Improving Engagement and Retention in Adult Care Settings for Lesbian, Gay, Bisexual, Transgender and Questioning (LGBTQ) Youth Living with HIV

– A Guide for Adult HIV Healthcare Providers

NASTAD™
NATIONAL ALLIANCE OF STATE & TERRITORIAL AIDS DIRECTORS

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INTRODUCTION

Every year in the United States, 5,000 young people under 25 years old become infected with HIV, mostly due to unprotected sex or needle sharing.[1] In recent years, advances in anti-retroviral HIV medications (ARVs) have significantly reduced AIDS-related mortality, giving these young people the chance to live long and healthy lives. Whether transitioning out of a pediatric or adolescent care setting into adult care, or moving directly from the point of diagnosis into adult care, young people living with HIV are entering a system that is not set up to meet their needs. Already, young people (15-24 years old) have the lowest utilization of medical office visits of any other age group.[2] In HIV care, this can have a devastating impact on adherence to ARV medication, treatment of opportunistic infections and prevention of transmission to others. Engaging and retaining young people in adult care is critical to their survival and to wider prevention and public health efforts, yet too many continue to get lost in the process.

The specific and often unaddressed needs of HIV positive lesbian, gay, bisexual, transgender and questioning (LGBTQ) youth further complicate this issue. The multitude of psychosocial and structural barriers that they face due to their sexual orientation or gender identity – mental health problems, homelessness, substance use and stigma – within a society that often misunderstands and mistreats them, makes coping and living with an HIV diagnosis particularly complex.

To date, there is scant literature on how to effectively treat LGBTQ youth (13-24 years old) in adult care settings that were infected with HIV via behavioral means. The majority of related research has focused on *transition out* of pediatric care settings for perinatally infected young people and recommendations have mostly targeted pediatric providers. As the population of transitioning and newly diagnosed young people grows, with the highest prevalence within LGBTQ communities, there is an urgent need to bring this topic to the fore among adult care providers. Therefore, the National Alliance of State and Territorial AIDS Directors (NASTAD) developed this issue brief to help health departments explore the unique issues affecting HIV positive LGBTQ youth, particularly those not perinatally infected, and assist adult HIV health providers as they *welcome them into* their care.

The following sections provide a general overview of LGBTQ youth living with HIV, barriers to engagement and a series of simple and applicable recommendations for improving engagement and retention in care for this population.

THE EPIDEMIC

At the end of 2008, there were nearly 40,000 young people, 13-24 years old, living with HIV/AIDS in the United States. Among males, 73 percent of infections were attributed to male-to-male sexual contact and 16 percent to perinatal transmission. Among females, 59 percent of infections were attributed to heterosexual contact and 34 percent to perinatal transmission[1]. Male-to-female transgender youth also have particularly high incidence of HIV infection.[11]

A QUICK OVERVIEW OF LGBTQ* YOUTH

LGBTQ youth have the same developmental challenges as all young people but with the potential added stress of minority sexual orientation and/or gender identity, internal and external homophobia, and limited family and peer support.[3] Institutionalized homophobia within schools, workplaces and health care

* The term "LGBTQ" refers to a large and diverse group of people whose characteristics and needs change from one individual to the next. When reading about the following sub-populations, it is important to remember that these are just a few of the many, and are themselves very broad and general. Sub-groups are not mutually exclusive; youth may fall across many subpopulations or none at all.

settings results in high levels of violence toward LGBTQ youth plus disproportionate rates of substance use, mental health problems, suicidal ideation, school drop-out and sexual risk-taking.[4] Twenty to 40 percent of homeless youth are LGBTQ, often as a direct result of "coming out" to families and being kicked out of the home.[5] Internalized stigma, in addition to living with a condition that is highly stereotyped and misunderstood, only exacerbates these problems. The pervasive discrimination and rejection experienced by so many LGBTQ youth on the basis of their sexual identity and/or HIV status means that in terms of health care and day-to-day life, many are going it alone. Therefore, the ability to reach them at all with healthcare, and then retain them in care, is ever more difficult.

Young Men Who Have Sex with Men (MSM)

Young men who have sex with men (MSM), ages 13-24 years old, are the fastest growing population of people living with HIV in the U.S.[6] and a high percentage do not know they are infected. Alcohol, methamphetamine and other drug use is common among young MSM and can lead to risky sexual behavior. Unfortunately, for young men growing up in an age where antiretroviral (ARV) medications have been readily available, some do not view HIV as dangerous and have become complacent about risky behavior.[7] This concern is heightened with recent advances in pre-exposure prophylaxis (PrEP), Truvada, a promising daily pill to prevent HIV transmission among MSM. Advocates fear that the availability of Truvada for PrEP could lead to a false sense of protection from HIV and increased risk-taking among young MSM.

