

## The Context of HIV/AIDS Housing in the United States

Today, there is more uncertainty in the AIDS housing field than ever before. Limited federal funding, the pervasive lack of affordable housing, the expanding number of people living with HIV/AIDS, and advances in AIDS treatment protocols all impact the planning for, and the provision of, AIDS housing and support services. It is within this context that the *Oregon Balance of State HIV/AIDS Housing Plan* was developed.

### A Brief History of AIDS Housing

In the last fifteen years, AIDS housing has developed to meet the housing and support service needs of people living with HIV/AIDS. The fluctuating nature of the disease suggests that some level of support services—case management, at a minimum, as well as access to community-based medical services—is a necessary component of all types and models of residential programs, whether provided on- or off-site.

The history of AIDS housing dates back only to the mid-1980s. The earliest projects were in “first-wave” communities: New York, San Francisco, and Los Angeles. At that time, no specific funding dedicated for AIDS housing existed, and the projects were developed with funding from local corporations and foundations, churches and faith-based communities, the generosity of individuals, some local government funds, and hours of volunteer labor. Many of these initial projects were small: four- to eight-bed group homes providing independent housing, or small facilities providing hospice care. All relied on volunteers to supplement few, if any, paid staff.

AIDS housing is very different in 2001. Any project that began in the mid-1980s and is still operating today has most likely undergone major physical remodeling and, in many communities, now meets local licensure requirements. Virtually every project that exists today has paid staff, receives government funding, has written operating policies, and would describe itself as targeting one or more specific needs in an overall housing continuum.

While the first providers of AIDS housing were nonprofits newly founded to care for people living with AIDS, in the 1990s much of the development and provision of AIDS housing shifted to mainstream affordable and supportive housing providers, as well as public housing authorities and local governments. The first phase of a national AIDS housing cost study, completed in 1999 by Vanderbilt University, found that nearly 28,000 units of housing in the U.S. are dedicated for people living with HIV/AIDS. Most of these units (17,190) are provided through the use of vouchers, integrating people living with HIV/AIDS into the mainstream community.<sup>4</sup>

---

<sup>4</sup> Rog, Debra, and Sidra Goldwater. *The Landscape of AIDS Housing*. Vanderbilt University. Washington, DC, 1999.

## Funding for HIV/AIDS Housing and Services

Since 1992, when the Housing Opportunities for Persons with AIDS (HOPWA) program was first authorized, the federal government has made available over \$1.27 billion in HOPWA funds to support community efforts to create and operate HIV/AIDS housing and provide related services. In 1992, there were 27 eligible metropolitan statistical areas (EMAs or EMSAs) and 11 states eligible to receive formula allocations of \$42.9 million in HOPWA funds. By 1995, funding had increased to \$153.9 million, but the number of grantees had increased to 66 (43 EMAs and 23 states).

In 2001, \$258 million in HOPWA funds are available for formula allocations and competitive awards. Although the HOPWA allocation increased by approximately \$26 million in FY 2001, additional jurisdictions are eligible to receive funding. A total of 105 jurisdictions—71 metropolitan areas and 34 states—received formula allocations in 2001. The Ryan White Comprehensive AIDS Resources Emergency Act (CARE Act), which provides funding for primary health care and support services for people living with HIV/AIDS, was re-authorized in 2000.

Many AIDS housing and service providers rely on funding from Ryan White and HOPWA to support their programs. The first phase of the AIDS housing cost study referenced above determined that 66 percent of the nation's AIDS housing providers received HOPWA funding for AIDS housing and services, while 55 percent received Ryan White funds. These two funding sources are extremely important to the ability of these agencies to provide AIDS housing and are often used in tandem—44 percent of AIDS housing providers indicated that they receive funding from both HOPWA and Ryan White.<sup>5</sup>

While the number of people living with HIV/AIDS continues to increase, funding for HOPWA and other federal and state housing programs remains under budgetary pressure. More individuals are eligible for and in need of services, and communities are faced with the challenge of utilizing limited resources to meet multiple needs.

