

# **SAN FRANCISCO HIV ESSENTIAL HEALTH BENEFITS**

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## *SF HIV HEALTH CARE REFORM TASK FORCE*

Just as the Affordable Care Act defines the Essential Health Benefits (EHB) required for credible health insurance coverage in the United States, we herein define the San Francisco HIV Essential Health Benefits (SF HIV EHB) that support the well-being of people living with HIV (PLWH). For over three decades, San Francisco's model of care for PLWH has demonstrated how a compassionate, progressive, organized response by a politically engaged, scientifically astute community results in positive health outcomes for all people impacted by the epidemic. At this time of great change in our nation's health care systems, we pause to codify the body of knowledge that we PLWH, medical and social service providers, advocates, and political leaders have amassed. Through this declaration, we call for sustainment of the comprehensive work required to meet the ever expanding and changing needs of people impacted by HIV.

Over the past eleven years, the number of PLWH in San Francisco has increased by 45%. Currently, almost 16,000 San Franciscans are living with HIV, with approximately 1,000 of them unaware of their HIV+ status. Statewide, approximately one in every 300 persons is living with HIV, while San Francisco shoulders a burden of one in every 50 residents infected with the virus. Roughly one of every four gay men in San Francisco is HIV+. African Americans in our city are infected with HIV at a rate three times higher than their proportion of the population. Homeless residents are four times more likely than people in stable housing to be HIV+ and persons 50+ years of age now comprise over 55% of people living with HIV.

Despite these challenges, San Francisco is ahead of the rest of our nation in preventing, testing, and treating HIV. Nationally, of the more than 1.2 million individuals living with HIV, only 30% are aware of their diagnosis, engaged in care, and taking treatment so that their viral load is undetectable. In San Francisco, 68% of PLWH know their status, are in care, and have an undetectable viral load thanks in large part to the robust local systems of prevention and care. In addition to specialized medical care, San Francisco provides an array of support services to ensure that people with HIV stay in treatment and manage their disease, thereby avoiding costly hospitalization and greatly reducing the chance of HIV transmission to partners.

The comprehensive array of services for PLWH in San Francisco is paid for through a complex web of grants, donations, private and public health insurance, local, and state and federal funding for services for PLWH who are uninsured and underinsured. The Federal Ryan White CARE Act funds core medical services—ambulatory and outpatient care, laboratory services, AIDS pharmaceutical assistance, preventative and wellness services, and medical case management. It also provides for supportive services for people with HIV/AIDS, including home health care, food and nutritional therapy, hospice, home and community based health services, psychosocial support, oral health care, comprehensive mental health services, comprehensive substance abuse services, legal aid, benefits counseling, systems navigation, housing, money management, and emergency financial assistance. While providers and clients may not always need to use every service offered to combat HIV, they are often essential tools in maintaining stability for those affected by the virus.

During the 11-year period that the rate of PLWH increased by 45%, San Francisco lost \$14 million in federal and state funding for essential services for PLWH and this was primarily due

to stagnant federal funding of the Ryan White Care Act. The Mayor, Board of Supervisors, community-based HIV/AIDS service organizations, their donors, volunteers, and employees have nobly stepped up to compensate for these cuts, but let there be no doubt that these funding reductions have negatively impacted the reach of service delivery. Growth in demand for services coupled with the cost of providing them has been met with flat state and federal funding which in truth, means service reductions. It is time to alter this downward curve and to strengthen the existing model of care for PLWH in San Francisco by dedicating ourselves to the preservation of the San Francisco HIV Essential Health Benefits package.

