TRANS HIV TESTING TOOLKIT

MODULE 2: HIV TESTING AND ENHANCED COMMUNICATION APPROACHES WITH TRANS PEOPLE
Having culturally competent communication skills when working with trans populations is necessary for effective HIV testing engagement. These interactions should take into consideration the life experiences and priorities of trans people to successfully implement effective HIV testing strategies. A well-informed and supportive dialogue establishes trust and rapport, and allows providers to better serve trans people with their HIV testing and prevention needs. This type of supportive communication facilitates engagement of trans people in their health care.

Incorporating culturally competent communication skills within the service delivery process lead to increased HIV testing engagement with trans people. The communication skills of a provider allows for enhanced risk assessment (e.g. building rapport with a trans person, providing a safe and trusting space for a trans person to identify and share risk behaviors, etc.). Providers are encouraged to be comfortable in HIV testing communications with trans people about their body parts and risk behaviors. These interactions integrate current HIV testing recommendations and active risk identification. The knowledge about trans lives, sexualities, and realities benefits a trans person because open connection and trust with a provider is an integral part to their self-efficacy around HIV testing and prevention while reducing stigma.

"Being able to get tested and know my status meant I could feel good about engaging in sex with my partners."
I. COMMUNICATION STRATEGIES

A. Culturally Competent Interview Guidelines Working with Trans Clients

In conducting an HIV testing session, these guidelines may assist in establishing open and supportive dialogue with a trans person.

Establish rapport and trust by acknowledging any differences in lived experiences between the client and the HIV testing counselor. If appropriate you can also ask, “It says on the paperwork that you filled out that your name is ___. Is that what I may call you or do you go by any other names that you’d like me to call you today?” (Not appropriate for anonymous sites). Next, “I’d like to tell you a little bit about what we’ll be doing today and how we can address your concerns.” (then explain the purpose of Ask questions necessary for your assessment, but be respectful by only asking what is needed. Avoid unnecessary probing questions about client’s gender identity. Many trans clients have some underlying internalized transphobia and are prone to be asked invasive questions (e.g., How long have you been on hormones?) that can make a trans person defensive and guarded. Don’t just ask people we think are trans about their gender identity. Instead, ask all clients about their gender identity. We can’t tell someone’s gender identity just by looking at them.

Frame questions in a way that will help decrease the perception of intrusion. Discuss why you may need to ask these questions. For example:

“Because we work with a lot of trans people, we have a couple of questions we ask everyone. What is your current gender identity and what sex were you assigned at birth?”

Discussing sexual behavior is important for assessing high-risk behaviors for HIV and other Sexually Transmitted Infections (STIs). “Please feel free to ask questions and to refuse to answer questions, but know that we only ask these questions to help us gain a better understanding of what you need and how we can help you.”

Do not make assumptions based on gender presentation. If clarification is needed regarding a term or behavior, ask or restate the term with what you believed it to mean.

Include current and past history of alternate gender affirming therapies (non-prescribed hormone use, non-medical grade silicone fillers – also known as black market or underground), substance use, sex work and violence in your assessment.
Each of the above factors may be assessed with sensitivity, respect, and consultation or referrals if needed. Make sure to have appropriate and safe referrals for issues regarding violence and mental health.

Be aware of signs of human trafficking, coerced drug use, and domestic violence and make referrals as indicated.

B. Sexual Risk Assessment

A primary goal of HIV testing in CBOs is to maximize the number of persons who are aware of their HIV status and ensuring that they receive linkage to appropriate care. Procedures should be established to inform clients of their test results. Trans people known to be at high risk for HIV can be advised of the need for periodic retesting and are supported in developing their communication skills towards safer sex practices and decreased HIV risk behaviors.

