

INVESTING IN HEALTH: SUPPORTIVE SERVICES FOR WOMEN LIVING WITH HIV/AIDS



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HIV Law Project

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HIV Law Project believes that all people deserve the same rights, including the right to live with dignity and respect, the right to be treated as equal members of society, and the right to have their basic human needs fulfilled.

These fundamental rights are elusive for many people living with HIV/AIDS. Through innovative legal services and advocacy programs, HIV Law Project fights for the rights of the most underserved people living with HIV/AIDS.

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Investing in Health: Supportive Services for Women Living with HIV/AIDS

Introduction

Supportive services are fundamental to making health care work for women living with HIV/AIDS (WLWHA). WLWHA face unique challenges to accessing and staying in care. Often low income, WLWHA tend to be significantly burdened by childcare and other responsibilities that regularly distract from or limit access to medical care. Social services help stabilize low-income women living with or at risk of HIV by providing a safe home, sufficient food, necessary child care, transportation to and from appointments, and an advocate to assist with pressing legal or mental health needs. When these needs are met, women can tend to the details and routines of their own health and healthcare.

This report surveys the literature about the distinct challenges women face in accessing HIV care and presents compelling research on the impact of supportive services. Studies repeatedly show that supportive services help reduce risk-taking behaviors, help women to connect to care and remain in care, and adhere to treatment.¹ In turn, supportive services have been shown both to improve health outcomes and reduce costs.

Because of the strong impact they have on maintenance in care and treatment and improved health outcomes, supportive services are elemental to achieving this country's HIV policy objectives. The National HIV/AIDS Strategy for the United States (NHAS), released in July 2010, set out three main goals: 1) reducing the number of people who become infected with HIV, 2) increasing access to care and optimizing health outcomes for people living with HIV, and 3) reducing HIV-related health disparities.² Supportive social services for women are instrumental in achieving precisely these three goals. These services reduce health disparities by addressing the unique barriers and challenges faced by women living with HIV/AIDS; increase access to care for women, improving adherence and optimizing health outcomes; and reduce new infections by decreasing infectiousness through retention in care and minimizing risk-taking behaviors. As women have become a larger

proportion of those infected with HIV, investment in social services is essential to realizing the triple goals of the NHAS.

Women Living with HIV/AIDS

Endemic Barriers Hinder Care and Treatment for Women Living with HIV/AIDS

As the HIV epidemic in the United States increasingly impacts low-income individuals and people of color, the number of women living with HIV/AIDS has risen dramatically. Women represented a small minority of AIDS diagnoses in 1985 (8%), but this percentage more than doubled by 1995 (20%) and tripled by 2000 (27%), approximately where it remains today.³ In the period between 1999 and 2003, new AIDS diagnoses among men rose only 1%, while diagnoses among women rose 15%.⁴

This growing number of WLWHA experience unique challenges related to care. Research indicates that women living with HIV have more difficulty accessing care than men.⁵ Women with HIV additionally have higher rates of expensive emergency room visits than men.⁶ One study of 2,864 PLWHA in the U.S. found that women were more likely than men to report needs competing with healthcare and that these competing needs strongly predicted high rates of hospitalization.⁷

WLWHA are also more likely than men to be poor. Nearly two-thirds of all women living with HIV and receiving medical care report annual incomes below \$10,000 (64%), compared with 41% of men.⁸ This is in part because WLWHA are less likely to be employed than HIV-positive men. In a 1994 study of 11 U.S. city and state health departments, 90% of WLWHA were unemployed, as compared with 77% of men living with HIV/AIDS.⁹ WLWHA are also less likely to be privately insured than men with HIV (14% of women compared to 36% of men), and they are more likely to be on Medicaid than men (61% of women compared to 39% of men).¹⁰ Further, most WLWHA are caring not just for themselves, but also for others. In fact, 60% of women in HIV care have minor children, and 76% of those women have

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minors living with them (versus 18% and 34%, respectively, of men).¹¹

Among women living with HIV and receiving medical care, nearly two-thirds report incomes below \$10,000 a year, compared with 41% of men.¹²

HIV/AIDS related disparities are significant not only between men and women but also among women of different racial backgrounds. The well-documented relationships among HIV incidence, poverty and race that facilitate transmission, hinder treatment, and complicate outcomes are particularly marked among women of color. In 2009, the AIDS diagnosis rates for female racial minorities dwarfed those for White women. The diagnosis rate for Black women compared with that for White women was 23:1, for women of multiple races it was 8:1, and for Latinas it was 5:1.¹³