## Affordable Housing

In addition to the funding concerns particular to HIV/AIDS housing and services, there is a crisis in affordable housing in the United States. Unprecedented economic growth has not raised all incomes equally, although it has raised housing costs. A recent study found that despite unprecedented economic growth, renters in the bottom quarter of income distribution actually saw their real income decrease from 1996 to 1998, while their rents increased.<sup>6</sup>

In many communities, low-income individuals currently housed in public and assisted housing would face significant challenges if forced to seek housing at market rates. Nowhere in the United States is the minimum wage adequate to afford the local two-bedroom Fair Market Rent.<sup>7</sup> Many people with disabilities rely solely on Supplemental Security Insurance (SSI) as their income, which is equivalent to only about 60 percent of full-time employment at federal minimum wage (\$5.15 per

---

<sup>5</sup> Ibid.

<sup>6</sup> Joint Center for Housing Studies of Harvard University. *The State of the Nation's Housing: 2000*. June 2000. Available online: [www.gsd.harvard.edu/jcenter](http://www.gsd.harvard.edu/jcenter)

<sup>7</sup> National Low Income Housing Coalition. *Out of Reach*, September 2000. Available online: [www.nlihc.org](http://www.nlihc.org)

hour). Nationally, a person depending on SSI must spend 69 percent of their income to rent a one-bedroom apartment, leaving just an estimated \$154 per month for food, clothing, medical, transportation, and personal expenses.<sup>8</sup>

## Complexity of Lives

The housing affordability crisis in the United States has been a driving factor for a burgeoning homeless population. It is estimated that on any given night, 750,000 Americans are homeless, and up to 2 million are homeless at some point each year.<sup>9</sup> Among more than 5,000 people living with HIV/AIDS surveyed by AIDS Housing of Washington in 23 areas around the country since 1993, 41 percent indicated they had been homeless at some point in their lives, and 7 percent of respondents were homeless when they completed the survey.<sup>10</sup>

People who are homeless often have multiple health issues, including mental health problems, substance use issues, and/or HIV infection. It is estimated that 25 percent of single homeless adults suffer from mental illness, while 30 to 35 percent of all homeless adults are abusing drugs or alcohol.<sup>11</sup> Thirty-five percent of AIDS housing consumer survey respondents were disabled by mental illness and 38 percent reported a disability related to substance use issues.<sup>12</sup> The U.S. homeless population has an estimated median rate of HIV prevalence at least three times higher—3.4 percent versus 1 percent—than the general population. Even higher rates (8.5 to 62 percent) have been found among various homeless sub-populations.<sup>13</sup>

Appropriate services and housing for people with histories of homelessness, mental illness, and substance use can make a critical difference in improving health and quality of life. For example, housing stability is often necessary for a person living with HIV/AIDS to gain access to health care and adhere to treatment regimens. Individuals who have had histories of chemical addiction, mental illness, and homelessness often need ongoing support services in order to maintain stable housing. People affected by these issues may need job skills training and ongoing support in order to obtain and maintain employment.

However, providing the level of support that many of these individuals need in order to maintain their housing and income is very expensive. Demands on all of the systems serving people living with HIV/AIDS are increasing and resources for meeting identified needs are not expected to increase significantly in the future.

---

<sup>8</sup> Technical Assistance Collaborative, Inc. (TAC) and the Consortium for Citizens with Disabilities Housing Task Force. "Affordable Housing System Fails People with Disabilities." *Opening Doors*. Issue 11. September 2000.

<sup>9</sup> National Alliance to End Homelessness. [www.naeh.org](http://www.naeh.org)

<sup>10</sup> AIDS Housing of Washington. *Consumer Surveys*. 1993-2000. Areas represented are: Alameda County, Atlanta, Chicago, Contra Costa County, Dallas, Fresno County, Kentucky, Maryland, Orange County, Philadelphia, Phoenix, Pittsburgh, Portland, Oregon, Riverside/San Bernardino Counties, San Diego County, Snohomish County, WA, Utah, Washington, DC, and Washington State.