Active efforts are essential to ensure that trans people living with HIV receive their positive test results and linkage to clinical care, counseling, support, and prevention services. CBOs should be aware that the Privacy Rule under the Health Insurance Portability and Accountability Act of 1996 (HIPAA) prohibits use or disclosure of a patient’s health information, including HIV status, without the patient’s permission.¹

1. Risk Assessment Questions for Trans People

- Culturally competent ways to ask questions of a trans person in HIV testing settings:
  - What is your name/ How would you like to be addressed?
  - What is your current gender identity?
  - What is your sex assigned at birth?
  - What is your preferred pronoun?
  - What types of partners do you have?
  - What are your HIV concerns?
  - How much do you know about pre-exposure prophylaxis (PrEP)?
  - Are you interested in PrEP?
  - How do you discuss/disclose your gender identity to sexual partners?
  - How are you able to negotiate safer sex practices?
  - What do you think prevents you from engaging in lower risk behaviors?
  - What’s your biggest challenge around protecting yourself from HIV?”
Questions that assess for other common trans health concerns:
- What drugs, substances, or medicine, if any, do you use?
- How do you use them? (do you inject, inhale, etc.).
- Do you use any hormones?
- If so, how do you use them? (Inject, patch, gel, etc.).
- Have you ever injected silicone?
- Where do you get your hormones and/or silicone injections from?
- Are you using clean works and needles each time?

Begin sexual risk assessments with 3 questions:

- Have you been sexually active in the past year?
- Do you have sex with men only, women only, men and women, trans men or trans women or non-binary people? (trans people may be sensitive with language describing partners)
- How many people have you had unprotected sex (receptive or insertive anal or vaginal sex without a condom, or sex without PrEP) with in the past 6 months?

The National LGBT Health Education Center, a program of the Fenway Institute has resources for sexual health histories. Included in this resource is Centers for Disease Control and Prevention (CDC) recommendations on sexual risk assessments. These are recommendations to increase your capacity to assess risk behaviors and increase trust between your organization and the trans community.²

Usually, a trans person with multiple sex partners, depending on the type of sex they are having and whether protection is used, should receive additional questions with the focus on CDC’s categorizations: Partners, Practices and protection from STIs, and Past history of STIs.

When asking questions about trans people’s partners, include questions about primary, casual or trans people as an option.
- Are you having sex with women only, men only, trans men, trans women or any combination? If yes: How many people have you had unprotected sex (receptive or insertive anal or vaginal sex without a condom, or sex without PrEP) with in the past 6 months?
- Do you know of your partner’s HIV status?
- How many sexual partners have you had in the past six months?
- Are you able to negotiate safer sex with your partners?

Couples Testing
Because HIV testing is not only available to individuals, but also couples (traditional, non-traditional) or people in sexual relationships with each other, there are added benefits to trans persons testing together with their partners when it is applicable. It may be helpful to use language such as this throughout HIV testing services:

“individuals and couples can get tested together…” or
“when individuals or couples get tested, you can be empowered.”

Be sure to include the benefits of couples testing and opportunities. Testing together is certainly available for trans people and their partners, and can help validate and strengthen relationships, and support HIV risk reduction behaviors.

2. Asking Sexual Behavior Questions S sensitively

Ask open-ended questions regarding sexual practices. Similar to HIV risk conversations, be direct and ask simple questions while assuring your clients’ confidentiality and establishing rapport. It is important to be sensitive to non-binary trans people when discussing body parts, sexual behaviors, and HIV prevention tools (e.g., condoms). It is also important to realize some trans people do identify themselves as binary, and prefer to discuss body parts, sexual behaviors, and HIV prevention tools using the language that applies to non-trans males and females. This can become complicated so it might be best ask the client how they prefer to use the language (or be guided by the terms they used in preceding communication with you).

For the sake of clarity in describing HIV and STIs practices and protection, we are using the binary language.

Here are some examples:
- What kind of sex are you having?
- Are you engaging in receptive sex?
- If so, what kind of receptive sex? (anal, vaginal, and oral)
“When taking a history of sexually transmitted infection, have a dialogue with your client about their concerns and questions. Engage trans people regarding their sex partners and partner types (monogamous, casual, anonymous) and behaviors that may put them at risk for STIs.”

- Are you engaging in penetrative sex?
- If so, what kind of penetrative sex? (anal, vaginal, and oral)
- Do you use measures to protect yourself from HIV and STIs?
- Tell me about these measures (or ask about condom use, PrEP use).
- Are there any questions or concerns you have regarding your sexual practices?