The potent combination of poverty and family responsibilities raises endemic barriers to effective treatment for women living with HIV/AIDS. Research shows that lower socio-economic status contributes to decreased adherence to HIV therapy. This decreased adherence arises in large part from (1) financial constraints that limit ability to pay for transportation, child care, and other needed services, and (2) preoccupation with immediate concerns, such as poor or unstable housing.¹⁴ The NHAS recognizes that “people with competing demands and challenges meeting their basic needs for housing, food, and child care often have problems staying in care.”¹⁵ Services for women must address both women’s unique caregiving responsibilities and the additional financial pressures experienced by so many WLWHA in order for care, treatment, and prevention strategies to be effective.^{16,17}

Social Services: Goals & Outcomes

Social Services Result in Beneficial Treatment and Public Health Outcomes

Recognizing that financial constraints and preoccupation with immediate needs present substantial barriers to accessing medical care, the NHAS underscores the fundamental role of social services in prevention strategies and encourages “policies to promote access to housing and supportive services ... that enable people living with HIV to obtain and adhere to HIV treatment.”¹⁸

Supportive services connect diagnosed individuals to care and help them remain in care and adhere to treatment regimens. Timely connection to and retention in medical care correlates both with better individual health outcomes for PLWHA and with better public health outcomes. Connection to care promotes adherence to treatment, a basic factor in the effectiveness of treatment, resulting in good health. Interventions that promote compliance with HAART can extend life by nearly three years (34.8 months).¹⁹ One study of 1,416 HIV-positive adults between 1996 and 2000 found a 33 fold increase in mortality with poor adherence (<75%) over greater adherence (>75%) to HAART.²⁰ These results reflect the fact that viral suppression requires adherence of at least 95%.²¹ Additionally, poor adherence to HAART often results in the development of drug-resistant strains of the virus, posing a health threat to the individual and to the public.²² Further, a groundbreaking study recently found that early and regular treatment virtually eliminated the risk of transmission between sero-discordant, heterosexual partners.²³ Thus, adherence to treatment is an essential component of good health for PLWHA.

Studies have shown that adherence to HAART depends not only on regular access to medicine but also on regular visits to a clinic and regular interaction with a healthcare provider. One study found that the number of days elapsed between clinic visits is positively correlated with higher viral loads.²⁴ This means that PLWHA must physically visit the doctor in order to maintain regular treatment behaviors and lower viral load,²⁵ rendering the removal of barriers to keeping these appointments essential. When patients feel that their doctor knows them well and as an individual, they are more likely to have positive and hopeful attitudes about their treatment and to adhere to HAART. One study

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of 1,743 patients in Baltimore found that patients who reported feeling that their doctors knew them well and met with them routinely were significantly more likely to adhere to their medication regimens.²⁶ Another study of 423 patients receiving HAART between 1998 and 2004 found that the number of missed appointments and the number of days elapsed between each appointment strongly correlated with the occurrence of new AIDS-defining illnesses and death.²⁷ Additionally, patients receiving routine medical care are significantly less likely to engage in HIV risk behaviors, as demonstrated by a recent study that found that those who attended at least three appointments in the past six months were much less likely to engage in unprotected vaginal or anal intercourse.²⁸

Interventions addressing pressures faced by people living with HIV/AIDS that promote compliance with HAART can extend life by 34.8 months.²⁹

In light of the vital nature of adherence to HAART and retention in care to better health outcomes among PLWHA, the results of the research highlighted below are striking. Again and again, social services are shown to promote adherence to treatment and retention in care. Accordingly, supportive services are essential to management and prevention of HIV/AIDS in the U.S., but they are also particularly crucial for WLWHA who have a unique need for these services.

Housing

Stable housing is the greatest unmet need of people living with HIV/AIDS.³⁰ At the same time, HIV prevalence among the homeless population is nearly nine times that of the general population.³¹ Half of all PLWHA—currently over 500,000 households—will require some form of housing assistance during their lifetimes.³²

HIV prevalence among the homeless population is nearly nine times that of the general population.³³

Homelessness is a significant health threat to any individual, but it can be particularly devastating for PLWHA, who often have complex medical regimens, must maintain adequate nutrition, and need to receive regular treatment and care from health and social professionals.³⁴ Without access to a safe and private place to store and take medications (some of which may need to be refrigerated), and to store and prepare food, an HIV-positive woman is far less likely to be able to take her medications regularly and as prescribed. Without a safe home to which she can retreat, the side effects of treatment become far more difficult to tolerate. And without a regular address at which she can be contacted for treatment and other service needs, her care may be unintentionally disrupted or terminated, due to lapsed or failed communications.