<sup>11</sup> Kilborn, Peter T. "Gimme Shelter: Same Song, Different Tune." *New York Times*, December 5, 1999.

<sup>12</sup> AIDS Housing of Washington. *Consumer Surveys*. 1993-2000.

<sup>13</sup> Song, John M.D., M.P.H., M.A.T. "HIV/AIDS & Homelessness: Recommendations for Clinical Practice and Public Policy." November 1999. National Health Care for the Homeless Council, Health Care for the Homeless Clinician's Network. p. 1. Available online: [www.nhchc.org](http://www.nhchc.org)

## Trends in the Epidemiology of HIV/AIDS in the United States

The number of new AIDS cases diagnosed in the United States each year has decreased steadily since 1993.<sup>14</sup> AIDS incidence levels are increasing among women, young adults, people of color, and people from rural areas:

- In just over a decade, the proportion of new AIDS cases reported among adult and adolescent women more than tripled, from 7% of cases reported in 1985 to 23% in 1999.<sup>15</sup>
- African American and Latina women together represent less than one quarter of all U.S. women, yet they account for more than three-quarters (77%) of AIDS cases reported to date among women in our country.<sup>16</sup>
- It is estimated that at least half of all new HIV infections in the U.S. are among people under 25, and the majority of HIV-infections among young people are transmitted sexually.<sup>17</sup>
- African Americans represented 47% of the AIDS cases reported in 1999, but are just 12% of the U.S. population.<sup>18</sup>
- In some rural areas of Georgia, Mississippi, and South Carolina, women comprised a quarter of cumulative AIDS cases by 1998, well beyond the national rate of 15%. Still, only about 1 in 16 women with AIDS lives in a rural area.<sup>19</sup>

## Medical Advances in Treating People Living with HIV/AIDS

People living with HIV/AIDS who are successfully being treated with Highly Active Anti-Retroviral Therapy (HAART)—often referred to as combination therapies or the ‘cocktail’—are experiencing significant improvements in health. Many people living with HIV/AIDS are considering re-employment and evaluating the impact that returning to work could have on their disability and medical benefits.

At the same time, however, not all individuals are able to access promising HIV treatments. The medications and monitoring associated with HAART are expensive—at \$12,000 or more each year—putting them well out of reach for people who do not have adequate insurance or access to state-run AIDS Drug Assistance Programs. Studies done in 1996, soon after these therapies were introduced, found that women, racial minorities, and injection drug users were significantly less likely to have access to them. More recent studies show that these disparities have diminished but persist to a lesser

<sup>14</sup> Centers for Disease Control and Prevention, National Center for HIV, STD, and TB Prevention, *HIV/AIDS Surveillance Reports*, Years-End 1993- 1999, Mid-Year 2000. Available on-line: [www.cdc.gov/hiv/stats/hasrlink.htm](http://www.cdc.gov/hiv/stats/hasrlink.htm)

<sup>15</sup> Centers for Disease Control and Prevention, National Center for HIV, STD, and TB Prevention, Division of HIV/AIDS Prevention. “HIV/AIDS Among U.S. Women: Minority and Young Women at Continuing Risk.” Fact Sheet (August 1999). Available online: [www.cdc.gov/nchstp/hiv\\_aids/pubs/facts/women.html](http://www.cdc.gov/nchstp/hiv_aids/pubs/facts/women.html). Updated with AHW tabulations of CDC Surveillance data for 1999.

<sup>16</sup> Centers for Disease Control and Prevention, National Center for HIV, STD, and TB Prevention, Division of HIV/AIDS Prevention. “HIV/AIDS Among U.S. Women: Minority and Young Women at Continuing Risk.” (August 1999). AHW tabulations of Surveillance Report data through the end of 1999 confirm that this continues to be the case.

