

targetHIV.org/IHAP

Assessing Needs, Gaps, and Barriers Washington State Statewide Coordinated Statement of Need

REGION	West
PLAN TYPE	Integrated state/city/county prevention and care plan
JURISDICTIONS	State of Washington and King County/Seattle TGA
HIV PREVALENCE	Medium

The needs, gaps, and barriers section of the Washington's Statewide Coordinated Statement of Need, which includes the Seattle/King County TGA, provides a concise description of their collaborative process to develop and conduct activities to collect information regarding needs, gaps, and barriers to HIV treatment and services, including consumer interviews, consumer surveys, case manager interviews and surveys, regional focus groups and End AIDS Initiative listening sessions. In addition to seeking input from those PLWH in care, they also collected input from PLWH not in care, persons at higher risk from infection, and people experiencing HIV-related health disparities. A unique aspect of this section was that they provided a "wordle" to illustrate the responses to the consumer and staff survey of service gaps and needs. They also provide a brief, but thoughtful discussion of the state's service needs and existing barriers.

SELECTION CRITERIA: ASSESSING NEEDS, GAPS, AND BARRIERS

Exemplary Assessing Needs, Gaps, and Barriers sections met the following criteria (based on the Integrated HIV Prevention and Care Plan Guidance):

- Includes description of the process used to identify HIV prevention and service needs of those at risk and PLWH
- ☑ Demonstrates engagement of those at risk and PLWH in planning
- ✓ Clear and robust description of service needs
- ✓ Clear and robust description of service gaps
- Clear and robust description of barriers (social, policy, health department, program, service provider, and client barriers).



Additional exemplary plan sections are available online: www.targetHIV.org/exemplary-integrated-plans

D. Assessing Needs, Gaps, and Barriers

Process

A collaborative process was used to develop the Integrated SCSN/Needs Assessment. The process used to collect the data was developed by the SCSN Steering Committee. This committee consisted of consumers, HIV Planning Ryan White A Program staff, WA State DOH Program Staff and Epidemiologists. Members of this team created a process to ensure consumer input that was representative of Washington State. Opportunities for input were provided by consumers receiving services from RW Part A & Part B as well as prevention services. Communities provided information regarding current HIV prevention and care services and those that are needed. In addition to seeking input from individuals familiar with the current HIV service delivery system we also attempted to gather information from

- PLWH who know their HIV status, but are not in care
- Persons at higher risk for HIV infection
- People experiencing HIV-related health disparities

This community input gathered was in addition to data gathered by PHSKC & WA State DOH HIV Assessment Units to complete the Epidemiological Profile. It consisted of the information from consumer interviews, consumer surveys, case manager interviews, case manager surveys, regional focus groups, and End AIDS Initiative listening sessions. The End AIDS effort provided multiple opportunities to reach PLWH, individuals at

risk for HIV, medical providers, supportive service providers, and other stakeholders. Input was received from all parts of the state and all communities affected by HIV. Feedback methods included an open-ended survey (available in English and Spanish.) One hundred thirty-seven responses were received. Six community forums were held around the state, in Seattle, Tacoma, Everett, Spokane, Yakima and Vancouver, as well as targeted community conversations. Through all of these methods, approximately 350 people provided invaluable feedback.

End AIDS Initiative

On World AIDS Day (December 1, 2014), Governor Inslee issued a proclamation to End AIDS in Washington. He set a goal of reducing new HIV diagnoses by 50% by 2020 and reducing disparities in health outcomes for PLWH. The proclamation tasked the HIV Planning Steering Group (HPSG), the statewide HIV treatment and prevention planning body, with overseeing a task force to put forward a set of recommendations on how the state can achieve the goals of the proclamation. The HPSG established the End AIDS Steering Team ("Steering Team") to engage in a community input process and draft the initial set of recommendations. The Steering Team included PLWH, staff members of CBOs, an HIV medical provider, public health representatives, and community members from Eastern and Western Washington. The End AIDS Initiative is an integral component of all planning activities in Washington State.

Service Needs

Clients expressed numerous service needs throughout this process, most of them focused on whole person solutions. The conversations which occurred as part of the community information gathering process clearly depicts clients which have complicated lives and need services that can be tailored to their specific circumstances. One size does not fit all.

Figure 1. Word picture created from consumer and case manager survey responses May2016



Service Need Listing from Brainstorm that Created Woordle (alphabetical)

- ACCESS TO MEDS
- CASE MANAGEMENT
- DENTAL: Should deal with whole person, not just what their insurance covers. For example, one client needed extensive dental work done, but plan would only cover teeth being pulled, so just the teeth were pulled and no other care was given.
- HOUSING: Not able to get affordable, low income housing. Some clients are not eligible for Section 8 housing. They were given a voucher for 2 months and then an extension, but then was kicked out of housing.

