mentors in and outside of my family, many young people, especially Black and Brown LGBTQ+ youth, do not have the same support networks and too often experience discrimination in work, housing, public assistance, and healthcare settings. My mentor provided me with problem-solving resources regarding disclosure, knowledge about HIV, and the impact of language and stigma that I often use to navigate a world where Black and Brown young people living with HIV don't feel valued. The Toolkit has a variety of resources—for young people living with HIV, mentors, and providers—to offer support and help to young people thrive, engage, and stay in adult care, despite their circumstances. The reality is that mentorship is more than just a relationship—mentorship is a lifeline. So the question is—what is stopping you from empowering the next young person living with HIV?

Best,
Toraje Heyward

# ACKNOWLEDGEMENTS

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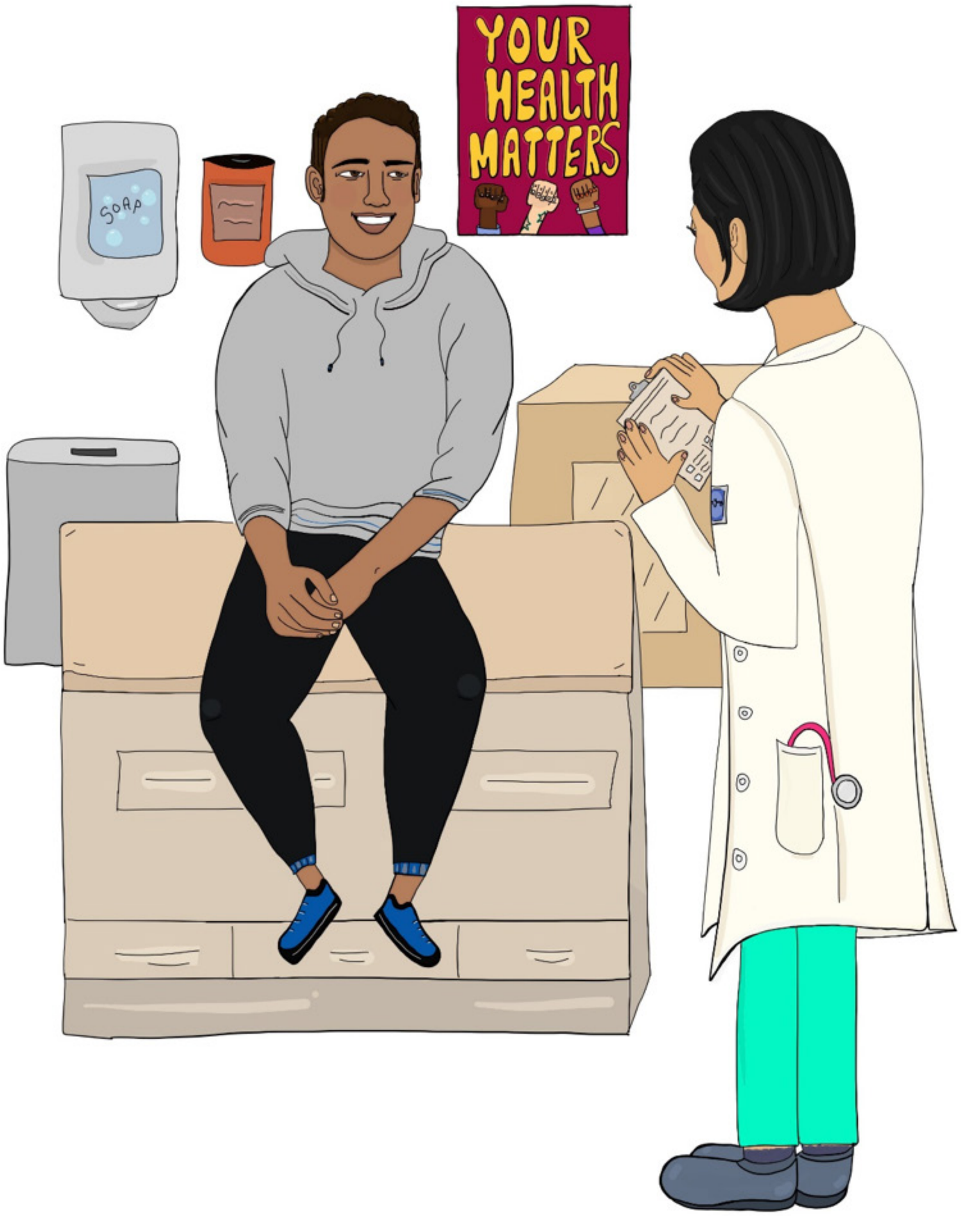

SOAP
YOUR HEALTH MATTERS

# OVERVIEW

**The transition to adult care can be described as "a multifaceted, active process that attends to the medical, psychological, and educational or vocational needs of adolescents."**

**Treadwell et al. 2011**

For young people living with HIV, a successful transition from adolescent HIV care into adult care can be fraught with difficulty and confusion. Successful transition requires an approach that centers the young person and offers them support and mentorship before and well into the transition.

Adolescent HIV clinics are often multidisciplinary. HIV care is integrated with primary care, sexual and reproductive healthcare, mental health, and substance abuse treatment. Education and adherence are prioritized as is case management. In contrast, many adult HIV clinics are housed within larger settings and rely on the patient to navigate the system and advocate for their own needs. Issues of medical insurance, patient confidentiality and informed consent can fall to the advocacy of the patient. Emerging young adults may feel intimidated, suffer from internalized and social stigma, lack self-confidence, fear HIV disclosure, and experience housing, employment and/or insurance instability that can negatively affect their transition from adolescent to adult HIV care.

Mentorship offers one strategy to assist young people living with HIV who are aging out of adolescent care to successfully transition into and remain in adult care. The Mentoring Support Network defines mentoring as "sharing knowledge, skills and life experience to guide another towards reaching their full potential; it's a journey of shared discovery."

Adults living with HIV can serve as effective mentors for young people living with HIV. They can share their knowledge, skills and life experience to help the young person navigate the healthcare system and find the support and resources they need to thrive.

Organizations interested in assisting young people living with HIV can implement mentorship programs by recruiting, training and linking adult mentors to these young people prior to, during and through their transition to adult HIV services.

This Toolkit includes best practices, innovative strategies, and community-driven solutions to ensure the establishment of effective mentorship programs for young people ages 16-24 living with HIV. It is designed to guide organizations wishing to support these young people to develop mentorship programs that will help them transition into and remain in adult care as they age out of adolescent services.

Mentors and mentorship programs vary in capacity, size, and demographics. This Toolkit does not embrace a one-size-fits-all approach. Instead, it provides actionable advice on implementing practices and procedures that support young people living with HIV to successfully transition to and remain in adult care.

This Toolkit has been developed to assist individuals, community-based organizations, providers, healthcare staff, and others that see the value of incorporating a youth-mentorship framework into their programming to support the transition process and ensure that young people living with HIV are successfully linked and remain engaged in an adult care setting. Recommendations serve as a guide and should be tailored to each individual young person.

# YOUNG PEOPLE & HIV

> **"From being born premature and now living with HIV, I can truly say that I have had my fair share of trials and tribulations. When I was diagnosed with HIV in April 2018, I realized that there is much work to do within our communities to ensure that stigma does not unleash its wrath on our Black and Brown boys, girls, men, women, and trans and gender non-conforming folks who have a chance to end the battle against HIV, stigma, and injustice."**
>
> **- Toraje, Youth Activist**

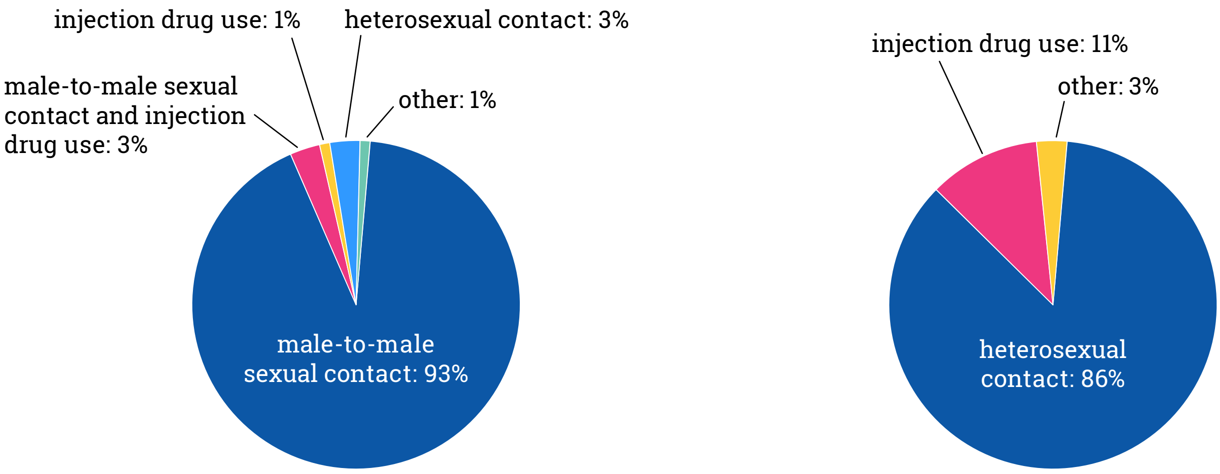
The CDC reports that in 2017, young people aged 13 to 24 made up 21 percent (8,164) of the 38,739 new HIV diagnoses in the United States and dependent areas. The majority of these young people were Black and/or Latinx young men who have sex with men (YMSM). Young people living with HIV are the least likely of any age group to be linked to care in a timely manner and the least likely to have a suppressed viral load.

Young people living with HIV face compounded challenges including homophobia, racism, poverty, isolation, and HIV stigma. These barriers can impact their health literacy and self-esteem resulting in high rates of homelessness, poor mental health, and increased use of drugs and alcohol. Addressing HIV in youth requires that young people have access to information and tools to get treatment and care and to thrive.

Mentorship is one evidence-based strategy to dismantle some of  these challenges, foster community among young people living with HIV and their allies, and help young people living with HIV find their own voices and advocate for their own needs when championing their health. Ultimately, quality mentorship programs support youth living with HIV live long, healthy and fulfilling lives.

# 1.1 QUICK FACTS

## New HIV Diagnoses Among Youth by Transmission Category and Sex in the US and Dependent Areas, 2017

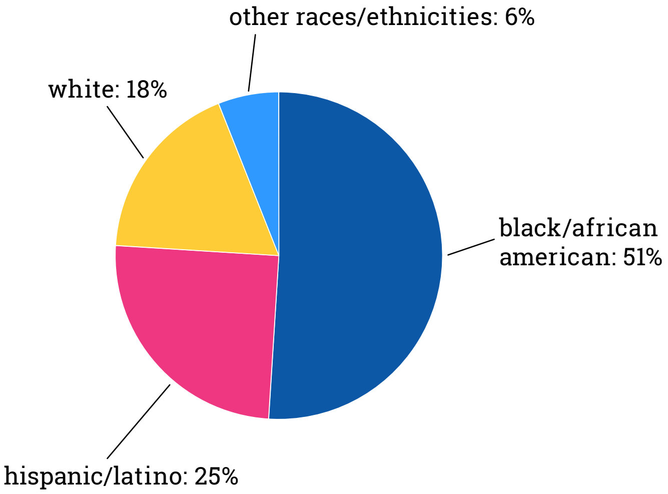


**Young Men**

**Young Women**

Adapted from CDC HIV and Youth Factsheet 2019

## New HIV Diagnoses Among Young Gay and Bisexual Men by Race/Ethnicity in the US and Dependent Areas, 2017



Adapted from CDC HIV Surveillance Report 2018

### For Every 100 Youth With HIV In 2015:

**36** received **some** HIV care

**27** were **retained** in care

**36** were **virally suppressed**

In contrast to other age groups, young people living with HIV have the lowest rate of viral suppression.

Adapted from CDC Selected National HIV Prevention and Care

# QUICK FACTS

## CONTINUED

- **Between 2012 and 2016,** HIV diagnoses among adolescents and young adults increased 6 percent whereas HIV diagnoses among adults declined or stabilized over the same period.
- **Between 2012 and 2016,** new diagnoses among Latinx YMSM increased by 17 percent and new diagnoses among Black YMSM increased by 9 percent.
- **The CDC reports that nearly half** of young people living with HIV are unaware of their status.
- **Only 51 percent of adolescents** and young adults who have been diagnosed with HIV achieve viral suppression.
- **Laws in many states make it difficult** for young people under age 18 to access PrEP without parental or guardian consent.
- **Young people ages 18 - 29 years** have lower rates of health insurance than do older individuals.

# 1.2 THE VOICES OF YOUNG PEOPLE LIVING WITH HIV

> **"In my transition to adult care I had an issue accessing consent forms, and I had a hard time obtaining my medical records. My adolescent doctor could have printed out my medical records or sent them to me and my new provider via a secure email."**
>
> **- Jorian, Youth Activist**

Young people living with HIV experience a myriad of issues before, during, and after receiving medical care. We interviewed a few young people living with HIV who recently transitioned into adult care:

1. **Describe your experience transitioning out of care as a young person.**

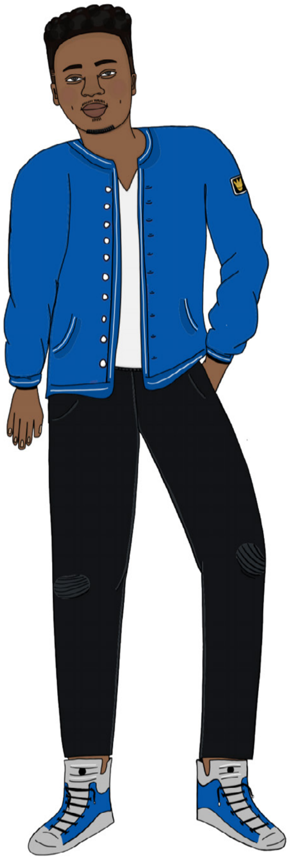
**Jorian:** "My experience transitioning out of care was anything but comprehensive. I was diagnosed with HIV in Florida and received little to no support from my doctor. This led me to move back to my hometown to be closer to family and improve my access to care."

**Tiffany:** "Although I was provided with a lot of information about HIV and navigating care from different directions, multiple people were telling me 'You have to enroll in this, this, AND that.' This included gynecological care, mental health, enrolling in the Affordable Care Act (ACA). I received questions like 'What kind of Ryan White do you need?' Aware that there are many parts of Ryan White, I used to think, 'What does that mean?'"

2. **Describe some effective practices for transitioning out of care.**

**Jorian:** "Providers and individuals that work with young people living with HIV should create a guide that lets people know how to get from Point A to Point B when transitioning out of care. This should start at the beginning of the process, maybe a year or 6 months before transitioning out. Supporters such as the mentor and case manager should affirm the young person. (e.g. You're 19, I am going to be there for you.) The mentor, and if applicable, pediatric doctor, should be in contact with the adult HIV care provider. This means that they should be in constant communication about transferring medical records, ensuring that the young person is comfortable with the doctor. **The ideal situation would be for the young person to be trained by their mentor or pediatric provider, if applicable, on how to navigate services and practice over time. Example trainings and tests can include: determining eligibility, completing paperwork, navigating transitioning process.**"

**Tiffany:** "This can happen by case managers enrolling youth in their correct AIDS Drug Assistance Program (ADAP)—approved ACA program. This enrollment should occur ahead of time so that they can get all of their information such as IDs, pay stubs, etc. together and submitted on time."