Homelessness is a complex stressor associated with high rates of depression, stress, and poor coping responses, all risk factors for low adherence to HAART. Caring for others in the face of the inconstancy of homelessness provides women an additional layer of anxiety. One study of 64 homeless mothers and 59 low-income housed mothers showed higher rates of depression and stress, and greater reliance on avoidant coping mechanisms among homeless than among housed women. The study found that 84% of homeless mothers met criteria for major depression, compared to 46% of housed mothers.³⁵

Perhaps unsurprisingly, homeless or marginally housed PLWHA 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 regimen than are stably housed individuals.³⁶ In fact, one study found a non-adherence rate of 67% among homeless people living with HIV/AIDS in Boston.³⁷

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The correlation between homelessness and HIV is further compounded for many women by histories of abuse. In fact, women who are homeless are more likely to have been, and to continue to be, survivors of abuse. This abuse can itself be a risk factor for HIV transmission, as women who have been abused are more likely to engage in greater sexual risk-taking behavior, such as exchanging sex for money or other goods.³⁸ Moreover, women in abusive relationships are often unable to control the terms of sexual engagement, including decisions about condom use.^{39,40} Homeless women may depend on abusive or coercive partners for basic necessities; as a result they are often unwilling or unable to negotiate safe sex and are all the more vulnerable to HIV infection.

Homeless or unstably housed persons are three to six times more likely to use drugs, share needles, or participate in transactional sex than stably housed persons with the same personal and service use characteristics.⁴¹

Even where a history of abuse is not an issue, housing status is closely linked to risk-taking behavior. In a longitudinal study of HIV-infected individuals, persons whose housing status worsened were over three times as likely to exchange sex for money or other needed goods, while persons whose housing status improved reduced their risk behaviors significantly, decreasing their chance of having unprotected sex by half.⁴² Research has also shown that homeless or unstably housed persons were three to six times more likely to use drugs, share needles, or participate in transactional sex than stably housed persons with the same personal and service use characteristics.⁴³

Several basic factors begin to account for the observed relationship between housing stability and high-risk behavior. First, the ability to practice safe sex or use clean needles is hampered when an individual lacks a safe and consistent place to store condoms or clean needles, or the resources to purchase these items.⁴⁴ Second, for those facing housing instability, with the pressures of

homelessness as a near total preoccupation, the need to practice safe sex or use clean needles may lose its place in the order of priorities. Stress related to homelessness is positively correlated with low HAART adherence.⁴⁵ Housing instability has been associated with not having a usual source of healthcare, postponing healthcare needs, and postponing medication needs. All of these behaviors affect persons at risk of having or who already have HIV/AIDS.⁴⁶ Third, lack of stable housing produces additional stressors that can spark or contribute to the problems of relationship abuse as well as drug and alcohol use, can magnify the fallout of these problems, and may render access to social services addressing these problems unlikely or unfeasible.⁴⁷

Given the extensive interplay between homelessness and HIV, it is unsurprising that stable housing has been shown to positively impact a woman's ability to manage her HIV treatment. In a six-month longitudinal study of adherence to HAART 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.⁴⁸ Further, providing housing to those at risk for HIV is known to be one of the most effective interventions available to protect against infection.⁴⁹

These sorts of improved outcomes, both for individual and public health, make housing a cost-effective investment. A 2007 analysis of the Housing and Health Study concluded that in light of HIV treatment costs (\$300,000 per individual), a housing intervention that included rental and utility assistance, housing advocacy, case management, and follow-up support would be cost-effective even if it prevented only one HIV transmission for every sixty-four clients served.⁵⁰

Investing in housing has also been demonstrated to be cost-effective by "substantially reduc[ing] utilization of costly emergency and inpatient health care services."⁵¹ While one study showed that unstably housed patients were more likely to make costly emergency room visits,⁵² two large-scale intervention studies demonstrated that supportive housing for persons with HIV/AIDS both improved

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health outcomes and reduced the use of expensive emergency and inpatient health care services. Such savings in costly health care services greatly exceeded the cost of housing assistance.⁵³

While the federal government provides assistance through the HOPWA (Housing Opportunities for Person with AIDS) program, the need for such assistance far outpaces availability.⁵⁴ And as demonstrated above, housing assistance and supportive housing are indispensable and cost-efficient elements of HIV prevention and care.

