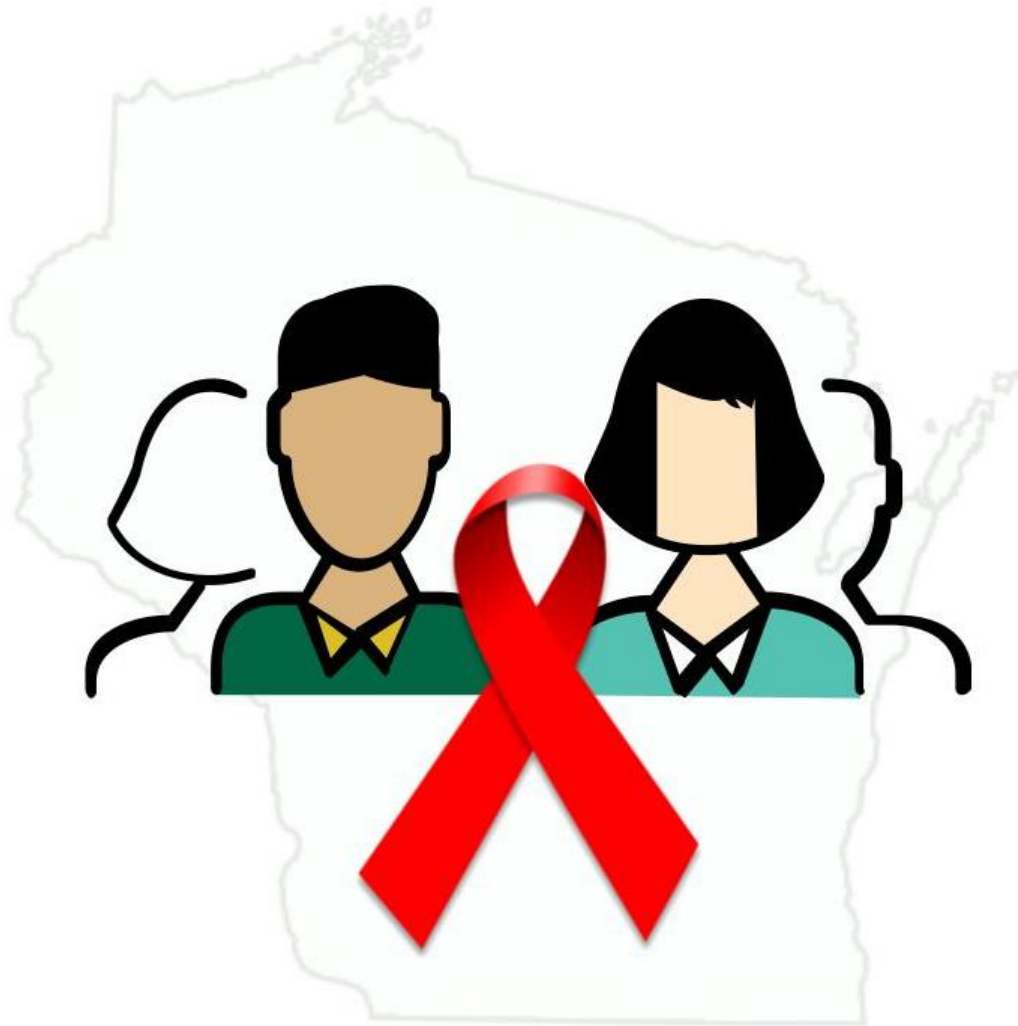


Wisconsin HIV Needs Assessment

Qualitative Report

Findings from Client and Key Informant Interviews



Wisconsin
Department of Health Services

Division of Public Health
P-01221 (03/2016)

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EXECUTIVE SUMMARY

As a condition of federal funding, the Wisconsin Department of Health Services (DHS) AIDS/HIV Program is required to submit to the federal Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA) an Integrated HIV Prevention and Care Plan, including a Statewide Coordinated Statement of Need (SCSN), for the period 2017–2021. The SCSN portion of the Integrated Plan and related needs assessment activities should:

- Identify and describe HIV prevention and care services that currently exist and those that are needed.
- Enhance the quality of services for people at higher risk for HIV and people living with HIV (PLWH).
- Identify barriers that impede access to existing services.

As part of the needs assessment, the Wisconsin AIDS/HIV Program collected information examining the needs of people living with HIV (PLWH) and the gaps and barriers they face when accessing HIV prevention and care services. Information was collected through qualitative interviews with clients and key informants. Clients were individuals who have ever received HIV prevention and/or care services at an HIV-related agency in Wisconsin. Most clients interviewed were living with HIV; other clients were people at risk for HIV. Key informants were primarily service providers who have insight into the lives of people who are at high risk for HIV or PLWH.

The AIDS/HIV Program worked with key informants and their agencies to recruit clients for interviews. The Program asked staff to identify clients who would be interested in speaking about their HIV-related experiences in exchange for a \$20 gift card. Twenty-eight clients were interviewed from April through October 2015. Interviews were conducted in-person or through phone conversations, depending on accessibility and the clients' primary residential location.

The majority of clients were recruited from the Milwaukee area (54%). Several clients were members of an HIV agency's consumer advisory board or worked or volunteered at an HIV agency. The majority of clients interviewed were male (64%).

The majority of interview questions asked of clients were similar to those of key informants. Clients and key informants differed in their comfort levels during the interview, consensus about the barriers and needs of PLWH, comments about agencies and their services, and perception of health successes.

In many cases, clients were less direct in responding to interview questions. Topics and themes emerging from the client interviews include the following:

- *Stigma and shame:* Clients revealed feelings of stigma and shame regarding how people became infected and about HIV infection itself, especially when initially diagnosed with HIV.
- *Confidentiality concerns:* Even though clients may have knowledge of HIV confidentiality laws, they expressed concerns that information is not kept private. This is a particular concern when clients know someone who is working at the HIV agency, clinic, or health department.
- *Misinformation and lack of HIV education:* Clients noted that many people in the community are unaware that HIV remains a health issue and unaware of the facts about HIV transmission.
- *HIV education among providers:* Clients reported a need for health care provider education focused on increased knowledge and skills in managing HIV infection and ways to effectively communicate with clients.
- *Mental health and alcohol and other drug use (AODA) issues:* Clients have mental health and AODA issues with varying levels of severity.
- *Insurance and health care costs:* Insurance and health care costs are a source of stress. Some clients were unaware of programs that assist with health insurance costs. Even if they have health insurance, clients said many details, like copays and deductibles, are difficult to understand.
- *Feelings about HIV medication:* People need time to adjust to new medication regimens. Many clients needed to change medication due to side effects. Clients felt that providers underestimated side effects. Clients also commented that medication is a constant reminder of one's HIV status.
- *Support:* Support networks help clients as they adjust their living situations to stay healthy with HIV.
- *Competing priorities and concerns:* Other personal priorities and concerns of clients compete with HIV medical care, including caring for others and how medical appointments affect employment and career development.
- *Feelings toward agencies:* For the most part, clients are generally pleased with their agencies; however, some improvements can be made, especially enhancing provider interpersonal communication skills.
- *Mistrust of the medical system:* Some clients expressed general distrust of the medical system and felt that either there was a cure that wasn't being revealed or that the medical system isn't interested in developing a cure because of profits to be made from HIV.

From February through July 2015, 46 key informants were identified and interviewed by AIDS/HIV Program staff. Interviews were conducted in-person or by phone; some were one-on-one interviews while others were group interviews. One or two DHS staff members interviewed key informants at a mutually agreed time and location. The majority of the key informants worked in Milwaukee (68%) and have worked or were currently working professionally in a field related to HIV prevention and care (98%).

Key informants reported the following barriers:

- *Barriers to testing:* Stigma, misinformation about HIV and personal risk, confidentiality concerns, and missed opportunities for testing with primary care providers and other settings and providers such as emergency rooms, urgent care centers, and dentists.
- *Barriers to getting linked and staying in HIV medical care:* Anticipated loss of the linkage to care (LTC) program, lack of resources and support at agencies not funded by the state, navigation of the health care system, transportation, competing priorities, and relationship with providers.
- *Barriers to becoming and staying virally suppressed:* Adherence difficulties and personal feelings about HIV medication.

Key informants acknowledged that people cycle in and out of HIV medical care due to a variety of factors. The main reasons clients return to care are feeling sick, having support or follow-up, having new motivating factors, or having a change in a life situation. Key informants also reported PLWH have concerns with appointment times, privacy and confidentiality, health insurance coverage, cultural competency among providers, and transportation.

Key informants most frequently identified the following services as being used and needed by PLWH:

- Housing
- Transportation
- Mental health and AODA services
- Medical case management
- Services related to health insurance
- AIDS Drugs Assistance Program (ADAP)
- Dental care
- Food pantry
- HIV testing
- Condom distribution

Services that are needed but limited in access and availability are housing, transportation, distribution of pre-exposure prophylaxis (PrEP), support systems and groups, prevention services, and hepatitis C treatment.

Although HIV is a disease that can affect anybody, key informants discussed how certain groups are more negatively affected and some of their specific needs and concerns.

Because many key informants have worked in the HIV field for several years, they were asked what is working well in Wisconsin's system of HIV prevention and care services and what should be prioritized for improvement. They were also asked to think about the state AIDS/HIV Program's role and what it can do to better support PLWH. Their responses varied depending on their agency affiliation and professional roles, but several key themes emerged, including the following:

- The AIDS/HIV Program, in general, has been supportive of agencies and provides guidance and relevant trainings. The surveillance data is consistently up-to-date and very helpful. However, the program should provide more opportunities for agencies to meet and coordinate their activities. The Program should also consider adopting more innovative prevention strategies, such as pre-exposure prophylaxis (PrEP), and offer relevant trainings to train people within and beyond the HIV field.
- Agencies tend to work in "silos," which are not effective in addressing the HIV epidemic. A better coordinated strategy between agencies, especially in Milwaukee, will help reduce duplicate efforts and reach more individuals.
- There needs to be more emphasis on prevention, especially awareness and education campaigns. These campaigns should be geared toward people in the community as well as non-HIV medical providers, clinics, and agencies.
- The Linkage to Care Program has been successful at helping PLWH connect with and stay in HIV medical care.

In conclusion, clients and key informants agree that there are major obstacles preventing PLWH from getting diagnosed, becoming linked to care, staying in medical care, and staying virally suppressed. Although clients and key informants reported positive aspects to Wisconsin's HIV prevention and care services, there are still unmet needs and ongoing barriers to resources and services that affect PLWH.

INTRODUCTION

As a recipient of Health Resources and Services Administration (HRSA) and Centers for Disease Control and Prevention (CDC) funds for Ryan White HIV/AIDS Program Part A and Part B, the Wisconsin Department of Health Services (DHS) AIDS/HIV Program is required to submit an Integrated HIV Prevention and Care Plan. This plan is used to guide Wisconsin's HIV prevention and care planning throughout the years and is updated as necessary to reflect any changes locally or in health care delivery systems. The plan should align with the goals of the National HIV/AIDS Strategy (NHAS) and serve as a tool to develop a coordinated approach that addresses the HIV epidemic in Wisconsin.

The Integrated Plan should include the Statewide Coordinated Statement of Need (SCSN) for 2017–2021. Federal guidance¹ regarding the SCSN portion of the Integrated Plan notes that the needs assessment activities should:

1. Identify and describe HIV prevention and care services that currently exist and those that are needed.
2. Enhance the quality of services for persons at higher risk for HIV and people living with HIV (PLWH).
3. Identify barriers that impede access to existing services.

The SCSN should be informed by the HIV Care Continuum and include input from representatives in a variety of areas, including but not limited to HIV prevention, surveillance, substance abuse, mental health, and others.

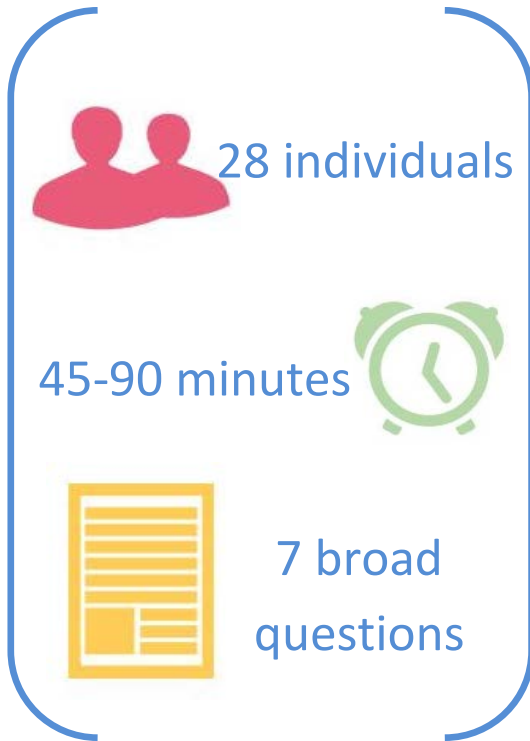
This report highlights the Wisconsin AIDS/HIV Program's effort to collect qualitative information relevant to the needs assessment process from two groups:

1. Clients – Mostly PLWH and recipients of HIV prevention and care services in Wisconsin.
2. Key informants – People who work in the field of HIV and/or have expertise about the needs of PLWH and the challenges faced by PLWH in accessing services.