For success in fighting the HIV epidemic, comprehensive services for PLWH must include:

- Ambulatory patient services (primary care; outpatient medical care)
- Emergency services
- Hospitalization (in-patient care; e.g. surgery, overnight hospitalization)
- Residential care facilities for the chronically ill
- Hospice care
- Home health care
- Rehabilitative services and durable medical equipment (e.g., physical therapy, assistive devices)
- Preventive and wellness services (e.g., physical and mental health screenings, wellness counseling, immunizations)
- Pregnancy care and family planning for women and men (preconception, safer conception)
- HIV-exposed newborn services, pediatric, and adolescent HIV care
- Laboratory services
- Prescription drug coverage
- Mental health and substance-related disorder services (counseling, psychiatry, in-patient/residential, medical detox, out-patient treatment)
- Dental care
- Case management, referral, and navigation services (medical and non-medical; support with linkage to and coordination of medical care and support services; chronic disease management)
- Employment services
- Psychosocial support for emotional well-being (structured peer counseling, education, navigation, and referral; support groups, activity groups, volunteer services)
- Peer advocacy and education
- Benefits counseling
- Money management
- Legal services (consultation, referral, and representation on civil matters such as housing, immigration, insurance, access to health care, and public benefits)
- Housing support (emergency stabilization housing, transitional housing, rental subsidies)
- Nutritional therapy, dietary education, food pantry, and delivered meals
- Emergency financial assistance
- Transportation support (affordable mass transit, paratransit, taxi and emergency transportation)

### Appendix A

Wrap-around support services for PLWH are often necessary because of some of the complex challenges that HIV presents in different realms of people's lives, as elaborated briefly below:

#### HIV and Stigma

HIV stigma is a powerful social and community force that affects every aspect of HIV treatment, care, and prevention. HIV stigma is the severe individual, family, community, and institutional rejection, abuse, shame, and discrimination directed at people living with HIV. Some people living with HIV are shunned by their families and communities while others face discrimination in healthcare settings. People living with HIV may face depression, loss of income, housing, rejection and social isolation, and poor treatment by healthcare providers. At its worst, HIV stigma leads to policies that deny people living with HIV their human rights. Stigma creates trauma around an HIV diagnosis and causes people to avoid HIV testing, increasing the numbers of people living with HIV who are unaware of their status. It also increases late-stage diagnosis and the fear of unintended HIV status disclosure decreases engagement in care and treatment adherence. These consequences erode the effectiveness of the system of HIV treatment and prevention. Stigma must be addressed in order to reduce new HIV infections and increase health outcomes for people living with HIV. Effective wraparound support services, such as individual mental health services and social support groups, are needed to assist people living with HIV in dealing with the effects of internal and external stigma. Services for people living with HIV must be accompanied by community- and systems-level stigma reduction. Engaging communities through information awareness and compassion-building activities can help to shift negative attitudes and beliefs. Similarly, changing discriminatory policies that target groups seen to be at-risk for HIV—most often gay men and transgender women, intravenous drug users, and sex workers—can improve the context for people living with and at risk for HIV.

#### HIV and Housing Stability

As the most recent San Francisco HIV/AIDS Housing Plan makes clear, for people living with HIV, housing is health care. Ensuring that people with HIV are housed is also a crucial HIV prevention strategy, as people are much less likely to transmit the virus when they are stably housed and their viral loads are suppressed. The demand for appropriate, affordable housing for people with HIV exceeds the supply. Housing in San Francisco has become increasingly expensive, exceeding the values established by the U.S. Department of Housing and Urban Development's Fair Market Rents and making it difficult for subsidy programs to be implemented effectively. Many of those who are newly diagnosed with HIV are homeless. The high number of PLWH at risk for being homeless, based on being low income and not receiving any housing subsidy is more than ten times the number of subsidies currently available. With additional resources, the City could provide more affordable housing for people living with HIV and prevent additional people living with HIV from becoming homeless.