### 3. Is there anything else you would like the person reading this to know?

**Jorian:** "Transportation to the new provider must be considered. In addition, the new provider should formally check in with the mentor and community-based organization to be well oriented about the needs of the young person transitioning into their care."

**Tiffany:** "The pediatric provider (if applicable) and community-based organization should openly communicate any changes that may impact their relationship. For example, if the provider is moving out of the state or the organization is ending some of its HIV-related services, by informing the young person early so that they can create a plan for a new doctor. The adult HIV doctor should be engaged in HIV and LGBTQ-competent trainings to understand pronouns, etc."

**Young people living with HIV may be especially likely to not be linked to HIV care because of**

| Individual | Social/Family | Structural |
|---|---|---|
| • Stigma and shame<br>• Denial<br>• Low education achievement<br>• Substance use<br>• Psychiatric disorder<br>• Fear of a new healthcare system or hospital | • Lack of health insurance<br>• Family dysfunction<br>• Past and current neglect/abuse | • Health care costs<br>• Services available<br>• Accessibility of facility<br>• Degree of "youth-unfriendly" staff and services |

Adapted from Kang SY et al. 2006; Hosek et al. 2008; Mill et al. 2008; Nachenga et al. 2009

# 1.3 SELF, SOCIAL AND STRUCTURAL STIGMA

> **"HIV stigma [impacts different] youth subgroups. [For instance, our approach to working with] young people born with HIV contrasts from our work with MSM ballroom members."**
>
> **- Chelsea, RAIN, Inc.**

Young people living with HIV often experience stigma related to their HIV status. The Centers for Disease Control and Prevention defines HIV stigma as, "negative attitudes and beliefs about people living with HIV. It is the prejudice that comes with labeling an individual as part of a group that is believed to be socially unacceptable."

There are multiple layers of HIV stigma including self, social, and structural. Each of these layers can negatively affect the health and well-being of young people living with HIV.

**Self Stigma**, also known as internalized stigma, happens when a person consciously or unconsciously accepts the negative ideas and stereotypes others have about people living with HIV and starts to apply them to themselves. HIV internalized stigma can lead young people living with HIV to feel shame, isolation and despair.

**Social stigma** is the negative attitudes and beliefs about a person based on perceived social characteristics that distinguish them from others in society. Social stigmas are commonly related to culture, gender identity, sexual orientation or HIV status. Young people living with HIV may feel social stigma because of their HIV status and may develop behaviors to hide their status. They may withhold disclosing HIV status or fail to adhere to HIV medication regimens in response to social stigma.

**Structural stigma** reflects the laws, policies, and procedures set by social institutions that hinder the rights and freedoms of members of stigmatized groups. Structural stigma also can be manifested through the absence of laws that protect LGBTQ youth and/or young people living with HIV from discrimination, such as losing employment or being denied health services due to one's identity or HIV status.

**A study from the International Center for Research on Women found that consequences of HIV-related stigma can include:**

- Loss of income
- Loss of hope
- Increased feelings of worthlessness
- Increased internalized stigma
- Receipt of poor care in the healthcare system
- Loss of reputation in the family and community

# 1.4 CHALLENGES TO TRANSITIONING INTO ADULT CARE

> **"People who aren't living with HIV can advocate for HIV-related stigma reduction interventions and policies that strengthen protections from discrimination for people living with HIV, and those that identify as lesbian, gay, bisexual, and transgender."**
>
> **- Lisa, Youth Activist**

Adolescence is a time of transition. For young people living with HIV, transitioning into adult care can prove difficult. Adolescent healthcare systems are often multi-disciplinary and integrate HIV care into primary healthcare services that also include sexual health, mental health, and drug and alcohol treatment. Education and case management enhance success. Adult healthcare settings often rely more on the individual to navigate the system and advocate for their own needs. According to the Department of Health and Human Services' Guidelines for the Use of Antiretroviral Agents in Adults and Adolescents with HIV, "Transitioning the care of an emerging young adult includes considering areas such as access to medical insurance; the adolescent's degree of independence/autonomy and decisional capacity; patient confidentiality; and informed consent. Also, adult clinic settings tend to be larger and can easily intimidate younger, less-motivated patients."

**Young people face a variety of challenges in efforts to transition into adult HIV care such as:**

- Lack of youth- and LGBTQ-friendly services
- Changing of care providers (requiring re-telling health history, re-establishing trust, etc.)
- Rigid scheduling policies of health providers
- Increasing responsibilities of the young person as they age
- Stigma, especially regarding disclosing HIV status
- Mental health
- Decreasing involvement of current adolescent caregivers as the young person ages out
- Lapses in health insurance
- Financial hardships
- Lack of transportation to new provider
- Issues regarding consent and confidentiality

Adapted from White PH and Cooley WC 2018

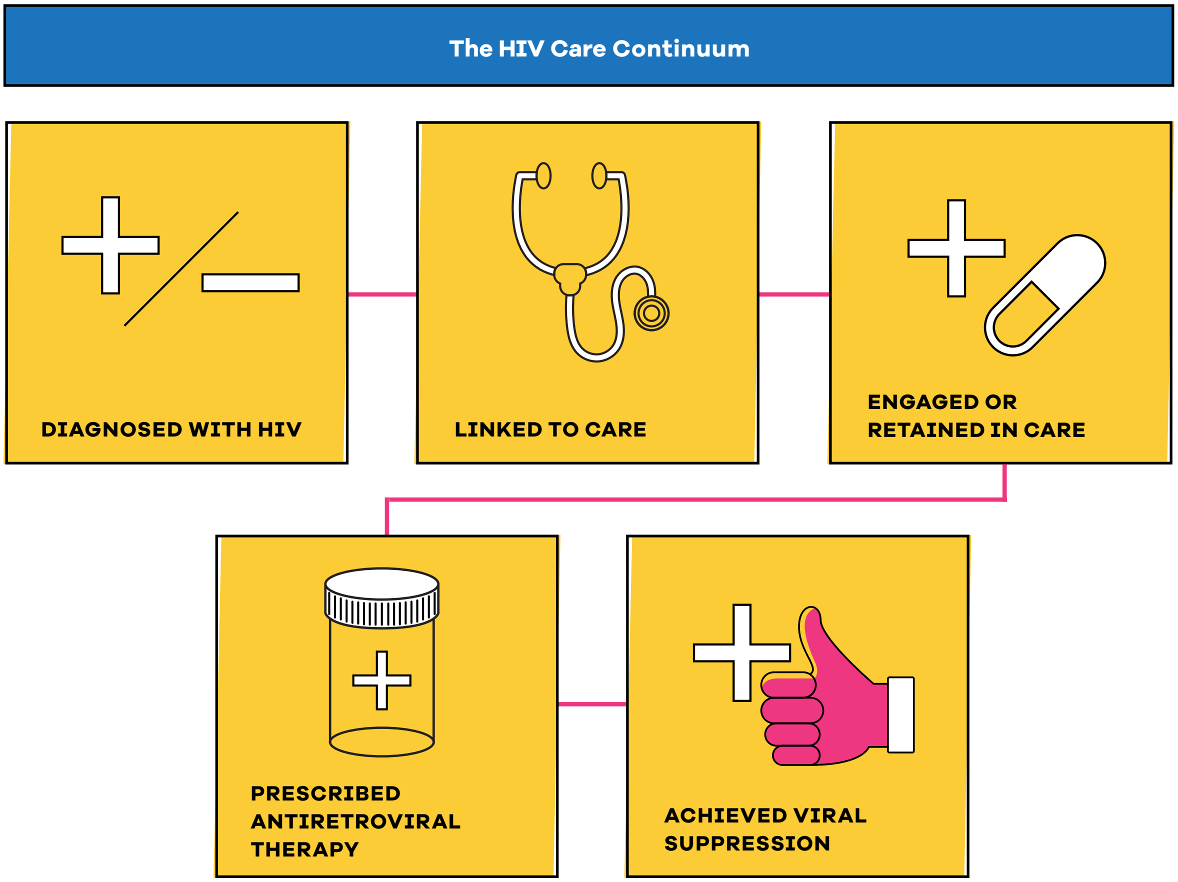
**In 2013 the American Academy of Pediatrics (AAP) released recommendations for transition to adult HIV care that include four steps:**

1. Development of written policies to guide transition
2. Joint creation of a transition plan by youth, family & providers
3. Planned facilitation of youths' connection to adult clinics as transition is initiated
4. Communication between adolescent & adult clinics during the transition process for quality assurance review

Adapted from Committee on Pediatric AIDS 2013

# 1.5 BARRIERS TO REMAINING ADHERENT

The Centers for Disease Control and Prevention (CDC) reports that people living with HIV should take medicine to treat HIV as soon as possible. HIV medicine is called antiretroviral therapy, or ART. If taken as prescribed, HIV medicine reduces the amount of HIV in the body (viral load) to a very low level, which keeps the immune system working and prevents illness. This is called viral suppression—defined as having less than 200 copies of HIV per milliliter of blood. HIV medicine can even make the viral load so low that a test cannot detect it. This is called an undetectable viral load. Achieving and sustaining an undetectable viral load not only helps prevent illness in the person living with HIV, but also greatly reduces forward transmission of HIV to sexual partners or through syringe sharing, and from mother to child during pregnancy, birth, and breastfeeding.


**The HIV Care Continuum**

Unfortunately, young people living with HIV also face barriers that increase their chances of nonadherence to treatment and act as a barrier to achieving an undetectable viral load. These barriers can be psychological (depression, perceived stigma, lack of support), medical (dissatisfaction with medical team, side effects), and logistical (inconvenience, forgetting). Assisting young people to redress these barriers is an essential strategy in supporting them to transition and remain adherent to an adult healthcare regimen.

# 1.6 MENTORSHIP AS A BRIDGE

Mentors play a key role in identifying the individual barriers to care faced by young people living with HIV. Mentors openly acknowledge that navigating the health system can sometimes be difficult, but demonstrate to the young person that they can work together to help them successfully obtain the services needed to help them stay healthy.

**Mentors can support young people by supporting them:**

- Develop life skills, such as self-care, advocacy, and health literacy
- Navigate logistics, transportation, medical insurance, social services, etc. before, during and after the transition
- Feel part of a strong and resilient community

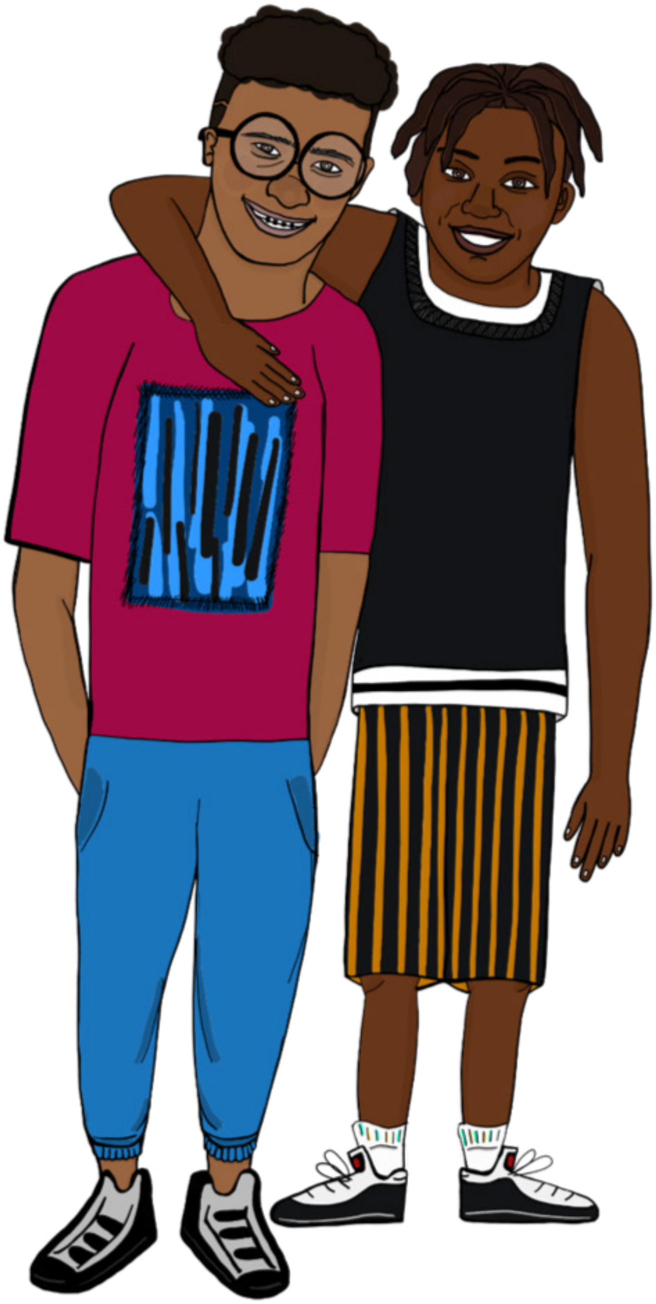
After the transition, mentors can work with young people to advocate for youth-friendly clinical policies and environments and encourage providers and staff to be advocates for young adult patients.

# THE POWER OF MENTORSHIP

Mentorship is recognized as an effective strategy to help young people living with HIV build the self-management skills needed to successfully enter and stay in adult care at a point in time when young adults are most likely to fall out of care.

Young people living with HIV typically enter adult care by the age of 25. However, they often face a variety of barriers during and after the transition, which may include concerns about confidentiality, privacy, and trust in the adult setting. Youth living with HIV may feel overwhelmed by the new healthcare facility and miss the trust they built with their adolescent provider.  They may not feel ready to make decisions or manage their healthcare on their own.

Fortunately, mentorship programs can help. Mentors can make personal connections, provide information, guidance, and share their own experiences with young people transitioning to adult care. Mentorship can help young people living with HIV gain the confidence and skills to manage and sustain their own healthcare.



# 2.1 CREATING A MENTORSHIP PROGRAM

> **"Our ultimate goal is for young people living with HIV to achieve and maintain viral suppression, [and] consistent retention in care."**
>
> **- Tony, AIDS ALABAMA**

**Creating a mentorship program at your organization or agency can support young people living with HIV to successfully transition to adult care. Organizations that may consider creating such a program include:**

- Adolescent HIV healthcare settings
- Adult HIV healthcare settings
- Community-based organizations
- Faith-based organizations

There is no one-size-fits-all approach to developing a mentorship program that supports young people living with HIV. In 2017, ViiV Healthcare first provided funding to a cohort of organizations across the country seeking to either pilot or expand a variety of programs approaching medical mentorship in different ways through the Positive Action for Youth (PAFY) initiative. The PAFY initiative was developed in response to the disparities young people living with HIV face as well as the rising rate of HIV diagnoses among youth, with the goal of supporting more young people navigate into and stay engaged in adult healthcare via mentorship. Advocates for Youth was also funded to conduct a collaborative co-creation process that would leverage the voices and expertise of the community as well as best practices, learnings and recommendations for medical mentorship shared by the first PAFY grantees. These organizations are an example of how to implement and sustain effective mentoring programs; many provided resources for this Toolkit. You can read more about each of their programs below.

**Abounding Prosperity** is a community-based organization based in Dallas, Texas. The organization's mentorship program is known as Project BEST/TEST. The Project links recently identified young men who have sex with men (YMSM) and transgender women of color living with HIV/AIDS, one-on-one, with a mentor who supports them as they navigate the HIV care system, connect with necessary supports, and build confidence in selecting and owning their regimen of care. Project BEST/TEST trains mentors and encourages at least two hours of mentoring per month to set and reach goals related to mentees' successful HIV care. Mentors provide in-person and electronic support. Mentors make referrals to services such as transitional housing, counseling, education, harm reduction, and linkages to support services.