This report provides a summary of the survey responses provided by clients and key informants and does not represent all the information the AIDS/HIV Program will use for assessing needs of PLWH and the gaps and barriers PLWH may face. The Program plans to use additional information collected through other initiatives, sources, and evaluation projects for this Integrated Plan.

¹ Centers for Disease Control and Prevention and the Health Resources and Services Administration. Integrated HIV prevention and care plan guidance, including the Statewide Coordinated Statement of Need, CY 2017-2021. June 2015. Available at <http://hab.hrsa.gov/manageyourgrant/hivpreventionplan062015.pdf>.

METHODOLOGY: CLIENTS



The AIDS/HIV Program worked with partner agencies to recruit clients to be interviewed for the needs assessment. The Program decided that agencies are better connected to clients and could identify clients able to speak openly and comfortably about their experiences with HIV prevention and care services in Wisconsin. Agencies were asked to approach potential clients to be interviewed and explain the needs assessment project. If clients were interested, their contact information was provided to the AIDS/HIV Program or the clients were provided the interviewer's contact information. The interviewer was an affiliated staff member of the AIDS/HIV Program without ties to any of the referring agencies.

The seven interview questions were broken down into the following categories:

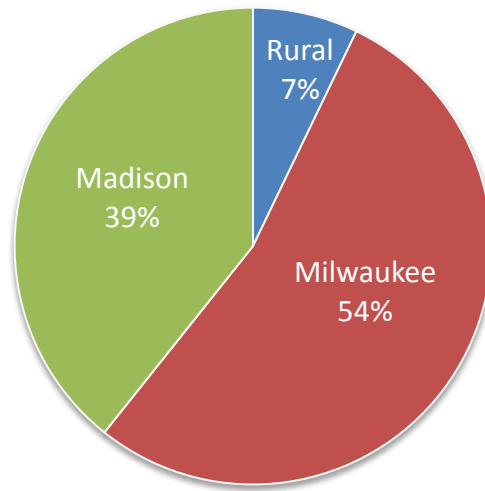
- Specific challenges and barriers accessing HIV-related services.
- General services used and/or needed.
- Feedback for broad improvements.

A majority of the interviewed clients were HIV-positive. Clients who live in Madison or Milwaukee were interviewed in person. Clients from the rural parts of Wisconsin were offered an in-person or phone interview and all chose phone interviews. Clients were offered a \$20 gift card for participating in the interview. Most of the interviews took place one-on-one. There were two group interviews, which took place with members of the following agency consumer advisory boards:

- Monroe, Inc., Milwaukee (six individuals)
- HIV/AIDS Comprehensive Care Program, University of Wisconsin Hospital and Clinics, Madison (six consumer advisory board members)

The majority of clients interviewed resided in the Milwaukee metropolitan area, which is the epicenter of the HIV epidemic in Wisconsin.

Figure 1 shows a distribution of the interviewed clients based on their primary location of residence at the time of the interview.

Figure 1. Client Primary Location of Residence

About two-thirds of clients interviewed were male, which is consistent with the disproportionate impact of HIV among males. Figure 2 shows the distribution of clients by gender:

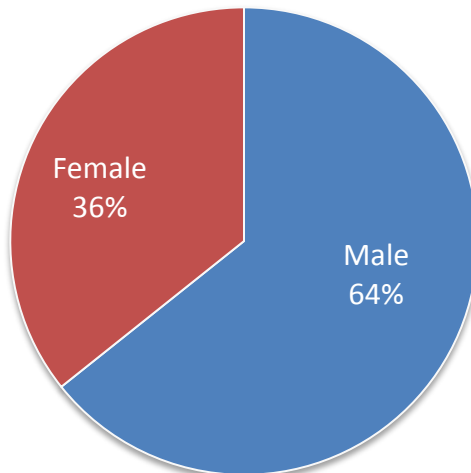
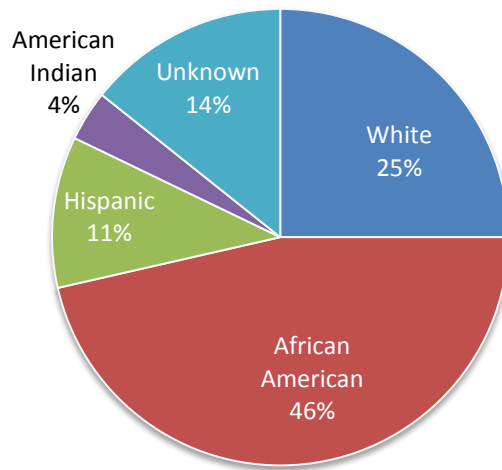
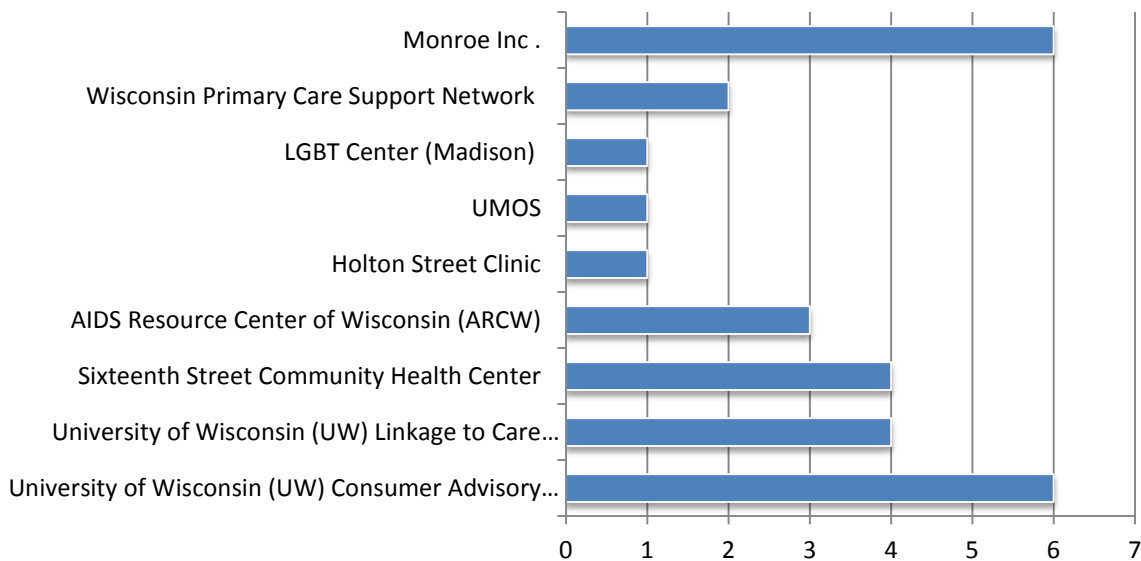
Figure 2. Client Gender Identification

Figure 3 shows the distribution of the interviewed clients' race/ethnicity groups. Information on race was missing from four individuals.

Figure 3. Client Race/Ethnicity

Clients were referred to the AIDS/HIV Program for interviews by state-funded HIV prevention and care agencies. Figure 4 depicts the distribution of clients by referring agency.

Figure 4. Client Referring Agency

METHODOLOGY: KEY INFORMANTS

Key informants were people working in grant-funded agencies that provide HIV prevention and/or care services: primarily community-based organizations, AIDS service organizations, health centers, and health departments.

The key informant interview tool was developed by AIDS/HIV Program staff. The tool consisted entirely of open-ended questions, in order to facilitate communication and enable unrestricted responses from key informants. The 19 interview questions were broken down into five categories:

- Specific challenges and barriers to accessing HIV-related services
- Providers' role
- General services used and/or needed
- Feedback for broad improvements
- Ways to solicit patient/client input for needs assessment

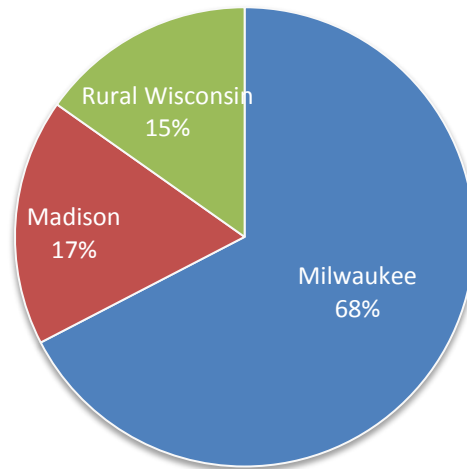


One or two DHS staff members interviewed 46 key informants between February and October 2015. Depending on the key informant's agency, some informants were interviewed in groups of two or more. A total of 35 interviews were conducted (6 group interviews and 29 individual interviews). Each interview ranged from 45 to 90 minutes.

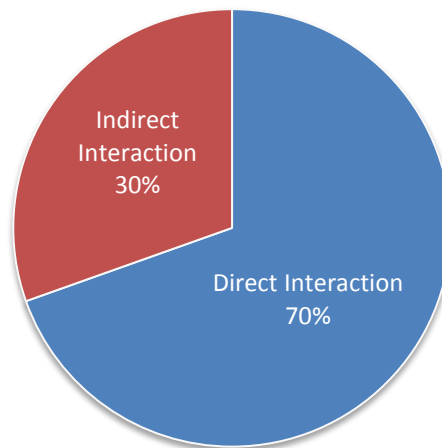
Most interviews were conducted in person at the key informant's agency (n=30). The interview tool and a diagram of the HIV care continuum were emailed in advance so that key informants, if they chose to, could prepare their answers.

A majority of key informants worked in the Milwaukee metropolitan area (68%). The over-representation of key informants from the Milwaukee metropolitan area was part of the needs assessment design because:

- Surveillance data in Wisconsin indicate that Milwaukee has the highest prevalence of HIV.
- Efforts were made to ensure that every Wisconsin grant-funded agency was represented in the needs assessment, and almost all of these agencies are located in Milwaukee.
- Five group interviews were conducted in Milwaukee, which meant more key informants were efficiently contacted and interviewed.

Figure 5. Primary Work Location of Key Informants

Key informants were asked whether they interact with clients on a regular basis. It was important that a majority of key informants have contact with clients so they could speak accurately about the needs of PLWH.

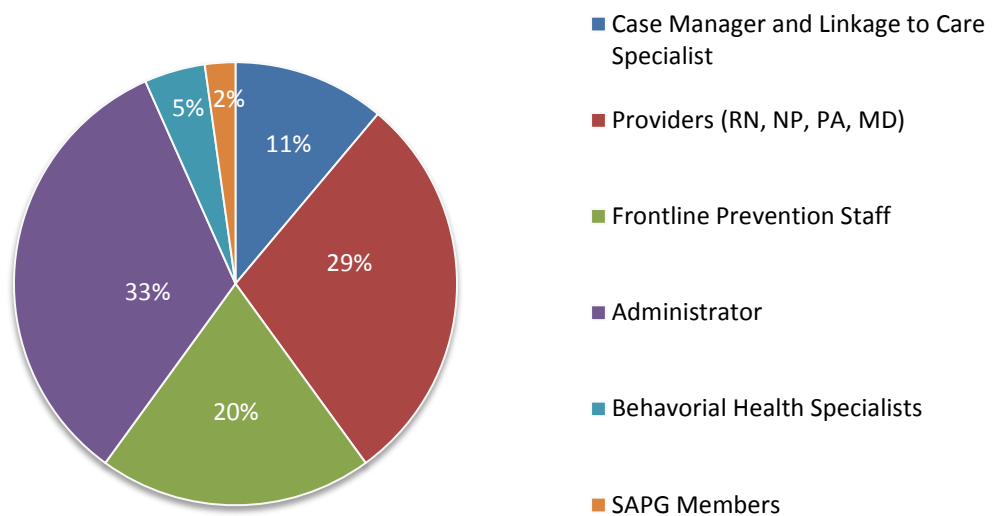
Figure 6. Key Informant Interactions with Clients

Key informants worked in a variety of roles, including:

- Case managers or linkage-to-care specialists who helped link clients to services.
- Health care providers who possessed credentials that allow for the treatment of STDs including HIV (all but one provider provided treatment for HIV).