#### HIV and Access to Healthcare + Treatment

Access to healthcare and treatment through public safety net programs as well as private insurance is a fundamental right for PLWH. Programs such as Medicare and Medi-Cal as well as private insurance plans provide PLWH the preventative and emergency services necessary to maintain and improve health, curb new infections, and reduce the overall healthcare burden on the City and County of San Francisco. In the age of the Affordable Care Act, PLWH have new opportunities for healthcare access, but are faced with unique challenges, particularly with respect to navigating complicated healthcare systems and key healthcare access support

programs such as the AIDS Drug Assistance Payment Program and Office of AIDS Health Insurance Premium Payment Program. These challenges are daunting, and PLWH require healthcare navigation services, benefits counseling and advocacy, and medical case management to overcome these barriers to healthcare and treatment, and ensure equitable access.

### HIV and Substance Use

Substance use has long been identified as a driver of the HIV epidemic. In San Francisco, four substances in specific have been widely acknowledged to contribute to the spread of the virus: alcohol, cocaine, methamphetamine, and poppers. In addition to increasing the risk of HIV transmission brought on by behavioral changes when under the influence, substance use can affect people's overall health and make them more susceptible to HIV infection. In those already infected with HIV, substance use can hasten disease progression and negatively affect adherence to treatment. HIV positive people who use alcohol or drugs are less likely to keep their medical appointments and less likely to adhere to their HIV medication schedule, which can result in higher viral loads and greater likelihood of infecting others. Access to culturally appropriate substance use services is a critical arm of primary care and an essential component of HIV prevention and care.

### HIV and Mental Health

Given the profound impact at every stage of life that living with HIV can have on the emotional wellbeing and mental health of individuals living with the illness, it is essential that PLWH have access to quality, informed, culturally aware mental health services. Some PLWH struggle with mental health issues due to pre-existing psychiatric conditions, co-occurring substance abuse disorders, challenging living environments, or simply due to the negative impact of societal stigma. Segments of society at highest risk for contracting HIV may already have a higher prevalence of anxiety, depression, and a history of substance abuse. Evidence also exists that these conditions are a response to the initial crisis of learning about one's HIV+ status, or to subsequent symptoms and disabilities associated with HIV-related illness. Regardless of its origins, the presence of significant emotional distress and/or psychiatric disorder in PLWH can be an obstacle to staying healthy. Mental health problems can impact medical treatment by negatively affecting medication adherence and overall participation in medical care and by interfering with engagement in healthy activities such as getting enough sleep, exercising, and avoiding risky behaviors. When supported by mental health care providers knowledgeable about HIV's impact on psychosocial wellness, however, PLWH are better equipped to manage their physical health, cope with the stresses of life, work productively, realize their full potential, and make meaningful contributions to their communities.

### HIV and Food Insecurity

Food insecurity is generally defined as the lack of safe, socially acceptable access to sufficient, nutritious food. PLWH are two times more likely to be food insecure in San Francisco. Those same food-insecure PLWH are twice as likely to have unprotected sex and 50% of them will have multiple sexual partners. Food insecure patients are more likely to be infected with HIV, to miss clinic visits, have lower adherence to medications that treat HIV, less viral load suppression, and face higher mortality rates. By providing safe, reliable and equitable access to nutritious food, we are able to improve the health of our clients, reduce the rate of new infections, lower the overall healthcare expense burden, and stabilize a fundamental component of our clients' lives.

### HIV and Aging

In San Francisco, over 55% of all HIV-infected adults are 50 years of age or older, and it is estimated that this threshold will be reached nationwide by 2015. The successful aging of the HIV-infected population and the reduction in HIV-related morbidity and mortality throughout the U.S. is due to the use of effective antiretroviral therapy and is a great accomplishment. However, older HIV-infected adults frequently face multi-morbidity, polypharmacy, and other geriatric conditions such as frailty. Many individuals also struggle with cognitive deficits and psychosocial issues such as depression, anxiety, and social isolation, and thus, need access to high quality social services. Although the aging of the HIV-infected population is a positive trend, older adults with HIV present challenges to the health care system and new strategies are needed for providing integrated HIV and geriatric care to meet the long-term needs of clients with increasingly complex needs.

