Social Services for Women Living With HIV—The Facts

Center for Women & HIV Advocacy at HIV Law Project

Introduction

More than 30 years into the epidemic, over 1.1 million Americans are living with HIV/AIDS. The burden of the disease is not spread equally; hardest hit are low-income people, people of color, and those in the Southern states. Blacks have the highest rate of new HIV infections and new AIDS diagnoses of any racial/ethnic group in the U.S.: the AIDS diagnosis rate per 100,000 for Blacks in 2008 was more than 9 times that of whites.[1] The Centers for Disease Control and Prevention (CDC) recently found that in poor urban areas of the U.S., 2.1% of heterosexual adults are living with HIV.[2] At the same time, the South accounted for 47% of new AIDS diagnoses in 2008, and has the greatest number of people estimated to be living with AIDS.[3] Finally, women now account for 27% of new HIV infections.[4] Women's care and service needs differ from those of men, and programming that supports women and meets their varied needs inevitably improves health outcomes.

In poor urban areas in the U.S., 2.1% of heterosexual adults are living with HIV.[2]

In the present fiscal climate, however, where social services are under attack at every level of government, the safety net for women and others with HIV/AIDS in the U.S. is weakening. Treatment is no longer guaranteed, and support systems for low-income people living with HIV/AIDS are in similar peril. But support services are an integral and cost-effective element of a comprehensive domestic HIV prevention strategy. Studies have demonstrated that interventions that promote compliance with HAART can extend life by 34.8 months.[5] Eliminating or reducing these services is both immoral and myopic.

Housing

HIV and homelessness are intimately connected.

• HIV prevalence among the homeless population is nearly nine times that of the general population.[6]

• Over 500,000 households in the United States with HIV/AIDS will require housing assistance at some point in their lives.[7]

• Homeless or marginally housed individuals are more likely to delay treatment, less likely to have regular access to care, less likely to receive optimal drug therapy, and less likely to adhere to their medication than are stably housed individuals—all of which increase the individual's viral load and decrease health outcomes.[8]

Housing services improve health outcomes.

• In a six-month longitudinal study of adherence to HAART (Highly Active Antiretroviral Treatment) regimens in New York City, residents in long-term housing were sixteen times more likely to report strong adherence to their treatment regimens than were unstably housed participants.[9]

• Persons with declining housing status are three times as likely to exchange sex for money or other needed goods, whereas persons with improving housing status reduce their risk behaviors by half.[10]

• Homeless or unstably housed persons are 3 to 6 times more likely to use hard drugs, share needles, or exchange sex than stably housed persons.[11]

• Women who are homeless are more likely to have been (and to continue to be) victims of abuse. In a study of HIV-infected adults, over 20% of women with HIV had experienced physical abuse since the time of their diagnosis.[12]

• Women who are homeless are more likely to use or abuse alcohol and illicit drugs—substance use can increase one's risk for HIV infection, either directly via IV drug use or indirectly by increasing risk-taking behavior.[13]

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• Providing public funds for housing assistance has been demonstrated to be cost effective by "substantially reduc[ing] utilization of costly emergency and inpatient health care services"[14] – specifically demonstrated by two large-scale intervention studies.

• Savings in costly health care services greatly exceed the cost of housing assistance, making housing assistance programs an intervention that is both effective and cost-efficient.[15]
• Housing assistance has the potential to prevent future transmission of HIV, since providing individuals with housing assistance can reduce the prevalence of HIV risk behaviors and thereby reduce an individual's risk of contracting HIV.[16]

Case Management

Case management services are essential.
• Since HIV-positive women are disproportionately low-income,[17] managing their disease often includes confronting the challenges, stressors, and disruptions that accompany poverty—pressures that are significantly alleviated by case workers who can help a woman manage her illness.

Case management improves health outcomes.
• Case management increases the likelihood that recently diagnosed patients will seek medical treatment,[18] and one study found that 78% of all PLWHA enrolled in case-management programs were linked to HIV medical care within 6 months of enrollment, representing a 30% increase over those without case-management services.[19]

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• A 2006 study found that participants with consistent case management services were more than ten times likelier to demonstrate CD4 cell count improvements of 50% or more than people without such services.[20]
• Case management has the ability to improve service provision and treatment outcomes.[21]
• Case management facilitates the ability for clients to stay stably housed.[22]
• Case management attends to the needs of clients' families, which in turn affords women the time and energy to devote to their own care—often a secondary priority for HIV-positive women with families.[23]

Mental Health Care

Mental health needs are often present for WLWHA.
• Women with HIV experience far higher rates of poverty, homelessness, domestic violence and substance abuse than members of the general population[24]—and a positive diagnosis compounds and multiplies these stressors.[25]
• It is estimated that over half of HIV-positive women have at least one psychiatric condition; rates of post-traumatic stress disorder alone reach as high as 35%.[26]
• Psychosocial factors can have a significant impact on the progression of HIV,[27] and patients suffering from mental health disorders experience elevated rates of HIV-related morbidity and mortality.[28]
• HIV-positive individuals with mental health disorders have been found to have lower medication adherence and decreased use of medical care.[29]
• Half of women living with HIV/AIDS (WLWHA) have experienced sexual abuse,[30] which leads to major depression, anxiety, post-traumatic stress, and substance abuse.[31]

Mental health services reduce risk-taking and improve health outcomes.
• A 2004 study reports that women with a history of sexual violence who received services were 150% more likely to reduce risky sexual behaviors, and were more likely to adhere to their medication than women who did not receive services.[32]
• A 2007 study found that HIV-positive participants in mental health treatment programs experienced a decreased use of illicit drugs and alcohol, and improvements in mental health.[33]
• Mental health treatment programs are associated with potential cost-savings, including decreased emergency room visits, and inpatient hospital stays.[34]

Food

Adequate nutrition is essential for, but sometimes sacrificed by, WLWHA.