Young MSM of Color

Rates of HIV infection among young Black men 13-29 years old are higher than among any other races/ethnicities.[8] Young Black gay/bisexual men are hardest hit, representing three-quarters of new infections among all young Black men and more infections than any other racial/ethnic group of MSM. In 2008, 17 percent of young Latino MSM were infected with HIV, with rising rates every year.[8] Many Black and Latino youth are diagnosed late in the course of their infection, putting them at increased risk for opportunistic infections and rapid progression to AIDS.[12] LGBTQ youth of color face special challenges. Not only do they experience stigma and discrimination from society at large because of their sexual orientation, but they may also face rejection by their own racial/ethnic communities, many of which strongly oppose homosexuality. Feeling that they have to choose between their ethnicity and their sexual identities, these youth are less likely to be involved with support organizations and activities targeting LGBTQ youth.[9]

Young Women

Young women who have sex with women (WSW) are often thought of as "safe" from negative health outcomes.[9] However, evidence suggests that many WSW also have sex with men. Over their lifetimes, they have similar rates of sexually transmitted diseases to all women, experience pregnancy at higher rates than heterosexual women and are less likely to use protection during heterosexual intercourse.[9] Therefore, WSW have the same sexual and reproductive health (SRH) needs as women who have sex with men, making adequate SRH services crucial for this population. Studies of pediatric HIV care have found that SRH services are limited in the pediatric setting. Often, providers assume that HIV positive young women do not want to have children or are not having sex. For sexually active young women, the adult care environment may be much healthier and more helpful in providing access to family planning and counseling services.[10]

Transgendered Youth

Male-to-female transgendered youth have particularly high rates of HIV infection and many providers are not prepared to manage the complexities of their situations. Transgendered youth may be taking or interested in taking gender-affirming hormone therapies or other medications in addition to their ARV therapy.[11] They also experience high rates of violence, victimization and suicide ideation.[9] In 2006, the National Institute of Mental Health reported that transgender women were less likely to receive ARVs than all other people living with HIV.[12] It

is less likely that a pediatrician will have any specialization in this area, so finding an adult care provider that is knowledgeable and experienced working with transgendered youth is likely easier and advisable.

WHERE ARE THEY COMING FROM?

Some youth will be transitioning out of pediatric health settings, while others will go straight into adult care after diagnosis. NASTAD recognizes the importance of understanding these contexts, in addition to how mode of transmission can impact engagement and retention in adult care.

Pediatric/Adolescent Care

Young people that contracted HIV at birth or early in adolescence are likely to have received care in pediatric and/or adolescent health facilities for many, if not all of their adolescent years. Clinically speaking, perinatally infected youth are more likely to be in advanced stages of HIV, with a history of opportunistic infections, co-morbidities, developmental delays and more resistant mutations of the virus resulting in complex medical regimes.[3] Their psychosocial needs are largely the same as those of their behaviorally infected peers. In pediatric/adolescent care, medical and psychosocial needs are often addressed together, through a multi-disciplinary, "1-stop shop" model. Coordinated services such as these are less likely to be available in adult care settings.

Youth's strong attachment to their adolescent care team, particularly among those who have not disclosed their HIV diagnosis to anyone outside their providers, makes leaving that team particularly challenging. Mutual feelings of attachment, coupled with distrust of the adult care system, mean many pediatric/adolescent providers are equally resistant to let go of their patients.[4,5,6]

Point of Diagnosis

Depending on age, age at diagnosis, readiness and/or clinical protocol, many young people will go directly to adult care without ever entering pediatric or adolescent HIV care settings. Some newly diagnosed youth enter a period of denial after receiving a positive test result, meaning they do not always enter care right away. Equally, a recent diagnosis may mean that youth are still learning to cope, considering suicide and unable to take responsibility for their care. They may experience more challenges to treatment adherence, have denial and fear of HIV, have misinformation about HIV and about their personal risk. They will likely have more distrust of the medical establishment, fear, disbelief in the effectiveness of treatment, low self-esteem, depression and anxiety, and an unstructured and chaotic lifestyle without family and social supports.[7]

These youth are likely experiencing illness for the first time in their lives, necessitating increased assistance with how to navigate the health care system, treatment adherence and health insurance benefits. If new to the health system overall, young people may bring previously unaddressed issues of substance use, anxiety and depression, intimate partner violence and others that require immediate attention.