- Frontline prevention staff members who provided HIV counseling and testing as well as Partner Services workers/disease intervention specialists.
- Administrators who managed and provided support to other staff members at their agencies.
- Behavioral health specialists who provided services such as psychotherapy.
- A Statewide Action Planning Group (SAPG) member who does not work professionally in the HIV field and does not fit into the other categories.

Figure 7. Key Informant Roles



KEY INFORMANTS VERSUS CLIENTS

The interview questions asked of key informants and clients were similar, to allow for comparison between groups. However, the questions were also tailored to account for differences in health literacy; for example, clients were not asked about systemwide activities or provider-specific questions.

At the beginning of each interview, key informants and clients were informed of the following:

- The purpose of the interview.
- How the interview related to the needs assessment and the Wisconsin AIDS/HIV Strategy, the state HIV plan.
- The interviewer's affiliation with the state AIDS/HIV Program and ties, if any, to the referring agency.
- The anonymity of all responses.
- The interviewee's ability to decline to answer any questions.

Because one staff member from the AIDS/HIV Program interviewed both key informants and clients, she was able to identify major differences between the two groups in their interview responses and personal demeanors.

| KEY INFORMANTS | CLIENTS |
|--|---|
| Comfort levels with interview process were generally high. | Comfort levels varied. |
| Generally, straightforward consensus about barriers and needs of people living with HIV. | Consensus about barriers and needs is less defined and straightforward. |
| Identified macro-level, "big picture" barriers. | May conceptualize macro-level barriers as a "regular way of life." |
| Offered both complimentary and critical comments regarding agencies' performances. | Provided mostly complimentary comments about agencies. |
| Use definable health outcomes as markers of health successes. | May perceive successes and health differently from objective markers. |

Comfort Level (as perceived by the interviewer)

In general, key informants appeared to be more comfortable and open during the interviews. Many individuals were prepared with written or initial responses to the questions. For questions for which they did not have an answer, they openly admitted to not having the right experience and/or knowledge to respond. Because many key informants have been working in the HIV field for many years, they were able to elaborate on the topics raised and provide specific examples.

Clients' comfort levels were varied and highly dependent on the individual. Clients who seemed most comfortable were clients who are part of consumer advisory boards, or work or volunteer at their referring agencies. Because these clients self-select to be part of their HIV agency, it is not unusual that they come to the interview with more confidence and comfort to speak about their HIV experience.

Despite the interviewer's best efforts to make the interview as comfortable as possible, clients may have found it difficult to talk about their HIV experience. Reasons may have included:

- Lack of familiarity with the interviewer.
- Hesitancy to be completely truthful because of concern that their responses will affect the services they receive.
- The interview format required the interviewer to record responses in writing, which may have impeded the conversation.

Interpretations of the Barriers and Needs of PLWH

Key informants have gained experience and insight in working regularly with PLWH and can usually summarize succinctly what they have learned regarding the barriers and needs of PLWH. In three or four key informant interviews, the interviewer was able to identify recurrent themes that addressed the major service barriers and the pressing needs of PLWH.

Clients who are part of consumer advisory boards or work/volunteer at an HIV organization were similar to the key informants in their responses. They drew from their personal experiences as well as those of their friends and family members.

Other clients answered questions in somewhat indirect ways. For instance, they may not have explicitly defined mental health issues as a barrier to care as key informants did; however, they may have shared their personal experience coping with depression. These indirect responses may also relate to how they define a barrier or a need, which is addressed in the next subsection of this report.

Clients shared their personal challenges and experiences living with HIV, which may be unique to the individual and not those of most PLWH. For example, one client talked about her living situation and struggles to get a couch for her apartment. While this struggle is important to this client, a struggle for a couch may not be applicable to other people. Because of each person's unique situation, it is more difficult for clients to reach consensus on the common barriers and needs for PLWH. Regardless, some overarching themes and ideas emerged from the responses and stories of PLWH.

Identification of Macro-Level Barriers

Key informants are service providers and people who are familiar with public health concepts. Key informants could identify macro-level barriers. They could express how an individual's living situation or AODA issues could hinder HIV care and how factors beyond an individual's control, such as transportation systems, adoption of a new health care system, and societal levels of discrimination, can affect PLWH.

In contrast, some clients did not define a barrier or a need the way key informants did. Clients who experienced certain barriers and circumstances every day may have considered them to be ordinary and not think of them as obstacles to HIV care. One client who had been homeless for seven years did not reveal during the interview that he was homeless or how lack of food or stable housing may have affected his HIV care. Another client was three hours late for the scheduled interview because she could not find transportation. When asked if transportation was an issue for her and whether transportation affected her HIV care, she reported "no."

Clients appeared to place a larger emphasis on personal responsibility, which decreases their likelihood of naming something as a barrier or need. Here are some examples:

- If a person cannot get to an HIV medical appointment, it is not because of the city's lack of an effective transportation system; it's because of the individual's unwillingness to prioritize HIV care.
- If a woman became HIV infected, it is not because she did not have the proper access to sexual health education; it is because she chose to have sex with an infected partner.
- A person infected with HIV at birth is different from someone who sexually contracted it by "being stupid."

One client said simply that there is a thin line and that the government should not have to "provide everything for us... when do we pull ourselves up by the bootstraps and take care of ourselves?"

Comments about Agencies

Key informants provided both complimentary and critical comments about their own agencies as well as others. This may be for the following reasons:

- Most key informants worked at a HIV-related agency and collaborated with or have knowledge of other agencies.
- Clients often share with key informants their experiences in dealing with other agencies.
- Most key informants had extensive experience and training in systematic thinking, which allowed them to constructively critique agencies' services and delivery systems.

In contrast, clients provided mostly complimentary comments about agencies. This may be for a couple of reasons:

- Clients may fear that their responses will be reported to their service providers.
- For HIV-positive clients who were dissatisfied with their service provider, the likelihood of them staying with that referring agency would be low.

Views on HIV Successes

All of the key informants reported knowledge of the HIV care continuum and answered questions based on this continuum. Key informants have clearly defined health markers for successful outcomes. These markers include consistent attendance at care and service appointments and laboratory evidence of viral suppression.

Because of these definitive markers, key informants may disagree with clients about clients' success in managing their health. A few clients reported doing "really well" and consistently attending appointments. However, referring agencies indicated that some of these clients struggle to attend appointments and to maintain low HIV viral loads.

FINDINGS REPORTED BY CLIENTS

The Statewide Coordinated Statement of Need requires that a needs assessment be conducted to ensure that the needs of people living with HIV are assessed and evaluated against existing resources. In addition, the needs assessment should be shaped in the context of the HIV care continuum.

During the needs assessment, clients and key informants were asked about any barriers that HIV-positive individuals face when trying to access services related to:

1. Getting tested.
2. Obtaining medical care.
3. Staying in care.
4. Becoming virally suppressed.

As noted previously, clients addressed barriers along the HIV care continuum in less direct and defined ways than did key informants. Clients were less likely to say “X, Y, and Z are barriers to testing and A, B, and C are barriers to linkage to care.” Instead, they expressed their thoughts through anecdotes and examples. Through these responses, the following common themes emerged.

Stigma and Shame

Some clients cited stigma and shame as a challenge for PLWH while others implied it. Clients reported feeling very aware of the stigma associated with HIV and how stigma affected them, especially when first diagnosed with HIV.

“We lose so much more than just our health. We lose our self-worth; we think we’re less than others; and we’re fearful that people will find out. It’s an all-encompassing disease.”

Many reported initially feeling concerned about people finding out their status, needing to “hide away” and isolate themselves, and feeling shunned by family and friends. Clients noted how stigma facilitates HIV transmission when PLWH are afraid to disclose their status to partners, feeling like they need to hide it or lie about it. One client talked about his experience on Grindr, a popular social media dating app. He discussed how many people put their HIV-negative status online “all the time.” He wondered how many of the negative statuses posted are accurate and if people would be interested in someone with an HIV-positive status.

There is stigma around how one became infected with HIV. A client who was born with HIV said there’s a difference between “catching [HIV] and acting stupid” and being born with HIV.

Another client, during the interview, reiterated multiple times that it was unfair he became infected with HIV, especially because he wasn't being promiscuous.

Other clients reported feelings of shame because they had become HIV infected through their personal actions and decisions. Some reported that it wasn't anybody's fault but their own because they "should have known better" and should have taken better precautions. One client reframed her HIV situation, believing that HIV is a punishment for having premarital sex. She even considered HIV a "good thing" because having a child might have caused her more trouble.

Clients emphasized the need of addressing stigma in order to empower people to get tested and to empower PLWH to stay in medical care. Examples of how stigma creates barriers to testing and keeping PLWH from participating in HIV care:

- Some clients may not attend their appointments or will only attend if they are not seen entering through the front door. This is especially true if the agency has an obvious AIDS/HIV affiliation.
- Some clients are worried about being seen at the pharmacy picking up their HIV medication. One client would pick up her medications at 3:00 a.m. to avoid being seen.

Because of HIV's disproportionate effect on Blacks, "[There is only one] channel that has HIV commercials. However, these commercials set people back. They shame people with HIV and make it seem like a scary thing."

Clients noted the news media tend to ignore HIV or portray HIV in a negative light. There is a lack of HIV-positive allies and role models. One client questioned if they were doing a disservice by hiding and not drawing attention to HIV, by not putting a name and face to the disease.

There is stigma associated with being gay. A client noted that HIV was a big issue among "down-low" Black men who have sex with men and identify as straight—men who think "I'm not gay, this is just sex." Another client, who identifies as being religious, expressed the need to educate young children because they're "too young to be thinking about being gay."

"Why can't [gay] people just be normal? They have to realize that they are not accepted, just tolerated."

Perceived Confidentiality

Clients discussed the importance of confidentiality when accessing HIV services. They stated that people typically do not want to get tested when they can be seen by others, regardless of test results. This includes getting tested around their friends in a bar outreach setting or at an agency like the AIDS Resource Center of Wisconsin (ARCW). Clients also do not like going to pharmacies like Walgreens or CVS; they might run into other people who question their medications or listen to their conversations with the pharmacists.

“Some places you think are confidential, but then you see people you know walk through the door or you see people in the waiting room.”

In a rural area or small town, accessing services is an even bigger problem because there is no place for clients to be anonymous. The person handing clients' HIV testing consent forms may be that person's neighbor or family member. Regardless of location, clients are concerned that their information does not stay confidential even though they know there are state and federal confidentiality laws in effect.

A client who is a member of the gay Black community in Milwaukee stated that agencies are using “too many people like me” to promote testing. This client personally knows the outreach workers and feels they may not keep information private. The temptation to gossip or share information is too great.

Misinformation

Clients reported the need for increased HIV awareness and education to address the misconceptions people have. Clients would like to see more education in schools, media campaigns about prevention and care services, and opportunities for PLWH to share their stories and normalize HIV.

In general, clients felt that people are not aware that HIV is a disease that can affect everyone and that it isn't just a “gay man's disease.” Some clients said that they did not realize HIV was an issue until they received their diagnosis.

“I was once asked by another individual who was also HIV positive: ‘Should I touch you then?’...this broke my heart.”

People unfamiliar with HIV may feel uncomfortable around PLWH because they fear they'll become infected with HIV. This discomfort is fueled by misconceptions about how HIV is transmitted.

Lack of HIV Education among Providers

Clients reported a need to educate health care providers. Clients shared their experiences with providers who, based on their actions, misinformed medical practices, and statements, did not appear to be educated on HIV. Their lack of education and experience working with HIV-positive clients negatively affected these clients' medical care experience. The following examples were cited in the interviews:

- A client switched providers because his provider was unwilling to consider other HIV medications despite the bad side effects he was experiencing.
- A nurse put on two gloves in front of a client during a medical visit.
- A client interacted with several providers who, even though they knew he was gay, never offered him an HIV test.
- A client interacted with providers at a major hospital who said they do not think about HIV.
- A client with HIV-related symptoms had to ask his provider to be tested for HIV after two wrong diagnoses.
- A client's doctor searched the Internet to answer the client's health questions.

One client, who previously resided in a rural town, suggested that rural doctors were less likely to keep up with the latest HIV information and treatments because they do not work with many PLWH.

Mental Health and Alcohol and Other Drug Abuse (AODA) Issues

Mental health and AODA issues were mentioned by some clients less directly than other topics. Some clients did not explicitly acknowledge having these issues but shared stories about mental illness or drug use. Other clients openly acknowledged taking psychiatric medications, having depression or anxiety disorders, seeing a psychologist or psychiatrist, and/or having a history of drug use.