When asking about partners of your trans client, it may be helpful to ask additional questions regarding their partner’s high-risk behaviors (injecting substance use or sex for trade). Assess risk for violence between your client and their partners.

When taking a history of sexually transmitted infection, have a dialogue with your client about their concerns and questions. Engage trans people regarding their sex partners and partner types (monogamous, casual, anonymous) and behaviors that may put them at risk for STIs.

Some example questions:
- Have you ever been diagnosed with any STIs? When? How were you treated?
- Have you had any recurring symptoms or diagnoses?
- Have you ever been tested for HIV, or other STIs? Would you like to be tested now (or today)?
- Has your current partner or any former partners ever been diagnosed or treated for any STIs? Were you tested for the same STIs?
- If yes, when were you tested? What was the diagnosis? How was it treated?

For more information on CDC risk assessment guidelines visit: [http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5019a1.htm](http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5019a1.htm) or see the National Transgender HIV Testing Day (NTHTD) and Toolkit Resources section of this toolkit.
II. KEY ISSUES TO TESTING

Trans people face multiple barriers to HIV testing that might prevent them from getting tested. For instance, rather than visit a test site where a trans person’s gender identity might be questioned, a trans person might decide to forgo the potential negative experience from HIV testing. The binary system of male and female sex classification that was once predominant in our society still remains today one of the many barriers that trans people face. Binary gender identification systems institutionalized by insurance, billing, coding and electronic medical health records create structural barriers for trans people.\(^4\) In most HIV testing sites, trans people are not allowed to self-identify their gender. Similarly, data systems do not capture non-binary gender classification. This often inhibits or prohibits trans people from accessing HIV testing and treatment services and leads to an underreporting of HIV impact on the population.

Many trans people do not feel respected by their health care provider and some trans people report having to educate their provider on their health issues.\(^6\) The lack of culturally sensitive health care providers contributes to an unsafe negative experience for trans people seeking HIV testing.

Increasing the cultural competency of HIV testing providers plays a major role in increasing HIV testing and prevention services among this population. Cultural competency, in this context, refers to the overall knowledge of the community, comfort with, and sensitivity to trans health concerns and HIV testing. A culturally competent provider does not need to be an expert or specialist in gender identity issues.

A culturally competent provider knows that gender identity can be unique to each individual. They are aware of the complex lived experiences of some trans people such as medical transition, trauma, discrimination and their relationships to society. Knowledgeable providers ask clarifying and relevant questions when necessary respect the bodily integrity and privacy of their client; and accept the gender identity, sexual orientation, and preferred pronouns as expressed by their client. Trans people who develop trusting relationships with providers are more likely to be continually engaged in their health care, and HIV testing and prevention services.

A. HIV Testing Issues Related to Trans People

Trans people experience key HIV testing-related issues in compounding ways. For example, a trans woman of color who identifies as Latina, speaks limited English, and engages in sex work may experience issues that affect her ability to access testing. In this case, the intersection of language accessibility, race, class, cultural norms, and employment plays a role in her ability to seek HIV testing services. During risk assessment, these barriers must be identified and addressed in a sensitive and
culturally responsive approach by staff. Although we do not have an exhaustive list of key issues for HIV testing, these points may be considered starting points for improved communication and competencies for HIV testing providers:

- Population includes specific issues that are experienced by groups within the broader trans community.
- Social determinants include larger contextual issues that are associated with the lived experiences of trans people that impact the individual’s decision/motivation to test or not to test for HIV.
- Interventions are HIV testing and prevention strategies that support dialogue and engagement of trans people and HIV testing programs.

