

30 FOR 30 CAMPAIGN

BRIEFING PAPER

Making HIV Care and Treatment Work for Women

Advocacy • Equity • Action

Introduction

With the implementation of the National HIV/AIDS Strategy (NHAS), the Affordable Care Act (ACA), and the continuation of the Ryan White CARE Act, we find ourselves in a fast-paced and dramatically changing health care delivery environment for all people. For people living with or affected by HIV these changes will provide great opportunities and challenges.

The Affordable Care Act has already provided opportunities for great strides in women's health including the adoption of the Institute of Medicine (IOM) guidelines on women's preventive health such as free HIV testing, intimate partner violence prevention and counseling, and sexually transmitted infection (STI) counseling. These types of critical services for women must also be explicitly integrated into HIV prevention and care.

A strong evidence base exists indicating that to be effective HIV prevention, care, treatment services for women must be family-centered, gender-responsive, and integrated. Such services are inevitably more resource-intensive than most HIV-related services currently provided in the U.S. – services designed over the last three decades primarily to meet the needs of men with no dependent children – but are ultimately more cost-effective. This paper summarizes the data showing that:

1. Effective HIV treatment and care for women can best be delivered through integrated, family-centered, gender-responsive, care and support systems.
2. Integrated women-centered systems are cost effective because they benefit not only women living with HIV but also their families and communities and can lessen the financial burdens on our health care systems generated in their absence.

The 30 for 30 Campaign is dedicated to ensuring that the unique needs of women living with and affected by HIV, including transgender women, are addressed in the national HIV response. We are especially committed to illuminating and eliminating the gaps in prevention and care services for Black and Latina women who currently make up over 80%¹ of the epidemic among women but only 12% and 14% of the US female population respectively.²

The Campaign is concerned with the current state of HIV prevention and care for women as studies continue to show that women, especially women of color, suffer consistently poorer health outcomes despite there being no significant clinical difference in treating men or women living with HIV.³

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WHAT WE KNOW

- Women living with HIV are more likely to be poor than men living with HIV. According to data, 64% of women in ongoing HIV care had annual incomes below \$10,000, compared to 41% of men.⁴
- More than twice as many HIV positive women (76%) as HIV positive men (34%) are living with, and caring for, at least one child under the age of 18.⁵
- Adherence to a prescribed ART regimen tends to *decrease* among women living with HIV as the number of children under 18 living in the home *increases*.⁶ Researchers hypothesize that this is associated with women's propensity to provide for their children's needs before their own.^{7,8,9} In one U.S. study, more than 10% of HIV positive women in treatment reported going without medical care for themselves in order to pay for household food and other necessities.¹⁰
- Transgender women with HIV may live in extreme poverty, are less likely to receive antiretroviral therapy (ART) than other groups¹¹, are less likely to report optimal adherence than non-transgender people, experience more challenges integrating HIV treatment regimes into their everyday lives¹², and report fewer positive interactions with health care providers¹³.

The contrast between health outcomes of HIV-positive women in Europe and the United States is startling. Women in Europe living with HIV experience slower disease progression and a 25% lower mortality rate than men with HIV.¹⁴ In the U.S., however, death rates are 20% higher among women living with HIV than among their male counterparts.¹⁵ Women in the U.S. are hospitalized at higher rates than men¹⁶ and experience more than twice as many HIV-related and AIDS-defining illnesses per person than men, even after controlling for injection drug use, differences in follow-up time, and other factors.¹⁷ In an interview with *Physician's Weekly*, Dr. Amie Meditz, lead author of the study on gender difference in AIDS-defining illnesses, posited that this rate of illness was less likely due to biological predisposition than to "socioeconomic factors such as access to healthcare, health behaviors, lifestyle, and environmental exposures".¹⁸

The challenges associated with effectively linking HIV positive women to care and retaining them as patients are manifold and complex. But changes to HIV care now being shaped by the implementation of the National HIV/AIDS Strategy (NHAS) and the Affordable Care Act (ACA), especially Medicaid expansion, provide a timely opportunity to achieve real progress in this area and ensure that proven methods for linking and retaining women in care are scaled up rather than eliminated in cost containment measures. This system-wide adjustment period also provides a chance to improve coordination and introduce or scale-up models specifically designed to increase the quality and accessibility of health care for women living with HIV.

