

**Treatment as Prevention to End a \$2 Billion Problem:
Expanding Targeted Community Services for Oklahomans
Living with HIV/AIDS**

Executive Summary

Three decades into Oklahoma's HIV/AIDS epidemic, 5,375 Oklahomans are currently living with the virus that causes AIDS,¹ and another 3,917 people that were infected with the disease have died.² The majority of these people live below or near the poverty line. The relationship between HIV disease and poverty is cyclical: the presence of one condition continuously increases the risk for the other.³ While medical advancements in the treatment of HIV/AIDS have significantly reduced HIV mortality rates over the past two decades, the social determinants of health remain as significant predictors for HIV prevention and treatment success, particularly for those who live in poverty.

Many social determinants of health are linked to the risk for contracting HIV and the greater likelihood for poor health and early death after infection. Failure to address social determinants thwarts the success of costly medical treatments, and significantly slows progress in reducing new HIV infections through secondary prevention efforts. To be successful in ending Oklahoma's HIV/AIDS epidemic, community efforts must inclusively address income and education barriers, transportation needs, housing opportunities, food insecurity and poor nutrition issues, mental health and the need for supportive social networks, while also reducing accessibility barriers to quality health care. The Oklahoma State Department of Health has identified significant service delivery gaps in many of these areas, and supports expansion of these services as part of its comprehensive strategic plan for improving the quality of HIV care in the state.⁴

The total burden of HIV infection can be measured through its economic, human, and community costs. Oklahoma's HIV epidemic has incurred an estimated \$2 billion in medical treatment costs for the lifetime health care of the 5,375 people who are still living with this disease (based on a \$379,668 lifetime average cost⁵). These estimates do not include medical costs associated with the treatment of co-morbidities, such as diabetes or kidney disease, nor do they include the lost productivity costs associated with HIV infection. HIV still remains a highly-misunderstood and stigmatized disease, which can prevent affected members of our community from fully integrating into society. Linking people living with HIV/AIDS to supportive and responsive social services can significantly improve health care outcomes, reduce overall medical costs and complications, allow people to reach their full productivity potential, and stop the spread of HIV.

Background to the Problem

Economic Impact. *An estimated 5,375 Oklahomans are living with HIV/AIDS,¹ and the lifetime direct medical costs associated with the treatment of these cases will likely exceed \$2 billion.⁵ In 2013, 437 new HIV/AIDS cases were diagnosed in our state,⁶ translating to an estimated \$166 million dollars of incurred future medical care costs from new infections this past year alone.⁵*

Delayed linkage to treatment⁷ and poor retention in regular medical care (i.e., medication non-adherence) are risk factors for costly HIV-complications, including AIDS and medication resistance.⁸ For example, the total monthly costs of HIV treatment are more than doubled once a patient's CD4 T-cells dip below 50 cells/mm³, a stage in HIV disease that often requires more medications and hospitalizations to manage AIDS-related side effects.⁹ Elevated HIV viral loads, another marker of suboptimal treatment, is also associated with higher costs of medical care.⁹ Because 80-90% of all HIV patients can achieve a suppressed viral load with early access and regular adherence to HIV medication, and since CD4 cells can be preserved and even improved at this same time, opportunities for cost savings in the treatment of HIV/AIDS rely heavily on a patient's ability to connect with care and remain fully adherent to available treatment options.¹⁰ Early HIV treatment and viral suppression can reduce the risk of HIV transmission to an uninfected partner by 96%, which presents an opportunity for additional cost-savings through the prevention of new cases of HIV.¹¹

People living with HIV/AIDS (PLWHA) are more likely to experience chronic health disorders compared to their HIV-negative counterparts, including cardiovascular disease, sudden cardiac death, insulin resistance, and bone disorders.¹² These health burdens are directly and indirectly driven by HIV infection and the side effects associated with its treatment, which further contributes to the economic toll of HIV infection on our health care system. The benefits of a healthy diet,¹² physical activity,¹² stress management,¹³ and smoking cessation¹⁴ all have positive impacts on disease outcomes for PLWHA, which can lead to potential cost-savings in the long run.

PLWHA:

People living with HIV/AIDS

Drivers of high health care costs:

- Poor medication adherence
- Low CD4 T-cell count
- Unsuppressed (high) HIV viral load

HIV viral load:

The number of copies of the HIV virus per mL of blood. As viral load increases, HIV damages CD4 T-cells, and eventually AIDS develops.

