



# HIV Peer Navigation Best Practices



POINT SOURCE YOUTH

**POSITIVE ACTION**



**This chapter is part of Point Source Youth’s National Youth Mentorship and Peer Navigation Initiative handbook.** Created with the help of our National Youth Advocates, and funded by ViiV Healthcare’s Positive Action for Youth (PAFY) Grant, this handbook was developed to train and support hundreds of youth mentors to provide peer navigation and support related to HIV-prevention, treatment, and care and housing to QTBIPOC youth. Click here to access the full handbook, with chapters on Youth Mentorship and Best Practices, HIV Peer Navigation Best Practices, Self-Care and Community Care, and more.

[Access the full handbook here.](#)

## TABLE OF CONTENTS

<b>HIV Peer Navigation Best Practices</b>	<b>3</b>
What kind of training should HIV Peer Navigators get?	3
A Note on Cultural Humility	12
<b>Endnotes</b>	<b>13</b>

# HIV PEER NAVIGATION BEST PRACTICES

A HIV Peer Navigator functions similarly to a Youth Mentor. This staff person should be a young person with lived experience, in a paid position to help the young person navigate their care.

The HIV Peer Navigator is a more specialized position than a Youth Mentor. This person should have specialized experience and knowledge about HIV. They may come into the role with this knowledge, or you may need to train them and help them develop their expertise.

According to our National Youth Advocates, an HIV Peer Navigator is an **“advocate for people within their community to outsiders”**. A peer navigator creates “a partnership” with the young person living with HIV; the reason for this is because the peer navigator has more experience with the systems that provide services such as healthcare and housing. Our National Youth Advocates noted that peer navigators also know what to say to providers to ensure the services the young person needs are attained.

## What kind of training should HIV Peer Navigators get?

National Youth Advocates recommended that HIV Peer Navigators should receive formal training on the entry into the homelessness system and healthcare system within your community, so that they can help the young person understand what to expect as they go through the process.

In many instances, the HIV Peer Navigator may already be familiar with these systems. Nevertheless, your organization should make formal introductions on behalf of the HIV Peer Navigator to the points of contact within each system that the young person will receive care from.

**What do HIV Peer Navigators do?** HIV Peer Navigators take on a variety of roles. They help young people by supporting access to care and helping to navigate them through various systems and services.

## Supportive services

### COORDINATING CARE WITH CASE MANAGERS

Case management services are a core component of the work with young people living with HIV. A Case Manager’s responsibility includes knowing where the resources are located. Due to an increase in demand for services, some case managers may be responsible for dozens of young people on their caseload. It’s important for Case Managers to connect and frequently meet with Youth Mentors and/or HIV Peer Navigators to ensure they are all on the same page and know the young person’s goals in their service plans. Creating this partnership ensures there is a collaborative approach.

We recommend Case Managers and HIV Peer Navigators meet consistently and communicate often. We also encourage you to define a crisis for both roles to help them determine when a supervisor should become involved. Lastly, we suggest that the job requirements and the division of responsibilities be clearly defined to both roles (and the young person receiving services too!) because there will be many times that the lines of a Case Manager and a HIV Peer Navigator. Please use this job description as a sample of a [HIV Peer Navigator](#).

Following these strategies and establishing expected meeting times between the two roles will result in a frequency of communication. Due to the increase in communication, Case Managers and HIV Peer Navigators may be able to identify crises before they happen and intervene sooner.

## REFERRALS TO DROP-IN CENTERS

Most Drop-In Centers are managed by peers and offer a community setting that provides a **supportive, safe and confidential environment**. Young people who are experiencing homelessness can get some of their most basic needs met such as a shower, meal, connection to a Youth Mentor, a referral for mental health counseling, and a link to medical care. In addition, many Drop-In Centers can hold medications and can distribute them daily, weekly, or monthly, if the young person is homeless.

Drop-In Centers are often open year-round and provide young people with an opportunity to improve their current quality of life by making connections to like-minded people and services without judgment.

In addition, social activities are offered in order to promote supportive experiences that empower young people to actively pursue their journey towards health and safety. We encourage you to look up and connect with your local Drop-In Center and ensure the HIV Peer Navigator has a strong relationship with their services.