KEY STRATEGIES FOR ENGAGEMENT IN CARE

This section will provide simple and applicable solutions for improving and increasing engagement in care for HIV positive LGBTQ youth. As with any young person, the overarching goals for treating LGBTQ youth are to promote healthy development, physical health, and social and emotional well-being.[8] For HIV positive youth, those goals also include increasing self-care behaviors, medical adherence and health-related interactions; reducing transmission and high-risk behaviors; and enhancing quality of life.[13]

Avoid Assumptions

One of the most important components of working with LGBTQ youth is to never make assumptions, particularly when it comes to sexual identity, gender and behavior. Assumptions can lead to missed information during patient visits or worse, a breakdown of trust.

Asking the Right Questions Can Make a Difference	
Young people may identify their sexuality differently from the way they behave.	**Ask whether the patient has had sex with men or women or both, regardless of how he/she identifies.**
Sexual behavior and identity can change over time.	**Ask about previous sexual behavior or sexual desires at every visit.**
Being in a committed relationship does not always equal monogamy.	**Ask questions about concurrent sexual partners.**
Youth may only identify sex as penile-vaginal intercourse.	**Ask about whether he/she has had vaginal, anal or oral sex in the past.**
Gender identity is distinct from sexual orientation.	**Don't assume transgender implies gay.**
Your patient is also an expert.	**If you need help with all of these terms, ask the patient to help define them!**

Adapted from Fenway Guide to LGBT Health Module 2

Create a Welcoming Environment

"One of the most important things that an adult provider needs to recognize is that first impressions are everything. If youth don't feel welcome or they are made to feel inferior or not intelligent -- especially if they are not cognitively ready to navigate the situation -- chances are they are not coming back and they will be lost to care" (Male, 29, Ohio).

"In our adolescent clinic, the walls are covered in graffiti and there are resources and flyers for youth. It's open on Saturdays. The adult clinic is not youth-friendly. The problem is that if they [youth] don't like it, they won't go" (Male, 20, Boston).

Pediatric and adolescent health settings are often decorated with culturally and age-appropriate artwork, equipped with relevant resources and brochures, and staffed by people that are enthusiastic about working with youth. An adult care environment that seems sterile and filled with people with whom youth cannot identify (e.g., older, sickly, etc.) could keep a young person from returning for care.

Creating a youth and LGBTQ friendly environment is a crucial component of services for HIV positive LGBTQ youth.

Creating a Youth-friendly Environment*	Creating a LGBTQ-friendly Environment**
Hold **flexible clinic hours** on weekends and in the evenings.	Provide comprehensive **training** for all clinic staff in the care and rights of LGBTQ youth. Make sure to include "frontline" staff; those that youth will interact with when they first walk in the door.
Cluster medical and mental health appointments together, and schedule them alongside other peer support and case management activities so youth have more of a **"1-stop shop".**	Make sure someone is there to greet young people when they walk into the clinic so they feel **welcome**.
Provide **travel** vouchers for public transportation.	Have posters and flyers with same-sex couples and transgendered youth.
If possible, create a **separate waiting area** for youth in which they can congregate, check email, etc. Provide **childcare** for youth with small children.	Provide information about safe sex, HIV prevention, and/or pregnancy prevention that is **appropriate** for LGBTQ youth (e.g., resources that only talk about heterosexual couples may not be received well).
Integrate intensive **case management** and relevant psychosocial support services.	Provide appropriate resources and referrals for **LGBTQ-friendly services** such as mental health, substance use and peer support.
Actively **involve** young people in program design and delivery.	**Involve** LGBTQ youth in the planning, delivery and evaluation of your program.
Expand **social media** use for engagement and retention (e.g., mobile phones and Facebook for appointment and medication reminders, and accessing results. Give youth beepers when they arrive for care so that they can leave the waiting room and be called back when they are ready to be seen.)	Discuss racism, sexism, homophobia and other forms of cultural oppression in your program. Get young people to generate ways to solve, limit or minimize the problems caused by cultural oppression.
Provide information and materials that are appropriate for young people.	**Refer** patients to providers that are enthusiastic about working with LGBTQ youth.