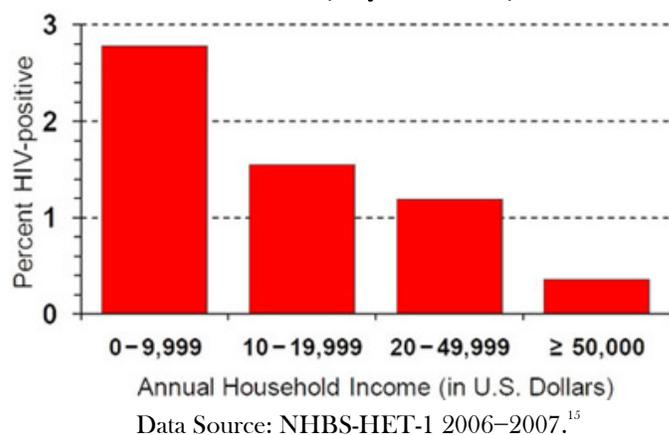
Viral loads can be suppressed in ~85% of all PLWHA if medications are taken regularly without interruptions in treatment.

Human Impact. *PLWHA are more likely to live in poverty,¹⁵ suffer from mental health¹⁶ and substance abuse disorders,¹⁷ experience food insecurity¹⁸ and housing instability,^{15,19} and to have a limited education.¹⁵ When these factors are coupled with the stigma and discrimination that accompany HIV/AIDS in Oklahoma²⁰ and throughout the U.S., opportunities for self-sufficiency and economic vitality are further compromised. The estimated costs of lost individual productivity associated with HIV infection exceeds four times the medical costs associated with HIV treatment,²¹ and minorities disproportionately experience the greatest burden of these productivity losses.*

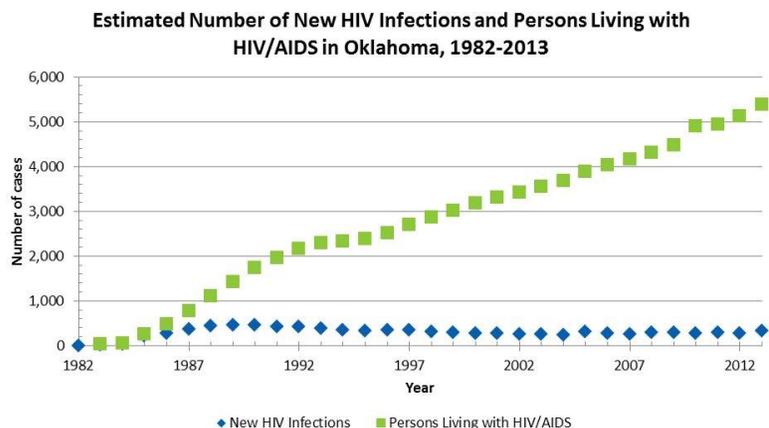
HIV Stigma:
Refers to prejudice, negative attitudes, abuse and maltreatment directed at people living with HIV/AIDS. Stigma is associated with negative self-image, depression, social isolation, and reduced life opportunities for PLWHA.

People living in poverty who suffer from mental illness or past traumas are more likely to use substances to self-medicate symptoms, which in turn leads to behaviors that place one at risk for contracting HIV,^{22,23} and if one is infected, spreading HIV to others. People living with HIV/AIDS are more likely to have experienced traumas as young children,²² and are more likely to experience major depressive disorders as adults.²⁴ Certain minority groups are also more likely to experience greater levels of homophobia, poverty, and racism, which complicate the successful management of depression and anxiety disorders.²⁵ These social determinants of health play a considerable role in determining the success of HIV medical treatment efforts, and therefore must be included as part of a comprehensive response to Oklahoma’s HIV epidemic. Programs that address these factors will not only improve the success rates of HIV treatment, but they can support PLWHA in reaching their full human potential.

HIV Prevalence Rate, by Income, within Urban Poverty Areas



Community Impact. *As life expectancy increases, HIV prevalence rates climb. The growing number of PLWHA in Oklahoma living at or near poverty place additional stressors on our current system of HIV care due to increased demands for social and medical services. At the beginning of the HIV epidemic, communities pulled resources together to provide programs that were focused on palliative care and other end-of-life services. As the focus of HIV treatment shifts from acute to chronic disease management strategies, communities that wish to be successful in managing today's HIV epidemic must now implement effective programs that keep patients engaged in treatment from the time of diagnosis and for the duration of their lifetime.*



In 2014, Oklahoma reached the highest HIV/AIDS prevalence rate in the history of the state, reflecting an increasing trend that began in the mid-1980s. Oklahoma is experiencing the largest demand for medical and social services, yet the capacity of HIV/AIDS organizations have not significantly expanded in the past decade. It is critical that medical and social service programs focus on cost-effective strategies to reduce the economic burden of HIV disease in our community in order to maximize the benefits of program services that operate on a finite amount of resources. Of equal importance, the community response to the state's epidemic must be inclusive. Nonprofits, private and public organizations, medical providers, PLWHA, and other community stakeholders are all essential components of our community that have the potential to provide collaborative solutions to this issue.