## Healthcare

**Referrals to healthcare providers** and establishing open communication with them is crucial to ensuring the stability of young people living with HIV. HIV Peer Navigators should have an understanding of the clinics your organization has linkages to, and they should also be treated as employees of your organization when they accompany a young person to an appointment.

We recommend that your organization inform the point of contact at the health clinic that HIV Peer Navigators were recently hired and that they represent your organization. If possible, provide an email introduction with an explanation of their responsibilities.

## ARV THERAPY

'ARV' is the acronym of '**antiretroviral**'. ARV therapy is the main type of treatment for HIV and AIDS, however it is not a cure. The goal of ARV therapy is to prevent people from becoming ill.

The most difficult part for some people with HIV may be the knowledge that ARV treatment medication will need to be taken **everyday for the rest of the person's life**. Adhering exactly to medications as they are prescribed can be a major life change for the person because it requires that the medication be taken at the exact dose and the exact time every day.

Treatment adherence can be **especially difficult if the young person has an unstable housing situation**, which is why it's crucial that housing and wrap-around services are offered to the person as soon as possible. In order to help the young person with treatment adherence, a referral to a HIV support group may be a good support system, if they are willing to consider this option. The support group may be able to offer tips on changes in their lifestyle or schedule that will help with taking medications as prescribed.

## SAFE SEX

PEP and PrEP are two great options to protect from transmission of HIV. We recommend that HIV Peer Navigators are well versed and comfortable discussing these options. Please see the links below for more information on safe sex practices, condom use, and dental dams.

- [Condom Fact Sheet](#)
- [Dental Dams](#)
- [Female Condoms](#)
- [Male Condoms](#)

**PEP (Post Exposure Prophylaxis)** means taking medications after you have been exposed to HIV to prevent getting HIV. PEP must be started within 72 hours (or 3 days) after you have been exposed to HIV. Every hour counts!

Transmission of HIV occurs with certain bodily fluids of a person with HIV such as blood, semen, or vaginal fluid. Exposure happens via vaginal sex, anal sex, or sharing needles with others. PEP may help the body's immune system stop the virus from replicating in the infected cells in the body. When taking PEP, the infected cells die naturally within a short period of time without producing more copies of HIV.

PEP is recommended if you're exposed to HIV during sex, after sharing needles or if sexually assaulted. If prescribed PEP, you'll need to take it once or twice daily for 28 days. It has side effects such as upset stomach and fatigue. Tell your healthcare provider if these symptoms worsen. PEP is not a substitute for regular protection such as PrEP, using condoms the right way every time you have sex, and using only new and sterile needles every time you inject.

**PrEP (Pre-Exposure Prophylaxis)** is a medicine that can prevent HIV. PrEP is for people who are HIV negative and at risk of getting HIV. This includes people who have a sexual partner who has HIV, people who don't always use condoms, people that have been diagnosed with a sexually transmitted disease (STD) in the last 6 months, or people who are sharing needles, or with a sexual partner who shares needles. PrEP does not protect against transmission of other STDs.

## NUTRITION

In addition to treatment adherence, it is important that the young person living with HIV pay close attention to their nutrition. We strongly recommend that young people are connected with dietitians in order to make certain they are receiving and following the nutrition needed to remain medically stable. An excellent national resource that provides education and guidance about healthy eating is [MyPlate](#) which is funded by the U.S. Department of Agriculture. On this website, there is a quiz to determine current eating habits. Once the [quiz](#) is complete, resources and recipes for healthy eating and cost effective food shopping are provided. In addition, there is an [app](#) that can be downloaded to help the young person further in establishing healthy eating habits.

## MENTAL HEALTH

Young people newly diagnosed with HIV need education and resources that, as one youth advocate noted, "can carry them onto the next day" because the news of this diagnosis is a shock to one's system. In addition, being diagnosed with HIV is not a death sentence. It's important for a HIV Peer Navigator to let the young person know that they have options, there are resources and it is possible to live a healthy and fulfilling life despite their diagnosis. It's also crucial that service providers and HIV Peer Navigators are [aware of the risk](#)

of suicidal ideation, thoughts of self-harm, or excessive drug use and create a safety plan (if needed) with the young person.

We provided a sample of a safety plan for you here. The safety plan can also include a follow up appointment to carry out the next steps in their treatment.