**AIDS Alabama** is a community-based organization in Birmingham, Alabama. The organization leads *Living Out Loud*, a mentoring project for youth living with HIV/AIDS (YLWHA), ages 13 to 24. Mentors provide support in medical adherence, self-advocacy, financial planning skills, and job or college readiness while making referrals and increasing access to transportation, mental health services, and housing assistance. Mentors are trained in multiple intervention programs including: *Choosing Life: Empowerment! Action! Results! (CLEAR); Women Involved in Life Learning from Other Women (WILLOW); Video Opportunities for Innovative Condom Education and Safer Sex (VOICES); Every Dose Every Day;* and *Partnership for Health Interventions.* To complement programming, the organization collaborates externally for medical care and housing.

**Center on Halsted** is a community-based organization in Chicago, Illinois. Its *U4U Program* creates a designated peer-supported space for youth living with HIV, ages 13 to 24. The program trains Youth Health Promoters to develop and manage drop-in sessions focused on supporting youth in developing the self-management skills needed to engage and stay in long-term adult care that works for them. The drop-in sessions are paired with an online community tool and youth-informed, fun, and accessible outreach materials that cover such topics as supporting successful youth transition into adult care, reducing fear of adult services, and showcasing the consequences and lessons learned from a lack of consistent self-care.

**RAIN, Inc.** is a community-based organization in Charlotte, North Carolina. The organization's *Empowering Positive Youth (EPY) Program* trains Peer Navigators and Youth Navigators to support young people living with HIV/AIDS to overcome barriers to care and achieve viral suppression. Through a tiered mentoring model, two Peer Navigators coach two Youth Navigators (who are former program participants). Youth Navigators in turn develop four to five Youth Leaders (current program participants) to act as peer mentors to a small group of program participants. Together, Peer Navigators train Youth Navigators in healthcare navigation, linkage, and referral while guiding Youth Navigators to implement leadership training for Youth Leaders. Together, these mentors guide program participants through ongoing support groups, education, prevention, and empowerment sessions.

**National AIDS Education and Services for Minorities (NAESM)** is a community-based organization in Atlanta, Georgia. NAESM provides *nSPIRE*, a mentoring program to increase linkages to care for newly diagnosed and re-engaged African-American Men Who Have Sex With Men (AAMSM), ages 16-24. Mentors work with young people to set goals, identify, and overcome barriers to healthcare to achieve viral suppression and connect socially with peers. By developing and supporting youth access to a network of peers and partners, NAESM supports young people in recognizing and surmounting the social determinants of health particular to AAMSM. To complement mentoring, nSPIRE works to develop and engage emerging youth in advocacy and community management.

## Additional advice for those considering a mentorship program include:

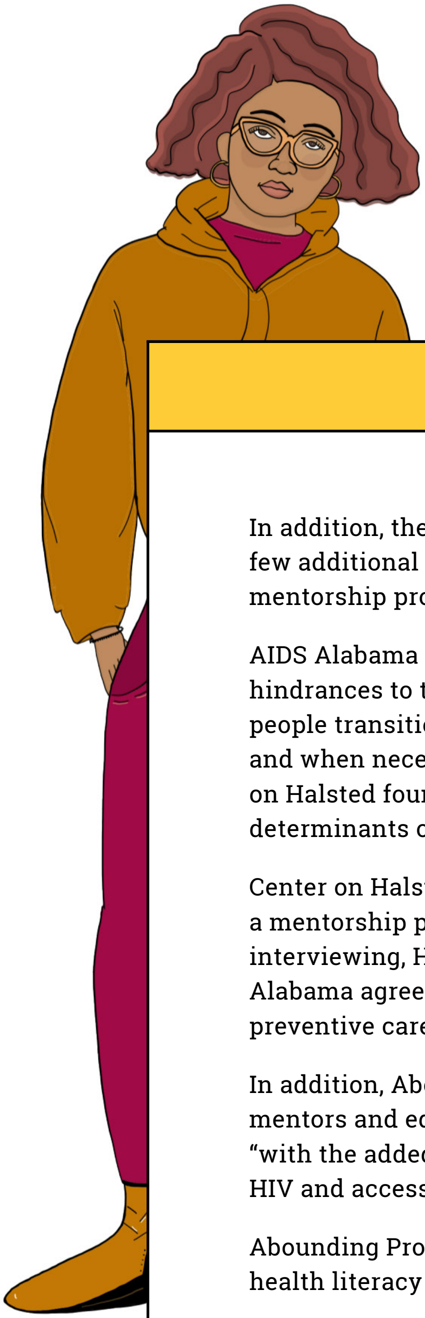
- **Honestly evaluate your organization's capacity to develop a mentorship program for young people living with HIV.**
  - Does your organization have a commitment to helping young people transition successfully to adult care?
  - Can your organization identify or hire at least one full-time staff person to develop and sustain the mentorship program?
  - Does your organization have connections with youth living with HIV?
  - Does your organization provide services that can help young people in their transition, including healthcare navigation, mental health or counseling, and first aid?
- **Understand the power and potential that mentors have—mentors can serve as a bridge between the young person, pediatric doctor, adult doctor, case manager, social worker, and even parent.**
  - Can your organization recruit and train mentors living with HIV that also reflect the cultural and lived experiences of the youth you wish to serve?
  - Are you willing to have mentors accompany young people to medical and support service visits? Assist with status disclosure?
- **Meet youth where they are and consider them and their needs as a whole person beyond their HIV status.**
  - Has the organization's staff been trained in the provision of youth-friendly and LGBTQ inclusive services?
  - Does the staff reflect the community you wish to serve? Will the mentors?
  - Can you provide or link to assistance related to education, employment, housing, child care?
  - Recognize the impact of stigma and create a plan to counter it.
  - Is the staff trained in youth-centered motivational interviewing and counseling?
  - Has the staff been trained in the impact of HIV stigma, adolescent development, and intersectionality?
  - Partner with and support community and healthcare initiatives that authentically support young people living with HIV.
  - Does your organization have established connections with healthcare and social support services in your community?

# 2.2 KEY CHARACTERISTICS OF MENTORSHIP PROGRAMS

A review of the literature and extensive exploration of the mentorship programs listed above unearthed key characteristics of mentorship programs that can help youth living with HIV successfully transition to and remain in adult care.

**Quality mentorship programs should:**

- Facilitate the early identification of young people living with HIV by providing referrals to HIV testing for contacts and partners of youth
- **Provide youth-centered counseling** to identify, assess and address a young person's barriers to linkage and retention in HIV medical care (e.g., paying special attention to housing, transportation, and support systems)
- Facilitate entry into medical care for young people living with HIV
- Facilitate linkages to needed support services
- Provide necessary follow-up to support young person's retention in care
- Have mentors accompany the young person to at least the first adult HIV care visit
- **Provide transportation** (funds, transit passes, etc.)
- Provide youth-centered education related to HIV, medical care, medications, and risk reduction
- Use youth-centered motivational interviewing techniques to engage and empower the young person toward self-management, including skills training on how to interact with medical providers
- Transition the young person from case management to self-management of their HIV medical care
- **Build relationships** and communicate with providers and community agencies to accelerate and enhance young person's linkage to and retention in care
- **Offer face-to-face counseling sessions** on HIV care, disclosure, and resolving real and perceived barriers to care
- Provide follow-up support **calls, texts, and reminders**
- **Utilize contemporary methods to communicate** (e.g., texting, social media, and email)
- Contact the young person often to ensure any changes or updates are documented and assessed for potential risk to retention and adherence
- Use a relational model vs. a transactional clinical model (e.g., **developing an interpersonal relationship** with the young person rather than one that appears as a task-list)
- Approach mentorship in a holistic way (supporting the young person with their resume, job search, enrollment in school, etc.)



In addition, the mentorship programs studied for this Toolkit identified a few additional **lessons learned** to assist others as they begin to implement mentorship programs.

AIDS Alabama identified stigma and lack of transportation as the primary hindrances to treatment and care. The organization offers assistance to young people transitioning to adult care that includes support navigating disclosure and when necessary, accompanying clients to medical appointments. Center on Halsted found feelings of isolation and housing instability were primary determinants of young people's inability to remain in care.

Center on Halsted also identified helpful competencies before implementing a mentorship program to include mental health, first aid, motivational interviewing, HIV navigation services, and personal cognitive counseling. AIDS Alabama agreed that therapy and mental healthcare should be included as preventive care for young people living with HIV as they transition to adult care.

In addition, Abounding Prosperity recognized the importance of training mentors and equipping them with the same resources as other support workers "with the added benefit that they have lived experience of being diagnosed with HIV and accessing healthcare and treatment".

Abounding Prosperity added that mentors should be well trained in HIV 101, health literacy and healthcare navigation.

# 2.3 STEPS TO EFFECTIVE MENTORSHIP PROGRAM IMPLEMENTATION

1. **Design and implement a structured and well-defined system that supports mentors. At minimum it should include:**
    a) Dedicated staff person
    b) On-going training, support and coaching for staff and mentors
    c) Resources, including referral sources for healthcare, mental health and support services that have been vetted and are culturally responsive to youth living with HIV, including YMSM, trans youth and youth of color
    d) Youth advisory council

2. **Establish a standardized title and position description for the mentors that address such questions as:**
    a) Will the positions be volunteer or paid?
    b) What are the minimum qualifications/ competencies you will look for in mentors?
    c) How many hours will mentors be expected to work per month?

3. **Establish protocols and procedures for the mentor program that address such questions as:**
    a) How will young people be referred to a mentor? Who will refer them?
    b) How will mentor caseloads be assessed?
    c) How will agency liability and risk be minimized?

4. **Train agency staff on the role of mentors in their work.**

5. **Design and implement a system of open communication and coordination with other team members, local hospitals, organizations, etc.that include:**
    a) Established points of contact with each service agency and organization
    b) A documented system of referral and case management
    c) A documented system for information sharing

6. **Develop and implement competency-based training for mentors and staff by:**
    a) Identifying training topics, trainers and schedule for training sessions
    b) Creating a system for assessing competencies pre- to post-training sessions
    c) Identifying on-going training and professional development opportunities for mentors and staff.

7. **Provide consistent administrative and clinical support for mentors.**

8. **Create a documentation system to describe and monitor mentor's and young person's activities that is linked to case management records.**

# 2.4 CREATING A MENTORSHIP PROGRAM

Before beginning to recruit mentors, it is important to fully define the role and responsibility mentors will play within your organization in general and with young people in particular.  Once the role of the mentors is clearly defined, it is easier to identify both the capacities needed in the mentor and the training the organization will provide them.

Some possible roles the mentor can fill include:

**A. Assisting the organization to identify potential mentees/young people living with HIV**

- Identifying young people who are newly diagnosed
- Identifying young people who are out of care
- Identifying young people experiencing delays in diagnosis or treatment, and/or missing appointments

**B. Assisting mentees to navigate the healthcare system**

- Linking or re-linking, young people to healthcare systems.
- Supporting coordination of healthcare, guiding young people along the continuum of healthcare and ensuring supportive services are appropriate to their needs (e.g., making medical appointments, accompanying the young person to appointments where necessary, identifying and eliminating delays in diagnosis or treatment, and interacting with the medical team to keep them informed of the patient's barriers, challenges, and needs).
- Supporting young people as they prepare for medical visits, identifying questions and concerns for discussion with the clinician, and communicating effectively with medical professionals
- Assisting with clinical-related resources and services
- Working with family members
- Assisting with health insurance paperwork or access to medical assistance
- Providing tailored health education designed to affect health-related attitudes and behaviors and support health management—this should include information about HIV and support in understanding treatment options presented by clinical providers

**C. Assisting mentees to obtain needed support services**

- Identifying and assisting young people to obtain supportive services such as housing, food, or childcare
- Providing emotional support and encouragement
- Providing or arranging transportation (bus schedule, directions, fare, etc.)
- Identifying and resolving other barriers to care

**D. Assisting mentees to develop life skills**

- Identifying training opportunities for mentees, including financial management, advocacy, resume writing, healthcare navigation, etc.
- Identifying opportunities for mentees to become mentors or to assist others
- Providing or identifying counseling related to education, employment, healthy relationships, etc.

# 2.5 RECRUITING MENTORS

**Perhaps it is obvious that for a mentorship program to be successful, it must recruit mentors that:**

- Understand and like young people
- Have the lived experience of being diagnosed with HIV and are currently in care
- Have roots in the community in which your agency serves
- Share other lived experiences or intersecting identities with the mentees/young people

Often, adults living with HIV want to give back to their communities. Identifying and training quality mentors may take a bit of time, but in the end, the success of the mentorship program largely rests on the dedication and capacity of the mentors and the agency's ability to train and support them. To recruit quality candidates, start with adult healthcare providers in your area. These providers may know adults living with HIV that would make ideal mentors. Expand recruitment to other agencies, including community-based organizations in your area using flyers, social media advertisements, and word of mouth. Provide open house sessions when potential volunteers can visit the agency and learn more about the program. Start small and build, culling lessons learned as you pilot and expand the program.

**SAMPLE MENTOR APPLICATION QUESTIONS**

1. Why do you want to become a mentor?
2. Do you have any previous experience volunteering or working with youth? If so, please specify.
3. What qualities, skills, or other attributes do you feel you have that would benefit a young person? Please explain.
4. Can you commit to participating in the mentoring program for a minimum of one year from the time you are matched with the young person?
5. Are you available to meet with a program participant, at minimum, eight hours per month and be in contact at least once per week? Please explain any particular scheduling issues.
6. Describe your general health. Are you currently under a physician's care or taking any medications? If so, please explain.
7. How would you describe yourself as a person?
8. How would your friends, family, and co-workers describe you?
9. Have you ever been investigated or convicted of sexually abusing or molesting a young person? If yes, please explain.

Adapted from Center on Halsted

**SAMPLE RECRUITMENT FLYER**

# Youth Thrive

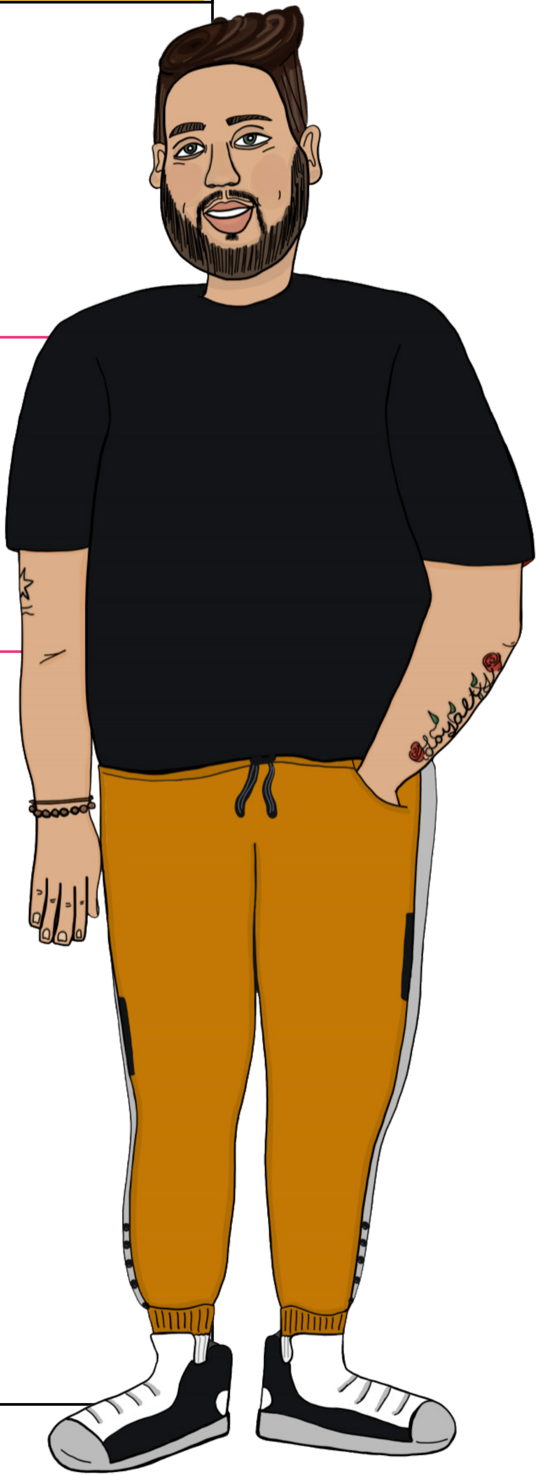
Seeks adults living with HIV to mentor and support young people living with HIV in our community.