Special populations. HIV is disproportionately affecting communities of color in Oklahoma, which already face economic disadvantage. Blacks had the highest rate of newly diagnosed HIV/AIDS cases in 2013 with a rate that was four-fold that for the entire state.⁶ Black females are being affected the hardest: the HIV incidence rate for black women was 7.8 times higher than the rate for white females in the same year. Hispanics and American Indians are also disproportionately impacted by new HIV/AIDS cases compared to whites.⁶ While the primary reasons for these rates are due to socioeconomic disparities between people of color and whites, it is important to still consider the importance of offering safe spaces for these groups to access care and the need to address any special population needs during service delivery.

HIV Care as HIV Prevention: An Effective Strategy to Stop the Spread of HIV/AIDS

The HIV Care Continuum: HIV Treatment as HIV Prevention. While there is no cure for HIV/AIDS, advances in its treatment now give patients the opportunity to chronically manage their disease, and if successful, the chance to have near normal life expectancy. Life expectancy after HIV diagnosis doubled from 10.5 years to 22.5 years between 1996 and 2005, with the average HIV positive individual gaining these 12 additional years due to advances in HIV medication options.⁹⁶ However, this ideal health trajectory following HIV diagnosis is dependent on a number of factors including: immediate *linkage* to medical care after diagnosis, regular access to medical care every 1 to 6 months (*retention*), daily adherence to HIV medication, and resources to access medical care including the financial means to afford transportation, physician visits, and drug costs, as well as the other necessary skills needed to navigate a complex health care system. Successful patients who can achieve these requirements can expect higher CD4 T-cell counts (i.e., a healthy immune system) and a suppressed HIV viral load (i.e., lower copies of the virus in the blood stream)—factors that will greatly slow disease progression, reduce one’s likelihood of developing AIDS, and stop the spread of HIV.

Those patients who are unable to remain engaged in care are more likely to experience hospitalizations, to develop secondary infections and other AIDS related immune disorders, and as a result, can expect a significantly lower life expectancy. The negative implications for poor engagement in medical care also extend beyond patient-level outcomes: the number of new infections in communities is directly related to the proportion of patients who have fallen out of care and the proportion of patients with high viral loads.²⁷ The early initiation of HIV treatment significantly reduces the likelihood of sexual transmission of HIV, and can reduce transmission rates to an uninfected partner by 96%.¹¹

This powerful relationship between retention in care and prevention of new cases has led the Centers for Disease Control and Prevention and the Joint United Nations Programme on HIV/AIDS (UNAIDS) to establish viral load suppression benchmarks for communities as a primary strategy for curbing new infections.^{28,29} Yet, the great potential of HIV treatment hangs on a number of contingencies.

Unlike the course of some chronic conditions that can be re-corrected if a patient temporarily falls out of care, such as high blood sugar levels in a diabetic, sporadic management and interrupted access to medications even once during an HIV patient's life course can translate to devastating changes in a his or her disease trajectory. Multiple missed doses can lead to HIV resistance to medications³⁰ which may eliminate a full class of treatment options. Many of the leading causes of missed doses can be traced back to social determinants of health: inadequate housing, food insecurity, mental health and substance abuse, social isolation, and poor literacy.

Women in general, as well as black and Hispanic males are less likely to equally benefit from gains in life expectancy and more likely to have detectable viral loads;²⁶ this is likely due to lower adherence rates and lack of routine medical care that are driven by the higher rates of poverty, HIV stigma, and poor education in these groups. To stop the spread of HIV in our community, comprehensive programs must address the social determinants of health for at-risk patients to ensure all people access care immediately following HIV diagnosis and can remain in care for the duration of their life.