## Life Skills & Support

HIV Peer Navigators or Youth Mentors can help with traditional life skills, like budgeting, shopping, cooking, and maintaining a social network.

HIV Peer Navigators can also help young people living with HIV develop life skills needed to emotionally and physically deal with their HIV status. This includes basic education, providing emotional support, teaching coping skills, disclosing their HIV status, and overcoming stigma.

Here are some strategies for professionals to deal with stigma and discrimination:

- Ensure Peer Navigators are part of your organization's team by inviting them to **training, staff meetings, and other events** offered throughout the year.
- Provide an opportunity for young people to **give feedback** on the services offered and determine if these services or interventions are stigma-free and reviewed by leaders at your organization.
- Establish linkages and relationships with community-based youth **support groups** for young people living with HIV.
- **De-stigmatize** HIV by talking openly with staff members about attitudes, feelings, fears, and behaviors.
- **Oppose** stigmatization in your organization (e.g., if you see a co-worker treating a young person with HIV with disrespect, talk to your co-worker on a one-to-one basis. Tell them what you saw and how the situation could have been handled differently).
- **Pay attention** to young people when they talk about their feelings and concerns related to stigma and discrimination, and report these back to other staff.

## HIV Myth-Busting & General Information

Here are some basic facts that young people with HIV should know, that HIV Peer Navigators can help clearly define:

- HIV is a **chronic disease**. With the right medicines and a healthy lifestyle, young people living with HIV have a long life ahead of them.
- People living with HIV can have a **sexual life** and sexual relationships.
- People living with HIV can **have children**.

- People living with HIV can have sex **without transmitting** HIV to their sexual partners.
- People living with HIV can **enjoy sexuality**. Many people think that sex is just about vaginal or anal intercourse. But there are lots of different ways to have sex and different kinds of sex.
- Decide **if, when, and how to disclose** your HIV status: Young people know best if and when it is safe to disclose their status. There are many ways that can help you to figure out how to tell your partner, such as visiting a counselor or a local support group.
- People have **different reasons** for not sharing their HIV status, often related to fear of stigma and discrimination within their community. One of the hardest things about dating, sex and relationships is the possibility of being rejected by someone. But there are lots of people who do not mind whether their partner is HIV-negative or -positive.
- **Practice safer sex:** Safer sex is a shared responsibility. When you share your HIV status, you and your partner can work together to make your sex life pleasurable and safe. Sometimes, people who live with HIV think they do not need to practice safe sex if their partner is also positive. But you can still pick up a sexually transmitted infection (STI) that can affect your health.
- Choose if, when, how many, and with whom to **have children**. People living with HIV can have healthy pregnancies and share a long life with their children. There is about a 25–30% chance that your child will be infected during pregnancy, labor and delivery. The risk is reduced to almost zero when preventative measures are taken. Talk to your health care provider and/or child health service provider when you want more information. If they cannot help you or you have a bad experience, speak to someone else.<sup>1</sup>

## Emotional Support

HIV Peer Navigators can provide an overview of what medical support looks like by walking the young person through the process, especially after they have tested positive for HIV.

Our National Youth Advocates noted the following: Testing for STDs and HIV includes a finger stick which is 93% accurate. If the results of the test indicate the young person is HIV positive, then the test is sent to a lab for confirmation. Our National Youth Advocates stressed that the moments after finding out the results of the finger stick test are incredibly crucial because the young person will likely be overwhelmed by the findings. Therefore, it is important that emotional support is provided **immediately thereafter**, rather than medical support.

The reason this window of time is important to note, is because the young person may “ghost” or disappear after the HIV results. The HIV Peer Navigator can help the young person see that there are supports available to them that can help them lead a full and happy life despite their status.

This non-judgmental, emotional support includes actively listening to the young person after they hear the results, providing validating statements of their feelings, and sitting with them as they process their feelings which may include feeling numb, angry, or a desire to flee. These reactions are all normal feelings to experience when a person receives traumatic information. Therefore, we strongly encourage all your staff to be trained and well-versed in trauma-informed care.

Our National Youth Advocates also noted that after hearing the news of their status, young people may need time to emotionally and mentally process the information. While this is a complicated time for the young person, the advocates strongly encouraged HIV Peer Navigators to inform the young person of the next steps so that they are prepared for what will come next.