Rental assistance, then would like housing that is up to health codes.

Housing options were extremely limited for justice involved individuals

Housing with no income requirements. Clients would like special funding for last months rent and deposit rent so that they can get into housing. Emergent situations. One example was partners/ two people whom separate...once person gets to stay in the housing and the other has to leave (become homeless).

Credit checks are an issue with getting housing.

- INSURANCE: Some clients still find it difficult to access and keep insurance coverage
- MENTAL HEALTH: Not enough visits per year are covered.
- LIFE INSURANCE
- PEER GROUP SUPPORT: Peers who have experience of HIV and how to get information out to others in the community.

Service Gaps

Routine Standardized HIV Screening for All Washington Residents

HIV testing is a cornerstone for HIV prevention and care, and a critical component of both the NHAS and Washington State's plan to End AIDS. Diagnosing people with HIV leads to long-term behavior change; allows at-risk HIV-negative persons the opportunity to consider PrEP, which can decrease the risk of transmitting HIV by 92 percent; and allows infected persons to initiate life-saving antiretroviral therapy, which can decrease the risk of transmitting HIV by 96 percent.

Stigma

One in Ten Washingtonians Living with HIV Are Undiagnosed Too many PLWH are unaware of their infection. The Washington State Department of Health (DOH) estimates that approximately one in ten PLWH in the state are undiagnosed. These individuals face the adverse health effects of untreated HIV infection and have the potential to unknowingly transmit HIV to others. In many instances, undiagnosed persons may not identify themselves as being at high risk for HIV, or may encounter stigma that inhibits them from testing or revealing risk behaviours to medical providers.

Access to Pre-Exposure Prophylaxis (PrEP)

Pre-exposure prophylaxis (PrEP) offers at-risk individuals a new tool for taking an active role in keeping themselves HIV-negative. PrEP involves taking a single pill (Truvada® [emtricitibine/tenofovir]) every day to avoid HIV infection. When taken consistently, PrEP reduces the risk of HIV infection in people who are at high risk by up to 92 percent. Based on this high level of protection and in recognition of the need for additional effective interventions that protect people from HIV, the updated 2015 U.S. NHAS includes PrEP as one of its four pillars of HIV prevention. The CDC likewise recommends that PrEP be used as a prevention tool for people who are at substantial risk for HIV, including persons in serodiscordant relationships, gay and bisexual men who have sexual partners of unknown HIV status, and persons who inject drugs. The 2015 DOH and PHSKC PrEP Implementation Guidelines further define characteristics of patients at high risk for HIV infection who are potential candidates for PrEP.

Healthcare Systems that Meet the Needs of Sexual Minorities

Gay and bisexual men have specific healthcare needs and our success in ending the HIV epidemic requires a greater effort to meet those needs. While national guidelines recommend that all Americans test for HIV at least once in their lifetime. both CDC and local guidelines in Washington State recommend that most gay and bisexual men test at least annually and that selected groups of gay and bisexual men test as often as four times a year. These guidelines also recommend that gay and bisexual men test frequently for other sexually transmitted infections.

Additionally, transgender/non-binary individuals have specific healthcare needs and providers and systems need to be better trained to provide responsive care in a welcoming environment. Furthermore, transgender/non-binary individuals, particularly transgender women of color, are disproportionately likely to be at risk for HIV. Integrating gender-affirming care and HIV prevention or treatment are essential to meeting the needs of the transgender/non-binary community.

Prevention, Care and Treatment Options for Substance Users, Including Persons Who Inject Drugs

Substance use undermines the success of HIV treatment. In King County, over half of all persons who are out of care use substances, and approximately 25% identify substance use a reason for their inability to receive care or for discontinuing their HIV medication. The failure to successfully treat persons who use substances perpetuates the cycle of HIV transmission and undermines the state's efforts both to prevent HIV transmission and avert the morbidity and mortality associated with HIV/AIDS.

Insurance Coverage and Affordable Healthcare for PLWH and Individuals at Risk for HIV

The Affordable Care Act (ACA) has fundamentally altered the health care delivery system and increased Washington State residents' access to medical care. As of 2014, an estimated 89 percent of the state's residents had health insurance. However, even with the advances in comprehensive access to health care, some aspects of the healthcare system still present impediments to the state's goals of ending the HIV epidemic in Washington.