* *Adapted from Young Adult Program, St. Lukes Roosevelt Hospital, New York City.*
** *Adapted from Health Initiatives for Youth, San Francisco, California.*

Address Institutional Stigma

Few population-based studies have documented health disparities among LGBTQ people, and even fewer on LGBTQ youth. However, widespread anecdotal data, from patients as well as practitioners, provide evidence that failures in the system remain. LGBTQ patients often face difficulties in accessing quality health services due to stigma, both real and perceived, within the medical community. Lack of education and training for health professionals surrounding the specific needs of LGBTQ youth, and communication shortfalls during clinical visits,[3] can have an enormous impact on a patient's health-seeking behavior and adherence to health recommendations. This fact cannot be overlooked when it comes to LGBTQ youth who often experience high levels of distrust of the health care system.

Young people return to environments where they know people care for them[2] so be empathetic, non-judgmental and kind. Remember that most HIV positive and LGBTQ youth have experienced a tremendous amount of trauma in their lives and have faced incredible adversity. Shifting your model of care from a "deficit" approach to an "asset," or resiliency model, will help them focus on a continuum of life rather than just a continuum of care.[2]

Building a positive relationship with your patients*
Spend **extra time** with new patients, helping them understand the significance of learning and understanding their lab results, adherence and building relationships with providers.
Get to know the patient as a **person** (e.g., partners, jobs, interests). Ask open-ended questions, like "What do you like to do for fun?" Help validate that they are "normal" youth.
Assist youth with their autonomy and self-acceptance, concerning both their sexual orientation/gender identity and their HIV status.
Encourage young people to keep a **list of questions** for you, perhaps in their phones, so that they feel prepared and confident when they attend appointments.
Create **open and honest** dialogue, particularly around sensitive issues. Remind them that what they say is confidential and that they can trust you.
Ask **non-judgmental questions** about sex, sexuality and sexual identity. Ask questions in a way that does not assume sexuality. For instance, instead of "Do you have a boyfriend/girlfriend?" ask, "Are you in a relationship?"
Respect and address **confidentiality** proactively – do not assume whom the young person has told about his/her sexual identity or HIV status, including other providers.
Be prepared to make appropriate **referrals and recommendations**, particularly for case management, mental health, housing, substance use and peer support.
Let youth use **their own terminology** for their sexual identity even if it does not match their behavior. For instance, some MSM do not identify as gay. Rather than ask, "Are you gay?" ask "Have you ever been sexually involved with men, women or both?"

* *Adapted from Fenway Guide to LGBT Health Modules 2 & 4. See these modules for comprehensive training on patient interviews with LGBTQ youth.*

Recognize the Individual; Treat the Whole Person

"Often providers expect youth to be fully able to engage in care the same way an adult will; that is not the reality. Especially if they have never dealt with care settings or have always had it dealt with for them. There are small steps that any setting can take to engage youth in a way that it is going to be affirming, accepting and meeting them where they are" (Male, 29, Ohio).

There is no prescribed age for transition to adult health care, though the majority of U.S. clinicians try to transition HIV positive youth into adult care by the age of 24.[17] That being said, chronological age is very different from developmental age, and the latter, in addition to patient readiness, is crucial to determining healthy engagement in care for HIV positive youth.[14] Assessing the patient from an ecological perspective, taking note of all of the biopsychosocial determinants that influence his/her health, in addition to making appropriate referrals for wrap-around services, is essential. With recent evidence that ARVs can prevent HIV transmission among sero-discordant couples,[15] support and education surrounding adherence become ever more crucial. Where possible, involve a social worker and/or case manager who can assess and address pressing issues. If a young person is transitioning from a pediatric/adolescent care setting, communicate with the provider team about how best to coordinate these services.

Addressing important psychosocial support needs
Adherence: Recognize that adherence to their ARV regimens is especially hard for young people living with HIV, particularly if they are struggling with many other aspects of their lives. Ensure that adherence support, through peer and professional counseling, is provided for all young people taking medications.
Substance use: Some youth need harm reduction education, motivational interviewing and/or introduction to rehabilitation and recovery therapy.
Longer-term housing: Transitional living programs for homeless youth offer an active alternative to shelters and can be designed to meet the specific needs of this sub-population.
Mental health: Understand that depression, anxiety and suicide ideation are both predictors and consequences of an HIV diagnosis. Screen for these issues and refer appropriately.
Disclosure: Recognize that disclosure of HIV status to others is one of the biggest concerns for HIV positive youth. Provide information and counseling surrounding healthy and safe disclosure to others.
Partner violence: Many LGBTQ youth living with HIV face high rates of intimate partner violence, particularly after disclosing HIV status. Programs should incorporate counseling, support and education surrounding domestic violence.
Peer support: Peer support can be offered through regular support groups, one-to-one mentorship, youth conferences, and social activities where education is provided in a fun setting. The role of older peers who have successfully transitioned and are engaged in adult care, who can serve as mentors, cannot be overstated.
Structural support: Link youth to services and programs that focus on money management, credit, decision-making skills, job training and educational opportunities.