Can you offer just two hours each week to help a young person navigate health and social services?

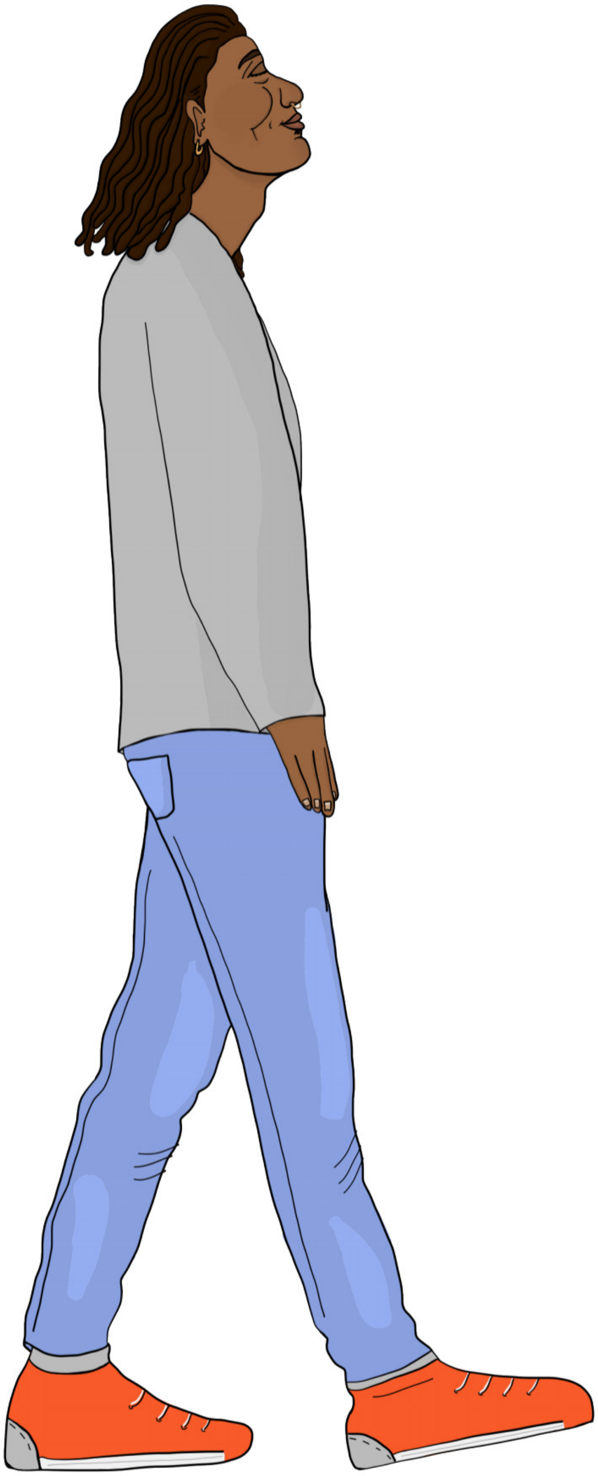
**You Volunteer. We Will Train.**

**Become a Mentor Today.**

For more information contact: info@SampleFlyer or call Sample at 555-555-5555



# 2.6 TRAINING MENTORS



Agencies or organizations implementing a mentorship program should provide mentors with an orientation to the program that includes information about: the agency and its mission, the mentorship program and its goals, the roles and responsibilities of mentors, and the name and contact information for the program manager of the mentorship program and their supervisor.

**In addition, minimum training should include:**

- HIV 101
- Healthcare Navigation
- Sexual, Social, Cognitive and Emotional Development of Late Adolescence 101
- Documenting the Mentoring Process (e.g., completing administrative paperwork)

Mentors also should be required to make personal visits to the primary healthcare and social service agencies to which they will refer mentees to begin building a relationship with these providers (including receptionists and intake workers).

**In addition, topics of quarterly training sessions for mentors might include:**

- Assessing One's Own Conscious and Unconscious Bias
- The Impact of Stigma on Health Behaviors
- Sexual Orientation and Gender Identity 101
- Updates in HIV Treatment and Care

| Sample Training Competencies | |
|---|---|
| **Competencies** | **Tasks** |
| Communication skills | • Motivational interviewing and harm reduction<br>• How to present information in a professional, efficient manner<br>• How to present young person's information and challenges when communicating with providers<br>• How to encourage young person to ask providers productive questions, getting them the information they need |
| Understand health care system (including availability of local medical and social services) | • Links with case management<br>• Makes referrals to housing, substance use, and mental health treatment<br>• Develops individualized service plans/assessments |
| HIV and healthy living | • Provides treatment motivation and adherence support |
| Confidentiality | • Adheres to Health Insurance Portability and Accountability Act of 1996 (HIPAA) regulations<br>• Addresses stigma and disclosure issues |
| Affordable Care Act | • Assist with patient navigation related to health care exchanges in local area |
| Other | • Support trauma-informed care |

Adapted from AIDS United 2015

# 2.7 ESTABLISHING POLICIES, PROCEDURES AND BOUNDARIES

When establishing a mentorship program, agencies must establish policies and procedures to keep mentors and mentees safe, and to limit potential liability and risk to the agency. It is always a good idea to consult legal advice when establishing such a mentorship program. Questions about how to vet mentors and mentees should be explored and policies adopted.

It also is important to establish guidelines for how and where mentors and mentees will interact and to establish youth-adult interaction policies if any mentees are minors.

**Questions your agency should explore to create policies and protocols include:**

- Will mentors be allowed to meet mentees in the mentor's or mentee's homes?
- Does the agency prefer meetings to take place at the agency or another public space?
- Will the agency provide mentors with special cell phones or emails to use with mentees to keep mentors' personal emails and phone numbers private?
- Will mentors be permitted to drive mentees in their personal cars or be limited to using Uber, Lyft or public transportation when with mentees?
- What are the rules regarding privacy and/or disclosure regarding medical conditions, mental health, drug and alcohol use, suicide ideation, etc.?

In addition, healthy mentor relationships include an explicit understanding of boundaries and the mentor's capacity to support the young person. When boundaries are too loose, they may be misinterpreted, and when they are too rigid, they can negatively impact the relationship. It's important for mentorship programs to help mentors define their boundaries and for mentors to have **open and honest communication** with their mentees about these boundaries. For example, mentors and mentees should talk about their expectations and goals for the relationship. They can emphasize values such as honesty, transparency, and commitment to trying to help. Mentors should determine and communicate what kind of access the mentee will have to them, for example, the hours they can and cannot be reached; and how they prefer to be contacted. Mentors should not be expected to have all the answers or be available 24/7. When boundaries and capacities change, those changes should be expressed to the agency and to the mentee as soon as possible.

# 2.8 ADDITIONAL TIPS FOR MENTORS

- Develop a rapport with the young person by understanding their strengths and weaknesses around accessing care.
  - **AIDS Alabama** uses the Brief Behavioral Assessment (see *Resources for Mentors*) to understand the challenges faced by young people living with HIV.
- Support young people, when necessary and with their permission, in identifying adult care providers that are willing to care for young adults
  - Peer navigators at **RAIN, Inc.** inform young people about their transition options which include supporting the young person in navigating the personalities of doctors, acclimating them to care in general, and discussing what best fits them.
- Recognize that mentorship may require supporting young people throughout the entire medical navigation process, from scheduling and rescheduling appointments, and attending those appointments until they are comfortable with their adult provider.
  - At **RAIN, Inc.**, in addition to connecting the young person to a doctor, the mentor attends the first few appointments until the young person is comfortable going alone.
- Understand that young people may have several mentors that serve different purposes in their lives.
- Remember to try not to be a parent or teacher when working with young people. Instead, mentors should play the role of a trusted ally who can raise issues to think about and answer questions based on knowledge and life experience.
- Understand that mentors fall under a variety of titles such as peers, volunteers, and staff members of clinics, health departments, and community-based organizations. This also includes individuals who are living with HIV and/or have similar life experiences to young people living with HIV.
- Ensure conversations are genuinely open and honest. In addition, expect difficult questions and moments, and be prepared to answer them honestly and directly.
- Understand the intersecting realities experienced by young people living with HIV, such as poverty, homelessness, lack of equitable access to education, healthcare, safety, support, and resources.
  - **The Center on Halsted** requires mentors to go through a rigorous vetting process and extensive training. U4U staff indicated that it was important to ensure that mentors are trained in the most appropriate ways to engage with young people. They are trained in setting boundaries, motivational interviewing, and other relevant topics (see *Resources for Mentors*).
- Provide youth-centered counseling to assess and address their barriers to linkage and retention in HIV medical care.
- It is important for the young person to feel comfortable with the provider, and if this isn't the case, mentors should help them switch to another provider.

# 2.9 MENTORSHIP RED FLAGS

Every now and again an agency may have recruited a mentor that is not a good fit for the program. When this is the case, assess if the behavior is one that can be changed with a bit of training. If so, provide the mentor the necessary help. However, if the behavior puts the program, the mentee or the mentor in danger, end the relationship immediately.

**Some behaviors that might serve as red flags include:**

- Mentors who focus primarily on their own personal needs
- Mentors who are over-involved, especially with a mentee that is a minor
- Mentors with unhealthy or negative beliefs or attitudes about sexual orientation, gender identity or HIV
- Mentors who engage in developmentally inappropriate behaviors
- Mentors who display excessive physical contact with others including mentees

# 2.10 INFUSING A YOUTH-ADULT PARTNERSHIP MODEL LENS

> **"It's everyone's responsibility to ensure that young people living with HIV have the right to accessible and affordable treatment. We must ensure that young people have the support needed to build the skills to successfully engage in care."**
>
> **- Tyreese, Youth Activist**

Adolescence is a time of great growth. Young adults, including those living with HIV, have lived experiences, perspectives and values. Some have experiences that make them wary of systems and institutions. Establishing mentorship programs that recognize and value the lived experience of both the mentor AND the mentee can go a long way in helping the program to be successful. One model that easily lends itself to recognizing the power of young people as well as the importance of mentorship is Advocates for Youth's Youth-Adult Partnerships (YAP) Model. The YAP Model was developed over two decades of intensive partnership work with young people all across the United States and abroad and can help mentors develop authentic and meaningful partnerships with their mentees.

Advocates for Youth recognizes that a true partnership is one in which each party has the opportunity to make suggestions and decisions, and in which the contributions, thoughts and experiences of each are equally recognized and valued. As a mentor, it is essential to recognize mentees as active partners, not passive recipients in the process of achieving linkage to and retention in adult HIV care. **Young people are seen as partners when mentors respect them as advocates of their health and recognize the greater impact youth bring when helping to determine transition-related plans about their care.**

**The YAP model**

- Listens to and integrates youth's realistic perspectives
- Recognizes and equally values the contributions, thoughts and experiences of both the young people and the adults involved in the mentor-mentee relationship
- Enables youth and adult mentors to work in full partnership envisioning, developing, implementing, and evaluating the mentee's transition into adult care

Sharing the power to make decisions with young people requires mentors to respect and have confidence in young people's judgment. It means mentors understand what the young person will bring to the partnership. They bring their experiences, their perspectives, their knowledge and their values.  Mentors also bring experience, perspectives, knowledge and values. Exploring these together will help establish respect for each other's expertise. Agreeing to find more information, or seek advice from other experts when needed can help establish boundaries and demonstrate that no one has all of the answers.

Mentors should be willing to provide additional training and support when young people need it (just as they would when including others in the decision making process). Both young people and mentors may need to embrace change in order for the partnership to work. For example, mentors may need to modify their ideas about what "is best" and about times and conditions under which the work proceeds. Similarly, young people may need to understand the limitations and realities that affect the development and operation of their transition into adult care.

By establishing an authentic partnership, everyone benefits. Young people become authentically involved as leaders of their healthcare transition.

**Youth-adult partnerships can also support young people develop:**

- **Problem solving skills**, including the ability to think abstractly, reflectively, and flexibly and the ability to arrive at alternative solutions to cognitive and social problems
- **Autonomy**, including a sense of identity and the ability to act independently and exercise control over one's environment
    - Examples include the ability to individually manage to refill and take medications on the correct schedule; make, cancel, and reschedule appointments; and seek out care without impediments.
- **Sense of purpose and future**, including having healthy expectations, goals, an orientation toward success, motivation to achieve, educational aspirations, hopefulness, hardiness, and a sense of coherence
    - Examples include the ability to reach out to the mentor for support, to maintain accountability, and pursue other goals in life without constant fear of stigma or disclosure.

To institute a YAP Model of mentorship, begin by explaining the model to the mentee.  Share that, while you as the adult mentor have experience living with HIV and seeking healthcare, you do not have all of the answers and may not know what is best for the mentee.  However, you can assure them that you will work together with them in a partnership to figure it out. Explain that you value their thoughts, feelings and experiences and will be looking to them to bring those to the process.

Then walk the walk. Do not make decisions for your mentee. Always explore options with them, seek out their thoughts, feelings and relevant experiences. Offer to help them get additional information. Share your experiences, then help them explore possible actions to determine which they think they want to try. Work with them to make their plan happen. Acknowledge that together you may not always make the right decisions, sometimes people learn from their mistakes and that is OK, but together you will figure it out. Build trust by demonstrating respect and partnership. Once you are on the partnership path, begin together to develop **a needs assessment** and **a transition plan.**

**Remember, Youth-Adult Partnerships include:**

- Establishing a personal and trusted connection
- Providing support in identifying barriers to care and in developing an action plan to address those barriers
- Identifying additional people who will support the young person's access to and retention in care
- Openly communicating to ensure optimal treatment adherence and retention in care through viral suppression

**Ways to Involve Young People Living With HIV in the Transition Process:**

| Actions to Take | Where To Implement |
|---|---|
| • Form a young people living with HIV transition advisory board<br>• Create a transition mentorship program (older young people mentor younger)<br>• Engage young people living with HIV in research, monitoring, and evaluation<br>• Allow young people living with HIV to be decision makers<br>• Engage young people living with HIV in communications, advocacy, and publicity<br>• Provide opportunities for young people living with HIV to provide feedback on the transition process<br>• Support young people living with HIV peer promotion/education and social networks<br>• Engage young people living with HIV in community outreach<br>• Engage young people living with HIV as trainers, staff, or volunteers<br>• Seek out opportunities to compensate young people living with HIV for their time | • Community-based organizations<br>• HIV clinical services<br>• HIV community and family services<br>• HIV advocacy efforts/programs |

Adapted from Family Health International 2005

# 2.11 ACHIEVING PROGRAM GOALS: SUCCESSFUL TRANSITION TO ADULT CARE

> **“Transition should be a careful and coordinated movement of young people from pediatric/adolescent to adult care. How the process is designed and implemented can impact successful engagement and retention in care longitudinally. Specifically, ineffective transition could result in gaps in care and treatment on HIV and other conditions; while effective transition can result in sustained viral suppression, better health, and psychosocial outcomes. There is a need for targeted focus on best strategies and practices and purposeful assessment of outcomes to inform optimal interventions. Included in best practices is the involvement of youth-friendly advocates such as peer navigators or specialists that can effectively support and assist, when necessary, the young person during the transition process.”**
>
> **Dr. Allison Agwu, M.D., ScM, FAAP, FIDSA**

Ultimately, the goal of the mentorship program is to support young people living with HIV successfully transition into and remain in adult care. A quality mentorship program is designed to provide young people with the support they need to navigate and stay engaged in the adult healthcare system.