In light of what we know the most urgent priorities for advancing HIV care for women in the U.S. are:

1. Securing family-centered and gender-responsive prevention, care, and treatment including culturally sensitive care for transgender and queer-identified women;
2. Integration of HIV/AIDS care, treatment and social service linkages with other health and social services routinely used by women, including sexual and reproductive health care; intimate partner violence prevention and support services; and financial assistance programs; and
3. Facilitative supportive and wrap-around services that are essential to women's ability to utilize HIV-related services effectively. These include, but are not limited to, transportation assistance, childcare, housing, legal services, psychosocial services, and peer-based support, education, and system navigation assistance.

Taking advantage of this unique opportunity will require re-thinking of the existing HIV/AIDS response, with an eye toward the areas in which that response needs to be adapted and/or expanded to serve women and their families more effectively. It will also require identifying existing approaches that work well and can be scaled up.

HIV-specific family-centered services began to emerge in the 1990s and have historically been supported primarily through Part D of the Ryan White CARE Act. Focused on improving care to women, children and youth, Part D services are targeted to families affected by HIV but do not typically include a full spectrum of service components vital to women. Two areas largely

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unaddressed by Part D, for example, are the integration of HIV care into other health care services such as sexual and reproductive health that women already access, and the need for systematic efforts to reduce stigmatizing attitudes toward HIV positive women where they live and among the health care providers they see.¹⁹ To make matters worse, Part D funding has never been sufficient to provide enough of the wrap-around services that women need to access care for themselves as well as their families.²⁰ These gaps are exacerbated by the fact that Part D has been flat funded for years, although the number of women living with HIV, and families affected by HIV has increased.

Research has shown that integrated and facilitative services are ultimately cost-effective for two reasons:

First, unlike service delivery designed for individuals, each dollar spent on these services benefits multiple people, given that women are frequently the primary caregivers for their children. Women, including women living with HIV, often also serve as unpaid caregivers for other family and community members who are elderly or ill. In one study of 700 U.S. women living with HIV, 53% identified themselves as caregivers and 43% reported that having HIV

made it harder to fulfill these responsibilities. This sentiment was more prevalent among women living in the U.S. South (50%) than among those living in the Northeast (37%).²¹ Services that meet women's needs also contribute to their ability to serve as caregivers. The consequent savings to public health and social services in an area constitutes a large but undocumented public financial savings worthy of more research.

Second, without such services, "treatment as prevention" strategies cannot work. If the rate at which women living with HIV are enrolled in care, retained in care, and adherent to their treatment regimens is not improved, then their ability to lower their viral load – and thus curtail onward transmission of the virus -- cannot improve.

As Secretary Hillary R. Clinton has observed, investing in women's health is, "not only the right thing to do; it's the smart thing to do."²²

Why Family-Centered and Women-Centered Gender-Responsive Care Matter

The President's Advisory Council on HIV/AIDS (PACHA) noted in its August 2011 letter to President Obama that "[m]any women experience poor health outcomes as a result of delayed entry into care and poor retention once in care, and are less likely to begin antiretroviral therapy due in part to insufficient women centered services, missed opportunities for linkage between services for sexual and reproductive health and HIV, inadequate supportive services, and socioeconomic barriers to care (such as poverty)."²³

Family-centered and women-centered gender-responsive care is care that treats women holistically, viewing and responding to their needs with conscious attention to their real-life circumstances. A physician practicing women-centered, gender-responsive care, for example, does not prescribe medication that must be taken with food without also ensuring that the woman has access to an appropriate and secure supply of food for herself *and her children*; or provides culturally competent HIV care for a transgender woman that both alleviates her distrust of service providers due to past negative experiences and provides accurate information on the interaction of her HIV regimen with her hormone therapy. Such care requires not only responding to patient's medical and social service needs once she walks in the door -- but also designing, funding, and

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implementing the services she needs to get to the services provider's doorstep in the first place.

The barriers that keep many women from accessing HIV care effectively are real and powerful and cannot be overcome without the development of service delivery patterns, approaches and structures that tackle them head-on. The toll of these barriers can be measured by women's disproportionate rates of illness, hospitalization, and death -- as well as in the cost to their children, families and communities when primary caregivers are incapacitated or absent due to hospitalization or death.