A housing intervention would be cost-effective even if it prevented only one HIV transmission for every sixty-four clients served.⁵⁵

Case Management

For HIV-positive women, who are disproportionately low-income,⁵⁶ managing their disease often includes confronting the challenges, stressors, and disruptions that accompany poverty. In order to access the range of services needed for treatment and social support, these women must regularly overcome the barriers of a complex and fragmented service delivery system.⁵⁷ Case managers can significantly improve HIV-positive women's ability to manage their illness by connecting them with vital health care and social services and by helping oversee adherence to treatment plans.⁵⁸ Further, case managers can serve as the hub of a provider network so that the logistical aspects of essential support systems do not become excessively burdensome.

The core tasks of case managers include:

- client identification, outreach, and engagement;
- medical and psychosocial assessment of needs;
- development of a service plan or care plan;
- implementation of the care plan by linking with service delivery systems;
- monitoring of service delivery and reassessment of needs; and

- advocacy on behalf of the client (including creating, obtaining, or brokering needed client resources).⁵⁹

The benefits of case management are well documented. By connecting clients with critical services, case managers play an essential role in improving the economic, social, physical, and emotional wellbeing of people living with HIV.⁶⁰ Contact with case managers has been strongly associated with a decrease in unmet needs, especially for supportive services such as income assistance, health insurance, home care, counseling, and housing.⁶¹ One study found that sustained contact with case managers helps clients stay stably housed.⁶²

With particular respect to patients' physical health, case management can help patients overcome fears about treatment,⁶³ increase the likelihood that recently diagnosed patients will seek medical treatment,⁶⁴ and positively influence the use of and adherence to antiretroviral therapy.^{65,66} A study based in ten American cities found that 78% of all PLWHA enrolled in case-management programs were linked to HIV medical care within six months of enrollment, representing a 30% increase over those without case-management services.⁶⁷ A study conducted over six months in 1997 of PLWHA who were receiving Ryan White ancillary assistance demonstrated that while 44% of people without case managers reported not having a regular place for healthcare, only 20% of people with case managers reported this.⁶⁸ Case managers not only connect women to care, they also connect women to the services, such as transportation, that allow them to remain in care, and as a result, improve treatment outcomes.⁶⁹

Because they support timely and uninterrupted access to treatment, case managers significantly improve health outcomes in a number of critical respects. A 2006 study of homeless and marginally housed individuals found that having case management was associated with improved adherence to antiretroviral therapy and improved CD4⁺ count.⁷⁰ This increase may be attributable to case managers' efforts in promoting medical compliance, including encouraging clients to adhere

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to treatment and care regimens, assisting in reporting side effects to primary care physicians, and checking in regularly to ensure timely prescriptions refills.⁷¹

The needs of a woman and her family are inherently interconnected, and case managers must often attend not only to the unique needs of their clients, but also to the needs of the clients' families. Specifically, case managers' aid in securing childcare, emergency food assistance, housing, and legal resources can help alleviate some of the stress that female heads of household and caregivers often face.⁷² Connecting women with services to help care for their families allows them time and energy to tend to their own health as well, often a secondary priority for HIV-positive women with familial responsibilities.⁷³

While case management proves essential to connecting women with needed services, at its most successful case management endows women with the skills they need to advocate for themselves.^{74,75} Case management can aid in developing self-efficacy, empowering women to manage their own care and treatment, and helping them to understand the social services available.⁷⁶ Case management teaches women to navigate social systems more capably and competently and to procure needed services more efficiently and effectively.⁷⁷ Case managers empower HIV-positive women to be more able and more likely to access needed care.⁷⁸

Mental Health

It is estimated that over half of HIV-positive women have at least one mental health condition, and rates of post-traumatic stress disorder (PTSD) reach as high as 35%.⁷⁹ WLWHA face weighty psychological burdens: nearly all report anxiety and depression related to caring for their children, the effect of their HIV status on their children or families, or loss of hope that they will ever have a child. Further, nearly all report facing these added burdens without a support network.⁸⁰ Women with HIV also experience far higher rates of poverty,

homelessness, domestic violence, and substance abuse than do members of the general population,⁸¹ and a positive diagnosis both compounds and multiplies these stressors.⁸² Further, the particularly strong correlation between HIV and domestic violence⁸³ amplifies the need for and benefits of mental health care for HIV-positive women.