The list below is based on a compilation of research and study of best practices of trans people and HIV programs throughout the United States.
Table 2.1. HIV Testing Key Issues to Increase Provider Testing Competency with Trans People By Population

<table>
<thead>
<tr>
<th>POPULATION</th>
<th>Description</th>
<th>Key Issues to HIV Testing</th>
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<tbody>
<tr>
<td>Transgender Populations</td>
<td>Trans women experience multiple layers of discrimination, transphobia, and institutional barriers that increase their risk for HIV</td>
<td>- Anticipate/be prepared for a trans woman’s possible increased sensitivity to her perception of an unwelcoming/ignorant reception and plan accordingly. Strive to create a welcoming, affirming environment.</td>
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<tr>
<td>Trans Women</td>
<td>Although HIV prevalence rates are higher among trans women of color, white trans women also share a burden of HIV</td>
<td>- Overlapping structural barriers to HIV testing include stigma, discrimination, racism, poverty, education</td>
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<td></td>
<td>In addition to the social and institutional barriers, trans women of color experience other forms of oppression including racism</td>
<td>- Fewer opportunities to negotiate safer sex practices because of the sometimes power imbalance between genders, resulting in riskier behavior</td>
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<td></td>
<td>Some who transition from male to female do not identify as trans at all, but simply as women</td>
<td>- Incentives for engaging in high-risk sexual behaviors outweigh the long term risks</td>
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<td></td>
<td>- Social, cultural issues regarding trust in health care services</td>
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<td></td>
<td>- Transphobia produces stress that can reduce one’s ability or willingness to engage in testing</td>
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<td></td>
<td>- HIV prevention and testing efforts should be targeted to African American, Latina,</td>
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<tr>
<td></td>
<td></td>
<td>Asian/Pacific Islander, and Native American trans women</td>
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<td>Transgender Populations</td>
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| **Trans Men**           | Assigned ‘female’ at birth and have a male gender identity and/or masculine gender expression  
                          May self-identify and express their gender in a variety of ways and often prefer certain terms and not others  
                          Some who transition from female to male do not identify as trans at all, but simply as men  
                          In general, trans men identify with male/masculine pronouns | The trans community is diverse and not enough research has been conducted with trans people in general.  
                                                        We have limited information about trans men in particular.  
                                                        Special HIV testing and prevention efforts can be directed towards trans men who have sex with men (TMSM).  
                                                        Trans men are often not easily identifiable or choose to not reveal their sex assigned at birth, “stealth”, that may affect their comfort in accessing HIV testing.  
                                                        There is a lack of trust among trans men regarding health care services. |
| **Trans Youth**         | Transgender and gender non-binary youth face challenges at home, at school, in foster care, and in juvenile justice systems  
                          Studies show that familial rejection can:  
                          - Increase LGBT youth’s likelihood for engaging in behaviors that put their health at risk;  
                          - Trigger depression and other mental health problems; and  
                          - In the worst of cases – may result in homelessness or suicide.  
                          Trans youth experience high rates of homelessness and suicide. | In the US, the age of consent for HIV testing varies from state to state. Some states have different ages of consent, as young as 12 or older at 14  
                                                        Issues are developing trust and understanding regarding the complexities of gender identity development.  
                                                        Adolescents do not always understand the full implications of living with HIV and the responsibilities that come with it.  
                                                        Different testing strategies need to be utilized with youth than are used for adults.  
                                                        Youth who are marginally housed and have lower economic backgrounds are often at greater risk for HIV. |
## POPULATION

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<th>Transgender Populations</th>
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<tr>
<td><strong>Gender Non-Binary Individuals</strong></td>
<td>Discrimination from society and even sometimes within the trans community</td>
<td>▪ Service providers do not understand their identity as gender non-binary individuals.</td>
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<td></td>
<td>Discrimination and denial of services or respecting gender non-binary identity from service providers</td>
<td>▪ Service providers do not know how to discuss appropriate risk factors with gender non-binary individuals.</td>
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<td></td>
<td>Barriers in changing legal identification documents and having no legal acknowledgement of gender identity</td>
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<tr>
<td><strong>Trans People who Inject Drugs (PWIDs)</strong></td>
<td>Trans individuals who engage in injection drug use experience many levels of risk: high vulnerability, stigma, invisibility, and behaviors</td>
<td>▪ Differentiate between hormone or silicone (soft tissue fillers) use vs. street drug use and risk associated with those activities.</td>
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<td></td>
<td>This population is highly underserved</td>
<td>▪ Integrate harm reduction model with HIV testing communication</td>
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<tr>
<td><strong>Sex Partners</strong></td>
<td>Sex partners of trans people are also at risk for HIV</td>
<td>▪ Support HIV positive trans people to disclose HIV status</td>
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<td></td>
<td>Sex partners of trans people are often left out of HIV testing and prevention efforts</td>
<td>▪ Encourage STIs testing</td>
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<tr>
<td></td>
<td></td>
<td>▪ Offer partner notification services</td>
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<td></td>
<td></td>
<td>▪ Include the benefits of couples testing and opportunities to include partners of trans people</td>
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<tr>
<td></td>
<td></td>
<td>▪ May not identify themselves at risk for HIV because they don’t identify as men who have sex with men (MSM)</td>
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Table 2.2. HIV Testing Key Issues to Increase Provider Testing Competency with Trans People by Social Determinants