Clients reported that these issues were most prominent when they were first diagnosed with HIV. They noted the following:

- Feelings of depression for extended periods of time.
- Attempted acts or thoughts of suicide.
- Self-medication with alcohol and/or drugs to cope with the news.
- Denial of HIV.

"I was a wreck. I wouldn't eat...couldn't sleep. I drank alcohol. I kept thinking 'Why me?' and 'What did I do to deserve this?'"

Other clients discussed how, in general, drug use affects people negatively. Drug use might be people's "main focus" and when people are "high for days...they can't or won't make it to their appointments." One client shared how she became HIV infected during a drug relapse and using protection was "the farthest thing from my mind."

People's addiction and drug use may also prevent them from obtaining or staying in stable housing. Many housing services and programs have strict rules about people being drug-free; for individuals who relapse or have difficulties accessing AODA services, getting access to housing services is difficult.

Clients also shared personal experiences that contribute to mental health problems. They included:

- Sexual assault.
- Guilt over losing family members to HIV.
- Anger and resentment about acquiring HIV.

Insurance and Health Care Costs

The topic of insurance and other health care costs was raised by several clients as a source of stress and impediment to optimal care. Clients presented the following scenarios:

- A client dropped out of care for over a year because she lost her job and her health insurance. She did not know the AIDS Drugs Assistance Program (ADAP) was an option or that she could call her agency to seek assistance. She assumed she was automatically ineligible for services.
- A client with a stable job and consistent insurance had difficulties understanding what his insurance would or would not cover in terms of HIV medical care and medications. He had to work with pharmacies and doctors to get HIV medications that would be covered by his insurance. He also had to figure out his deductible and copays and re-budget accordingly. It took him approximately two years to sort through the financial logistics of his HIV care.
- An undocumented client was not sure whether she was eligible for assistance.
- A client reported feeling "stuck" about wanting to enter the workforce but feared losing current health insurance benefits and access to health care.
- A client commented that ADAP is not sufficient to cover basic health care costs. While it was noted that it is a great benefit to have HIV-related health care costs covered by ADAP, there are health needs other than HIV that are not addressed by ADAP.

"[Insurance] plays a big role because they won't see you without it.... and I was afraid to call. Who wants to waste time making appointments if they weren't getting paid for it?"

"One of the things that impacts medical retention is cost."

Feelings about HIV Medication

Most clients reported having no issues with their HIV medication. However, after being prompted to elaborate, some clients described negative side effects and feelings about pill fatigue.

The side effects can be “just as bad as HIV... it’s almost like you’re trying to help something by hurting something else. It seems to destroy the body in other places...”

Almost all clients had to switch HIV medications at some point because of side effects. The side effects included feelings of being “tired or crazy,” confusing dreams and night terrors, itching, and gagging.

Some clients talked about their experience working with providers to switch their HIV medication regimen. Clients felt that some providers underestimated the side effects. Providers were

reluctant to switch medications if they thought that the current regimen, despite side effects, was working to reduce a client’s HIV viral load. Clients felt that these providers lacked up-to-date HIV education and were too focused on lab tests rather than on the clients themselves.

Several clients talked about the adjustment to HIV medication, not just to the side effects, but also the act of taking them consistently. Remembering to take the HIV medication can be difficult, especially for someone who has never taken any medications before. Some clients discussed how easy it was to forgo their medication, especially when they were not feeling sick and did not feel they needed it.

One client talked about when she would hide medications and throw them away because she was tired of taking them and did not see the benefit. During one of her medical visits, the doctor (who was unaware of what she had been doing) saw her lab values and told her to keep doing what she was doing. Upon hearing this remark, this client felt that her decision was validated and continued to neglect her medication. The next visit, the doctor realized something abnormal was occurring after seeing an increased viral load test. He took time to ask her about her medication routine and to educate her on the virus, lab results, and HIV medication’s role. After that visit, this client was provided additional support such as directly observed therapy (DOT). She worked with nurses to develop a plan to take her medication every day and learned to reframe negative thoughts about her medication.

Taking your HIV medication is “something you have to remember to do, because it’d be fatal if you forget.”

Another client discussed how taking medication becomes a “process” and that he sometimes experiences a negative response like anxious feelings and stomach pains at the thought of taking medication. Every day he has to plan ahead how he will take his medication because it needs to be taken with food.

A few clients commented that taking medication is a constant reminder they have HIV. One client said that the only reason he thinks about HIV is when he's taking the medicine.

All clients said they understood the importance of the medication and how adherence improves health outcomes.

Support

“A lot of gay people don't have family or close familial ties... when they see my family, they try to latch onto mine.”

Most clients reported having a good support system and identified individuals with whom they have shared their HIV status. Interviewed clients have shared their HIV status with family members such as older daughters and sons, their partners, and friends. Several of these clients acknowledged that they were fortunate to have a support system and acknowledged that not everyone had support.

Clients spoke about the value of peer, family, and/or partner support. Several suggested creating a peer support system, similar to Alcoholics Anonymous meetings or Big Brother, Big Sister programs. Having peers can help individuals navigate through the medical processes and prevent a lapse in HIV medical treatment. Clients stated that a peer navigation system would be helpful, especially for those newly diagnosed with HIV.

One client, who serves as a peer navigator, said that while doctors and nurses possess an academic, scientific approach towards HIV, they may not seem as credible as a peer—someone who is going through a similar situation.

While clients discussed the importance of support groups, they identified some issues. One client expressed frustration about support groups being geared too heavily toward gay men. She reported feeling like “the only woman in Wisconsin with HIV” and wished there was a better way to connect with people she could relate to. Another client, who has been HIV-positive for many years, said she had felt too embarrassed to attend support groups and that it took her a long time to get over that feeling. However, she has made it a goal to attend more often and is now finding the support group to be helpful.

“I was nervous [for my first appointment]. My partner at the time was with me. If it weren't for him, I probably wouldn't have made it through. He went with me to my first appointment and then afterwards.”

Another client suggested offering more activities to connect PLWH—not just activities like support groups—things like social events open to PLWH, their friends, and families.

Competing Priorities and Concerns

Clients echoed key informants' sentiments about competing priorities and concerns that PLWH have in their lives. These priorities include securing/keeping employment, taking care of family members, and finding stable housing. The following examples were discussed during the interviews:

- A client was out of medical care for a year because she was caring for her grandchildren.
- A client was currently living with his mother who was on dialysis and needed assistance.
- Two clients were actively seeking employment.
- A client felt he could not take time off work to attend medical appointments.
- One client felt that PLWH have to choose between advancing their careers and maintaining benefits and access to services/programs.
- Another client felt that PLWH, especially gay men, do not possess basic life skills that help them succeed (such as job interviewing skills, budgeting).

"I recently lost my job... I've been sending résumés everywhere."

Feelings toward Agencies

As noted previously, clients generally provided complimentary comments about the agencies from which they receive services. When asked how their agencies were treating them, clients responded with comments such as "everything is going well," "doing fine, cannot complain," and "everything is perfect."

"They are here for us. I feel like an individual and feel like I'm heard and seen at the same time."

A few clients, while overall still very complimentary, were also critical of some agencies and their providers. Clients expressed these sentiments:

- Providers not as culturally competent as they should be.
- Providers not comfortable talking to patients and lack bedside manners and behaviors.
- Providers only look at the clients' HIV health, but not other aspects of their lives.
- Agencies needing to implement different prevention and care strategies, rather than repeating activities that are ineffective at reaching at-risk populations.

"People will ask questions and be nosy... you can only go there twice before you get noticed and asked a bunch of questions."

Clients who provided constructive, often critical, comments were either part of an agency's consumer advisory board or work/volunteer at an HIV agency. These clients also had feedback for agencies with which they previously had contact. One client disliked an agency because it was not comfortable and he knew and saw too many people. Another client said the same agency was uncomfortable because there was drama among clients and it could serve as a "hook-up spot" (people get hit on just sitting in the waiting room or smoking a cigarette outside).

One client indicated she would rather drive farther away from home to get services from an agency that makes her feel welcomed instead of judged. At her former agency, she interacted with a staff member who was rude. Although she admitted that things may have changed since she last went to this agency, she would rather not return. She also said this agency was too crowded and she would like it to be more spacious.

Mistrust in the System

Although clients, for the most part, felt comfortable reaching out to their agencies for assistance and HIV medical care, some clients expressed mistrust in the medical system.

One client jokingly expressed his thoughts on the conspiracy theory, that there exists an HIV cure but that people do not want to release the cure because they are making so much money off the current HIV drugs. This client also said he believes the government may have created HIV. Another client echoed similar statements, indicating the medical system's "disinterest in making a cure."

"I think there's a cure that people are not sharing... there is too much money in the health care field to want to give it out."

FINDINGS REPORTED BY KEY INFORMANTS

Key informants were more concise and direct in their responses. They tended to elaborate on their answers by providing concrete examples and recommendations regarding HIV prevention and care services. Although the key informants provided detailed, comprehensive responses, it is important to note that the majority of key informants are not actual recipients of HIV prevention or care services. Their comments and expertise regarding HIV prevention and care services and programmatic activities varied depending on their agency affiliation, work location, academic background, history, relationship with clients, and life experiences.

The following sections pertain to answers provided by key informants.

Barriers to Getting Tested

Stigma

HIV testing has stigma associated with being gay, promiscuous, and HIV positive.

Stigma was the most commonly cited barrier for individuals getting tested. Key informants discussed in depth how HIV testing is frequently associated with being either HIV positive (regardless of test results) or being gay. In Wisconsin, commonly known testing agencies such as the AIDS Resource Center of Wisconsin (ARCW) and Diverse and Resilient are known for their HIV prevention and care services. As a result, people are reluctant to seek testing in these agencies because they do not want to be seen or automatically labelled as HIV positive or gay.

“Stigma is still, unfortunately, huge in our community.”

Misinformation

There are common misconceptions about HIV that may deter individuals from feeling like they need to get tested for HIV or feeling empowered to know their HIV status.

Key informants discussed the many misconceptions that people have about HIV and HIV-related risk behaviors. These misconceptions affect how likely someone is to access testing resources. Several misconceptions were frequently mentioned among key informants.

- **Misconception: HIV/AIDS is no longer an issue.** Key informants felt that awareness of HIV is waning and health education on HIV is limited, even in schools. Many people perceive

themselves to be at low risk for acquiring HIV and may choose not to get tested. Similarly, people who do not identify as gay or do not recognize that their behaviors are risky do not believe they need to be tested.

- **Misconception: HIV is a “gay disease.”** This relates to the perception of risk. If an individual engages in men who have sex with men (MSM) behavior but does not identify as gay, he may not believe that HIV affects him. Alternatively, some gay-identified men assume they will become infected regardless of what they do and may opt not to get tested.
- **Misconception: Being diagnosed with HIV is the equivalent of a death sentence.** As a result, people may feel reluctant or fear getting tested, not wanting to know their status or face what they perceive as a dreaded outcome. There is fear associated with HIV testing.
- **Misconception: HIV testing is the same as STD testing.** When individuals undergo testing for sexually transmitted diseases (STD), they may assume they are tested for HIV when they are not. They then assume that HIV is not an issue when it is not mentioned during the STD visit.

Testing Logistics

There are mixed opinions about whether individuals know where they can access HIV testing.

Although urban areas have many HIV testing sites, some key informants stated that individuals in the community may not know where they can get tested. Reasons for not knowing include lack of access to regular health care resources and assumptions about not qualifying for testing services (especially among the undocumented population).

Individuals who typically do not get tested in clinic settings may rely on testing in outreach settings. If organizations are not consistent about when and where they do outreach testing, clients cannot rely on outreach to get routine testing or refer their peers. Individuals may not know where else they can get tested for HIV.

Other key informants based in urban settings suggested that most people in the community know where to get tested but decline because of other barriers or for other reasons.

Key informants from rural areas suggest that individuals may lack knowledge about testing and how to access testing because testing resources are very limited in these areas.

Confidentiality

Individuals’ perceptions regarding confidentiality affect their likelihood of getting tested for HIV.

Several key informants identified confidentiality as being an issue in two different ways:

- People who might be tested by a member of their social network or in their communities fear their status will be disclosed.
- People may feel more anonymous and less identifiable if they test at a place with fewer associations (relates back to stigma). If they test at a known “MSM testing place,” that can be personally identifying.

In rural areas, confidentiality is a bigger issue because the communities are smaller and confidential, anonymous testing sites are harder to reach. For instance, the Price County Health Department is the only confidential testing site within an 11-county area.

Missed Opportunities with Primary Care Providers and Other Testing Avenues

There is a lack of provider implementation of HIV testing.

