

# WISCONSIN AIDS/HIV PROGRAM NOTES

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## Needs Assessment Qualitative Report: Summary of Findings from Client and Key Informant Interviews

As a condition of funding by the federal Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA), the Wisconsin Department of Health Services (DHS) AIDS/HIV Program is required to submit an Integrated HIV Prevention and Care Plan for the period 2017-2021. The Integrated Plan must include a Statewide Coordinated Statement of Need (SCSN) and conduct other needs assessment activities in order to:

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

This issue of *Wisconsin AIDS/HIV Program Notes* summarizes the findings from client and key informant interviews that were undertaken by the Wisconsin AIDS/HIV Program in developing an Integrated HIV Prevention and Care Plan for 2017-2021.<sup>1</sup> The full and in-depth qualitative needs assessment report is available on the website of the Wisconsin Department of Health Services at <https://www.dhs.wisconsin.gov/publications/p01221.pdf>.

### Overview of the process

As part of needs assessment activities, the AIDS/HIV Program collected information examining the needs of clients 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 in Wisconsin.

Clients were individuals who have ever received HIV prevention and/or care services at an HIV-related agency. Most clients interviewed were living with HIV. Other clients were persons at high risk for HIV. Key informants were service providers and others who have insight into the lives of people who have or are at high risk for HIV.

### Clients

The AIDS/HIV Program worked with key informants and their agencies to recruit clients for interviews by requesting them to identify clients who would be interested in speaking about their HIV-related experiences in exchange for a 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.

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<sup>1</sup> Melody Yee, former Centers for Disease Control and Prevention Public Health Associate, and Kathleen Krchnavek, HIV Prevention and Policy Specialist, Wisconsin State Laboratory of Hygiene, were lead staff in planning and implementing the qualitative needs assessment and developing the qualitative needs assessment report.

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

Most client interview questions were similar to interview questions of key informants. However, clients and key informants differed qualitatively in several areas: comfort levels during the interview, consensus about the barriers and needs of clients, comments regarding agencies and their services, and perception of health successes.

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

- *Stigma and shame:* Clients revealed feelings of stigma and shame regarding how people became infected and regarding 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 an 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.
- *Lack of HIV education among providers:* Clients reported a need for health care provider education to increase provider knowledge and skills in managing HIV infection and effectively communicating with clients.
- *Mental health and alcohol and other drug use (AODA) issues:* Clients have mental health and AODA issues of 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 were 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.

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- *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 health care system isn't interested in developing a cure because of profits to be made from HIV.

### **Key Informants**

Between February and July 2015, 46 key informants were identified and interviewed by AIDS/HIV Program staff. Interviews were conducted in person or over the 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 key informants worked in Milwaukee (68%) and had previously worked or were currently working in a field related to HIV prevention and care (98%).

Key informants reported the following barriers related to HIV prevention and care:

- *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 non-funded state agencies, 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 is feeling sick, needing support or follow-up, having new motivating factors, or change in a life situation. Key informants also reported clients 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 clients:

- 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

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Services that are needed but with limited access and availability:

- Housing
- Transportation
- Distribution of pre-exposure prophylaxis (PrEP)
- Support systems/groups
- Prevention services
- Hepatitis C treatment

Because many key informants have worked in the HIV field for many 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 clients. Their responses varied depending on their agency affiliation and professional roles, but several key themes emerged, including the following:

- In general, the AIDS/HIV Program 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 for individuals 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 people.
- Prevention needs more emphasis, 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 clients connect with and stay in HIV medical care.

### **Summary**

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 agreed that once people are "in the system" (meaning, once they are in care), there are resources available to assist and keep them in care. Nevertheless, clients and key informants 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 care insurance), are not directly related to HIV but have direct impact on the quality of life of people living with HIV. A few clients and most key informants acknowledge that these issues require a broader, more comprehensive and coordinated approach.

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

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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.

The complete report of the qualitative needs assessment, *Wisconsin HIV Needs Assessment Qualitative Report: Findings from Client and Key Informant Interviews*, is available on web at <https://www.dhs.wisconsin.gov/publications/p01221.pdf>.

Findings of the qualitative needs assessment 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, which will be submitted to the federal funding sources in fall 2016.