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<tr>
<th>SOCIAL DETERMINANTS</th>
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<th>Key Issues to HIV Testing</th>
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| Socioeconomic Status (SES) | Socioeconomic status (SES) underlies three major determinants of health: health care, environmental exposure (e.g., industrial waste, residential crowding, noise pollution), and health behavior | - Trans people don’t go outside their neighborhoods because they don’t feel safe. Alternatively, some trans people don’t feel safe in their own neighborhoods.  
- HIV testing site locations should be convenient to the community  
- Sites should assess safety, testing confidentiality, and other barriers to testing |
|                     | Influences access to HIV testing services due to limited income, education, and occupation opportunities |                  |
|                     | Living in an economically depressed and dangerous neighborhood               |                  |
| Linguistic Competence | The system of linguistic knowledge possessed by native speakers of a language | - Increase capacity for HIV testing for non-native speakers (e.g. mono-lingual trans Latinas)  
- HIV testing and outreach materials can be made available in various languages  
- Increase trust in HIV confidentiality  
- Utilize peers to reach out to this segment of the population  
- Use of family members as translators may breach client confidentiality |
<p>|                     | Language can be a barrier to testing                                         |                  |</p>
<table>
<thead>
<tr>
<th>Issue</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>Immigration Status</strong></td>
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<tr>
<td>Trans people immigrate to the United States to flee persecution and seek safety</td>
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<tr>
<td>Immigration status can create a level of distrust due to concerns about residency status</td>
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<tr>
<td>Acculturation may affect high levels of discrimination</td>
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<tr>
<td>CBOs may consider being responsive to local demographics and target populations</td>
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<tr>
<td><strong>Sex Work</strong></td>
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<tr>
<td>One of the few viable work roles for some trans people</td>
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<tr>
<td>A segment of the trans female community engages in sex work for a variety of motivational factors</td>
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<tr>
<td>Multiple sex partners, fewer opportunities to negotiate harm reduction practices, and underlying substance use issues may contribute to greater HIV exposure</td>
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<tr>
<td>Reduce stigma</td>
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<tr>
<td>Be sensitive to shaming</td>
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<tr>
<td>Offer PrEP or PEP as an HIV prevention tool</td>
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<tr>
<td>Session can be focused on HIV risk reduction and immediate needs of client</td>
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<tr>
<td>Sex work can have different contextual meaning (survival, career, street)</td>
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<tr>
<td>Assess for signs of violence and coercion</td>
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Table 2.3. HIV Testing Key Issues to Increase Provider Testing Competency with Trans People by Interventions

<table>
<thead>
<tr>
<th>INTERVENTIONS</th>
<th>Description</th>
<th>Key Issues to HIV Testing</th>
</tr>
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</table>
| Sexual Networks        | A group of people that are connected to one another through intrapersonal sexual activity | ▪ Consider including sexual networks in HIV testing recruiting strategies  
                         |                                                                             | ▪ Disclosure can be challenging among some networks due to internalized transphobia or stigma  
                         |                                                                             | ▪ Disclosure around gender identity with sexual partners  
                         |                                                                             | ▪ Invisibility of some partners                                                                 |
| Couples Testing        | Both partners tested at the same time HIV testing approach that involves both partners’ testing and receiving their results together, encouraging open communication and trust  
                         |                                                                             | ▪ Lack of HIV testing provider awareness around HIV testing needs of trans couples, including serodiscordant relationships  
                         |                                                                             | ▪ Need to increase communication skills  
                         |                                                                             | ▪ Disclosure among partners or sex networks can be challenging due to internalized transphobia, stigma, or shaming.  
                         |                                                                             | ▪ Invisibility of some partners (e.g., cis men whose primary partners are trans women) |