Depending on the state your organization is in, the Health Department may contact the young person directly to get details of their health and history, which our National Youth Advocates described as a very impersonal interaction. Therefore, they encourage HIV Peer Navigators to remain in close contact with the young person in order to empower them to tell others they have been intimate with about their status before the Health Department informs their partners.

In addition, depending on the state your organization is in, a person with knowledge of their HIV status can face serious legal consequences if they continue to have unprotected sex, despite knowing their status.

Overall, the most important takeaway from this moment is that it is traumatic to hear that you are HIV-positive.

In addition, depending on the young person's network of friends or support, it's possible that their status will be known, and they may be ostracized from their community. Therefore, the HIV Peer Navigator's role is to remain present with these feelings, be supportive, and remain in close contact with them to help the young person through the difficult next steps.

## Coping Strategies

- **Ask for help** from someone you trust by knowing who you consider part of your **“safe support system or chosen family”**.
- **Practice disclosing** your status with your safe support system or chosen family.
- **Establish a community** and seek out other people who are living with HIV and ask them:
  - What do you wish you had done differently after you were diagnosed?
  - What do you wish you had learned sooner about HIV and treatment options?
  - How is your life different after learning of your status?
- **Test** how your partner might react by asking questions like:
  - What do you think of HIV?
  - Have you ever met someone with HIV?

**Safe support system or chosen family are a person(s) that you can call on when you are in crisis and will listen to you vent without judgement.** If the young person does not have someone like that in their life, it may be a good role for the Youth Mentor to fill, provided the appropriate boundaries. In our opinion that boundary can be created when the Youth Mentor creates a safety plan with the young person.

- **Change the channel** in your mind when you are feeling down by doing things that soothe you, such as the **grounding techniques**.
- **Learn something new** to get out of the negative thinking loop you are in (i.e. watch YouTube videos on a new hobby you're interested in and try it out.)
- Think of the one **song** that makes you feel good about yourself. Sing it and play it on repeat until you feel cozy and confident in your skin.



- **Change your environment** and go for a walk. Be in nature, notice the trees, feel the air on your skin, and notice the colors and smells that surround you.
- Establish a **daily routine** that you can realistically implement. Start off small, for example, by setting an alarm to eat dinner at the same time every day.
- Always remember that there are **options** at every turn. For example, when you have a decision to make, think of all the possible choices you have and determine which choice will lead to the outcome you are hoping to see.
- Persist in living your **true and best life**. Never, never, never, give up.
- Create **meaning** in your life. Think about your hopes, dreams, inspirations, and carry something with you that reminds you of these values.
- **Reach out** and ask for help. Talk to others who have similar experiences and values in order to access the resources needed.

## Disclosing HIV Status

One of the most difficult aspects to being diagnosed with HIV is the limited access to information and resources. Because young people have their whole lives ahead of them, they have important questions to ask themselves such as:

- Can I have an intimate relationship with my partner?
- How do I tell my support system about my HIV status?
- Who can I trust to guide me through this process and tell me where to get help?

### PRO TIP

It is important for service providers and HIV Peer Navigators to understand the weight of these questions because often young people do not know whom to turn to for answers. As noted earlier, there are Department of Health laws that govern HIV status notifications that vary from state to state.

Either way, the decision of if, when, and how to disclose one's HIV status is an **individual choice**. Therefore, it's important that service providers and HIV Peer Navigators provide young people with the education needed to make an informed decision about sharing their status.

We encourage you to look up your own **state laws** regarding disclosure of HIV status and provide young people with the education they need to make an informed choice.

Our National Youth Advocates also noted that when the general public hears "HIV" people usually think of sex, specifically gay sex, which results in further stigmatization. The fact is HIV can still be transmitted intravenously. Therefore we encourage service providers and HIV Peer Navigators to be well versed in the transmission of HIV, testing sites, and the treatments available, which we have outlined throughout this handbook.

Homophobic, biphobic, and transphobic language is pervasive, and it affects many people. When this language is unchallenged it has a damaging impact on young people and may lead to stigmatization further down the line.