Research suggests that over half of HIV-positive women have at least one mental health condition and up to 35% suffer from PTSD.⁸⁴

PLWHA with mental health conditions experience elevated rates of HIV-related morbidity and mortality.⁸⁵ This may be due in part to the fact that mental illness reduces an individual's ability to mount an effective immune response against the virus,⁸⁶ increases the likelihood of engaging in risk behaviors as a way to mitigate stress, and negatively affects motivation to alter risk behaviors or make other positive steps to increase quality of life.^{87,88} As a result, HIV disease progression is often more rapid in women who have mental health needs.⁸⁹

Researchers have found that HIV-positive women with depression are twice as likely to die from the disease as those who were never depressed.⁹⁰ Depression is also associated with a greater decline in CD4 count, controlling for antiretroviral treatment.⁹¹ The problem of HIV and mental illness comorbidity is more pronounced in women than in men. Studies have indicated that rates of major depression in HIV-positive populations tend to be highest among women engaging in high-risk behavior.⁹² Untreated, mental health conditions can also affect a woman's ability to manage her disease: HIV-positive individuals with mental health conditions have been found to have lower medication adherence and decreased use of medical care.⁹³

A shocking half of all women living with HIV have experienced sexual abuse.⁹⁴ This history often results in psychiatric conditions, including major depression, anxiety, post-traumatic stress, and

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substance use.⁹⁵ Mental health interventions have been shown to be effective in this context. In a 2004 study of women with a history of sexual violence, those who participated in an intervention examining their sexual histories and linking these experiences to their current decision-making were 150% more likely to reduce risky sexual behaviors (such as unprotected sex) than women who did not receive the intervention.⁹⁶ In addition, these women were more likely to adhere to their medication than those not enrolled in the intervention program.⁹⁷

Mental health interventions have the demonstrated potential to increase treatment adherence and to help reduce risk-taking behaviors, thereby slowing transmission of HIV. In a study published in 2007, HIV-positive participants in a mental health treatment program achieved decreases in the use of drugs and alcohol, as well as improvements in mental health.⁹⁸ Individuals in the study also demonstrated improved capacity to manage their disease progression, including increased usage of both antiretroviral and appropriate psychiatric medications.⁹⁹ One study found that, overall, clinics that employed a mental health professional had fewer missed appointments, and other research found that substance abuse services had a similar effect.¹⁰⁰

Finally, mental health services are cost-effective. The 2007 study demonstrated the potential cost-savings associated with these programs, most notably decreased emergency room visits and inpatient hospital stays for participants compared to individuals who did not receive the intervention.¹⁰¹ Another study noted that providing antidepressant therapy for women living with both HIV and depression resulted in decreased medical costs overall.¹⁰² Given the potential reductions in risk-taking behaviors, improved treatment adherence, improvements in mental health, and the cost savings associated with mental health interventions, it is clear that mental health services are an essential component of HIV care and prevention.

Abuse victims who participated in an intervention examining their sexual histories were 150% more likely to reduce risky sexual behaviors than women who did not receive the intervention.¹⁰³

Food/Nutrition

Good nutrition is vital for all people living with HIV. In addition to being an essential element of general good health—important when the body is under the stress of any disease—the specific progression of HIV/AIDS makes nutrition a salient concern for PLWHAs, their caregivers, and social service providers. A study in Atlanta found that food insufficiency was a better predictor of non-adherence to HIV treatment than years of education, employment status, income, housing, depression, social support, and non-alcohol substance use.¹⁰⁴

The need for increased nutrition in PLWHA was identified early in the epidemic, when the correlation between HIV infection and unintended weight loss was first noted.¹⁰⁵ Significant unintentional weight loss, known as “wasting,” was identified by the CDC in 1987 as one of the defining conditions of HIV/AIDS.¹⁰⁶ Wasting has tremendous implications for the health of PLWHA: loss of muscle mass inhibits the ability to maintain normal levels of activity,^{107,108} which in turn affects quality of life, health, and productivity.¹⁰⁹ The malnutrition associated with wasting also leads to nutritional deficiencies that can challenge an individual’s ability to mount an effective immune response.^{110,111} Research has linked reduced levels of one micronutrient, Vitamin B-12, with rapid disease progression that can lead to poor health outcomes and increased mortality.¹¹² Weight loss can further weaken the immune system by depleting CD4 cells; these cells serve a crucial role in the body’s immune response system, and disease progression may hinge