National HIV treatment cascade. In the U.S., only 25% of all people living with HIV/AIDS have achieved an ideal health trajectory as defined by a suppressed viral load.²⁹ A majority of people infected with HIV have not been linked to treatment or only receive sporadic or infrequent medical care, experience social and financial barriers to medication adherence, and as a result, have a weakened immune system (i.e., a low CD4 T cell count) and/or a high HIV viral load. The costs associated with delayed entry and interrupted access to care can directly drive inpatient health care costs, which are significantly higher in groups with low CD4 T-cell counts.⁹ The Ryan White system of care, which provides low-income clients with access to social and medical services, has achieved higher rates of retention and viral suppression compared to other national estimates, yet disparities exist within this system, in particular for youth aged 13-34 years and racial minorities.³¹

Oklahoma’s treatment cascade. Recent efforts by the Oklahoma State Department of Health to estimate the status of Oklahoma’s treatment cascade suggest we fare better than the national average for both retention in care and viral suppression for those people who have been linked to care; this success is likely due to the combined efforts of the state’s Ryan White-funded medical and social programs along with the comprehensive set of social services that are available to PLWHA through AIDS services organizations (ASOs) in our state, including housing, nutrition, mental health, and intensive case management services. Yet, our success is limited by the capacity of these programs—still only half of all people with HIV in Oklahoma receiving treatment have achieved a suppressed viral load. Suboptimal rates of viral suppression can be directly linked to poor medication adherence, which studies suggest is influenced by food insecurity, housing instability, and education. An estimated two-thirds of all PLWHA in Oklahoma who access Ryan White-funded services are food insecure,²⁰ and an estimated 15-20% are unstably housed at any point in the year. These social determinants must be addressed through supportive food, housing, and economic stability programs if we expect to achieve benchmark goals for 90% of all PLWHA receiving treatment to achieve viral suppression by 2020.²⁸

Linkage to Care: Entry into medical care after an HIV diagnosis is made.

Oklahoma’s linkage to care rate by 3 months of diagnosis: 64%

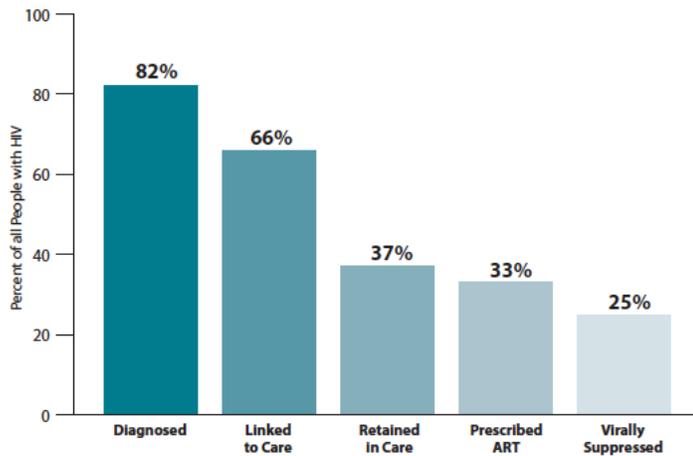
Retention in Care: Regular receipt of HIV primary care services after diagnosis.

Oklahoma’s retention in care rate: 58%

Viral Suppression: When copies of the HIV virus fall below 200 copies per mL.

Oklahoma’s viral suppression rate: 49%

OVERALL: Of the 1.1 million Americans living with HIV, only 25 percent are virally suppressed.



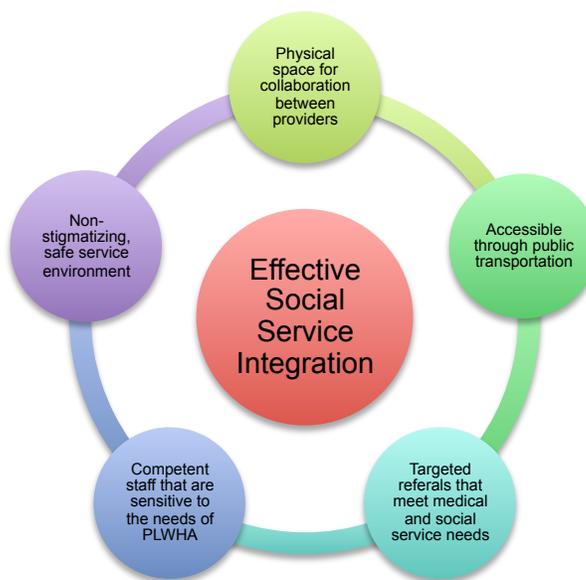
The Essential Role of Integrated Social Services

Experts project the burden of caring for the growing number of HIV-positive people who also have other co-morbidities will require concentrated medical and community-based efforts that integrate HIV services at the community level.³² Communities must provide adequate supportive services to address the social determinants of health in order to maximize the success of costly medical efforts.