Most key informants discussed the CDC testing guidelines for HIV testing and the importance of regular HIV testing. Key informants also discussed how many testing opportunities are missed because providers and agencies are either unaware of or do not follow HIV testing guidelines.

Regarding primary care providers, key informants mentioned the following:

- Unless providers are HIV-savvy, they may be unaware of testing guidelines. Other priorities during a medical visit may outweigh that of HIV testing.
- Providers may not ask about sexual health and risk behaviors unless it’s the primary purpose of the visit. During routine or unrelated health visits, providers may not be comfortable asking about sex and other risk behaviors; therefore their risk assessments may be inadequate.
- Providers do not understand that HIV is an “opt out,” not an “opt in,” test. Providers may be unaware that they can order an HIV test as part of a regular routine blood check as long as a patient is informed of this.

“People who have primary care physicians are not being tested as they should.”

In general, key informants agree there is a lack of education and training for health care professionals not working directly in HIV. Many primary care and emergency room (ER) providers do not know to test for HIV even when patients present with symptoms and/or self-identify as gay, bisexual, or transgender. For example, one key informant is currently working with a transgender person who had multiple visits to the ER before she was offered HIV testing and diagnosed as HIV positive.

Other examples of potential testing avenues that might be missed opportunities include blood and plasma centers, dental offices, and urgent care centers.

Other Barriers Mentioned

These barriers were mentioned by a few key informants.

- **Transportation:** Individuals may not have access to transportation; multiple visits back and forth to discuss results can be a challenge.
- **Mental health and AODA issues:** Individuals may have mental health issues that prevent them from seeking HIV testing services.
- **Incentives:** Key informant comments about incentives were mixed. Some felt that incentives can discourage people from getting tested regularly because there's no intrinsic motivation; others felt that incentives are necessary because information alone is not sufficient to compel people to get tested.
- **Focus on targeted testing:** Some key informants felt that people who are at risk or are HIV infected do not get tested because the emphasis is always geared towards MSM.

Barriers to Linkage to and Retention in Care

Key informants mentioned that many barriers to getting initially linked to care are similar to the ones to staying in medical care. Unless otherwise specified, this section discusses the barriers that affect people living with HIV and their ability to get initially linked to and stay in care.

Loss of Linkage to Care Program (LTC)

The Linkage to Care Program (LTC) has been great at helping people be linked to and retained in care. The loss of these specialists in the future may lead to fewer HIV-positive individuals being linked to or retained in care.

A majority of key informants agreed that the LTC Program through the Wisconsin AIDS/HIV Special Project of National Significance (SPNS) Initiative has greatly improved the ability of HIV-positive individuals to be linked to care and to stay in care. This program is especially effective for linking people to care because the initial period after an HIV diagnosis is when individuals need the most help trying to work through the health care system and understand how their HIV will fit into their lives.

“In terms of getting people into care... how much better can it get than the Linkage to Care Program?”

LTC Specialists are effective in many ways.

- They can connect individuals to resources specific and nonspecific to HIV. These resources include housing, food pantry, employment, and others.
- They are trained to understand insurance eligibility and options.
- They are not working for any specific agency and can offer individuals many options while not representing or advocating for any one agency or provider.

- They assist in helping individuals navigate the health care system and will provide some “hand-holding.” It is not unusual to have LTC Specialists go to appointments with individuals or help with scheduling appointments.
- They follow up on people who do not make it to their appointments. They work with these individuals to get to their appointments and may provide transportation if necessary. Without LTC Specialists, agencies may not be able to follow up due to competing priorities or certain limitations (e.g., staff members cannot transport clients in their personal cars).
- They have the ability to call and text, which has been crucial in maintaining consistent contact with people living with HIV. According to key informants, most agencies now do not allow employees to text their clients.

“Linkage to Care [Program] is a wonderful, wonderful thing.”

One key informant said that people currently in care will become vulnerable as the LTC Program winds down. Although agencies will do their best to reach out and continue to help people stay in care, ultimately, agencies cannot replace LTC Specialists.

There are limitations to the LTC Program.

- LTC is only available in Madison and Milwaukee.
- LTC Specialists are not as accessible to individuals who are diagnosed with HIV in the private sector or at a non-counseling, testing, and referral (CTR) site.

Lack of Resources and Support for People Diagnosed at Non-State-Funded Sites

Some providers at non-state-funded testing sites lack the training or knowledge to provide support and resources to individuals newly diagnosed with HIV.

According to key informants who are state-funded, many staff members in hospitals or private settings have not been trained on how to appropriately deliver positive test results and provide support. For instance, one person with HIV found out she was positive through the phone. She was told, “There is good news and bad news. What do you want to hear first?” As a consequence of not having adequate support, individuals may feel too traumatized to seek out HIV medical care.

Few staff in hospitals and private facilities know that the Linkage to Care Program is a resource; they also do not have their own version of LTC. If individuals do not show up for appointments, the staff may not notice or may not have the resources to track them.

“There’s still a gap for people who are getting diagnosed outside state-sanctioned testing sites... [especially when most people] are getting diagnosed in private places in Wisconsin.”

In addition, these facilities do not know what's available for HIV-positive individuals in terms of resources and medical care. They probably only know about ARCW (either through an existing relationship with ARCW or if they searched on the Internet for HIV medical care, ARCW is the first agency that appears). If individuals do not want to be a client of ARCW, they may drop out of care because they think ARCW is their only option.

Navigating the System

Many people diagnosed with HIV are being introduced to the health care system for the first time and may not know how the system works.

“[People] don’t know how to navigate a system that large... and it can be overwhelming. It’s a luxury [of the middle class and above], knowing how to navigate the medical system.”

Most key informants agree that both general and HIV-specific systems are difficult to navigate, especially for someone who never had regular access to health care. Some people may not be familiar with preventive care. Their family members may have avoided medical care, sought care only when they felt really sick, or used the emergency room as their primary source of care.

Finding out they are HIV positive and being introduced to the system in this way is overwhelming. Fear of not knowing what to expect or how to enter and stay in the system may deter people from seeking or staying in care.

There are many aspects of the health care system to which individuals may not be accustomed, such as:

- **The importance of scheduling and attending appointments.** Individuals may not comprehend the negative consequences of “no-show” appointments at certain agencies.
- **The ability to ask questions during their appointments.** Individuals may fear asking what they think are naïve questions.
- **The specific procedures that agencies have in place.** For instance, one agency requires that a client makes an appointment through a case manager prior to seeing a doctor. This may be a barrier if clients do not know or like this policy.

“...it takes a level of tenacity to navigate the system.”

Transportation

Individuals may not show up to their medical appointments because they have very limited resources or transportation options.

Key informants discussed lack of transportation as a major barrier to being linked to or retained in HIV medical care in both urban and rural areas. People may not have the resources necessary to make it to their appointments.

For Milwaukee, most key informants agree that the public bus system is not sufficient. People who cannot get to their appointments independently may rely on friends or family members to drive them to their appointments. However, this may require HIV disclosure, reliance on other people's schedules, and reimbursement for gas.

There are existing services for medical transportation. Some of these services are difficult to use. Informants found the Medicaid transportation service challenging. Someone wanting to use this service must call 48 hours in advance. This is problematic if people do not remember when their appointments are or if they forget to call two days prior. The phone line may also have long wait times, which is a problem for individuals who have limited phone minutes.

"I wouldn't know what the [health] outcomes would be if I wasn't able to transport people to their appointments."

In rural areas, HIV medical services may be so limited that people would have to travel one to two hours by car for appointments. Even for those with cars, transportation is a barrier because the distance puts strain on their vehicles and requires money for gas.

Providing bus tickets or reimbursement for gas does help increase individuals' likelihood of making it to appointments. However, this is true only if the bus system is sufficient or if the person has a car.

Competing Priorities

Individuals may not be able to focus on their HIV medical care due to other competing priorities.

Key informants spoke of numerous competing priorities for PLWH. People's lives are "chaotic," and HIV medical care is often not something they can or want to deal with.

"People will always work on their most pressing needs first."

Examples of competing priorities include:

- **"Maslow's Hierarchy of Needs":** When individuals do not have consistent places to live, food to eat, or job security, their HIV medical care is not the highest priority.
- **Employment:** A majority of agencies only operate from 9:00 a.m. to 5:00 p.m. Individuals who are working during this time may not be able to afford to take time off.
- **Family duties, including child care:** Individuals, especially women, may defer their own health care needs to take care of others. For parents, finding child care may be difficult.

Because most agencies do not have child care and most medical transportation services do not allow extra passengers, parents may forgo their medical care.

Providers

Issues with health care providers can deter people from staying in medical care.

Some key informants suggested that providers, especially doctors and case managers, affect individuals' willingness to stay in medical care. Provider-related factors that can negatively affect retention in care include:

- **High turnover.** HIV is a lifelong disease, and individuals want to trust and feel safe with their providers. The turnover in providers makes it difficult for individuals to establish continuous relationships and may discourage them from continuing medical care.
- **Dissatisfaction.** People may not like their current providers and may not have the skills to ask about switching providers or to explore other options at other agencies.
- **Lack of diversity among providers.** In general, people who work in the medical care field do not reflect the population most affected by HIV. They may not be as able to connect and relate to clients. Culture competency continues to be an issue.

Other Barriers Mentioned

Other factors mentioned by a few key informants include:

- **Mistrust in health care systems.** Certain populations, like Blacks, are historically more likely to distrust government and health care facilities. These views may influence them to defer medical care until their HIV disease worsens.
- **Mental health and AODA issues.** People living with HIV who suffer from mental health or AODA issues struggle to stay in care consistently.
- **Stigma.** People are concerned about who might see them entering or being at a facility that is designated to provide HIV/AIDS-related services. Most clients experience stigma attached to being HIV positive.
- **Issues with health care coverage.**
 - Individuals who experience lapses in or a complete loss of health care coverage may not know how to obtain assistance and may assume they can no longer afford medical care.
 - Certain populations, like undocumented individuals, may automatically assume they are ineligible for any assistance.
 - Copays and deductibles may present financial challenges.
- **Denial or “feeling fine.”** Individuals may be in denial about their HIV status or may feel they do not need HIV medical care.
- **Interactions with the jail system.** Individuals entering the jail system for short stays are likely to experience a break in medical care.
- **Individual readiness.** Some people may lack the readiness or motivation to engage in the HIV medical system and services.

Barriers to Becoming and Staying Virally Suppressed

Barriers mentioned previously in regard to staying in medical care also affect a person's likelihood of reaching and maintaining a virally suppressed, undetectable HIV load. Below are barriers specific to achieving viral suppression.

Difficulties with Adherence

Individuals may face difficulties taking HIV medications consistently for a variety of reasons.

Key informants discussed the difficulties in adhering to HIV treatment regimens.

There are many reasons why adherence might be difficult.

“Even I mess up when taking my medications... what about people who lack skills for that or aren't emotionally able to handle it?”

- For people living with others, it's hard to keep private the fact that one is taking HIV medications.
- Individuals who are away from home overnight may find it difficult to plan ahead and bring HIV medications with them.
- For people in transient living situations, having a safe space to store HIV medications may be a challenge.
- People who cycle in and out of the jail system may experience difficulties trying to maintain HIV treatment in jail or returning to regular treatment after release. (This also affects retention in medical care.)
- Younger people with HIV may not think about long-term health and may not feel sick. Taking medications for the first time can be a major life adjustment.
- Side effects of medications make it difficult for individuals to adhere to the treatment regimen.

Personal Feelings about HIV Medication

Individuals' negative feelings towards their HIV medication may lead to a lapse or complete stop in adherence.

Key informants discussed the feelings people have when taking HIV medication:

“It's a constant reminder that [you] have HIV.”

- For many, taking medication is a constant and unsettling reminder of how they were infected. Deciding not to take medication may be a way of coping.
- It is not uncommon for individuals to feel “burned out” and experience pill fatigue.

Other Barriers Mentioned

These barriers were mentioned by a small number of key informants.

- **Misinformation.** Individuals may not understand how the virus works or what “undetectable” means. They may also get information from inaccurate sources that discourage consistent medication adherence.
- **Cost of medications.** Copays and cost of medications may be too high.
- **Mailing of medications.** In some situations, medications are mailed to people’s homes. This can be a deterrent if a person isn’t home to receive the package or is living with someone else and hasn’t yet disclosed his or her HIV status.

Returning to Medical Care

Because HIV is a chronic, lifelong disease, it is not uncommon for people to cycle in and out of HIV medical care. Key informants were asked, “What prompts people living with HIV who have stopped receiving medical care to come back into care?”

Getting Sick

Key informants most commonly cited becoming or feeling sick as the reason individuals return to medical care.