The toll in societal and financial terms can be expressed in the high cost of in-patient care -- occurring when women become so ill that postponing care is no longer an option -- the costs generated by additional HIV infections caused when "treatment as prevention" doesn't work because of erratic adherence, and the costs to social services as children and the elderly become homeless or hungry when their women caregivers are disabled by HIV-related illness, or orphaned when a mother dies.

Substantial research has identified the barriers that stand between women living with

HIV and the clinic's front door. The NHAS includes various initiatives designed to enhance enrollment and retention in HIV care including HPTN 065 (TLC+) and the 12-Cities Project. The NHAS contains scant attention, however, to the very specific barriers that women face and what it would take to remove or reduce their impact. Thus, it does not contain provisions for, nor does it articulate specific goals and measurable milestones in the development of women-centered, gender-responsive or family centered care.

Barriers and Proposed Solutions to Achieve Women and Family Centered Care

The following are issues that women identify as serious barriers to accessing care and solutions that, when implemented, have been shown to ameliorate those barriers.

Insufficient time and resources to attend to HIV-related appointments. *Women's Health USA 2011* showed that women overall, independently of HIV status, report more logistical barriers to accessing medical care than do men. This could be ameliorated by integrating HIV-related medical care into health services that women already receive (such as sexual, reproductive, maternal, and pediatric care), so as to reduce the number of appointments a woman has to keep to maintain her health. Linking HIV-related clinical and case management services to other social and health care services they already use would be similarly efficient, removing barriers by saving time and money (childcare and transportation costs). The Memphis Center for Reproductive Health, known as Choices, for example, has developed a program called Parallel Paths (or Caminos Paralelos) to provide HIV-sensitive SRH services to women living with HIV. Through outreach and training with HIV care and service providers on the SRH needs of positive women, they have been able to increase their provision of services to women living with HIV and have served up to 114 HIV-positive women, after having served none (to their knowledge) in previous years.²⁴

Lack of access to health care providers with combined expertise in HIV care, the psychosocial context of HIV, and in dealing with women's cultural and gender-based needs effectively. This is partially addressed in the NHAS by the planned provision of AIDS Education and Training Centers (AETC) training to build providers' cultural competency and the number of providers with HIV expertise, as well as in the new "Enhancing Engagement and Retention in Quality HIV Care for Transgender Women of Color" demonstration projects. The need to expand access to providers with HIV expertise in Federally Qualified Health Centers (FQHCs) and other Medicaid-funded service delivery sites is particularly urgent in the context of the ACA, which will expand Medicaid provision and in some cases shift HIV care to FQHCs. Failure to address this gap adequately will have critical consequences, particularly in states that already

have few FQHCs and weak Medicaid systems, as is frequently the case in Southern states in which women are heavily impacted by HIV.

There is no mention in the NHAS, however, of plans to assure that HIV-positive women are seen by providers trained to deliver women-centered, gender-responsive care that addresses critical health issues including fulfilling the reproductive desires and intentions, the impact of stigma and discrimination on transgender women, intimate partner violence, and the challenging and potentially dangerous disclosure dilemmas experienced by women living with HIV. Disclosing her HIV status to her partner may put her at risk of violence (if she is blamed for “bringing HIV into the house”), abandonment, or loss of custody of her children. Disclosure to other family or community members may also lead to social ostracism of herself and/or her children, loss of housing, and job loss or other forms of employment discrimination. Providers who are not sensitized to these issues may – albeit inadvertently – put women at risk for violence or threats to their health and the health of their families and communities.

In addition, the frequency of negative experiences with medical and service providers who openly stigmatize HIV-positive women’s reproductive choices,²⁵ or who stigmatize transgender women who seek HIV services²⁶ constitute a major barrier that discourages women living with HIV from accessing care and services. Provider training must explicitly emphasize these aspects of non-discrimination to assure women are not lost to care.

Inability to secure trusted and affordable child-care. This could be ameliorated by provision of low-cost or free childcare services in medical facilities, increased access to reliable, affordable, community-based child care, and the adoption of family-friendly office hours on evenings and weekends to make it possible for other family members to stay with children (or others, such as elders requiring care) while women attend their appointments. Such hours would also facilitate access to care for women who cannot afford to miss work in order to go to medical or social service appointments.