[Stonewall UK](#) outlined the following definitions:

“**Homophobic language** is a language that is used either with the intention or has the effect, of discriminating against someone based on a person’s actual or perceived lesbian or gay identity, or because they have lesbian or gay family members or friends. Bi people can also be targeted by homophobic language if somebody thinks that they are lesbian or gay. Homophobic language can also include denying somebody’s lesbian, gay or bi identity or refusing to accept it.

**Transphobic language** is language that is used either with the intention, or has the effect, of discriminating against someone based on a person’s actual or perceived trans or non-binary identity, or because they have trans or non-binary family members or friends. This can also include denying somebody’s gender identity or refusing to accept it.”

We encourage you to look at this [toolkit from Stonewall UK](#) for ideas on how to tackle homophobic, biphobic, and transphobic language at your organization.

## Addressing Stigma

The mental health of a young person living with HIV is crucial to be mindful of because of the stigma they may face from those around them. When we describe stigma, we mean that the person experiences **condemnation and rejection because of a specific characteristic**, like their HIV status. When a young person living with HIV is stigmatized by others it means they are degraded and seen as “less than”. People stigmatize others because they aren’t educated on the nuances and developments of HIV/AIDS treatment, and because they are afraid of the unknown.

Without the right support system this stigmatization by others can lead the young person to stigmatize themselves and feel shame and isolation. These feelings can lead to a host of issues such as: withdrawal from their support system, not following up to treatment appointments, not accessing services out of fear that their status may be revealed and that they will be discriminated against by others.

Other issues that may come up because of self-stigmatization include feelings of depression and anxiety. This domino effect may then lead to failing to care for their basic needs which may impact their housing stability and lead to poorer nutrition which will impact their overall health and stability.

Our National Youth Advocates noted that receiving mental health treatment when the young person’s first diagnosed is a determining factor to getting HIV treatment and taking ARV medication. They also underscored the suicidal shock that young people may experience immediately thereafter which can include participating in forms of self-harm such as an overindulgence in drugs and sex to escape their devastation.

Therefore, we encourage you to use [the safety plan](#) to help steer a young person into understanding their triggers, their coping skills, who to reach out to for help, and provide them with [988 The Lifeline](#). 988 The Lifeline is a national hotline across the United States that you can text or call which to access help during in a mental health crisis.

## Navigating Various Systems of Care

HIV Peer Navigators are essential in steering young people through the systems of care that they will need in order to access services, treatment, and housing. The responsibility of HIV Peer Navigators should include **knowledge of entry points** for specific systems (i.e. who are the service providers, who to call for an intake appointment, etc.,) and the required identifying **documentation** needed to access services. Documentation such as state IDs can become complicated for people in the LGBTQIA+ community who may have a different gender expression from previous photos or gender markers on their IDs. In addition, having these forms can become even more complicated when the young person has lost their housing, has entered the shelter system, or their families never gave them access to these forms.

Therefore, we recommend that service providers have knowledge of the process needed to obtain IDs and to train the HIV Peer Navigator on this process. We also recommend you introduce HIV Peer Navigators to the other providers or stakeholders that you regularly make referrals to; following through with this introduction, ensures the HIV Peer Navigators will experience a warm handoff when they start doing outreach on behalf of the young people they serve.

## The Homelessness System

As already mentioned, it's important for the HIV Peer Navigator to know who your key stakeholders are in the community. An invaluable aspect of onboarding a HIV Peer Navigator includes walking them through the homeless shelter system so that they have a full understanding of the different systems a young person experiencing homelessness interacts with. We also recommend the HIV Peer Navigator become familiar with the local homelessness prevention provider and rapid rehousing provider.

**Rapid re-housing** is a solution to homelessness designed to help individuals and families quickly exit homelessness and return to permanent housing. It is offered without preconditions (such as employment, income, absence of criminal record, or sobriety) and the resources and services provided are typically tailored to the unique needs of the household. It includes three core components: housing identification, rent assistance and move-in assistance, and case management.<sup>2</sup>

**Host Home programs** build off the continued legacy of QTBIPOC mutual aid practices. Host homes provide young people experiencing housing instability with affirming, stable, short-term housing for 1-6 months, wrap-around case management services, and peer support. The goal of short-term host homes is to provide a safe, temporary, welcoming space for up to six months where young people have time to repair their relationships with self-identified and chosen family and/or make decisions about other housing options with the support of a caring housing case manager and affirming adult mentor.