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on the decreased concentration of these cells in the bloodstream.¹¹³ In a 1995 study of PLWHA, weight loss was a significant predictor of decreased CD4 counts.¹¹⁴

In order to protect against the harms associated with disease-related weight loss and to maintain normal body weight and physical activity levels, HIV-positive individuals require roughly 10% more food energy than do their sero-negative counterparts,¹¹⁵ and individuals living with an AIDS diagnosis are recommended to increase their intake by an additional 30%.¹¹⁶ These nutritional requirements are even more demanding for WLWHA caring for HIV-positive dependents, as children living with HIV/AIDS require as much as 100% more food energy than their sero-negative counterparts to avoid weight-loss.¹¹⁷ It is essential that PLWHA maintain not only a calorie-rich but also well-balanced and healthy diet to maintain adequate nutrition.¹¹⁸ Adequate food resources and nutritional guidance are critical to addressing these increased needs in order to prevent the negative effects on disease management and health outcomes that accompany significant weight loss and malnutrition.

Women living with HIV/AIDS in particular require food resources and guidance as many of the same factors that put women at risk for HIV—poverty, racial and economic segregation, childcare responsibilities, and unstable housing—also impede the ability of women living with HIV/AIDS to maintain adequate nutrition.^{119,120} More than 10% of female HIV patients report having foregone medical 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.¹²¹ Such trade-offs can have devastating impacts upon a woman's health and wellbeing, and the health of her family as well.

More than 10% of female HIV patients have foregone medical care to pay for basic necessities; 7% report having gone without food or other basic necessities in order to pay for medical treatment.¹²²

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.^{123,124} First, access to food and nutrition counseling can support effective drug therapy.^{125,126} Optimal food consumption also promotes absorption of medication, and regular meals can reduce medications' side effects, increasing the likelihood of compliance with treatment such as HAART.¹²⁷ Studies have demonstrated that interventions that promote compliance with HAART can extend life by nearly three years.¹²⁸

By slowing disease progression and reducing complications associated with HIV treatment, nutrition services have the potential to be a cost-saving measure. In fact, while in-home food delivery services average approximately \$1,500 per person, per year¹²⁹, the average hospital stay for a PLWHA in 2007 was over 13 days, at an average cost of over \$2,000 a day in 2006.^{130,131} And on average, WLWHA have more and longer inpatient stays than men with HIV.¹³² Consequently, food services have the potential to reduce significantly the need for expensive medical services. As food programs and nutritional counseling can greatly improve physiological health outcomes and promote increased activity levels that allow patients to better meet their families' basic needs, these services should be considered an integral aspect of HIV support and treatment programs.

Childcare and Mothering Concerns

Women often bear the brunt of childcare and domestic responsibilities.¹³³ This burden is felt acutely by HIV-positive women, who are overwhelmingly the primary or sole providers for their children.^{134,135} In New York City, for example, women head 79% of those households with children that receive public assistance from the HIV/AIDS Services Administration.¹³⁶ Familial obligations can have a significant impact on an HIV-positive woman's ability to manage her illness. In one survey

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of Indiana HIV service providers, 73% found childcare to be an overwhelming need among their female clients; 42% of those same providers found that childcare needs were not met at all and 46% stated that the need was only somewhat met.¹³⁷ Notably, childcare responsibilities were cited by more providers (59%) than any other single factor as an overwhelming barrier to service usage by their female, HIV-positive clients.¹³⁸

Women tend to prioritize the needs of their children and others over their own. As one HIV-positive woman from Los Angeles said, “We are taught to take care of others first. And that’s what we do. We save ourselves for last.”¹³⁹ This tendency can impair a woman’s ability to comply with HIV care and treatment, resulting in skipped or delayed medical appointments, failure to take medications regularly, and inadequate rest or nutrition.^{140,141} Data analysis from the HIV Cost and Services Utilization Study demonstrates that women are 70% more likely than men to delay care because of competing caregiver responsibilities.¹⁴² Missed medical visits can have significant consequences for a woman’s health and may help to explain why women, particularly women of color, have been found to have a lower survival rate from HIV/AIDS than men.¹⁴³

Women are 70% more likely than men to delay care because of competing caregiver responsibilities.¹⁴⁴