Safe, Stable and Affordable Housing for People Living with and At Risk for HIV

Homelessness is a significant barrier to wellness for PLWH. When a person's primary focus is finding food to eat and a safe place to sleep, treating one's HIV becomes a lower priority. The lack of housing stability can lead to consequences including: missed medical appointments, lost or stolen medications, higher viral loads, worse health outcomes, and increased risk of transmission to others.

Whole Person Healthcare to PLWH

The need for an integrated system of HIV care that provides truly comprehensive services is now more important than ever. The PLWH who remain out of care and unsuppressed often confront tremendously difficult social circumstances exacerbated by complex medical conditions. Mental illness and substance use disorders (SUD) are common among persons living with HIV. Of those enrolled in Medicaid in 2007 who had HIV, fifty percent had a dual diagnosis with substance use disorders or mental illness. The structure of the health care system often creates barriers to successful, comprehensive care. These barriers include; preconditions for entering some systems that make it impossible for whole-person health to be addressed (for instance, you need to be sober to get housing, or you need to have addressed your mental health issues before getting treatment for substance use disorders) structures that require patients to consistently attend appointments or comply with rules that they cannot comply with and stigma. Stigma associated with being HIV-positive, having mental health and/ or substance use disorder issues, being gay, or being a person of color can compound the challenges for these individuals. PLWH over the age of 50 face the additional vulnerabilities of aging. Successfully meeting the needs of the most vulnerable patients requires a willingness and commitment to restructure the health care system. In some instances, this will also require new resources as existing federal programs are not designed to pay for the care of the most difficult-to-treat patients.

Comprehensive Sexual Health Education, and Interventions for Washington Youth

Young people need to have the information, tools, and resources to understand risks and make sound decisions about their sexual health throughout their lives. This is necessary to enable them to protect themselves against sexually transmitted diseases (STDs), including HIV, and unintended pregnancy. Comprehensive, medically-accurate and culturally relevant sexual health education that is LGBT-inclusive equips young people with this information.

Meaningful Community Engagement and Empowerment for People and Communities Disproportionately Affected by HIV-Related Disparities and Stigma

PLWH have been at the forefront of policy and programmatic interventions since the beginning of the epidemic. These efforts have directly contributed to a dramatic increase in HIV awareness, and access to and retention in HIV-related medical care. Many planning bodies, including Ryan White Planning Councils, require representation of PLWH. Yet survey responses and comments in community forums indicate that our public and private sector HIV services could do more to more fully engage and empower PLWH and communities disproportionately affected by HIV. This request for inclusion and leadership opportunities (in design and decision-making) is not only about community empowerment - a worthwhile goal in itself - it is also about making all HIV community services more responsive to community needs and therefore more effective

· Lack of knowledge about HIV: Survey respondents and participants in community forums report a lack of knowledge about and awareness of HIV among affected communities as well as the public at large. This lack of knowledge was seen as contributing both to HIV risk and HIV-related stigma.

Service Barriers

HIV-related stigma and health disparities are most commonly identified as significant barriers to seeking and accessing HIV screening, accessing culturally appropriate healthcare and support services, utilizing HIV treatment or prevention regimens, and staying retained in care.

• Stigma: Stigma was the barrier most commonly identified through surveys and in community forums. The multiple stigmas that affect many PLWH and communities affected by HIV cut across all aspects of the care continuum.

People living with and at risk for HIV often experience multiple and overlapping stigmas. These many include stigma associated with HIV, HIV testing and pre-exposure prophylaxis (PrEP); sexual orientation or gender identity; race or ethnicity; poverty or homelessness; mental health conditions and substance use disorders (SUD); aging (especially for people over age 50 living with HIV) and others. Furthermore, persistent disparities, particularly disparities by race and ethnicity, related to HIV risk, diagnosis rates and health outcomes result in unacceptable health inequities.

- · Social determinants of health, including poverty and its effects: PLWH and individuals at risk for HIV often live in poverty. Housing instability and homelessness, food insecurity, lack of transportation, and other issues related to poverty are significant barriers to accessing and staying in care.
- Healthcare access and costs: Many survey respondents noted the high cost of HIV-related healthcare, as well as challenges accessing culturally responsive HIV medical care providers (including LGBT-sensitive providers), mental healthcare and other specialists, particularly in rural areas.
- Substance use disorder and mental health care treatment needs: Many PLWH and individuals at risk for HIV are also facing challenges with substance use and mental health conditions, as well as challenges with the availability and cultural appropriateness of the services.