• Significant unintentional weight loss ("wasting") was identified by the CDC in 1987 as one of the defining conditions of HIV/AIDS.[35] Wasting leads to the loss of muscle mass, which inhibits normal activity,[36] and affects quality of life, health, and productivity.[37]

• HIV-positive individuals require roughly 10% more food energy than do their sero-negative counterparts;[38] individuals living with an AIDS diagnosis may experience food energy needs as much as 30% higher than others.[39]

• Weight loss can further weaken the immune system by depleting CD4 cells, which serve a crucial role in the body's overall immune response system.[40]

• More than 10% of female HIV patients report having foregone care to pay for basic necessities, while 7% report having gone without food or other basic necessities in order to pay for the cost of their medical treatment.[41]

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Food services are cost-effective and significantly improve outcomes.

• Nutrition services have the potential to be a cost-saving measure—in 2003 while the mean cost of in-home food delivery services was $1,507 per person per year, the average cost for a single day of hospital care for an individual with HIV/AIDS was $4,574.[42]

• Ensuring that women with HIV have access to quality food, receive regular nutritional counseling and maintain appropriate levels of physical activity can significantly reduce the complications associated with wasting and malnutrition.[43]

Childcare and Mothering Concerns

Demands of childrearing are an impediment to self-care for WLWHA.

• In New York City, women head 79% of the households with children that receive HIV/AIDS Services Administration funds.[44]

Women are 70% more likely than men to delay care because of competing caregiver responsibilities.[48]

• In one study, 59% of women surveyed cited childcare responsibilities as an overwhelming barrier to accessing the medical and social services needed to maintain their HIV treatment programs.[45]

• Another study indicated that service providers perceive childcare to be the biggest barrier to the effective provision of HIV/AIDS support services to female clients.[46]

• Few HIV service centers are equipped to provide childcare or even to offer child-friendly scheduling.[47]

• Data analysis from the HIV Cost and Services Utilization Study demonstrate that women are 70% more likely than men to delay care because of competing caregiver responsibilities.[48]

Childcare Services Make Medical and Social Services Accessible for WLWHA

• HIV support services can help to address both the logistical and psychological burdens that HIV-positive mothers experience. Service centers that offer flexible hours and low-cost or free childcare services can minimize the barriers HIV-positive women face in accessing needed care and services.[49]

Transportation

Lack of transportation is a principal barrier to care.

• According to one study of PLWHA, more than one-third went without care or postponed care due to lack of transportation or another competing need.[50]

• A 2005 study in North Carolina found that both rural and urban HIV/AIDS case workers reported lack of accessible transportation to be a barrier to medication adherence for clients: 58% of rural case managers and 30% of urban case managers rated lack of transportation a "major problem."[51]
• Researchers studying appointment attendance at a community HIV clinic in Brooklyn, New York found that lack of transportation contributed to missed appointments.[52]

58% of rural HIV/AIDS case managers in North Carolina report that lack of transportation is a significant barrier for their clients' medication adherence.[51]

Legal Services

Legal problems are often a barrier to good health.
• The primacy of legal services for HIV has prompted the Centers for Disease Control to issue a recommendation that all individuals receiving a positive diagnosis for HIV/AIDS be immediately referred to legal services.[53]
• Legal providers are essential as a partner in care in myriad ways, including representation in discrimination cases, family law matters,[54] immigration status adjustments, and debtor-creditor issues. • Legal services routinely help people living with HIV/AIDS access the public benefits for which they are eligible, or dispute improper terminations or cuts in assistance.[55]
• Many HIV-positive women depend on Supplemental Security Income (SSI), Social Security Disability Income (SSD), or private insurance payments—legal services attorneys work to win eligibility for these benefits, and to fight wrongful recoupments, so that the fight for financial survival need not constantly interfere with medical treatment, and the optimization of health.[56]

Legal services improve health and safety outcomes, and are cost-effective.
• Ensuring access to legal services for individuals with significant medical needs has been shown to have significant benefits—one study of cancer patients demonstrated that legal services helped to reduce anxiety and stress, alleviated financial worries and improved financial conditions, and maintained treatment adherence.[57]
• Access to legal services was one of the most important factors in achieving a twenty-one percent decrease in the reported incidence of domestic violence in the United States from 1993 to 1998.[58]
• Providing such assistance is also cost-efficient—a New York State Department of Social Services study of a homelessness prevention program focused on legal services found that the program generated a return of four dollars for every dollar of public funds invested.[59]
• The services provided to clients by legal services can help reduce the need for public assistance—in 2003, Legal Aid of Nebraska obtained over one million dollars in child support awards on behalf of its clients, promoting women's self-sufficiency by reducing their need for state-supported funds and other aid.[60]

Conclusion

Women living with HIV/AIDS often balance competing responsibilities, caring for themselves while also caring for others. At the same time most women are making difficult choices about how to allocate precious, limited resources: time, money, and energy. Supportive services, including housing, case management, mental health care, food, childcare, transportation, and legal services make it possible for WLWHA to better attend to their own health while also attending to others. And supportive services help poor women to comply with complex medical regimens, despite the rigors of living in poverty. Cuts to supportive services for PLWHA will be universally devastating, but they will especially hurt women and the children and others for whom they care. It is abundantly clear that supportive services improve health outcomes which in turn saves money now and in the future. Preservation of these services is sound policy for the health of individuals and families, and the public health.

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