**Direct Cash Transfers (DCT)** are proven to meet the needs of young people remotely, digitally, and efficiently. Program staff distributes cash to youth either remotely or safely in person at a frequency (weekly, bi-weekly, or monthly) that works best for them.

**Homelessness prevention** services include eviction prevention programs that offer rental assistance. Another form of homelessness prevention includes **Housing Choice Vouchers**.

We also encourage you to consider building a resource directory that the HIV Peer Navigator can use to make referrals for the young adults they will work with.

## The Criminal Justice System

We recommend that you introduce the HIV Peer Navigator to your local legal aid service provider. If you don't have a linkage with one, create one! It's important to have an ally in the criminal justice system because of discrimination and racism that BIPOC people experience. Some legal service providers offer training to service providers so that you understand the scope of their work. Inquire if that is a resource they offer and invite the HIV Peer Navigator to this training.

If the young person is involved in the legal system and has been assigned a probation officer, we encourage your organization to make linkages with them, as long as the young person consents to this exchange. Establishing a relationship with their parole officer ensures that all parts of the young person's life are coordinated together which can lead to more stability in their lives.

## The Mental Health System

Due to the increase in need for mental health services, we want to underscore the importance of a directory of resources. To get you started, please [visit this link](#) to find treatment providers nationwide.

## A Note on Cultural Humility

As you think about the life skills your organization will teach and provide resources to, we recommend you reflect on the [Cultural Humility model](#) reviewed on page 10 in the full handbook. Here are some concrete examples of cultural humility from our National Youth Advocates.

- Remember that lived experience does not come from a textbook, school, networking event, or other professional experiences. HIV Peer Navigators are a valuable part of your team because the young people you serve can be authentic with them since they know what it's like to have experienced and traveled through some of the same systems of care.
- As a service provider it's important that HIV Peer Navigators carry out the roles that are within the confines of their job descriptions. Therefore, as already mentioned, outline the boundaries of the HIV Peer Navigator relationship with the young person and specify what is and is not permissible (i.e. dating clients is not allowable, a young person needs to know that the HIV Peer Navigator is a mentor not their friend or partner.)
- Establish milestones of success with the HIV Peer Navigator by creating [S.M.A.R.T.I.E](#) (Specific, Measurable, Attainable, Realistic, Timely, Equity, Inclusion) goals they should achieve within the first 90 days of their employment.
- Provide support to the HIV Peer Navigator by ensuring they receive regular supervision, and implementing an annual review of their work.
- Remind yourself as an organization of the value of this role. HIV Peer Navigators and Youth Mentors should be compensated accordingly. For example, payment in the form of gift cards is not acceptable. They should be paid equitable wages compared to other employees at your organizations because they are using a great deal of their own energy to draw from their experiences to do this work.

- Review the HIV Peer Navigator’s job description and make certain you are not asking them to work outside of their scheduled hours or assigning them tasks beyond their job description just because they have the skills to do so.
- **Notice if you are talking down** to the HIV Peer Navigator or Youth Mentor. Sometimes older adults can forget how hard it is to be young, which pressures the young person to filter themselves (*see page 8 of the full handbook*).
- Give the HIV Peer Navigator or Youth Mentor the space to communicate effectively. Provide a space for them to provide feedback when they have felt slighted or left out.
- Listen to the HIV Peer Navigators and Youth Mentors when space is created for them to talk versus trying to explain things to them or carry out your own agenda.

Our National Youth Advocates provided these poignant examples so that your organization can help HIV Peer Navigators and Youth Mentors feel welcomed and a part of the team. We hope that this will help you avoid making the same pitfalls and instead focus on the mission together.

## ENDNOTES

- 1 Addressing the Needs of Young. People Living with HIV. A Guide for Professionals. [https://aidsfonds.org/assets/resource/file/PY\\_Adressing%20the%20needs%20of%20young%20people%20living%20with%20HIV.pdf](https://aidsfonds.org/assets/resource/file/PY_Adressing%20the%20needs%20of%20young%20people%20living%20with%20HIV.pdf)
- 2 [Rapid Re-Housing Works - National Alliance to End Homelessness](#)