Before transitioning into adult care, it is important that the young person is ready.

**Mentorship programs should support young people build the following capacities before they are transitioned to adult care:**

- Knowing when to seek medical care for symptoms or emergencies
- Identifying symptoms and being able to describe them
- Making, cancelling, and rescheduling appointments
- Arriving to appointments on time
- Calling ahead of time for urgent visits
- Requesting prescription refills correctly and allowing enough time for refills to be processed before medications run out
- Negotiating multiple providers and subspecialty visits
- Understanding the importance of health insurance, how to select an appropriate healthcare plan, and how to obtain it and renew it
- Understanding social services and entitlements and knowing how to access them

For more information, see *Retention Readiness Indicator Tool* in *Additional Resources*)

As the mentor assists the mentee, they continue to build the mentee's confidence and ability to navigate the system.

**Mentors can assess whether or not they are on the right track by observing signs such as:**

- The young person has accepted their HIV status and is oriented toward future goals and hopes, including long-term survival.
- The young person has learned the skills needed to negotiate appointments and multiple providers in an adult practice setting.
- The young person has achieved personal and medical independence and is able to assume responsibility for their treatment and participate in decision-making.
- The mentor and adolescent provider, if applicable, are familiar with the adult HIV provider and practice setting, and direct communication about an individualized plan for the young person has taken place.
- If applicable, mental health services have been transitioned at the same time as medical services.
- Psychosocial needs are met and entitlements are in place (e.g., housing, health insurance, transportation, etc.).
- Life skills have been addressed (e.g., educational goals, job training, parenting, etc.).
- The young person receives uninterrupted comprehensive medical care.

**Mentors should work with program staff to re-evaluate transition goals when a young person:**

- Misses multiple appointments
- Discontinues medication
- Abuses substances such as drugs or alcohol
- Loses entitlements such as health insurance, transportation, or childcare
- Suffers from unstable housing

| **Name:**<br>**DOB:**<br>**MR#:**<br>**Date initiated in adult care:** | **Discussed? (Y/N)** | **Goal Date for Completion (month & year)** | **Goal** | **Goal Completed Date *If goal not completed, new goal date (month & year)** | **Goal Completed? (Y/N)** | **Notes** |
|---|---|---|---|---|---|---|
| **Health Knowledge** | | | | | | |
| Interacts directly with the adult health care team and asks questions. | | | | | | |
| Explains knowledge surrounding HIV. | | | | | | |
| Identifies symptoms of grief, and has identified a person who they can speak with when grieving. | | | | | | |
| Can describe stigma and its impact. | | | | | | |
| Current with immunizations and health screenings. | | | | | | |
| Able to answer questions such as “What is HIV? What are T cells? What is a viral load? | | | | | | |
| Can verbalize names and dosages of medications. | | | | | | |
| Can verbalize rules for taking medications (with food, etc). | | | | | | |
| Able to fill prescriptions and obtain refills. | | | | | | |
| Can verbalize known possible side effects of medications. | | | | | | |
| Takes medications independently. | | | | | | |
| Able to independently make appointments. | | | | | | |
| Able to independently give history. | | | | | | |
| Can verbalize when and how to call the doctor. | | | | | | |
| Can verbalize when and how to access urgent/ emergent care. | | | | | | |
| Able to set up transportation for appointments. | | | | | | |

Adapted from Bartlett et al. 2011 & the New York State Department of Health AIDS Institute

As a mentor, it is important to remember that the HIV care transition is only one of many transitions young people experience during this crucial time of growth and development.

### Mentors Support Young People to Build Skills that May Close Gaps in Care

**Young People living with HIV typically enter adult care by the age of 25.**

**BARRIERS WHEN ENTERING ADULT CARE**

- Worried about confidentiality, privacy, and trust in adult setting
- Overwhelmed by change, lost in the system
- Afraid to ask for help and support
- Unsure how to make decisions to manage own healthcare

**MENTORS CAN:**

- CONNECT PERSONALLY
- PROVIDE INFO & GUIDANCE
- SHARE EXPERIENCES

**...so that young people living with HIV gain the confidence & skills to manage their own healthcare**

**Youth-Mentor Partnerships Include:**

1. Establishing a personal and trusted connection
2. Joining support in identifying barriers to care
3. Providing support in developing an action plan to address barriers
4. Identifying additional people who will support the young person's access to and retention in care
5. Open communication to ensure optimal treatment adherence and retention in care through viral suppression

**Mentors and mentorship programs can do a variety of things to support young people living with HIV's transition to adult care**

1. Orienting adult HIV providers
2. Bringing adult providers to the adolescent clinic and/or community-based organization, if applicable
3. Using affirmative language when working with the young person (e.g., "You have options: if you don't have family insurance, or if you want a new provider, there are ways to navigate these issues to ensure that you receive affirming care.," "Change is OK," "Feel free to communicate your needs, you are your best advocate," "You have a right to know about accessing travel support to appointments and who to go to about your care," 'You are more than HIV.")

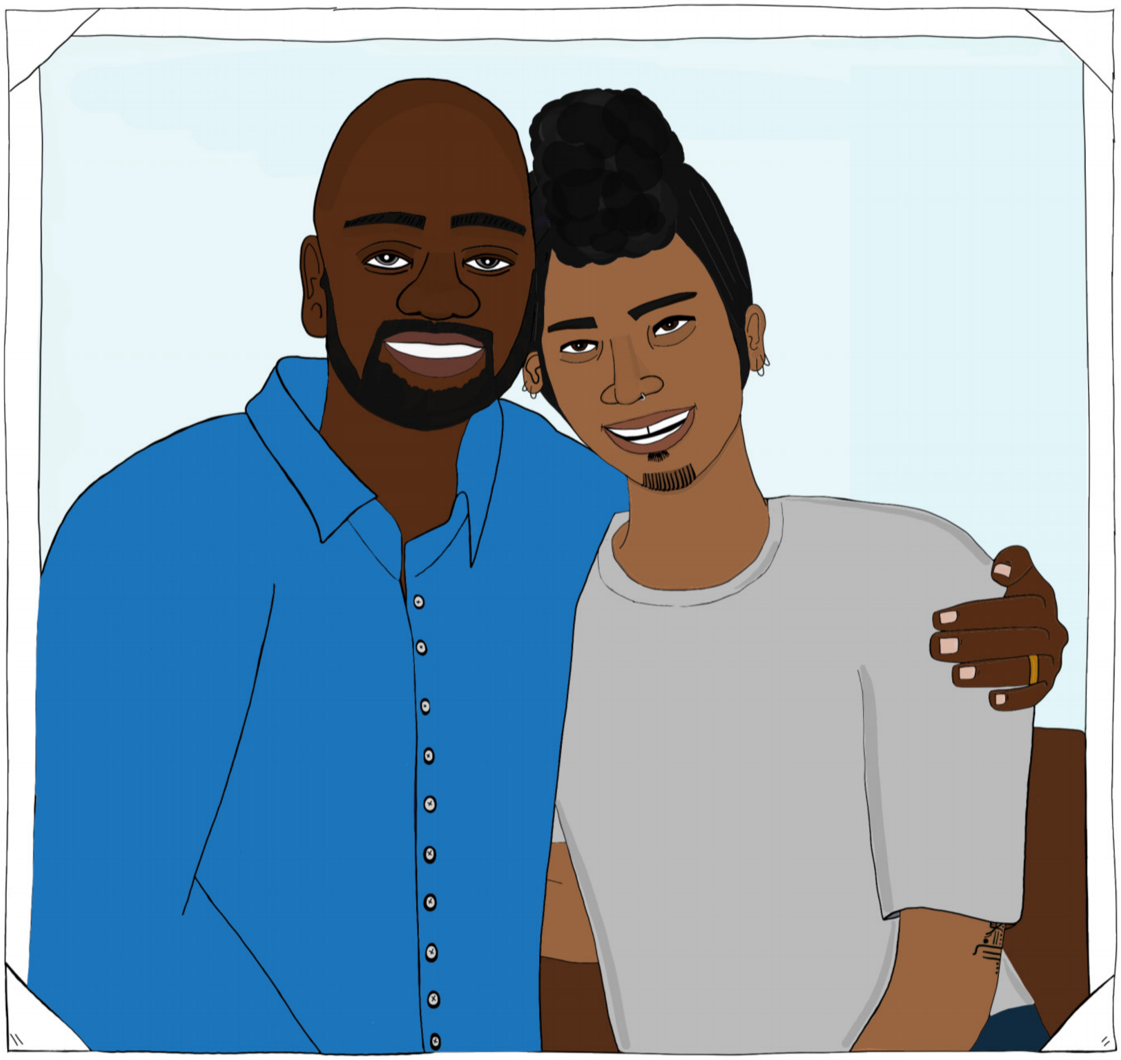
## Additional Resources

Adolescent Health Initiative: LGBTQ Friendly Services Starter Guide
AIDSinfo Glossary of HIV/AIDS-Related Terms
AMAZE: HIV 101
AMAZE: Living with HIV
American Medical Association: Creating an LGBTQ-friendly Practice
Trans in the South Guide
True Colors Fund: Youth Collaboration Toolkit
National Youth HIV/AIDS Awareness Day
POZ 2019 HIV Drug Chart
Retention Readiness Indicator Tool

## Free Mentorship & HIV Care Trainings

Adolescent Development E-Learning Module
Common Mental Health Disorders in People Living with HIV
Health Literacy and HIV Care: A Practical Guide for Medical Case Managers
HIV Navigation Services
Linkage and Retention in HIV Care
Mental Health and HIV Treatment and Care Part 1: Screening for Improved Health Outcomes
Motivational interviewing
Motivational Interviewing and Medical Case Management Training
Patient Navigator Training Collaborative
Patient Navigator Introduction to Motivational Interviewing Workshop
Personal Cognitive Counseling
Southeast AIDS Education & Training Center Program
University of Michigan's Adolescent Health Initiative

# RESOURCES



# RESOURCES FOR MENTORS

**AIDS Alabama Living Out Loud - Brief Behavioral Assessment**
***Client Needs Measure***

Please indicate how often over the LAST 2 WEEKS you have been bothered by any of the following problems.

For each question, please indicate the answer that best applies by marking an "X" in the corresponding box like this: ☒

It is very important that the responses be recorded within the space allotted.

| | Not At All | Several Days | More than Half the Days | Nearly Every Day |
|---|---|---|---|---|
| 1. Little interest or pleasure in doing things | ☐ | ☐ | ☐ | ☐ |
| 2. Feeling down, depressed or hopeless | ☐ | ☐ | ☐ | ☐ |
| 3. Trouble falling asleep or staying asleep, or sleeping too much | ☐ | ☐ | ☐ | ☐ |
| 4. Feeling tired or having little energy | ☐ | ☐ | ☐ | ☐ |
| 5. Poor appetite or overeating | ☐ | ☐ | ☐ | ☐ |
| 6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down | ☐ | ☐ | ☐ | ☐ |
| 7. Trouble concentrating on things, such as reading the newspaper or watching television | ☐ | ☐ | ☐ | ☐ |
| 8. Moving or speaking so slowly that other people could have noticed? Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual | ☐ | ☐ | ☐ | ☐ |
| 9. Feeling nervous, anxious or on edge | ☐ | ☐ | ☐ | ☐ |
| 10. Not being able to stop or control worrying | ☐ | ☐ | ☐ | ☐ |
| 11. Worrying too much about different things | ☐ | ☐ | ☐ | ☐ |
| 12. Trouble relaxing | ☐ | ☐ | ☐ | ☐ |
| 13. Being so restless that is is hard to sit still | ☐ | ☐ | ☐ | ☐ |
| 14. Becoming easily annoyed or irritable | ☐ | ☐ | ☐ | ☐ |

## Barriers Assessment Document

**1** Issue(s) to be addressed:

**2** Barriers to solution(s):

**3** Resource(s) being utilized:

**4** If issues are related to medication, is the young person currently adherent? (Y/N)

a. If no, what medication(s) are needed or should the young person be taking?

**5** Feedback

a. Present:

b. Behavioral Suggestions:

c. Medical Suggestions:

d. Resource Suggestions:

Adapted from RAIN, Inc

| Interview with the Young Person | |
|---|---|
| **Question** | **Notes** |
| Who are you living with and how long have you lived with them? Do you get along well with them? Is anyone else in the house living with HIV? Do you help to take care of them? | |
| Whom do you feel close to? Whom can you go to for emotional support? | |
| Do you go to school or work outside the home? | |
| How often in the last week, have you used cigarettes, alcohol, or other drugs? | |
| Have you disclosed your HIV status? If yes, to whom? If you haven't disclosed to anyone, why not? | |
| Do you belong to a community/religious organization or support group that gives you the support you need? | |
| Have you experienced negative attitudes or treatment because of your HIV status or for other reasons? Has anyone caused you harm in the past (for example hurt you physically or unwanted sexual encounters)? | |
| How is your mood now? Do you feel sad or depressed? What changes have you noticed in your mood? | |
| Do you have financial support? Whom do you go to when you need help with financial support? | |
| Other than coming to me, do you go to any other clinical or traditional healers for health services? | |
| Are you having sex? Are you using a family planning method? What is it? Do you use condoms? | |
| How do you remember to take your medications daily? How do you remember to return to the clinic for appointments? Who helps you with this? | |
| What other questions or concerns do you want to discuss today? | |
| | |

Adapted from ICAP 2011

### Assessing Mental Health

The young person might not always be able to answer the questions as they are posed below, so it may be helpful to ask questions in other ways or in an indirect manner.

| Topic | Question | Yes or No |
|---|---|---|
| **Medications** | During the past 12 months, were you ever on medication/ antidepressants for depression or nerve problems? | |
| **Major Depression** | During the past 12 months, was there ever a time when you felt sad, angry, or depressed for 2 weeks or more in a row? | |
| | During the past 12 months, was there ever a time lasting 2 weeks or more when you lost interest in most things like hobbies, work, or activities that usually give you pleasure? | |
| **General Anxiety Disorder** | During the past 12 months, do you ever have a period lasting 1 month or longer when most of the time you felt worried and anxious? | |
| **Panic Disorder** | During the past 12 months, did you have a spell or an attack when all of a sudden you felt frightened, anxious, or very uneasy when most people would not be afraid or anxious? | |
| | During the past 12 months, did you ever have a spell or an attack when for no reason your heart suddenly started to race, you felt faint, or you could not catch your breath? (If respondent volunteers, "only when having a heart attack or due to physical causes," mark "No.") | |

The young person should be considered positive for symptoms of mental illness if they responded yes to any question. Refer to a mental health professional.