### HIV and Gender Identity

Transgender people in general and trans women of color in particular, are disproportionately impacted by HIV and AIDS. In a recent meta-analysis (Baral et al, Lancet, 2013) it was reported that trans women in the U.S. were 34 times as likely to be living with HIV than their non-trans male or female adult counterparts. In addition to the high prevalence rates for HIV, and in spite of concerted efforts by SFDPH at improving health outcomes, trans people are less likely to link to and remain engaged with the public health system. Social determinants of health further exacerbate health outcomes for all trans communities. Social bias and the lack of opportunities for academic preparation lead many trans women to experience low rates of meaningful employment, dependence on sex work, and drug use as coping strategies. Gender based violence is rampant and few resources are in place to counter its effect on trans men and women. In order to mitigate these social determinants there will need to be an increase in the number of programs and competently trained medical professionals who are able to respond to the population's specific health care needs.

### HIV and Employment Services

While employment needs and interest among PLWH are high, employment services for vocational rehabilitation have not successfully been integrated into the HIV continuum of care and prevention. Knowledge about and attention to employment services is often limited among HIV service providers and policymakers. In recent years, there has been an increase in awareness of this need at the federal level through the National HIV/AIDS Strategy—bringing attention to the intersection of HIV, poverty, and employment—which highlighted employment among key focus areas for the improvement of health outcomes, and reduction of new infections and health disparities. In San Francisco, over half of the 16,000+ people living with HIV/AIDS are estimated to be unemployed. Employment services and vocational rehabilitation address key structural barriers to engagement in the workforce by PLWH, optimizing treatment as prevention.

### HIV and Incarceration

On any given day between two and five percent of the adults incarcerated in the San Francisco county jails are HIV+. These HIV+ men, women, and transgender prisoners are among San Francisco's most marginalized populations. They are frequently mentally ill and/or substance using, about one-third are frequently homeless, and they are predominantly men of color who have not routinely accessed healthcare services when not in custody. They need access to drug treatment and mental health services and they need housing, food, and health care. If they are

transgender, many of their family ties have been severed and they suffer from isolation and a fracturing of their community with an arrest and release pattern seen frequently in the San Francisco criminal justice system. Rarely is HIV treatment a number one concern for these vulnerable people—more likely, housing, access to food, and legal matters are their primary preoccupation. The dwindling housing supply in the Bay Area, taken in combination with escalating rents, results in a criminal justice system population for whom HIV status, care, treatment, and prevention are secondary to the fulfillment of basic needs. Specialized support services are essential to help this population consistently access contemporary HIV care and treatment and support services in order to break from the cycle of incarceration, release, and recidivism.

### HIV and Immigration

Immigrants living with HIV face a range of challenges. Many have made their way to San Francisco to escape years of persecution and limited access to health care. Undocumented immigrants are specifically excluded from health insurance coverage through the Affordable Care Act. There are no specific studies documenting the needs of immigrants with HIV, but there has been some compelling work done to describe the needs of the Spanish-speaking HIV+ immigrant community in San Francisco, which, in 2012 was estimated to be over 1600 individuals. San Francisco's HIV Health Services Planning Council, the local planning body charged with prioritizing federal Ryan White CARE Act funds, considers this group to be a "special population" because of linguistic or cultural barriers to care, severe poverty, and legal status barriers. Because deportation carries the threat of renewed harassment and the loss of medical care, immigrants with HIV from all countries tend to remain deeply hidden, isolated from the very communities and services that could support them. The challenges and language limitations of these immigrant groups, in addition to the stigma they face as a result of their HIV diagnosis, aggravate an extreme situation of cultural and social isolation. To meet the complex needs of this population, support services providers must be equal partners with medical providers in order to ensure quality support in addition to quality medical care.