Adding to this challenge is the lack of medical facilities or service organizations geared towards the needs of HIV-positive mothers and caregivers. Few HIV service centers are equipped to provide childcare or even to offer child-friendly scheduling, which would allow women the flexibility required to schedule appointments around the demands of ferrying children to and from school, preparing meals, and other caretaking responsibilities.¹⁴⁵ Yet family-friendly services are essential to keeping women in care. When one New Orleans clinic discovered that the percentage of missed visits was especially high among women, they surveyed clients for input. In response to the suggestions received the clinic created a maternal-child program, offering

free on-site childcare during the mothers’ appointments, merging mother and child medical visits, and offering private and specialized care to women. The percentage of women’s missed visits decreased dramatically.¹⁴⁶ In another study of 279 WLWHA in St. Louis, Missouri, the rate of adherence to treatment jumped from 60% to 71% after provision of childcare services.¹⁴⁷

As noted above, the relationship between a patient’s mental and physical health can be significant,¹⁴⁸ and the competing demands of childcare and HIV treatment present a psychological, as well as logistical, component.¹⁴⁹ In addition to managing the basic biological needs of their children and themselves, HIV positive women must deal with the stress of illness specifically as it relates to mothering. For many, this includes the difficulty of disclosing the illness to children, fear for the continued caretaking of children as the mother’s illness progresses, concern about stigma children may experience, and a sense of broad-ranging guilt.¹⁵⁰

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 help women balance caregiving with an appropriate level of self-care, minimizing the barriers HIV-positive women face in accessing needed care and services.¹⁵¹ Further, support groups, individual therapy, family education, and a healthcare approach that integrates both physical and psychological care systems can be valuable aids in helping women with HIV learn to cope with their illness and care for their families effectively.¹⁵²

Transportation

Because women living with HIV are more likely than their male counterparts to be low-income, they are more often lacking a vehicle or money to pay for insurance or to access public transportation.¹⁵³ Interviews of PLWHA conducted by Center for Research on Women in Memphis established that less than 50% of PLWHA use private vehicles to

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access medical care, citing high gas prices and parking prices as barriers.¹⁵⁴ Many parts of the country where infection rates among women are high, such as the South, lack extensive public transportation systems, preventing women without cars from accessing treatment.¹⁵⁵ Lack of transportation, or the money to pay for transportation, is a very literal obstacle to accessing needed support services. This barrier is compounded by the limited number of clinical providers and HIV specialists¹⁵⁶ in many parts of the country.

Without means to travel the sometimes lengthy distances to medical or social services, a woman living with HIV may be hindered in her efforts to manage her disease and preserve her health. In one study of 2,864 adults receiving care for HIV in the U.S., 26% of WLWHA reported postponing care due to lack of transportation, compared with only 12% of men.¹⁵⁷ Further, a 2005 study in North Carolina found that both rural and urban HIV/AIDS case workers reported lack of accessible transportation to be a significant barrier to medication adherence for clients: 58% of rural case managers and 30% of urban case managers rated lack of transportation a “major problem.”¹⁵⁸ Similarly, researchers studying appointment attendance in Brooklyn, New York found that lack of transportation and childcare were reasons for missed appointments.¹⁵⁹

Focus groups of HIV-positive women reinforce these findings. According to one HIV-positive woman in Los Angeles, “It’s not just a matter of whether, for instance, healthcare is available. For women, there always seems to be the question, ‘How am I going to get there?’”¹⁶⁰ An Indiana study found that groups of WLWHA, including those with access to public transportation or transportation provided by care coordination sites, identified lack of transportation as a major barrier to accessing care: for some, existing transportation systems were simply inadequate, for others anticipating or managing transportation schedules proved overwhelming, especially in conjunction with childcare needs.¹⁶¹

Transportation services allow poor women to access needed medical care and services. In a study of 999 HIV-positive patients in Boston, access to and use of

transportation support through Ryan White funding was significantly correlated with retention in primary care.¹⁶² Interventions that increase access to transportation have also been shown to be effective in helping WLWHA keep medical appointments. A 2007 study of a sample of women who missed many appointments provided them with 6 months of transportation and found significantly reduced missed appointment rates as a result.¹⁶³ These services, therefore, are essential to keeping women in care.