Difficulty navigating an overwhelmingly complex services system. This could be ameliorated by expanding access to culturally relevant peer navigation programs that provide women with trusted guides easily understandable information to assist them in determining how best to get what they

need from our highly fragmented service delivery systems. In addition, by serving as role models, peer navigators can enhance and support the professional assistance provided by professional case managers and build women’s confidence and determination to stay in care and on treatment.²⁷

Lack of awareness of the need for HIV testing and the importance of ongoing care if positive.

Integrating HIV care and education into other health care services for women and their families such as sexual, reproductive, maternal, and pediatric care, can increase awareness and uptake of critical HIV services. This would not replace but rather build on the targeted community education and testing promotion campaigns currently being implemented through the NHAS. Women who are offered testing by a trusted health care provider or who are encouraged to engage with HIV medical care by a social services case manager often take the recommendations more seriously than they otherwise would.

Overall lack of availability of wrap-around and facilitative services²⁸. These services may not be gender-specific but are, nevertheless, essential to getting women to the front door of a care provider’s office by synergizing the use and effectiveness of HIV-related services.

Vital wrap-around/facilitative services include those that ensure 1) housing stability, 2) adequate nutrition, 3) targeted case management, 4) transportation resources, 5) legal assistance, 6) mental health screening and care, and 7) treatment for substance use. Plans for expanding access to the latter two are well represented in the NHAS. Ongoing support for the other five, however, is uncertain as they are now provided to women living with HIV primarily through Ryan White Part D and the Housing Opportunities for People with AIDS (HOPWA) programming, both of which are currently unable to keep pace with existing levels of need and both of which may come under attack with the implementation of health care reform. Ongoing or increased erosion of these wrap-around services will have costly consequences to public health and social services systems overall.

Housing: 75% of U.S. women living with HIV must house not only themselves but also their children, and frequently other dependents, including adults. This complicates the challenge they face. A woman may be ineligible for housing in shelters or group living situations if she has children with her. Conversely, she may become ineligible for

subsidized housing when her children leave home if her eligibility is conditional on her role as a parent. Markedly, the leading cause of homelessness among women and children is domestic violence.²⁹ According to the CDC “one in four women have been the victims of severe physical violence”³⁰ at home and racial disparities in intimate partner violence are startling³¹. Given the strong bi-directional correlation between intimate partner violence and HIV³², women’s risk of acquiring HIV and of suffering poor health outcomes once positive is already elevated. Homelessness simply compounds it further. Homeless families comprise approximately one third of all homeless people in the U.S. and 84% of homeless families are headed by single women with children. People whose housing status has worsened (usually by becoming homeless) are four times more likely to exchange sex for money or other necessities, while those whose housing situations improve tend to reduce their HIV risk behaviors by half.³³ Research shows that stable housing is vital to ARV treatment adherence³⁴ and highly cost-effective, given that the prevention of even one new HIV infection can save up to \$300,000 in treatment.³⁵

Case management services: In the Bronx, Manhattan and Queens, New York, the Comprehensive Medicaid Case Management Program (known as COBRA) illustrates the cost savings of providing intensive case management to people who have difficulty accessing HIV medical care and/or other services. COBRA’s small, interdisciplinary Health Home Teams assess each client’s bio-psychosocial status and collaborate with the client to work toward feasible goals. These services help clients obtain and stay in primary medical care and achieve access to necessities including temporary shelter, permanent housing, adequate nutrition and other entitlements.

Case managers also assist clients in obtaining resources to meet the children’s needs for emergency food assistance, safe shelter, and childcare. They are often instrumental links to the legal services women need to pursue child support, or escape a violent partner.

It has been documented that these services benefit not only the client and their families, but also provide public health benefits by helping people with HIV to adhere to ARV regimens more consistently^{36, 37}. In one 2008 study conducted in ten U.S. cities, 78% of all participants utilizing case management services were using medical care within six months of trial enrolment; a rate 30% higher than among those not utilizing case management.³⁸

Transportation and food: Two other necessities often provided by wrap-around services are transportation and food. Lack of a vehicle or money for public transportation – exacerbated by the very limited number of HIV-experienced health care providers in many areas – makes it literally impossible for many women to get to the front door of an appropriate HIV care provider. In one North Carolina study, 58% of rural HIV case managers and 30% of urban case managers cited lack of transportation as a major barrier to care for women.³⁹

The HIV Law Project notes that, “many of the same factors that put women at risk of 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.”⁴⁰ This food insecurity compromises the effectiveness of whatever medical care someone with HIV is receiving because adequate daily nutrition is critical to medication absorption and to reducing ART-induced side effects (which affects compliance with one’s ART regimen).