If a mental health professional is not available, refer the adolescent to the most qualified health or community care provider. This may include lay counselors, peer support groups, spiritual caregivers, or other sources of support that exist in your community.

**Date:** ____________________________

**Positive Screen:** **Yes** **No**

**Action taken (education provided, etc.):**

Adapted from HIV Resource Group 2011

## Adherence & Re-Adherence Support Prior to Treatment

### Checklist of Education and Counseling Topics

☐ Disclosure status

☐ Daily habits, young person’s thoughts toward health and medicine use

☐ Thoughts of family/caregiver toward medicine use (if applicable)

☐ Family/caregiver preparation in supporting the young person with adherence (if applicable)

☐ Potential barriers to treatment adherence

☐ Risk of others discovering HIV status, handling stigma associated with treatment

☐ Purpose of medicine and how it works

☐ Importance of treatment adherence and risks associated with poor adherence

☐ Medication names, what each looks like, routes, possible side effects, and management of side effects

☐ Plan for medication schedule once treatment begins

☐ What to do if young person forgets to take a pill or runs out of medicine

### Adherence Tips

- Prior to beginning treatment, allow the young person to practice adherence by using practice “pills” such as vitamins or Tic Tacs using a pill box

- Identify a family member/caregiver with the young person who can provide medication reminders

- Identify a medication schedule through using cues such as meals or tooth brushing, and encourage placing of medications where the adolescent will see them during regular activities

- Plan for use of adherence reminders including alarm clock, cell phone alarm, etc.

Adapted from Bosteels and Goetghbuer 2008

## Adherence Readiness Quiz

The following quiz can help to determine if the young person is prepared to start & adhere to their medications. Ask the young person how ready they feel if they were to start taking HIV medications today. Have the adolescent read each of the following statements, and on a scale of 1 to 5, rate how ready they feel today to make the following changes (input a number from 1 to 5 for each item.) Tell the young person that they should tell you how they are honestly feeling (not what they think you want to hear.) See the following scale to assist you with your responses.

**1 = Not at all ready 2 = Mildly ready 3 = Moderately ready 4 = Quite ready 5 = Extremely ready**

**If you were going to start taking, or retaking, HIV pills today, how ready would you be to:**

| Readiness | Number |
|---|---|
| **Make the necessary changes in your diet (i.e., eat at regular times, take pills with certain foods)** | |
| **Accept the idea of taking these HIV pills for a long time (e.g. years)** | |
| **Schedule time out to take your HIV pills (e.g., take a lunch break)** | |
| **Deal with bringing your HIV pills to social activities (e.g., sporting events, friend's house)** | |
| **Take many pills (e.g., more than 10) several times a day at specific times** | |
| **Ask for support from your friends to remember to take your HIV pills** | |
| **Set an alarm or calendar time on your phone to remind you to take your HIV pills** | |
| **Continue taking your HIV pills, even if you experience unpleasant side effects (e.g., vomiting, diarrhea, change in body shape)** | |

### SCORING

After the survey has been completed, add the numbers together for each response and divide by 10. Scores of 31.50 and greater indicate that the adolescent is adherent ready. Scores below this cutoff indicate that further exploration is required to address concerns, ambivalence, and knowledge gaps.

**Total Score:** ____________________

**Adherent Ready:** **Yes** **No**

Adapted from Balfour et al. 2007

## Adherence Assessment Tool

To determine the adolescent's medication adherence since the last visit, ask the following questions and document your findings. Use this assessment as a guide to adherence education opportunities.

**Date:** ____________________________

**Total Pills Missed:** ____________________________

| Question | Notes |
|---|---|
| **How have you been feeling since the last visit?** | |
| **Have you experienced any changes in your household work? If yes, what are they?** | |
| **Have you experienced any changes at school? If yes, what are they? Are you attending regularly? How are your grades? Any problems with teachers or peers?** | |
| **How has your mood been? Have you felt sad or depressed?** | |
| **Have any of these factors affected your daily routine?** | |
| **Is there anyone who helps you remember to take your medication? How often do they remind you?** | |
| **Have you experienced negative attitudes or treatment because of your HIV status or for other reasons? Has anyone caused you harm in the past (for example hurt you physically or unwanted sexual encounters)?** | |
| **What time do you take your medications every day?** | |
| **Since our last visit have you taken any doses that were at different hours of the day, if yes, why?** | |
| **In the past week, have you missed any doses? If yes, what happened?** | |
| **In the past month, have you missed any doses? If yes, what happened?** | |
| **Since our last visit, have you missed any doses? If yes, what happened?** | |
| **If yes, can you describe what happened?** | |
| **Which days did this occur?** | |
| **If this happens again, what can you do to help you remember to take your medication?** | |
| **Have you noticed any side effects from the medications? If so, what are they and did they contribute to you not taking the medication?** | |
| **Do you have any questions about your medications?** | |

Adapted from ICAP 2011, and Jacob and Jearld 2007

## HIV Knowledge Assessment

Assess your client's knowledge surrounding HIV by providing the following statements and request a true/false response. The adolescent should be able to respond correctly to all statements prior to transition. After the adolescent has taken the assessment, review the answer key on the following page with the adolescent to identify where additional information is needed.

| Statements | True (T), False (F), Unsure (U) |
|---|---|
| HIV and AIDS are the same thing. | |
| HIV is a virus that attacks a person's immune system. | |
| The cells of the immune system that fight infection are called "CD4 cells." | |
| The amount of HIV in a person's blood is called viral load. | |
| There is a cure for HIV. | |
| You can tell a person has HIV by looking at them. | |
| People with HIV may feel healthy for years, even if they are not on treatment. | |
| A person with HIV will stay healthy if their CD4 cells are high and their viral load is low. | |
| Even though a person with HIV may feel healthy, the virus can still be damaging their immune system. | |
| People with AIDS may get sick easily, lose weight, and have yeast infections, pneumonia, and low CD4 cells | |
| It is okay to miss doses of medication. | |
| I should call the doctor/nurse/pharmacist before I stop my medication. | |
| If I miss doses of medicine, the virus can become resistant and the medicine won't work. | |
| I should see the doctor and check my CD4 cells regularly. | |
| If my viral load is "undetectable," it is less likely that I will transmit HIV and less likely that I will get sick. | |

Adapted from Jacob and Jearld 2007

| HIV Knowledge Assessment Answer Key (F = False, T = True) | |
|---|---|
| **Statements** | **True (T), False (F), Unsure (U)** |
| **HIV and AIDS are the same thing.** | **F** - HIV is the virus that causes AIDS. |
| **HIV is a virus that attacks a person's immune system.** | **T** - HIV attacks a person's immune system, including the CD4 cells, resulting in higher susceptibility to illness. |
| **The cells of the immune system that fight infection are called "CD4 cells."** | **T** - CD4 cells help the body fight infection. |
| **The amount of HIV in a person's blood is called viral load.** | **T** - The amount of HIV in the body is measured through a laboratory test called the viral load. |
| **There is a cure for HIV.** | **F** - While treatment is available to control HIV, there is no cure |
| **You can tell a person has HIV by looking at them.** | **F** - There is no way to tell that a person has HIV by their appearance. |
| **People with HIV may feel healthy for years, even if they are not on treatment.** | **T** - The course of HIV varies for each person, but many people with HIV can feel healthy for a long time. |
| **A person with HIV will stay healthy if their CD4 cells are high and their viral load is low.** | **T** - A person is more likely to stay healthy if their immune system is strong and they have less HIV in their body. |
| **Even though a person with HIV may feel healthy, the virus can still be damaging their immune system.** | **T** - Even though a person may not feel ill, when present the HIV virus can cause damage to the immune system. |
| **It is okay to miss doses of medication.** | **F** - In order to stay healthy and prevent resistance to HIV medication, no doses should be missed. |
| **I should call the doctor/nurse/pharmacist before I stop my medication.** | **T** - The HCP should be notified before medications are stopped. |

Adapted from Jacob and Jearld 2007

| **HIV Knowledge Assessment Answer Key (F = False, T = True)** | |
|---|---|
| **If I miss doses of medicine, the virus can become resistant and the medicine won't work.** | **T** - Missing doses of HIV medication increases the risk of the virus becoming resistant. |
| **I should see the doctor and check my CD4 cells regularly.** | **T** - Regular visits to the HCP to check CD4 cells are an important part of routine care for HIV. |
| **If my viral load is "undetectable," it is less likely that I will transmit HIV and less likely that I will get sick.** | **T** - When the viral load is "undetectable," there is a very small amount of HIV in the body, making it less likely that one will transmit HIV and more likely that one will stay healthy |

Adapted from Jacob and Jearld 2007

| Comprehensive Transition Tool | | | |
|---|---|---|---|
| **Self-Management Task** | **Discussed? (Y/N)** | **Goal for Task (Month/Year)** | **Goal Reached? (Y/N)** |
| Interacts with providers; asks questions. | | | |
| Identifies symptoms of grief and a person they can speak with when grieving. | | | |
| Describes stigma and its effects. | | | |
| Explains what HIV is. | | | |
| Explains what CD4 cells are. | | | |
| Explains what a viral load is. | | | |
| Explains names/dosages of medications correctly each time there is a medication change. | | | |
| Discusses pros/cons of contraception options. | | | |
| Explains STIs include transmission and prevention. | | | |
| Independently gives medical history. | | | |
| Explains reasons for disclosure and disclosure methods. | | | |
| Attends first peer support group. | | | |
| Describes side effects of medications. | | | |
| Verbalizes when and how to call doctor and emergency care. | | | |
| Identifies members of the health care team, roles, and how to contact them. | | | |
| Lists community services for YPLWHIV and accesses them independently. | | | |
| Fills prescriptions and refills them independently. | | | |
| Takes medication independently and is adherent to medications. | | | |
| Makes and attends appointments independently. | | | |
| Sets up transportation for appointments independently. | | | |

Adapted from Bartlett et al. 2011

## Mentor Schedule/Communication Options

Please choose your preferred schedule options and number them 1-3 in order of your preference. We will make every effort to honor your first choice but please be advised that, as this program is based on participant need, we may not be able to honor your first choice.

_____ (A) **once a week meeting** (either Tuesday or Friday 2pm-3pm) and available for a phone call three or four days, weekly, you determine availability

_____ (B) **bi-weekly meeting** on a Saturday 2pm-5pm and available for a phone call three or four days, weekly, you determine availability

_____ (C) **available for a phone call three or four days, weekly,** you determine (either Tuesday or Friday

**Please be advised:** you will not use your own phone number for calls (a google number will be provided to you) this will prevent mentees from having your personal number and give you control of when you can accept calls directly to your phone.

**Select the time frame(s) that work best for you**

(Please select at least two time frames when you will be able to receive a call and/or text message)

_____ **10am - 12pm**

_____ **12pm - 3pm**

_____ **3pm - 6pm**

_____ **6pm - 8pm**

**Preferred Method of Communication:**

_____ **Text Message**

_____ **Phone Call**

_____ **Other**

Adapted from Center for Halsted's U4U Mentoring Program

## Sample Mentor Interest Survey

What are the most convenient times for you to meet with your mentee? Please check all that apply:

_____ **Weekdays**

_____ **Lunch**

_____ **After-school**

_____ **Evenings**

_____ **Weekends**

_____ **Other**

Please indicate the age group(s) you are interested in working with:

_____ **ages 11 - 14**

_____ **ages 15 - 18**

_____ **ages 19 - 21**

Ethnicity: ________________________________

Do you speak any languages other than English?

What are your favorite subjects to read about?

What is your current job, if applicable, and how did you choose this field?

What is one goal you have set for the future?

Adapted from Center for Halsted's U4U Mentoring Program

## Mentor Self Assessment

### Check your Privilege

Are you a man mentoring a young woman? A white person mentoring someone who is Black? Reflect on how your privilege may influence your interactions with your mentee. Talk to others who have mentored across difference. Affirm to your mentee that you understand the isms and privilege.

### Check your Communication Style

Are you an aggressive or passive aggressive communicator? How will your communication style and privilege potentially impact your mentees? What can you adapt, modify or change about how you engage?

### Check your Experiences

What were your experiences with mentorship? What are your beliefs about it and how will that influence your choices? What did you learn about mentorship from being a mentee?

## Mentorship Tips 101: The Three C’s

### Consistency

In whatever support you provide, do it routinely, Consider weekly or monthly check-ins based on what works for you both. This helps build trust and lets your mentee know you are there for them.

### Consent

Request permission when engaging. For example: “Is it ok to talk right now? Is it okay to give you a hug?” Respect your mentees boundaries.

### Confidentiality

Discuss the things that you may be required to share with others based on your professional relationships. Honor and protect their privacy.

## U4U Mentor Training & File Checklist

☐ **U4U Mentor Training & File Checklist:**

- ☐ Online Program Overview (Date of Completion: ______________________ )
- ☐ Boundary Assessment (Assessment Must Be Attached)
- ☐ Mentor Contract (Contract Must Be Attached)
- ☐ Boundary Assessment (Certificate Must Be Attached)

☐ **In-person Training Completed:**

- ☐ HIV Confidentiality & Law (Date of Completion: ______________________ )
- ☐ Mentor Application (Must be Completed on Database & Attached)
- ☐ Mentor Interest Survey (Must be Completed on Database & Attached)
- ☐ Schedule Options Form (Date form received: ________________________ )

U4U Mentor Intake Checklist Completed By: ________________________

Date of Checklist Completion: ________________________

Adapted from Center for Halsted's U4U Mentoring Program

## Sample Annual Mentors Recruitment Plan

**Recruitment Objective**

Attract new mentors matched with youth by expected Month, Day, Year

**Target Audience**

Young people living with HIV, between the ages of 13-24, and identify as Black and/or Latinx

**Positioning Statement or Core Communication Message**

To support a young person transition into care and learn the importance of self-care

**Promotional Materials**

- Mentoring program brochure
- Informational flyers
- Newsletter
- Press releases
- Program presentation with notes and handouts
- Website development

**Promotional Activities**

- Place brochure and flyers throughout the community
- Display tables at local events
- Distribute press release and PSA to local media
- Make personal contact with key media and organization leaders
- Present to community organizations and local hospitals

Adapted from Center for Halsted's U4U Mentoring Program

# RESOURCES FOR YOUNG PEOPLE/ MENTEES

**Medication Worksheet**

| Medication | What Do I Take It For? | Do I have any Reaction(s) or Side Effects? | When Do I Take It? And How Often? | How Will I Remember to Take It? | Additional Notes |
|---|---|---|---|---|---|
| | | | | | |
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**I should contact my healthcare provider immediately if:**

**My healthcare provider's contact information is:**

Adapted from Robinson et al. 2006

## My Health Journal Part 1

- Ways that I can keep myself healthy include . . .
- The people who encourage and help me to take care of myself are . . .
- When I have questions about my health, I can talk to . . .
- When I feel ill, I will take the following actions . . .
- Some actions that I can take to help me remember my medicine are . . .
- What do I want to talk about only with my healthcare and community care providers?
- What do I want to talk about, only with my mentor?
- What do I want to talk about only with my family?
- What do I want to talk about only with my peers/friends?
- What do I want to keep to myself and not share with anyone?