Couples can be understood as “traditional” (primary sex partners) or “non-traditional” (casual sex partners).
## INTERVENTIONS

<table>
<thead>
<tr>
<th>Approach</th>
<th>Description</th>
<th>Key Issues to HIV Testing</th>
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</table>
| Disclosure of HIV-positive Status        | HIV status sharing by HIV positive trans person  
Sharing HIV status is a personal choice, however various states have differing laws regarding sharing of HIV status with partners  
Laws that criminalize HIV discourage testing and knowing one’s status because knowing one’s status can hold the person criminally liable if they transmit the virus to someone else | ▪ HIV status can be stigmatizing particularly for trans people  
▪ Criminalization laws discourage trans people from knowing their status  
▪ Increase communication skills among HIV positive trans women regarding status sharing  
▪ Reduce internalized transphobia and stigma related to HIV status |
| Partner Counseling and Referral Service (PCRS) | The PCRS can help an individual with notifying their partners regarding HIV and STIs diagnosis  
PCRS programs are often led by local health departments. This can occur in four ways:  
1) self referral; 2) provider referral; 3) contact referral; and 4) dual referral | ▪ PCRS programs are often not tailored to the specific needs of trans people. Trans relationships and sexual partners are complex (e.g., primary, exchange, casual)  
▪ Fear and shame associated with health department involvement  
▪ Trans people have higher potential for loss to follow up |
| Linkages                                 | An integral part of the Continuum of Care linking patients who have received a diagnosis of HIV to engagement in care  
Due to structural issues, research has reported trans HIV positive people are often lost to care | ▪ HIV testing without linkage does not provide optimal benefit  
Programs and services are often not culturally competent to trans community needs  
▪ Follow-up and adherence to care can be challenging due to conflicting priorities |
<table>
<thead>
<tr>
<th>Approach</th>
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<th>Key Issues to HIV Testing</th>
</tr>
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</table>
| HIV Testing Incentives   | Aims to increase HIV testing by offering incentives (e.g. voucher, cash, gift card) as a motivational factor  
Has shown to increase HIV testing | ▪ Efficacy in use of HIV testing incentives  
▪ Potential incentive misuse  
▪ Costly                        |
III. HIV TESTING RECOMMENDATIONS FOR TRANS PEOPLE

CDC recommends health care providers test everyone between the ages of 13 and 64 at least once as part of routine health care. A general rule for those with risk factors is to get tested at least annually. Additionally, CDC has recently reported that sexually active gay and bisexual men may benefit from getting an HIV test more often, perhaps every 3-6 months. Although this recommendation does not specifically include trans people, research on HIV prevalence among this population puts trans women at high risk for HIV.

Behaviors that put people at risk for HIV include having vaginal or anal sex (without a condom or without being on medicines that prevent or treat HIV, or sharing injection drug equipment with someone who has HIV). Recognizing the distinction that trans people refer to their body parts and identify their risk behaviors differently is beneficial to HIV test providers. This allows HIV test providers to address the unique HIV testing needs of trans people.

If a trans client answers yes to any of the following questions, they are encouraged to get an HIV test more often, every 3 – 6 months:

- Have you had sex with someone who is HIV-positive or whose status you didn’t know since your last HIV test?
- Have you injected drugs (or steroids, hormones, or silicone) or shared equipment (such as needles and syringes) with others?
- Have you exchanged sex for drugs, housing, or money, etc.?
- Have you been diagnosed with or sought treatment for STIs (e.g. syphilis)?
- Have you been diagnosed with or sought treatment for hepatitis or tuberculosis (TB)?
- Have you had sex with someone who could answer yes to any of the above questions or someone whose history you don’t know?

“Recognizing the distinction that trans people refer to their body parts and identify their risk behaviors differently is beneficial to HIV test providers. This allows HIV test providers to address the unique HIV testing needs of trans people.”