### HIV and Culture of Origin

When PLWH enter into the Continuum of Care, they bring their own cultural values and beliefs into the system; it is therefore imperative that PLWH receive care in a safe space from providers who are cognizant of how culture impacts engagement in health care and health behaviors. It is vital that HIV providers adopt cultural competency standards of care. In accordance with the National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (the National CLAS Standards) care setting should "provide effective, equitable, understandable, and respectful quality care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy, and other communication needs." For example, cultural factors may impact attitudes towards medications; sensitivity to these attitudes can have profound implications for adherence to antiretroviral medications and retention in care. It is thereby necessary to sufficiently supply PLWH with appropriate providers, ones who accurately reflect the populations they serve, speak the same language, and respond to cultural needs when addressing key components of care, including education, treatment, and prevention of HIV.

### HIV and Social Isolation

Social isolation relates to both community- and self-imposed isolation, and can be the result of multiple factors including stigma, aging, abuse and reduced overall health. It relates less to the

quantity of relationships than the quality. PLWH who are socially isolated are more likely to engage in unprotected sex, to have lower medication adherence, and are less likely to access medical and social services. Due in part to a lack of trusted supports and struggles with intimacy, they are also more likely to be anxious and depressed, and less likely to disclose their disease status to friends or partners. Long-term survivors are more likely to be single and live alone, and to self-isolate due to health-related issues, including post-traumatic stress and depression. Effective psychosocial support programs and community-building events, coupled with mental-health services, allow PLWH to connect socially and emotionally with their peers and to explore and reconcile root causes of isolative behaviors, all of which form the foundation for the development of lasting relationships.

#### HIV and Pharmacy Access

Community specialty pharmacies play an important role in HIV care including: medication synchronization, adherence counseling, HIV-related benefits navigation support, walk-in pharmacy access, and local delivery services. HIV patients tend to have complex medication regimens from multiple providers requiring specialized attention. The literature has shown specialty community pharmacies improve clinical outcomes in this population. A widely debated issue surrounding mail order pharmacies is whether they can be a means for cost savings. The literature does not show clear outcomes in this respect as many studies show savings in one area, such as a dispensing fee, yet increases in others, for example higher premiums. In 2013, a CMS study showed that mail order drug costs were as much as 83% higher than community pharmacy prices. HIV disproportionately affects marginalized populations, who may benefit from multiple face-to-face interactions and from close coordination between the pharmacist, physicians, and other members of the patient's care coordination team. For homeless patients, mail order is a clear barrier to pharmacy access, and among minority populations the literature shows decreased utilization with mail order, suggesting education and income as barriers to mail order pharmacies. In order to achieve vital HIV medication adherence goals and support retention in and coordination of care, it is important that we maintain community pharmacy access for people living with HIV.

#### HIV and Maternity/Paternity

In the last decade, all babies in San Francisco were born free of HIV—many to HIV+ fathers and mothers. Parenting and childbearing desires are normal and common among those living with or affected by HIV. PLWH or those in a relationship with someone who has HIV, face stigma from family, friends and medical providers surrounding their desires to have children. Supporting those living with HIV with family planning and safer conception options is a critical component of a wellness model, providing opportunities to engage in care and support people with their life goals, while also preventing sexual and perinatal HIV transmission.

Regardless of the source—Ryan White Care Act, Housing Opportunities for People with HIV/AIDS, Section 8, MediCal, Medicare, Covered California, Private Insurance, San Francisco General Fund or other sources—we must ensure peak-level funding focused toward PLWH. Investment of public and private funds focused on the aforementioned Essential Health Benefits is imperative. Maintenance of the San Francisco HIV Systems of Care in the current Affordable Care Act environment through the provision of the San Francisco HIV Essential Health Benefits is vital to the common goal of ending the HIV epidemic.

*SF HIV EHB continued*

*Appendix B*

Acknowledgements

The San Francisco HIV Essential Health Benefits document was created by the San Francisco HIV Health Care Reform Task Force with the input of representatives from the following agencies:

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