## My Health Journal Part 2

- What do I do to stay healthy? Do I exercise, eat healthy, and get enough sleep?
- How do I feel about my body? Do I feel over- or underweight?
- Am I having difficulty in school or work?
- Am I getting along with other people?
- Do I do things that put my health at risk?
- Do I ever take substances, such as drugs and alcohol, to help deal with my life situation?
- When do I feel sad? Do I have thoughts of low self-esteem or hopelessness?
- What do I do to make myself feel better when I am feeling down?
- What do I do to stay healthy? Do I exercise, eat healthy, and get enough sleep?

Adapted from USAID Toolkit for Transition of Care & Other Services for Adolescents Living with HIV 2014.

## My Support System

**Who supports you in your life? They could be family members, friends, nurses, doctors, counselors, or someone else.**

Name:

Relationship:

Why I trust this person:

Ways this person supports me:

Ways I support this person:

Name:

Relationship:

Why I trust this person:

Ways this person supports me:

Ways I support this person:

Name:

Relationship:

Why I trust this person:

Ways this person supports me:

Ways I support this person:

Adapted from USAID Toolkit for Transition of Care & Other Services for Adolescents Living with HIV 2014.

## Mapping Out My Support Network

| Title | Name | Contact Info | How They Support Me |
|---|---|---|---|
| **Mentor/Peer Navigator** | | | |
| **Primary Care Doctor** | | | |
| **Specialty Doctor(s)** | | | |
| **Nurse(s)** | | | |
| **Dentist** | | | |
| **Therapists (physical, occupational, speech)** | | | |
| **Pharmacist** | | | |
| **Mental Health Professional** | | | |
| **Social Worker/ Case Manager** | | | |
| **Parent(s)/Guardian(s)** | | | |
| **Friend(s)** | | | |
| **Others (describe):** | | | |
| | | | |
| | | | |
| | | | |

Adapted from Transition HIV+ Youth from Adolescent to Adult Services: Adolescent Provider Toolkit 2010.

| What I Need to Know about the Adult Provider & Clinic | |
|---|---|
| **Clinic Name:** | **Notes** |
| **Clinic Address:** | |
| **Clinic Phone Number:** | |
| **Clinic Website:** | |
| **How I Can Get There:** | |
| **Clinic Hours:** | |
| **Doctor Name(s):** | |
| **Nurse Name(s):** | |
| **Receptionist Name(s):** | |
| **Differences between adolescent and adult clinic:**<br>**Length of a visit**<br>**Structure of a visit**<br>**What the doctor does**<br>**What the nurse does**<br>**Role of Mentor**<br>**Role of Social Worker**<br>**Role of Case Manager**<br>**How often I need to schedule a visit** | |
| **Additional Information:** | |

Adapted from Transition HIV+ Youth from Adolescent to Adult Services: Adolescent Provider Toolkit 2010.

## Mapping Out My Goals and Medication Worksheet

| Accomplishments | How Can I Get This Done? | When Can I Get This Done? | Date Completed |
|---|---|---|---|
| Finish school | | | |
| Find a job | | | |
| Get job training | | | |
| Take my medicine without reminding | | | |
| Refill my medicines at the pharmacy | | | |
| Make appointments | | | |
| Attend a support group | | | |
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Adapted from Robinson et al. 2006

| Guide to Health & Social Resources | | | | |
|---|---|---|---|---|
| **Service Type** | **Name of Organization** | **Description of Services** | **Phone & Address of Organization** | **Hours/Days of Operations** |
| | | | | |
| | | | | |
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| | | | | |

Adapted from Robinson et al. 2006

## My Goals

Goal:

How can I accomplish this?

How will I overcome potential challenges?

Who can help me and how?

When do I want to accomplish this?

Goal:

How can I accomplish this?

How will I overcome potential challenges?

Who can help me and how?

When do I want to accomplish this?

Goal:

How can I accomplish this?

How will I overcome potential challenges?

Who can help me and how?

When do I want to accomplish this?

Adapted from USAID Toolkit for Transition of Care & Other Services for Adolescents Living with HIV 2014.

## My Goals Continued

- The accomplishments that I am most proud of . . .
- My greatest strengths are . . .
- Some things that I would like to accomplish are . . .
- Some things about me that I would like to work on are . . .
- What do I want to talk about only with my healthcare provider?
- What do I want to talk about only with my family?
- What do I want to talk about only with my peers/friends?
- What do I want to talk about only with my teacher or another adult?
- What do I want to keep to myself and not share with anyone?

Adapted from USAID Toolkit for Transition of Care & Other Services for Adolescents Living with HIV 2014.

## Disclosing on MY Terms

- Who knows my HIV status?
- Why do I want to tell someone about my HIV status? Whom do I want to tell?
- Why would I want to keep my HIV status private, to myself? Whom do I not want to know?
- What would I say if someone asked me about my HIV status?
- How would I tell someone I am living with HIV?
- Have I ever told anyone about my HIV status? What happened? What would I do differently next time?
- What do I want to talk about only with my healthcare provider?
- What do I want to talk about only with my family?
- What do I want to talk about only with my peers/friends?
- What do I want to keep to myself and not share with anyone?

Adapted from Robinson et al. 2006

## My Sexual & Reproductive Health Journey

- What does having a partner/boyfriend/girlfriend mean to me?

- What does sex mean to me?

- What does gender mean to me? What about sexual orientation?

- Do I have questions or concerns about gender, sex or sexuality? Whom can I talk to about them?

- If I plan to have sex, do I know how to use internal and external condoms? Where do I get them?

- Do I feel comfortable talking to my partner about using condoms?

- How do I tell my partner about my HIV status? When?

- Have I ever told a partner before about my HIV status? What was it like?

- When I choose to tell my partner, what might I do differently next time?

- Do I want to have children one day?

Adapted from Robinson et al. 2006

## Stigma

- Have I ever experienced stigma?
- Where and why did I experience it?
- What are my feelings about this experience?
- What are actions I can take to reduce stigma?
- Do I feel comfortable talking about stigma to someone? Who would this be? What will I say?

Adapted from USAID Toolkit for Transition of Care & Other Services for Adolescents Living with HIV 2014.

### Assessing Mental Health

It is important to understand the stigma that you experience and begin to think about ways that you can address it. The following is an action plan to help you. Consider all of the sources of stigma that you experience in your life and think about steps that you can take to deal with it in a healthy way. Share this with your provider, your counselor, or a loved one so that they can support you in acting on your action plan.

| Problem | Action Step | Resources Need | By Whom | By When |
|---|---|---|---|---|
| **I feel lonely since being diagnosed with HIV** | Tell my best friend to let them know how I am feeling. | None | I will talk with them. | Tomorrow |
| | Make an appointment to speak with a counselor or mentor. | A counselor or mentor that works at the clinic or in a community-based organization. | I will make the appointment, and tell my friend so that they will encourage me to follow through. | I will do this the next time I have an appointment at the CBO or clinic. |
| | Join a peer support group. | Access to a peer support group. | When I ask the mentor or counselor during the appointment. | I will do this the next time I have an appointment with counselor or mentor. |
| | | | | |
| | | | | |
| | | | | |
| | | | | |

Adapted from The Policy Project n.d.

## Self-Management Checklist Part 1

### At the Doctor’s

| Self-Management Task | Yes (Y), No (N), Sometimes (S) |
|---|---|
| I interact directly with my health care team | |
| I make my own appointments with my doctor | |
| I know when and how to call the doctor when I have questions | |
| I know when and how to access urgent/emergency care | |
| I know and can verbalize my medical history | |
| I know and can verbalize my immunization history | |
| I organize transportation to my appointments | |
| I know the names and dosages of my medications | |
| I take my prescribed medication for HIV/AIDS every day | |
| I do not have any difficulty taking my HIV medications on time | |
| I know the rules for taking my medications (e.g., with food, not before bed, etc.) | |
| I order my medication refills and pick them up | |
| I know the possible side effects of my medications | |

Adapted from Transition HIV+ Youth from Adolescent to Adult Services: Adolescent Provider Toolkit 2010.

| Self-Management Checklist Part 2 | |
|---|---|
| At the Doctor's | |
| **Insurance** | **Yes (Y), No (N), Sometimes (S)** |
| I know what type of insurance I have | |
| I know the limits of my insurance | |
| I know how to contact the insurance company with questions | |
| I file my own insurance claims | |
| know when the insurance from my caregiver ends | |

Adapted from Transition HIV+ Youth from Adolescent to Adult Services: Adolescent Provider Toolkit 2010.

| **Self-Management Checklist Part 3** | |
|---|---|
| **Testing and Screening** | |
| **Self-Management Task** | **Yes (Y), No (N), Sometimes (S)** |
| My most recent CD4 cell (T-cell) cell test was within the last 3 months | |
| I know my most recent CD4 cell (T-cell) count | |
| I know my most recent CD4 cell (T-cell) percentage | |
| My most recent viral load test was within the last 3 months | |
| I know my most recent viral load count | |
| I have had a PPD test (for tuberculosis) within the last year | |
| I had had a blood test for Hepatitis C within the last year | |
| I had a blood test for syphilis within the last year | |
| I have been screened for alcohol & substance use within the last year | |
| I do not have any difficulty taking my HIV medications on time | |
| I have been screened for mental health issues in the last year | |
| I have had a pelvic exam, including a pap smear, within the last year | |
| I have had a rectal exam, including an anal pap smear, within the last year | |

Adapted from Transition HIV+ Youth from Adolescent to Adult Services: Adolescent Provider Toolkit 2010.

| My Plan for Achieving Self-Management Skills | | |
|---|---|---|
| **Skill** | **Barriers to Achieving Skill** | **Strategies to Overcome Barriers** |
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Adapted from Transition HIV+ Youth from Adolescent to Adult Services: Adolescent Provider Toolkit 2010.

## RYAN WHITE HIV/AIDS PROGRAM PARTS

**Description:** The Ryan White HIV/AIDS program is the payor of last resort. Program funds may not be used for services if another state or federal payor is available. The Program eliminates duplication with other federal programs. The Ryan White HIV/AIDS Program is divided into five Parts, following the authorizing legislation.

**Part A** funds medical and support services to Eligible Metropolitan Areas (EMAs) and Transitional Grant Areas (TGAs). EMAs and TGAs are counties/cities that are the most severely affected by the HIV epidemic.

**Part B** administers funds for states and territories to improve the quality, availability, and organization of HIV health care and support services. Recipients include all 50 states, the District of Columbia, Puerto Rico, Guam, the U.S. Virgin Islands, and the five U.S. Pacific territories/associated jurisdictions. In addition, Part B also includes grants for the AIDS Drug Assistance Program (ADAP).

**Part C** administers funds for local, community-based organizations to provide comprehensive primary health care and support services in an outpatient setting for people living with HIV through Early Intervention Services program grants. Part C also funds Capacity Development grants, which help organizations more effectively deliver HIV care and services.

**Part D** administers funds for local, community-based organizations to provide outpatient, ambulatory, family-centered primary and specialty medical care for women, infants, children, and youth living with HIV. Part D funding may also be used to provide support services to people living with HIV and their affected family members.

**Part F** funds support clinician training, technical assistance, and the development of innovative models of care to improve health outcomes and reduce HIV transmission. These programs include:

- **The Special Projects of National Significance (SPNS) Program,** which supports the development of innovative models of HIV care and treatment to quickly respond to the emerging needs of clients served by the Ryan White HIV/AIDS Program. SPNS advances knowledge and skills in the delivery of health care and support services to underserved populations living with HIV. Through its demonstration projects, SPNS evaluates the design, implementation, utilization, cost, and health-related outcomes of treatment models and promotes the dissemination and replication of successful interventions.

- **The AIDS Education and Training Centers (AETC) Program,** which supports a network of eight regional centers (and more than 130 local affiliated sites) and national centers that conduct targeted, multidisciplinary education and training programs for health care providers treating people living with HIV. The AETC Program also funds a Physician Assistant/Nurse Practicioner Program.

- **The Minority AIDS Initiative,** which Congress established in 1999 under the Ryan White HIV/AIDS Program Parts A, B, C, and D, improves access to HIV care and health outcomes for dispraportionately affected minority populations, including Black/African-Americans.

All Ryan White HIV/AIDS Program Parts may support the provision of oral health services. However, two Part F programs focus on funding oral health care for people with HIV:

- **The HIV/AIDS Dental Reimbursement Program (DRP),** expands access to oral health care for people living with HIV while training additional dental and dental hygenie providers. To achieve its goals, DRP provides reimbursements to accredited dental schools, schools of dental hygenie, and postdoctoral dental education programs

- **The Community-Based Dental Partnership Program** increases access to oral health care services for people living with HIV and administers education and clinical training for dental care providers, especially those practicing in community-based settings.

Adapted from HRSA Ryan White HIV/AIDS Program Fact Sheet 2019

# RESOURCES FOR MEDICAL PROVIDERS

## Adolescent Clinical Transition Document

| | |
|---|---|
| **Name:** | **Telephone number:** |
| **Date of Birth:** | **Address:** |
| **Sex:** | |
| **Emergency Contact Name:** | |
| **Emergency Contact Address:** | |
| **Date and Age of Diagnosis:** | **Current Medication Regimen:**<br>**Past Medication Regimen (and reason for switch):** |
| **Past medical History:** | **Past Psychosocial History:** |
| **Date of First CD4 Count:** | **Date of Last CD4 Count:** |
| **First CD4 Count:** | **Last CD4 Count:** |
| **Date of First Viral Load:** | **Date of Last Viral Load:** |
| **First Viral Load:** | **Last Viral Load:** |
| **Additional Notes:** | |

Adapted from USAID Toolkit for Transition of Care & Other Services for Adolescents Living with HIV 2014.

## Health Resources and Services Administration Standards
## Performace Measure: Annual Retention in Care

**Description:** Percentage of patients, regardless of age, with a diagnosis of HIV who had at least two (2) encounters within the 12-month measurement year.

**Numerator:** Number of patients in the denominator who had at least two HIV medical care encounters at least 90 days apart within a 12-month measurement year. At least one of the two HIV medical care encounters needs to be a medical visit with a provider with prescribing privileges.

**Denominator:** Number of patients, regardless of age, with a diagnosis of HIV who had at least one HIV medical encounter is a medical visit with a provider with prescribing privileges or an HIV viral load test.

**Patients Exclusions:** Patients who died at any time during the measurement year.

**Data Elements:** Does the patient, regardless of age, have a diagnosis of HIV? (Y/N)

a. If yes, did the patient have at least two medical care encounters during the measurement year? (Y/N)

i. If yes, did the patient have a HIV viral load test within the measurement year? (Y/N)

ii. If yes, did the patient have at least one additional medical visit encounter with a provider with prescribing privileges within the measurement year? (Y/N)

iii. Or, did the patient have two medical visits with the provider with prescribing privileges within the measurement year? (Y/N)

## Annual Retention in Care Evaluation

**Description:** Percentage of patients, regardless of age, with a diagnosis of HIV who had at least two (2) encounters within the 12-month measurement year.

**Numerator:** Number of patients in the denominator who had at least two HIV medical care encounters at least 90 days apart within a 12-month measurement year. At least one of the two HIV medical care encounters needs to be a medical visit with a provider with prescribing privileges.

**Denominator:** Number of patients, regardless of age, with a diagnosis of HIV who had at least one HIV medical encounter is a medical visit with a provider with prescribing privileges or an HIV viral load test.