Sickness may not always be associated directly with HIV disease. Individuals may experience opportunistic infections or a new event of STDs such as gonorrhea, chlamydia, or syphilis. These events may cause individuals to seek care with their HIV or other care provider, at a hospital, or at an STD clinic where they may be reconnected with their HIV care provider.

Intentional Support

Key informants discussed the effectiveness of an intentional intervention, follow-up, or support that inspires individuals to reconnect to care. These efforts came in many forms:

- **Intentional follow-up via agencies:**
 - A “coordinated, aggressive outreach strategy that pulls people back in,” such as the Linkage to Care Program, has been successful in helping individuals return to medical care.
 - Other strategies include case managers following up on their clients who have not been seen in a while.
- **Peer, friend, or family support:** An individual might be assisted by peers, friends, or family members to set up and attend their medical appointments.

- **Provider support:** An individual who feels comfortable and has a good, stable connection with a provider may be encouraged to return to medical care.

New Motivating Factors

Key informants shared examples of new intrinsic reasons for individuals who choose to return to care. The reasons given were greatly varied, with no consensus; a few key informants mentioned the following:

- A crisis that leads to the need to access other resources, such as housing or health care.
- An “epiphany” and the desire to be healthy and change their lifestyle.
- A new relationship and the desire to disclose their HIV status.
- A readiness to face their HIV diagnosis and go to medical care.
- A transformative life experience, such as becoming pregnant or having a near-death situation.

New Positive Situation

Examples of these positive changes include:

- Securing stable housing and employment.
- Regaining health insurance.
- Addressing substance use issues.

“Something has changed.”

Concerns about HIV Services

In an effort to improve Wisconsin’s current HIV prevention and care services, key informants were asked, “What common concerns do your clients have about their HIV-related services? Examples include appointment times, insurance coverage, paperwork, LGBT sensitivity issues, etc.”

Appointment Times

Most of the key informants agree the customary appointment times may not work for clients. Agencies usually operate on an “eight-to-five” time frame, which coincides with clients’ work schedules. Clients may not have paid sick time and cannot afford to skip work for HIV-related appointments.

“Having an appointment is not the same as being able to keep it.”

Key informants say that clients desire evening or weekend hours so they do not have to choose between going to work and earning an income or keeping their HIV medical care appointment.

Privacy and Confidentiality

Key informants discussed clients' concerns regarding privacy and confidentiality. Clients do not want their presence at an agency to imply or disclose their HIV status and/or sexual orientation. Key informants suggested that the following characteristics of an agency make clients feel uncomfortable:

“The fear of seeing someone [they know] in the waiting room is real.”

- If the agency has an obvious HIV association (especially agencies that only serve HIV-positive individuals). The HIV association is felt to be stigmatizing, and people don't want to be seen walking into an HIV clinic.
- If the agency has an open, visible waiting room that may allow other people to see clients and make assumptions.
- If the agency employs providers who personally know and interact with clients. This is especially true in rural areas where providers can be someone's “neighbors, aunts, uncles, cousins, etc.”
- If the agency is perceived as not following confidentiality laws and procedures.

Health Insurance

Key informants discussed clients' confusion and anxiety about health insurance, especially after the implementation of the Affordable Care Act (ACA). Clients need assistance regarding:

“People get really confused by the whole system of how to get insurance.”

- Whether they qualify for insurance and if so, what kind.
- What services Ryan White funds will cover.
- The different health insurance terms and what they mean to clients (e.g., copays and deductibles).
- Filling out paperwork appropriately.

One key informant talked about how case managers are spending the majority of their time helping clients understand health insurance and fill out paperwork. She suggested that this logistical service is “impeding care.”

Cultural Competency

Key informants felt that agencies need to seriously consider cultural competency when providing services. Cultural competency encompasses several key characteristics:

“I wonder.... are we providing the best-quality care?”

- **Being mindful of the targeted community.** A key informant stressed that certain groups, such as transgender individuals, are not accessing the traditional prevention and outreach services like CTR and group level interventions.
- **Understanding the differences between working with adults and youth.** A key informant shared how youth need to find a setting where they feel comfortable. If agency staff members are not patient and accessible, youth will not want to come back or seek their services.
- **Being educated about the LGBT community.** Some key informants believe that LGBT competence is “limited in so many care organizations” and that agencies should provide more training and education on how to effectively serve LGBT clients.

Other Factors

These factors were mentioned by a few key informants.

- **Transportation.** Many key informants acknowledged that transportation—getting to and from an agency to get tested for HIV or receive medical care—is a major logistical concern for clients.
- **Child care.** HIV prevention and care agencies are not the best place to bring young children.
- **Establishing relationships with providers.**
 - Staff may lack the experience or necessary techniques to connect with clients.
 - There is a huge turnover in providers.
- **Different physicians for HIV medical care and primary care needs.** One key informant suggests that splitting care in this manner is less effective because neither physician becomes familiar with the clients’ entire health needs.

Comfort Level of Providers

Key informants were asked to describe their comfort level and that of their colleagues in working with clients.

Among providers who currently have or previously had direct interaction with people living with HIV, an overwhelming majority reported feeling very comfortable and able to have conversations about risk behaviors, especially in an HIV or STD clinic. Those who provide

The majority reports feeling “very comfortable” with their clients.

administrative or supervisory support report that their staff members are trained to have those conversations and have resources to deal with uncomfortable situations.

One key informant responded that she felt only slightly comfortable talking about risk factors even though she “talks about condoms all the time, using lube, reducing the number of partners, and disclosing status.” Another said that “it

is never comfortable” but that he’s consciously aiming to improve his ability to be more approachable.

Some key informants expressed concerns about their colleagues’ comfort levels. Examples of their comments include:

- “I’m not sure if anyone would admit to feeling uncomfortable...we’re going to be in trouble if people say they’re comfortable talking about risk factors.”
- “There are doctors who are not comfortable...if you ask certain things, it might not be okay.”
- “Some staff members may be uncomfortable talking about risk factors, particularly around sexual assault.”
- “It’s obvious they don’t even want to hear the answers to the questions...they’ll ask the question just to flip the page.”
- “Some don’t and can’t even think about the different ways to have sex.”

Regardless of their responses, key informants agree that trainings are helpful to increase staff comfort level. Suggestions for future and continued trainings include motivational interviewing, cultural competency, and STDs.

Services Needed

Federal guidance points out that the needs assessment should “[identify] current resources available to meet the needs [of people living with HIV] and [determine] what gaps in HIV prevention and care services exist.”

The Wisconsin AIDS/HIV Program funds HIV prevention and care services as well as support and ancillary services. Key informants were asked:

1. What services do your clients utilize the most?
2. What services do your clients need but are unable to access? What are the reasons they can’t access them?

Top 10 Services Mentioned by Key Informants



Housing



Transportation



Mental Health and
AODA Services



Medical Case
Management



Services to Understand
Health Insurance



AIDS Drug Assistance
Program (ADAP)



Dental Care



Food Pantry



HIV Testing



Condom Distribution

Additional Background: Housing

“Housing, housing, housing. And there’s not enough it.”

Key informants consistently cited homelessness as a problem among people at high risk for or infected with HIV. A key informant noted “you will do all sorts of things to get a home” and

getting housing is so much more important than the possibility of feeling sick in the future. As a result, housing services are the most commonly used services. However, key informants implied that they are also some of the most difficult services to access.



The most frequently mentioned issues regarding housing and shelter were:

- Housing is generally very expensive and hard to find.
- People living with HIV might face restrictions that prevent them

from accessing affordable housing.

- Many housing complexes have strict no-drug policies and require individuals to be completely clean (drug-free) before and throughout their stay. This policy extends to drugs such as tobacco and marijuana. People with alcohol and other drug abuse (AODA) issues may not be able to meet this criterion.
- One key informant mentioned that she's seen empty beds at Wisconsin Housing that simply aren't being used because of this rule.
- If an individual has any sort of criminal record, this person, if offered a housing lease, might face an increased security deposit or be offered only a six-month lease.
- There is stigma associated with some housing complexes. The stigma attached to ARCW housing may deter individuals from seeking that resource. According to one key informant, "everybody knows that's the AIDS house."
- Housing and shelter services are not transgender-friendly.
 - Many men's shelters do not allow transgender individuals because they might be sought for sex.
 - There are only a few women's shelters available. These shelters prohibit transgender individuals with male sexual anatomy.
- Housing services usually have long wait times. The wait lists are usually years long and the application process may be protracted.
- Concern about the safety of these housing complexes is also an issue.

Additional Background: Transportation

Access to transportation was named frequently as a barrier for many individuals. Key informants discussed the various ways they assist people living with HIV obtain transportation (distribution of bus tickets, cab rides, use of their own vehicle, etc.). However, these resources are limited and transportation remains a challenge for many people.



Reasons why transportation services are difficult to access include:

- Individuals may live too far to use the bus systems, even with assistance of bus tickets. This is especially true in rural areas.
- Services may require individuals to schedule transportation up to two days in advance. Generally, individuals only call for services when they need it immediately.
- There is a lack of non-English-speaking transportation services.

Additional Background: Mental Health and AODA Services

“[The limited access]...is borderline negligent.”



Key informants agree that mental health and AODA services are a need for many people living with HIV. Although there has been an increased effort to provide mental health services (e.g., UW partners with Journey; Froedtert has funds for a nurse practitioner to provide therapy; ARCW has psychiatry services), access still remains a problem. One key informant talked about individuals having mental health needs that could benefit from therapies. Not only would clients' mental health improve, but they would be more likely to stay in HIV medical care. Unfortunately, the majority of key informants believe that Wisconsin is not meeting those mental health needs.

Challenges individuals encounter when trying to access or maintain mental health or AODA services include:

- **Long wait lists.**
 - Individuals with high needs may be placed on waiting lists for a minimum of six months. This is especially true for individuals who only have Medicaid.
 - This long waiting period might lose people who are interested in getting help for their AODA issues. They may only be willing to seek help for that immediate time period.
- **Lack of psychiatrists.** Across Wisconsin, there is a shortage of psychiatric services. It's difficult to make referrals.
- **Affordability, which ties into health insurance coverage.** Substance abuse treatment is often not affordable or not covered by a person's insurance. Most treatment requires large out-of-pocket costs.
- **Stigma.** Stigma may prevent individuals from admitting they have mental health needs or attending appointments with behavioral specialists.

Additional Background: Medical Case Management

“If there isn't medical case management, there is no program—period. It's the oil in the engine that makes everything move.”

Key informants spoke empathetically about the use of medical case management and its use. Most agree that without medical case



management, people living with HIV would not be linked to other social services. Case managers play a large, continuous role in

supporting HIV-positive individuals. Case managers may also inadvertently deter individuals from care, especially because they serve as a first point of contact. A key informant described how one client felt neglected because of unreturned phone calls. Another key informant discussed how the frequent turnover in case managers makes it difficult for individuals to establish trust with providers and agencies.

Additional Background: Services Needed to Understand Health Insurance

People living with HIV continue to use services to access and navigate health insurance. Key informants, particularly case managers and Linkage to Care Specialists, noted how much time was spent helping clients enroll for health insurance through the Affordable Care Act or through BadgerCare Plus.

Services Needed, but Limited in Availability and Access

“We aren’t talking about PrEP! It’s not going to work for everyone, but for those it will work for, we should make it easy as possible for them to get it.”

Access to Pre-Exposure Prophylaxis (PrEP)

The key informants who mentioned PrEP all agree that not much is being done to educate



the community about or provide PrEP. Froedtert and UW provide PrEP to their patients, but key informants from those agencies state the people who are most at risk for acquiring HIV are not the ones who are aware of and/or seek PrEP.

Key informants spoke of the Wisconsin AIDS/HIV Program’s role with PrEP, particularly whether the state was going to promote and increase access to PrEP. A key informant pointed out “PrEP is an area that needs leadership.” As of October 2015, there is not a standard policy or procedure for implementing PrEP. There is also no public policy or funds to support delivery of PrEP.

Support System/Groups

Key informants indicated that people living with HIV have a desire to connect with others like themselves who understand what it is like living

“People feel alone and say they want a place to connect with others, but don’t access support groups. What’s the barrier?”

with HIV. The informants talked about having more than one group for HIV-positive individuals because different populations and groups are affected.

Despite this need, support groups are not accessed. Transportation, time, and confidentiality are reasons key informants gave why current support groups are not being used.

Key informants noted there had been support groups but were not aware if the groups continued operating or if they were successful.