PLWHA who receive social support from people within their communities experience greater health-related quality of life, including gains in mental and physical health.^{33,34} Opportunities for social inclusion and support protect PLWHA from social isolation and support healthy integration in society.^{35,36} AIDS services organizations (ASOs) provide a gathering place for people affected by and living with HIV/AIDS to receive such support. These environments provide PLWHA with support to practice healthy behaviors while discouraging risk behaviors such as substance abuse. The effect of an inclusive community (when measured as social capital) is so powerful that it may protect against HIV infection rates at the population level.^{36,37} Communities wishing to build social capital must offer opportunities for healthy socialization and other community involvement that establish community trust.

Elements Required for Social Service Integration. The characteristics of *AIDS services organizations (ASOs)* can make a significant impact on the success of medical efforts, patient quality of life, and community HIV prevention efforts. Clients receiving services from organizations that are “highly integrated” are more likely to experience higher CD4 gains over time compared to clients who receive services from providers with low service integration.³⁸

Successful integration of social services across the HIV continuum of care requires ASOs: 1) to have established mechanisms in place that support networking and collaboration between the ASO and other agencies; 2) to deliver quality services that are accessible by public transportation; 3) to provide appropriate referrals and facilitate linkage to care; 4) to employ staff that are highly competent in the specialized needs of PLWHA and that have strong relationships with referral sources, 5) to provide services that are perceived by clients as non-stigmatizing.³⁸



AIDS Services Organizations (ASOs):

Community-based organizations that deliver social services to PLWHA.

Evidence-based services offered by ASOs that can improve health outcomes for PLWHA include: case management, mental health and support groups,³³ housing, nutrition, employment services, and health literacy programs.

The case for coordinated care. A systematic review of 28 studies conducted in 2013 recommended HIV case management as a beneficial model of care for HIV patients.³⁹ When HIV case management focuses on linking clients to their required health and social services, case management can reduce early patient mortality through its effects on retention and adherence. Furthermore, case management increases success rates for entry, linkage, and retention in HIV medical care. Early case management after HIV diagnosis can increase the likelihood of client linkage to care at 6 months by 40%. Interventions based on supporting patient self-management improves linkage to, and possibly retention in, care.⁴⁰ HIV case management is especially critical for young adults, for newly-diagnosed individuals, and for patients who are food or housing insecure, or who lack adequate transportation.

Case management can address the unmet needs of people that, if left unaddressed, act as legitimate barriers to HIV treatment and promote behaviors that can lead to the spread of HIV disease.³⁹ Ancillary services are significantly associated with an increase in an individual's likelihood of entering medical care and maintaining appropriate medical care services for HIV. Receipt of ancillary services is associated with a three-fold increase in both entry and continuity in appropriate medical care, particularly when the ancillary services match documented needs.⁴¹

Documented ancillary needs for Oklahoma include employment and legal assistance, housing and nutrition services, and transportation. Integrated social service models of care can more effectively link clients to these needs.⁴ The provision of multiple services within one agency to support case management efforts would further benefit outcomes for PLWHA in Oklahoma based on outcomes observed in other states.⁴² Case management that links clients to those resources that meet unmet needs may reduce HIV mortality by keeping clients retained in care, playing a role in CD4 T cell counts through the promotion medication adherence, and supporting overall improvements in physical health.

In summary, support services significantly increase access to and retention in HIV primary care. Social services that are coordinated and integrated as part of the treatment cascade can significantly improve the efficacy of medical efforts. A multidisciplinary team model of HIV care is most beneficial, and health and social services that are tailored to the express needs of patients lead to better care and improved health outcomes.⁴³

Conclusion

Oklahomans living with HIV/AIDS have benefitted from collective medical and social service efforts by providers within our state. These benefits are apparent in the number of PLWHA in our state who have been successfully linked to care and achieved a suppressed viral load compared to the national average. Our current system of care reveals opportunities for significant improvement, specifically opportunities for targeted social service programs that focus on linking and keeping people engaged in HIV treatment by improving those social determinants of health that are fundamental for quality of life. Providing low-income PLWHA with integrated social service that increase their access to food, housing, and economic stabilization programs is a cost-effective strategy that will assuredly improve linkage, retention, adherence, and viral suppression rates in our state, which in turn, will help bring an end to the HIV epidemic in Oklahoma.

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