**Patients Exclusions:** Patients who died at any time during the measurement year.

**Data Elements:** Does the patient, regardless of age, have a diagnosis of HIV? (Y/N)

a. If yes, did the patient have at least two medical care encounters during the measurement year? (Y/N)

i. If yes, did the patient have a HIV viral load test within the measurement year? (Y/N)

ii. If yes, did the patient have at least one additional medical visit encounter with a provider with prescribing privileges within the measurement year? (Y/N)

iii. Or, did the patient have two medical visits with the provider with prescribing privileges within the measurement year? (Y/N)

## Annual Retention in Care Evaluation

**U.S. Department of Health and Human Services Guidelines:**

**Adolescent/Adult Guidelines:** “Several laboratory tests are important for initial evaluation of 1 patients with HIV upon entry into care, and some tests should be performed before and after initiation or modification of antiretroviral therapy (ART) to assess the virologic and immunologic efficacy of ART and to monitor for laboratory abnormalities that may be associated with antiretroviral (ARV) drugs. Table 3 outlines the Panel on Antiretroviral Guidelines for Adults and Adolescents (the Panel)’s recommendations on the frequency of testing. As noted in the table, some tests may be repeated more frequently if clinically indicated.” (Page B-3 of guidelines)

Additionally, Table 3. Laboratory Testing Schedule for Monitoring Patients with HIV Before and After Initiation of Antiretroviral Therapy indicates viral load test should be performed at entry into care; ART initiation or modification; two to eight weeks after ART initiation or modification; in patients on ART every three to six months; every six months of the patient for patients adherent with consistently suppressed viral load and stable immunologic status for more than two years; treatment failure; clinically indicated; and if ART initiation is delayed. (Pages C-2 through C-4 of guidelines)

Pediatric Guidelines: “After the initial phase of ART initiation (1 month–3 months), 2 clinicians should assess a patient’s adherence to the regimen and the regimen’s effectiveness (as measured by CD4 cell count and plasma viral load) every 3 months to 4 months. Additionally, clinicians should review a patient’s history of toxicities and evaluate a patient for any new AEs using physical examinations and the relevant laboratory tests. If laboratory evidence of toxicity is identified, testing should be performed more frequently until the toxicity resolves.” The Panel on Antiretroviral Therapy and Medical Management of Children Living with HIV finds value in continuing to perform viral load testing every 3 to 4 months to provide enhanced monitoring of adherence or disease progression among children and adolescents. Some experts monitor CD4 cell count less frequently (e.g., every 6 months to 12 months) in children and adolescents who are adherent to therapy, who have CD4 cell count values well above the threshold for OI risk, and who have had sustained virologic suppression and stable clinical status for >2 years to 3 years. Some clinicians find value in scheduling visits every 3 months even when lab testing is not performed, in order to review adherence and update drug doses for interim growth” (D-3 of guideline) Additionally, Table 3. Sample Schedule for Clinical and Laboratory Monitoring of Children Before and After Initiation of Antiretroviral Therapy indicates viral load tests should be performed at entry into care; pre-therapy; ART initiation; weeks two to four on therapy, every three to four months to monitor ARV adherence; and when switching ARV regimens.

Adapted from Health Resources and Services Administration Standards. 2019.

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**For Additional resources, check out:**
**advocatesforyouth.org/mentorship**

# 4.2 GLOSSARY

**Acquired immune deficiency syndrome (AIDS)** the stage of HIV where the immune system is severely compromised and some illnesses may cause major problems

**Access to care** following diagnosis, an individual promptly begin receiving needed medical, medical-related, and social services; service providers have the skills and the cultural competence to meet their needs

**Adolescence** the period following the onset of puberty during which a young person develops from a child into an adult.

**Antiretroviral Drugs/Antiretroviral Therapy (ART)** drugs, typically pills, that are prescribed preventively as a treatment for HIV

**Assigned sex at birth** the sex, usually male or female, assigned to a child at birth, most often based on the child's external anatomy. Also referred to as birth sex, natal sex, biological sex, or sex.

**Cluster of differentiation 4 (CD4+)** a protein embedded in the cell surface of T-supporter (lymphocyte) cells; HIV invades cells by first attaching to the CD4 receptor.

**CD4+ count (or, T-cell count)** the actual number of T-supporter cells in a microliter of blood. The CD4+ count is lower in people whose immune system has been affected by HIV.

**Cisgender** a person whose gender identity and assigned sex at birth correspond (e.g., a person who is not transgender).

**Community Based Organization (CBO)** an organization that provides services on a local level.

**Gay** a sexual orientation that describes a person who is emotionally and sexually attracted to people of their own gender. It can be used regardless of gender identity, but is more commonly used to describe men.

**Gender identity** a person's inner sense of being a boy/man/male, girl/woman/female, another gender, or no gender.

**Gender expression** describes the ways (e.g., feminine, masculine, androgynous) in which a person communicates their gender to the world through their clothing, speech, behavior, etc. Gender expression is fluid and is separate from assigned sex at birth or gender identity.

**Gender non-conforming** describes a gender expression that differs from a given society's norms for males and females.

**Heterosexual (straight)** a sexual orientation that describes women who are emotionally and sexually attracted to men, and men who are emotionally and sexually attracted to women

**Homophobia** the fear of, discrimination against, or hatred of lesbian or gay people or those who are perceived as such.

**Human immunodeficiency virus (HIV)** a virus that attacks the body's immune system, which is crucial to fighting off infections and diseases. The virus, if untreated, can cause someone to develop AIDS

**LGBTQ** an acronym for "lesbian, gay, bisexual, transgender, and queer/questioning"

**Lesbian** a sexual orientation that describes a woman who is emotionally and sexually attracted to other women.

**Linkage to care** a systematic process of initiation of HIV-related medical, psychological and social services for people newly diagnosed with HIV.

**Mentor** an individual that supports someone's personal growth and development by providing meaningful guidance, resources, and coaching

**Mentorship** a mutual, committed relationship designed to promote personal and professional development

**Men who have sex with men/Women who have sex with women (MSM/WSW)** categories that are often used in research and public health settings to collectively describe those who engage in same-sex sexual behavior, regardless of their sexual orientation. However, people rarely use the terms MSM or WSW to describe themselves.

**Medical adherence** refers to whether an individual takes their medications as prescribed, as well as whether they continue to take a prescribed medication

**Non-binary (NB)** describes a person whose gender identity falls outside of the traditional gender binary structure.

**Peer navigator** medication adherent role models usually living with a shared experience and a shared community membership as the populations they work with

**Post-exposure prophylaxis (PEP)** an HIV prevention strategy that involves taking HIV medications immediately after a potential exposure, such as condomless sex without the use of PrEP

**Pre-exposure prophylaxis (PrEP)** a medication taken daily that can reduce a person's chances of acquiring HIV by up to 92%

**Retention in care** young people living with HIV complete their treatment regimens and continue regular medical visits for chronic illnesses, which supports them in avoiding complications and hospitalizations and contributes to improved health status.

**Ryan White** a federally mandated program, which provides HIV-related health services to disadvantaged individuals who are underinsured or lack sufficient healthcare coverage to combat HIV seroconversions.

**Same gender loving (SGL)** a term used as an alternative to the terms gay and lesbian. SGL is more commonly used by members of the Black community

**Social stigma** negative stereotypes and social status of a person or group based on perceived characteristics that separate that person or group from other members of a society.

**Structural stigma** societal conditions, policies, and institutional practices that restrict the opportunities, resources, and well-being of certain groups of people.

**Transgender (Trans)** describes a person whose gender identity and assigned sex at birth do not correspond. Also used as an umbrella term to include gender identities outside of male and female. Sometimes abbreviated as trans.

**Trans man/transgender man/female-to-male (FTM)** A transgender person whose gender identity is male may use these terms to describe themselves. Some will just use the term man.

**Trans woman/transgender woman/male-to-female (MTF)** A transgender person whose gender identity is female may use these terms to describe themselves. Some will just use the term woman.

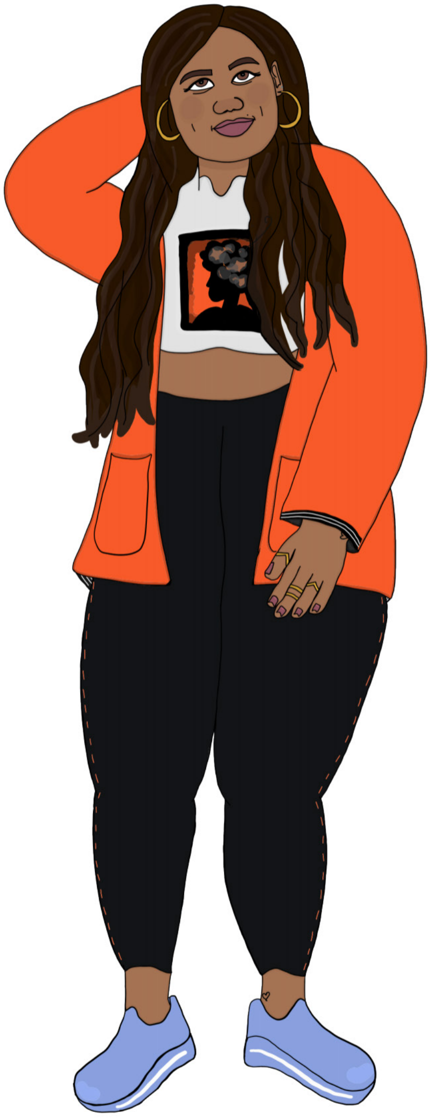
**Transition** a multifaceted, active process that attends to the medical, psychosocial, and educational/vocational needs of adolescents as they move from the child focused to the adult focused healthcare system

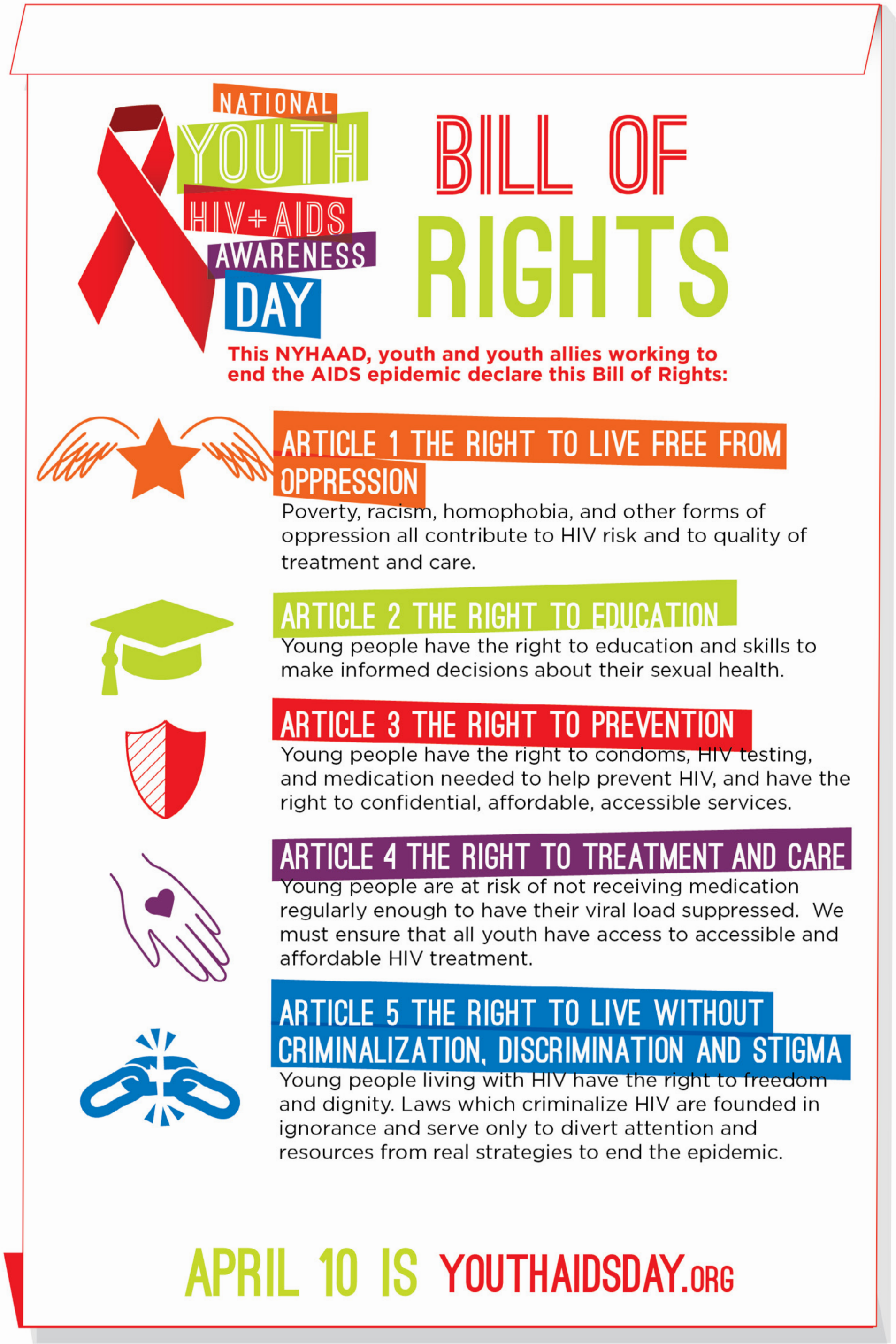
**Transphobia** The fear of, discrimination against, or hatred of transgender or gender non-conforming people or those who are perceived as such

**Undetectable** people in this group know their HIV positive status. They see a medical provider regularly and take their HIV medications as prescribed. Consequently, the amount of HIV in their blood is lower than the threshold detectable by available tests.

# 4.3 NATIONAL YOUTH HIV/AIDS AWARENESS DAY

Every April 10th, on National Youth HIV/AIDS Awareness Day (NYHAAD), students organize around ensuring the rights laid out in the NYHAAD Bill of Rights are guaranteed to all young people. The Bill of Rights can assist mentors in reminding everyone of the rights that young people have.





NATIONAL YOUTH HIV+AIDS AWARENESS DAY

BILL OF RIGHTS

**This NYHAAD, youth and youth allies working to end the AIDS epidemic declare this Bill of Rights:**

**ARTICLE 1 THE RIGHT TO LIVE FREE FROM OPPRESSION**

Poverty, racism, homophobia, and other forms of oppression all contribute to HIV risk and to quality of treatment and care.

**ARTICLE 2 THE RIGHT TO EDUCATION**

Young people have the right to education and skills to make informed decisions about their sexual health.

**ARTICLE 3 THE RIGHT TO PREVENTION**

Young people have the right to condoms, HIV testing, and medication needed to help prevent HIV, and have the right to confidential, affordable, accessible services.

**ARTICLE 4 THE RIGHT TO TREATMENT AND CARE**

Young people are at risk of not receiving medication regularly enough to have their viral load suppressed. We must ensure that all youth have access to accessible and affordable HIV treatment.

**ARTICLE 5 THE RIGHT TO LIVE WITHOUT CRIMINALIZATION, DISCRIMINATION AND STIGMA**

Young people living with HIV have the right to freedom and dignity. Laws which criminalize HIV are founded in ignorance and serve only to divert attention and resources from real strategies to end the epidemic.

APRIL 10 IS YOUTHAIDSDAY.ORG

Advocates
for Youth
Young. Powerful. Taking Over.

1325 G STREET NW, SUITE 980
WASHINGTON DC, 20005 USA

★★★★
CHARITY NAVIGATOR
Four Star Charity