Prevention Services

Some key informants discussed how more efficient efforts should be directed toward HIV prevention, including the following:

- Alternative ways to get people tested for HIV besides use of incentives and the venue of PrideFest
- Better condom distribution at bars and clubs
- Better coordination about where agencies conduct outreach HIV testing

“We could end HIV as an epidemic with enough resources in prevention.”

A key informant noted that she doesn’t know how much prevention is offered, especially when she and her colleagues see the same number of people being infected with HIV year after year.



Hepatitis C Treatment

A few key informants talked about hepatitis C being an increasing health problem that needs to be addressed. Although needle exchange programs exist, not many services or providers treat hepatitis C. Some key informants expressed a hope that ADAP will cover hepatitis C treatment costs.

Vulnerable Populations

HIV is a disease that affects some populations differently than others. Key informants were asked what unique challenges or barriers they noticed for specific groups they serve and what additional services they might need.

Vulnerable populations as identified by key informants included the following:

- Men who have sex with men (MSM)
- People of color

- Women
- Transgender people
- Youth
- People who use drugs

Men Who Have Sex with Men (MSM)

Key informants agreed that MSM are at higher risk for acquiring HIV and other STDs. They also stated that MSM face heightened levels of stigma. Being gay or being a male who has sex with other males may put MSM at risk for being barred from their family's home, becoming isolated from their friends and family, having mental health issues, and experiencing hateful acts. One key informant in a rural area described a story about an HIV-positive MSM who sought care at the ER for influenza and felt disrespected by the doctor. Because of stigma, MSM may not be open about their sexual orientation and fear seeking HIV testing and/or care.

Stigma can have a layering effect for individuals with multiple risks, behaviors, or identities that are viewed by others as unacceptable. This frequently results in discrimination. A key informant noted that certain subgroups and subpopulations are experiencing a variety of “-isms” (sexism, racism, homophobia, judgment about drug use, etc.) and how HIV experience only adds an additional layer of stigma. One key informant suggested that Black MSM have less support than white MSM; another informant noted that Black MSM are the “biggest group struggling with social barriers.”

MSM may experience internalized homophobia that leads to risky behaviors and self-medicating coping mechanisms. Their personal feelings about their sexuality and behaviors may lead to a diminished desire to protect themselves.

MSM communities in Wisconsin are small, and the Black MSM community in Wisconsin is even smaller. For Milwaukee, that has several implications.

- Because the Wisconsin AIDS/HIV Program emphasizes the importance of targeted testing, agencies in Milwaukee are consistently doing outreach and testing efforts directed towards Black MSM. Black MSM are bombarded with testing messages and may experience “testing fatigue.” In addition, because testing messages usually mention incentives, Black MSM may test for HIV only if they can receive an incentive.
- Many partners are being identified multiple times by MSM receiving Partner Services and other Disease Intervention Specialist-related services. This indicates how small the sexual network is and how easy it is for STDs, including HIV, to spread.

Key informants noted that it is difficult for MSM to access culturally competent care. Providers may make incorrect assumptions about MSM relationships, HIV testing knowledge, and risky behaviors. MSM may feel uncomfortable discussing risk with their providers, especially if they feel judged or if they misunderstand a provider's use of terminology (e.g., terms like “receptive anal sex”).

People of Color

Some key informants discussed how stigma affects people of color, especially in the Black and Hispanic communities. Key informants described how, historically, people of color experience systematic racism and health disparities. For instance, jail sentencing and incarceration are disproportionately high among Black males. In addition, certain Black and Hispanic faith communities and members may have less favorable or negative attitudes toward LGBT persons.

Key informants stated that people of color may seek health care only during emergencies or through the emergency room instead of routine primary care. One Black key informant talked about a person's childhood experience: "If you grow up watching your parents not manage their diabetes or other health problems, you're going to think you can get by without managing your HIV." Another key informant noted that many Hispanics don't seek preventive health care and only seek care when it is absolutely necessary.

People of color may forgo medical care because they mistrust and/or fear the medical system. A key informant mentioned how his Black patients were more likely to be curious about why they have contracted HIV and to ask questions about the origin of HIV.

Key informants discussed the need for increased peer support for MSM and people of color. They also discussed the importance of having providers that are members of the population they serve. There are very limited options for HIV treatment in Milwaukee for people who only speak Spanish. Few agencies have nonwhite staff members. One person noted that ARCW is a "pretty white organization" and that Black people do well when they see people that appear to be from the Black community and who share their reality.

Women

Some key informants did not have much to say about women and HIV because they see and serve so few women at their agencies. Other key informants felt that women are often overlooked because they "are not the traditional faces of HIV." Providers may not offer women HIV testing because they are not considered a high-risk population.

Women may not perceive themselves to be at risk or may not know their partners are at risk. As a result, finding out about their HIV status comes as a shock. One key informant shared a story about a divorced woman who was surprised and confused about her HIV test results. Another discussed how some women become aware they are HIV-positive when applying for health insurance or marriage licenses rather than from routine testing in medical settings.

For women who are HIV-positive, maintaining care may be difficult because of child care needs. Typically, there is no child care at HIV agencies and, depending on the age of the children, women may not want their children to know their HIV status. HIV care may be less of a priority when women are responsible for taking care of their children or other family members. Key

informants noted that women “take care of everything but themselves” or that they “take care of others first.”

Women may feel alone and unsure of how much support they have. A key informant commented that some women feel concerned about whether they will ever date again or be married because they are HIV-positive. They may feel a sense of shame, believing that they chose their partners poorly and that their decision is a reflection of who they are as individuals.

A key informant discussed her experience working with people (women in particular) who act like adolescents because they have been abused and have not matured mentally or emotionally. Like youth, they may not know how to navigate the health care system.

Transgender People

A few key informants talked about transgender individuals and their difficulties in accessing services. Transgender people may not be granted access to housing or shelters because of their appearance. One informant noted that transgender people are the “most oppressed [and] least accepted” group and that they have the “least amount of support in terms of medical care.” They face a lot of stigma, even within the transgender community. Transwomen, in particular, are more vulnerable to homelessness and violence. They are often subject to sex work and sexual assault.

In terms of health care services, few providers can deliver transgender-specific services (hormone therapy, breast augmentation, gender reassignment, etc.). If an individual could find these services, health insurance may not cover these services.

One key informant shared how transgender individuals’ priorities may be different from other people’s priorities. Transitioning may be the number one priority. It is important for agencies to consider a client’s transition when trying to provide testing and care services. A key informant talked about how her agency is working to provide transgender health services such as hormone therapy as a way to draw transgender individuals into their agency and encourage HIV testing.

Youth

Key informants did not define the age range for “youth” but agreed that younger people living with HIV experience particular challenges that are different than those for adults. Several key informants suggested that HIV programs are not youth-friendly. Conforming to the medical system and its structure is not easy for youth. Younger people may not understand what services are available and how to access them. They may also be uncertain about confidentiality policies, especially if they are currently covered by their parents’ health insurance. It may take more time for youth to establish trust with providers who are older than they are.

Youth are also more likely to have more sex partners, hook-ups, and sexual activity. They may feel invincible and that HIV is an “old-person disease.” One key informant suggested this may be due to a lack of accurate sexual health education in schools.

People Who Use Drugs

Key informants identified drug users, particularly people who inject drugs (PWID), as a vulnerable population. Addiction to drugs may drive risky behaviors such as trading sex for money or drugs and sharing needles.

Drug users may also be less likely to be retained in care or to be virally suppressed. Adherence to medication may be negatively affected by drug use; people may not always be truthful about drug use with providers because they fear being judged; and they may not keep their HIV appointments when using drugs.

Key informants stressed the importance of having affordable, accessible AODA treatment services and hepatitis C treatment services for people infected with HIV and HCV. Two key informants advocated for making AODA services affordable, available, and on-demand when people are willing to undergo treatment.

People in Jail or Prison

A few key informants talked about people in jail and/or prison systems. A key informant who provides HIV testing discussed the challenges of getting people tested for STDs and HIV in jail. Not only is it hard to get people tested, it is also hard to notify individuals about test results, especially when they leave the jail system. Jails are also very heterogeneous in services; they vary in size and quality of health care. Because there is less oversight and people stay in jail for short durations, HIV-positive individuals may not be able to take their HIV medication as prescribed.

Key informants pointed out that the prison system is different. Informants from Madison said that incarcerated individuals have access to good HIV medical care and counselling from the nurses. Because they are able to see their doctors either over Skype or in-person at the UW Hospital, individuals feel more connected and supported. With the help of the Linkage to Care Program, a majority of individuals continue their medications after they are released. However, inmate clients still feel stigmatized and stressed during their in-person medical visits when they are physically “shackled” as they enter and exit the clinic.

Systemwide Activities

A majority of key informants have worked in the HIV/AIDS field for several years. They communicate and collaborate frequently with the Wisconsin AIDS/HIV Program, their local health department, and other partner agencies. Based on their previous interactions with

various stakeholders, key informants shared what they thought was working well in Wisconsin and what should be prioritized for improvement. They also provided ideas about what the AIDS/HIV Program could do to promote and improve health outcomes for people at risk for or living with HIV.

The answers varied depending on the roles of key informants, their affiliated agencies, and their locations. Because this question was broad and open-ended, there was not a clear consensus. Some comments noted below were stated by one or two key informants.

Note: “” indicates that the overarching topic was mentioned by at least four key informants in some manner.*

| WHAT HAS BEEN WORKING WELL | |
|-----------------------------------|---|
| State Involvement* | <p>State staff members provide good support and technical assistance; they also stay relatively active.</p> <p>The state provides good trainings, especially in HIV prevention.</p> <p>The epidemiology and state lab testing are highly reliable.</p> |
| Testing Technology* | <p>Agencies know about the new testing algorithm and understand the phases of HIV and how they relate to testing.</p> <p>Rapid testing is much more “accessible and palatable.” It helps normalize testing and does not require blood to be drawn.</p> |
| Linkage to Care Program* | <p>LTC specialists improve client facilitation into care.</p> <p>LTC specialists are great at providing test results easily and promptly.</p> <p>The LTC program is effective at creating links to other agencies; their primary obligation is to the client, not their agency placement.</p> |
| AIDS Drug Assistance Program | <p>ADAP is a good base for patients, especially for those who do not have any health insurance.</p> <p>ADAP has no wait list.</p> <p>Fiscal resources are always available for HIV medications.</p> |

| | |
|--------------------|--|
| Agency-specific | <p>AIDS Resource Center of Wisconsin (ARCW)</p> <ul style="list-style-type: none"> • ARCW's philosophy of integrated care and "one-stop-shop" model is working. • Anybody in Wisconsin can access and be connected to prevention and care services. • ARCW's needle exchange program is working well. • A non-ARCW key informant said that ARCW has good services if clients can get in; the drawback is that their model is dependent on people coming into the office to get services. |
| | <p>Milwaukee Health Services (MHS): Primary care services are working well. They provide increased interaction with patients and more coordinated care.</p> |
| | <p>Sixteenth Street Community Health Center: The medical case management is good because they have a walk-in policy; no appointment is necessary.</p> |
| | <p>University of Wisconsin (UW) Hospital in Madison: The interdisciplinary team at UW is involved with patient care, and the providers offer good education.</p> |
| Prevention-related | <p>Condoms are being distributed in more community-based places.</p> <p>Views about targeted testing are mixed. Some believe that efforts are successful and that more people are getting tested; others believe that targeted testing has not been successful in testing PLWH who are unaware, especially because most diagnoses are coming from the private sector and not through state-funded sites.</p> |
| Wisconsin | <p>There is great collegiality among agencies and providers. Wisconsin HIV prevention and care stakeholders know each other and meet often.</p> |

| WHAT SHOULD BE PRIORITIZED FOR IMPROVEMENT | |
|--|---|
| Staff-related* | <p>Because of the need for more services and outreach efforts, there should be more funding to hire local agency staff members to do prevention and care services around the state.</p> <p>For instance, there are more people living with HIV, but case managers are struggling to keep up with caseloads and meet expectations.</p> <p>There should be more emphasis on workforce development and capacity building. Staff members need to be encouraged and supported to attend trainings and networking opportunities. Trainings should help staff members develop their cultural competence skills to better work with clients.</p> <p>Trainings should also be directed toward primary care physicians who may be less knowledgeable about HIV, PrEP, and LGBT issues.</p> <p>Several key informants expressed concern about staff turnover within agencies and the Wisconsin AIDS/HIV Program.</p> |
| Prevention-related* | <p>In general, prevention needs to be prioritized.</p> <p>A few key informants suggested that prevention should focus more on specific groups such as communities of color or MSM. Agencies should get better at using social media and Internet outreach; outdated strategies like the information and referral hotline should be defunded.</p> <p>There needs to be more education and awareness about HIV—directed not just to individuals in the community, but to other agencies, health departments, non-HIV providers, schools, churches, etc.</p> <p>Targeted testing may have the undesirable consequence of missing people in certain groups (e.g., college students, sex workers, and women). According to one key informant, because all agencies seem to be targeting the same areas and/or populations, it may be an ineffective use of resources.</p> |