Legal Services

Provision of legal services has been shown to have distinctly positive effects, including improved individual health, on the lives of people with HIV/AIDS. A 2002 study reviewed the need for, availability of, and impact of legal services for PLWHA and determined that “[Legal] services improve access to health care, housing, and support services through education, empowerment, and enforcement of legal rights.”¹⁶⁴ It found that these services were especially effective in guaranteeing access to and the maintenance of health care services¹⁶⁵ primarily by addressing issues that would otherwise compete with these priorities.¹⁶⁶ A 2007 survey by LegalHealth in New York City assessed the impact of legal services on individuals with cancer. Of the respondents, 83% said legal assistance helped reduce their stress, 51% reported that it had a positive effect on their financial situation, 33% stated that it positively affected their family or loved ones, and 23% and 22% respectively claimed it helped them maintain their treatment regimens and keep medical appointments.¹⁶⁷

The need for access to legal services is arguably even more urgent for people living with HIV, given the strong association between poverty and HIV status, the historical stigma associated with the disease,¹⁶⁸ the heightened risk of discrimination in employment, housing, and other contexts, and the negative health outcomes associated with stress and anxiety for PLWHA.¹⁶⁹ Studies show that individuals perceiving higher levels of cumulative negative life burden and stress-inducing circumstances have viral loads twice

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as high as those with lower levels of negative life burden, controlling for adherence to HAART.¹⁷⁰ Furthermore, higher levels of stress are associated with faster disease progression.¹⁷¹ The resolution of these cases is essential, therefore, in diminishing stressors and ensuring stability.

Lawyers for women living with HIV routinely preserve housing through successful representation in eviction proceedings, and improve housing conditions through affirmative legal action against delinquent landlords. When faced with an eviction or illegal housing conditions, and no lawyer, women living with HIV are vulnerable to the increased viral loads and transmission risks discussed in the Housing section above. Eviction prevention services are also cost-efficient. A New York State Department of Social Services study of legal services focused on homelessness prevention found that the program generated a return of four dollars for every dollar of public funds invested.¹⁷²

Legal services also routinely help people living with HIV/AIDS to access public benefits, including public health insurance, for which they are eligible, or to dispute improper terminations or cuts in assistance.¹⁷³ Similarly, many HIV-positive women depend on Supplemental Security Income (SSI), Social Security Disability Income (SSDI), or, occasionally, private insurance payments. Legal services attorneys fight on behalf of eligible clients to obtain these benefits, and to oppose wrongful recoupments, so that the struggle for financial survival need not constantly interfere with medical care and treatment, and the optimization of health.¹⁷⁴ Without legal representation to ensure HIV-positive women's access to public assistance, disability insurance, and health insurance, treatment retention decreases and women are exposed to significantly more severe disease outcomes¹⁷⁵

Resolution of immigration matters is also central to improving the health of many women living with HIV. Legal services that allow an individual to adjust her immigration status lead to a cascade of essential positive changes that ultimately affect her health: the woman gains the ability to work, to access benefits and services, and to connect to medical care

and treatment. Without legal assistance, HIV-positive women would face this multitude of time-consuming, depleting, and marginalizing struggles alone and in many cases would be denied access to essential services because of her immigration status.¹⁷⁶

Legal services that address domestic violence, an epidemic among women living with HIV, also result in improved health outcomes. As discussed earlier, HIV infection among women is strongly correlated with experiences of abuse. Legal services programs enable women to seek vital long-term solutions to escape abuse permanently. Analysis of data collected by the Area Identified National Crime Victimization Surveys showed that if a woman has access to legal services in her county of residence, she is significantly less likely to be battered.¹⁷⁷ This same survey concluded that such 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 1998.¹⁷⁸ In addition to protecting women from violence, legal services reduce the costs associated with abuse, such as medical care and counseling. According to the cost benefit analysis of a proposed program in Wisconsin, preventing one assault per victim would avoid \$3,000 in costs per victim represented.¹⁷⁹ A reduction in emergency hospital visits, and the trauma underlying these visits, affords women the opportunity to focus on optimizing their health generally, not just on surviving the abuse.

In all of the areas described above, lawyers are fighting the legal battles, and vindicating their clients' rights, so that WLWHA can give adequate time and mental resources to their health maintenance. The quality of life and health gains HIV-positive women experience through provision of legal services, coupled with the potential cost-efficiency of these initiatives, demonstrates the value of legal service programs.

Conclusion and Recommendations

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. Additionally, supportive services help poor women to comply with complex medical regimens, despite the rigors of living in poverty. For women living with HIV/AIDS, there can be no effective medical care without supportive services.

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, families, and the public.

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