A 2006 study showed that in-home food delivery services cost an average of \$1507 per person *per year*⁴¹, over three hundred times less than the average \$2000 *per day* hospital cost for a person living with HIV.⁴² As noted above, women living with HIV tend to have more and longer hospitalizations. Thus, the cost-effectiveness of assuring food security is indisputable.

WHAT NEEDS TO BE DONE MOST URGENTLY

The NHAS Implementation Plan must be revised prior to its two-year review to include specific goals and measurable milestones in the development of structural guidelines and models designed to increase the quality and accessibility of health care for women living with HIV and their families. At minimum, these include:

- Federal funding requirements (and funding incentives) to encourage providers to integrate HIV-related medical care into sexual, reproductive, maternal, and pediatric care, as well as to establish effective links between these and the provision of HIV-related case management and IPV services.

- Implementation plans prioritizing widespread action to increase the number of providers with HIV expertise in FQHCs and other Medicaid-funded provider sites, particularly in Southern states and rural areas. The AETC-provided training in cultural competency received by these new care givers (as per NHAS plans) must be expanded to include cross-cultural training on gender-related issues including sex roles, intimate partner violence, fertility planning and the health and service needs of transgender women.
- Specifically articulated plans for ameliorating the logistical barriers that make it difficult for women to keep medical/social service appointments and stay in care. These must address, at minimum, transportation assistance, expanded childcare options, access to respite services to cover women's other care-giving responsibilities (such as unpaid elder-care), nutritional adequacy (which, unmet, leads to skipping appointments due to illness), transgender-specific care needs and concerns, and the case management and peer facilitation services support to access needed HIV testing, medical and social services, as well as to stand up to the stigmatizing treatment women receive from some service providers.
- A commitment to supporting provisions within Affordable Care Act implementation that

emphasize strong gender, linguistic, and cultural competence standards for patient navigation and that prohibit States from requiring Navigators to be licensed insurance agents or brokers.

- Designated allocation of resources to HOPWA, Ryan White CARE Act Part D, and Medicaid-funded providers of wrap-around services to expand access to transportation, housing, and other services designed to meet the needs of women with children and, thus, facilitate their retention in HIV care.

Conclusion

The 30 for 30 Campaign was founded to guarantee that the unique needs of women living with and affected by HIV are met in this changing health care delivery and prevention environment. The Campaign is made up of a diverse and far-reaching group of organizations from every region of the United States. We include national and local advocacy and service delivery organizations – all dedicated to ensuring that the health and rights of women living with and affected by HIV/AIDS are upheld. With confidence and urgency the Campaign encourages policy makers to take swift action to implement the HIV care and treatment programs and services we know work for women.

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Chairperson: C. Virginia Fields, MSW

Consultant: Anna Forbes, MSS

Member Organizations: The Afiya Center HIV Prevention & Sexual Reproductive Justice, African Services Committee, AIDS Alabama, AIDS Alliance for Children Youth & Families, AIDS Foundation of Chicago, AIDS United, Bailey House, Campaign to End AIDS (C2EA), Center for Health and Gender Equity (CHANGE), Center for HIV Law and Policy (CHLP), Community Healthcare Network, HIV Law Project, HIV Prevention Justice Alliance, Housing Works, International Community of Women Living with HIV/AIDS (ICW), IRIS Center, Memphis Center for Reproductive Health, National AIDS Housing Coalition (NAHC), National Black Leadership Commission on AIDS, Inc. (NBLCA), National Black Women's HIV/AIDS Network (NBWHAN), National Health Law Program (NHeLP), National Women and AIDS Collective (NWAC), Sisterlove. Inc., SMART University, South Carolina HIV/AIDS Council, Southern HIV/AIDS Strategy Initiative (SASI), U.S. Positive Women's Network (PWN), The Well Project, The Women's Collective, Women Organized to Respond to Life-threatening Diseases (WORLD), Women with a Vision

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