<sup>17</sup> Centers for Disease Control and Prevention, National Center for HIV, STD, and TB Prevention, Division of HIV/AIDS Prevention. “Young People at Risk: HIV/AIDS Among America’s Youth.” Fact Sheet (August 1999). Available online: [www.cdc.gov/nchstp/hiv\\_aids/pubs/facts/youth.html](http://www.cdc.gov/nchstp/hiv_aids/pubs/facts/youth.html)

<sup>18</sup> Centers for Disease Control and Prevention, National Center for HIV, STD, and TB Prevention, Division of HIV/AIDS Prevention. *HIV/AIDS Surveillance Report*. 1999;Vol. 11, No. 2.

<sup>19</sup> Voelker, Rebecca. *The Journal of the American Medical Association*. HIV/AIDS Information Center. January 7, 1998, vol. 279. “Rural Communities Struggle with AIDS.” Available online: [www.ama-assn.org](http://www.ama-assn.org)

extent.<sup>20</sup> Another study published in 2001 estimated that nearly all of the 750,000 people living with HIV in the United States would have met the criteria for being offered HAART, but that only about 200,000 were using it.<sup>21</sup>

Furthermore, reports suggest that as many as a third of all individuals treated with HAART drugs since 1996 have not seen their health improve.<sup>22</sup> Even individuals who are closely monitored and have their medications adjusted as frequently as every three months are experiencing failure. There is now a growing consensus that continuous HAART therapy is not a viable option, even for those who experience some health improvements, due to the severity of short- and long-term side effects.<sup>23</sup>

## Sustaining AIDS Housing

The focus of AIDS housing providers has shifted from helping people at the end of their lives to helping them transition to living with HIV and AIDS. AIDS housing providers are seeing more and more clients with histories of homelessness, mental illness, and/or substance use, with HIV often secondary or tertiary among a client's concerns. Measurements of success for tenants are more complex: positive outcomes range from housing stability, improved health status, and sobriety, to decreasing use of nonprescription drugs and gaining life skills that may lead to employment.

Much of AIDS housing began as a vision that included a complicated web of paid and volunteer services focusing on compassionate care. Now, AIDS housing is often based on long-term contractual relationships, tenants' ability to pay rent and meet lease requirements, and the provider's community-wide collaborations and multiple funding sources. Providers have not only had to learn to operate permanent housing within the context of landlord-tenant laws, but also to gain a high degree of sophistication in accessing a range of state and local funding sources and partnering with mainstream housing and social service agencies.

Providers outside of metropolitan areas, especially in the scattered towns of rural America, have their own challenges, including transportation to care, minimal community knowledge of the disease, and a lack of rental housing units. Rural AIDS housing providers are also often constrained by their own lack of experience in housing, few partnering or collaborative opportunities, and limited funding opportunities. They have had to learn to innovate and stretch their dollars any way they can (often with short-term rental assistance programs) to serve their growing client base.

While the AIDS housing community's goal of meeting the housing needs of people living with HIV and AIDS has not changed, the AIDS service and housing world has changed dramatically. The challenge for AIDS housing providers is to ensure that resources will be available to clients over the long term, and to find the balance between flexibility and stability.

---

<sup>20</sup> Sambamoorthi, Usha, PhD, Patrick J. Moynihan, PhD, Elizabeth McSpritt, MD, MPH, and Stephen Crystal, PhD. "Use of Protease Inhibitors and Non-Nucleoside Reverse Transcriptase Inhibitors Among Medicaid Beneficiaries with AIDS." *American Journal of Public Health*. September 2001, Vol. 91, No. 9. Pages 1474-1481.

<sup>21</sup> Kahn, James G., MD, MPH, Brian Halle, MPP, MA, Jennifer Kates, MPA, MA, and Sophia Chang, MD, MPH. "Health and Federal Budgetary Effects of Increasing Access to Antiretroviral Medications for HIV by Expanding Medicaid." *American Journal of Public Health*. September 2001, Vol. 91, No. 9. Pages 1464-1473.

<sup>22</sup> Laurie Garrett. "The Virus at the End of the World." *Esquire*, March 1999, p. 104.

<sup>23</sup> Fauci, Anthony MD of the National Institute of Allergy and Infectious Disease quoted in Lands, Lark. "Treatment: Stop + Start". *POZ*. October 2000.