Solve Access Issues

Health care access is a major issue for HIV positive LGBTQ youth due to lack of insurance, homelessness and unemployment. In rural settings, patients must travel a substantial distance for HIV, mental health and substance use care.[2] Many young people fear disclosure by insurance companies to parents or guardians so they access care in community-based settings that do not require health insurance.[9] LGBTQ youth may not know where to go for LGBTQ and youth friendly care, and one negative experience could persuade them to disengage completely.

A recent study by the Health Resources and Services Administration (HRSA) found that newly diagnosed, HIV positive young Black MSM are more likely to go to their first doctor's appointment if the person who diagnoses them picks up the phone and schedules that appointment.[16] This simple gesture can be lifesaving.

Providing Access to Comprehensive Services
Provide **case management** services to support youth with transportation, health insurance and benefits.
Offer travel **vouchers** or bus fare.
Link youth to **peer support groups** that can help keep them engaged.
Have a **list of providers** within the region ready at each point of diagnosis to ensure successful referrals into care.

Highlight Sexual and Reproductive Health (SRH)

Comprehensive, LGBTQ and youth-friendly SRH services are essential for this population. Young people may engage in sexual risk-taking as a coping mechanism to deal with a recent diagnosis, feelings of hopelessness or preoccupation with illness. They may also engage in unsafe sex as a means of gaining peer acceptance and coping with experiences of stigma.[17] Sexual curiosity and risk-taking are inevitable components of adolescent development. Like their uninfected peers, young people living with HIV have the right to seek sexual fulfillment and they should be equipped with the knowledge and skills to protect themselves and their partners.

Providing sexual and reproductive health services
Support young people with information and education surrounding positive sexual health and prevention, self-esteem, self-efficacy and the ability to manage high-risk situations.
Provide social support services and counseling surrounding **family planning** and parenthood.
Link pregnant youth to appropriate **antenatal care** and education and counseling on how to reduce the risk of mother-to-child transmission during pregnancy, delivery and breastfeeding.
Ask youth about their **fertility intentions** and desires. Recognize that expectations for sex, intimacy, loving relationships, children and family are no less evident in HIV positive young people or in those that are LGBTQ.
Provide appropriate support for youth involved in **survival sex work** (providing sex for money or resources), particularly if they are homeless.
Provide **assertiveness training**, particularly for those youth still struggling with "coming out." This should include training on condom negotiation and communicating about safe sex options.

Strengthen Youth Voice…and Listen

The meaningful involvement of young people living with HIV in the planning and delivery of their care and support is a critical and often under-addressed component of youth engagement in adult care settings.[18] Putting youth at the center of their care will not only ensure that their individual needs are met, but that the system as a whole becomes more welcoming and sustainable for young people over time.

Involving youth
Create a **mechanism for young people** to provide feedback to providers about the quality of care they are receiving. Examples include a youth advisory board, anonymous suggestion boxes and simply asking them during visits.
Teach **decision-making skills** so youth are able to make informed decisions around high-risk behaviors as well as important decisions about their healthcare.
Create **safe spaces** for young people to meet and network with one another within the clinic setting. Knowing they are not alone will strengthen their voice and their incentive to stay engaged in care.
Provide paid or volunteer **opportunities for young people** to work in the clinic, particularly as peer educators and counselors.
Introduce youth to peer education trainings, advisory boards and other outreach opportunities that will strengthen their ability to **advocate for themselves.**

CONCLUSION

LGBTQ youth living with HIV in the U.S. remain a hidden population. Stigma and misunderstanding at the individual, community and institutional levels, coupled with a health care system that is not prepared to receive them, pave the way for a disease burden that is impossible to manage. Failing to successfully engage and retain these youth in adult care not only jeopardizes their health and wellbeing; it threatens the success of HIV prevention efforts to date, which could cost valuable lives and resources. It is timely and urgent that we shift our focus to retaining HIV positive LGBTQ youth in adult care, and begin an honest dialogue with young people and one another about how we are going to do it.

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