| | |
|--|---|
| Coordination and communication* | <p>Key informants stressed the importance of providing a more unified approach for HIV prevention and care. Agencies often work in “silos.”</p> <p>The coordinated approach should include nongrant agency agencies that are doing work related to HIV prevention. For example, United Way funded a teenage pregnancy reduction campaign.</p> <p>The community itself needs more access to information. Agencies should learn how to deliver relevant information and engage community members in their planning processes.</p> |
| PrEP distribution* | Provide more education to agencies and increase availability of PrEP for individuals who are at high risk for HIV. |
| Support for individuals most at risk for acquiring or transmitting HIV | <p>If they are HIV-negative, what can be done to make sure they stay negative? Support services seem to be available only for individuals who are HIV-positive.</p> <p>If they are HIV-positive, what can be done to help get them virally suppressed? Individuals who are “spotty” with their care should receive more intensive medical case management and/or LTC support.</p> <p>Access to medication and linkage to care need to be improved for HIV-positive people who are in the jail system.</p> |
| Data use | The state should do more with real-time data, especially because the state knows where people fall along the HIV care continuum. The state could use this information to identify people who need additional support and help. |
| Funding for other health issues | There are underlying health issues that affect HIV retention care. They include mental illness, substance abuse, and hepatitis C. Funding to address these issues would be helpful. |
| Agency and government policies that allow for texting clients | Some government phone data plans have limited minutes but allow for texting even if the minutes run out. Texting helps case managers link clients to services and stay connected with clients. |
| Examination of other states’ initiatives and adoption of them if appropriate | Other states may have ideas that can be implemented in Wisconsin. |
| Focus on the aging population | The aging population of PLWH faces unique challenges. |

| WHAT THE STATE SHOULD DO | |
|---|---|
| Coordination of more meetings, trainings, etc.* | <p>For agencies—coordination will allow staff members from different organizations to network and learn about existing services available.</p> <p>For the community—coordination will let the state seek insights and gauge what community members need.</p> |
| Trainings* | <p>Offer more training opportunities for staff. Identify opportunities for cross-training. This can be done by offering continuing education credits for nurses, doctors, and others to increase knowledge about HIV best practices and recommendations.</p> <p>Open up and require trainings not just for frontline staff, but also for leaders and supervisors. These trainings should cover topics such as trauma-informed care and diversity and inclusion.</p> <p>Make trainings more accessible. Put the trainings online and make them available for nontraditional agencies. In addition, refrain from restricting trainings to prevention-only or care-only staff-- the information and tools provided can be applicable to both sections.</p> |
| PrEP* | <p>Other states have taken more initiative and a direct approach toward PrEP; in contrast, Wisconsin has taken a passive role in the distribution of PrEP. As a result, agencies are unclear about the state's role in PrEP distribution.</p> <p>The state should think about PrEP and how to promote it responsibly. It should also set clear protocols and guidelines for agencies to reference.</p> |

| | |
|--------------------------------------|---|
| Focus on prevention-related efforts* | <p>The state should fund educational programs, media outreach, and other resources to help people get relevant health information.</p> <p>Focus on improving condom use and understanding the challenges to condom use, but also identify innovative strategies beyond condom distribution and testing outreach.</p> |
| Accountability | State and local agency staff must be accountable for maintaining current knowledge and skills. Agencies must be accountable for providing tools and resources for their employees to do their jobs effectively. |
| Leadership development | The state should address disparities in the workforce, especially because the workforce does not reflect the populations being served. One of the ways to do so is to identify potential leaders and provide them with mentorship and training. |
| Hepatitis C | Stay updated on the emerging hepatitis C epidemic because it is becoming a big issue. |
| Partner Services (PS) | <p>Make sure that cases are assigned appropriately and efficiently. If they have to be reassigned, make sure the reassignments are a good use of time for Disease Intervention Specialist workers.</p> <p>The state should also provide rural health departments not providing PS with education about HIV and PS. This will make it easier for the PS provider coming from outside the county to connect with clients.</p> |

CONCLUSION

Most clients and key informants believe that Wisconsin, as a whole, is doing better when compared to other states in terms of providing HIV services to people who need them. The majority of clients and key informants agree that once individuals are “in the system” (meaning, once they are in care), resources are available to assist and keep these individuals in care. Regardless, they report that barriers remain for people who are at high risk or currently living with HIV to access services, both HIV- and non-HIV-related.

Some issues, such as stigma, health literacy, and continuous access to basic life resources (e.g., secure employment, housing, health insurance), are not directly related to HIV, but have a direct impact on the quality of life people living with HIV can have. A few clients and most key informants acknowledge that these issues require a broader, more comprehensive and coordinated approach and that they may be outside the scope of the AIDS/HIV Program.

Other issues, such as use of different prevention strategies, availability of PrEP, and development of peer support networks, may require additional internal discussions and collaborations among community members, agencies, and local and state health departments. Shifts in budgeting and prioritizing may need to occur in order to address the sentiments echoed by clients and key informants.

Details from this report will be used to identify and assist in the development of goals, objectives, strategies, activities, and resources for Wisconsin’s HIV Integrated Prevention and Care Plan. A condensed summary of this report will be included in the Statewide Coordinated Statement of Need section of the HIV Integrated Prevention and Care Plan. A summary will also be made available to partner agencies, key informants, and community members.

LIMITATIONS

The data collection process for this qualitative needs assessment has several limitations.

Key informants were identified by state AIDS/HIV Program staff and were based on who the Program thought were most knowledgeable and comfortable with the primary population being served, people living with HIV.

For clients to participate in the survey, the AIDS/HIV Program depended on grant-funded agencies for client referrals. While efforts were made to ensure specific groups were represented (Black MSM, people of color, individuals living in Milwaukee, etc.), all clients who were referred by a grant-funded agency were offered an interview. As a result, certain groups may be overrepresented and others underrepresented.

Interviewers' methods of compiling notes and data differ from interview to interview. Interviewers may have taken hand-recorded notes or entered them electronically via computer. The style of note-taking may have affected interviewees' comfort level and conversation style during the interviews.

APPENDIX

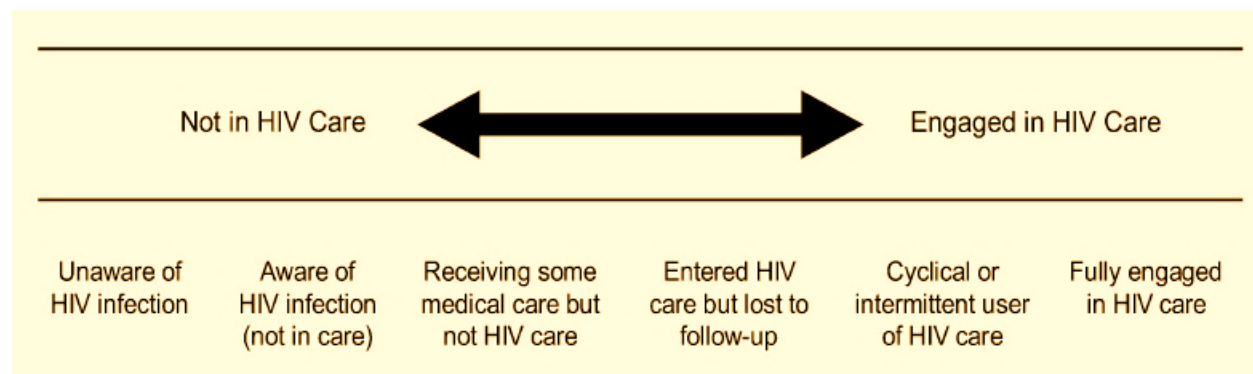
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HIV Care Continuum

HIV Care Continuum

The HIV care continuum—sometimes referred to as the HIV-treatment cascade—is a conceptual model representing the sequential steps or stages of HIV medical care that people living with HIV go through from initial diagnosis to achieving the goal of viral suppression (a very low level of HIV in the body). In addition, care continuum data shows the proportion of individuals living with HIV who are engaged at each stage. The continuum has become a routine tool for federal, state, and local agencies to:

- Monitor engagement in care and health outcomes.,
- Identify health disparities.
- Prioritize strategies and interventions.
- Evaluate the impact of prevention, care, and treatment initiatives.



In prioritizing needs assessment efforts within the context of the HIV care continuum, the Wisconsin AIDS/HIV Program will focus the 2015 needs assessment on the following priority HIV-positive populations:

- Persons unaware of their infection.
- Persons aware of their infection but not linked to HIV medical care.
- Persons not retained in HIV medical care.
- Persons not virally suppressed.

Key Informant Tool

Key Informant Interview Tool

Name:

Agency Name and Location:

Interviewer:

Date:

Good afternoon, my name is _____ and I'd like to thank you for your time today. As part of its HIV planning process, the Wisconsin Department of Health Services AIDS/HIV Program is conducting their statewide needs assessment. This needs assessment helps us at the state level to identify service gaps, develop comprehensive plans for prevention and care, and create strategies for addressing these needs. We appreciate this opportunity to hear about your experiences working with persons at risk and persons living with HIV (PLWH) individuals.

First, I'd like to ask you a question about the challenges and barriers that HIV positive individuals face along the HIV care continuum.

What are some barriers that HIV-positive individuals face when trying to access services related to HIV, such as...

- Getting tested?
- Obtaining medical care?
- Staying in care?
- Becoming virally suppressed?

What prompts PLWH who have stopped receiving medical care to come back to care?

What are common concerns your patients/clients have about their HIV-related services?

Examples include appointment times, insurance coverage, paperwork, LGBT sensitivity issues, etc.

What unique challenges or barriers do you notice for the specific populations you work with, such as men having sex with men (MSM), drug users, or people of color?

- How is HIV testing different for women, MSM, and drug users?
- How is HIV treatment different for women, MSM, and drug users?

Now, I'd like to ask more specifically about your role in the HIV care continuum.

How do you stay current about services available to your HIV-positive patients/clients at other agencies?

How would you describe your comfort level in discussing risk behaviors with your patients/clients?

For physicians, NPs, PAs only: Where do your patients receive their primary care?

The AIDS/HIV Program contracts funds to support HIV prevention and care services. HIV prevention services include condom distribution, targeted testing, and awareness campaigns, whereas HIV care services include outpatient medical care, oral health care, mental health services, outpatient AODA services, medical care management, legal services, housing assistance, and medical transportation. The next questions pertain to the range of these services.

Which services do your patients/clients utilize the most?

Which services are most critical for addressing the needs of patients/clients? Why?

Which services do your patients/clients need but are unable to access? What are the reasons they can't access them?

What other services would your clients benefit from if they were made available?

What needs are specific to certain populations, such as men having sex with men (MSM), drug users, or people of color?

How could we strengthen communication among agencies regarding services that are available to PLWH in the community?

As a person who works in HIV care and prevention, I'm sure you have some ideas about what is working well and what can be improved on.

What is working well?

What should we prioritize for improvement?

What are ways that you/your agency can facilitate improvements for HIV prevention and care?

What can we at the AIDS/HIV program do to improve HIV prevention and care?

We're looking for ways to engage our community members.

What can we do to solicit input from community members who are directly affected by HIV?

Would you be willing to assist us in our efforts to recruit persons who are HIV positive to provide their perspective for our needs assessment?

Do you have any thoughts, suggestions, or ideas you'd like to share with us at this time?

Client Interview Tool

First, I'd like to ask you some general questions about challenges you, your friends, or family have faced or when it comes to receiving HIV prevention and care services.

What are challenges people experience when trying to access services related to...

- Getting tested?
- Getting HIV medical care?
- Staying in HIV medical care?
- Taking HIV medication?

When it comes to receiving HIV-related services, whether that is receiving an HIV test or getting medical care at a health care agency, what are concerns people have?

Examples include appointment times, insurance coverage, too much paperwork, cultural competency issues, etc.

Please think about HIV testing and medical care services. If you could make one improvement, what would it be?

Now I'm going to ask you questions related to the services you, your friends, or family may have experience with. The services can be HIV specific such as HIV testing, medical care management, and medication assistance programs. They can also be non-HIV specific like dental care, housing assistance, food pantry, and mental health.

What services do people who are at high risk for HIV or are HIV positive use the most?

What are some services people need but can't access? Why are these services are so difficult to access?

What other services would people benefit from if they were made available?

Is there anything else you'd like to share with us at this time?