Sustaining Care, Treatment and Essential Services for Women Living with HIV and the Future of the Ryan White Program

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The landscape of health care in the United States is changing. The Affordable Care Act (ACA), with its expansion of insurance coverage and emphasis on prevention, wellness, and coordinated "whole person" care, has the potential to significantly increase access to comprehensive care for women living with or at risk for HIV. Within this health system transformation, the Ryan White Program will also need to adapt.

It is too early to know the exact impact that the ACA will have on access to HIV care (and thus too early to make major changes to the Ryan White Program). But the HIV community is already considering how to integrate the health care needs of women living with and at risk for HIV into health reform as well as the future role of the Ryan White Program. As this discussion continues, lawmakers should consider the following issues to ensure that women living with HIV can access comprehensive, coordinated health services, like those currently provided by the Ryan White Part D Program.

- **Women living with HIV have unique health and service needs.**

Women comprise approximately 24% of all people living with HIV, and accounted for 20% of new HIV diagnoses in 2010.[1] Women of color are disproportionately impacted; over 75% of women testing positive for HIV in 2010 were African American or Hispanic.[2] For women, HIV is interwoven with issues of health (including sexual and reproductive health), race, ethnicity, gender, gender identity, intimate partner violence, trauma history, and poverty.

- The majority of women living with HIV have incomes below the federal poverty level (FPL), meaning that added to their health care needs, women are likely to have unmet housing, nutrition, and other social service needs.[3]
- Often, women are the primary caretakers of children and other family members and are likely to put the needs of family members above their own health care needs. Of adults in care for HIV, women are more likely than men to have minor children (60% vs. 18%) and to have those children living with them (76% vs. 34%).[4] Services and care must be accessible for women with childcare responsibilities.

- Women face cost-related and logistical barriers to health care, including taking time off work, finding childcare, and transportation. These constraints present particular barriers to low-income women.
- Intimate partner violence and power dynamics in relationships can impact women's ability to negotiate use of male condoms (or otherwise protect themselves from the sexual transmission of HIV and sexually transmitted infections), as well as to remain in care and adherent to medication if they do acquire HIV. Data show that women with HIV are twice as likely to be survivors of intimate partner violence,[5] and one study demonstrated that women with HIV who had experienced trauma in the past 30 days were 4 times more likely to fail treatment.[6]
- Women with HIV are at increased risk for developing or contracting a range of conditions, including human papillomavirus, which can lead to cervical cancer, and severe pelvic inflammatory disease.[7] In addition, women with HIV who are in their childbearing years are likely to have needs in relation to fertility desires, child spacing, and contraception. Thus, provider expertise in OB/GYN care and sexual and reproductive healthcare for women with HIV is critical to ensuring good health outcomes for women living with HIV.
- According to the Centers for Disease Control and Prevention, only about half of women who are diagnosed with HIV are in care, and only 4 in 10 have the virus under control.[8]

These factors impact women's health and social service needs, and affect their ability to access care, treatment, and services. Because of these factors, women need health services that integrate chronic disease management, primary care, sexual and reproductive health care, services that address intimate partner violence and promote healing from trauma, and supportive services.

- **For years, the Ryan White Program Part D has been integral to addressing the unique needs of women living with HIV, and ensuring access to care, treatment, and services they need. As the total number of women living with HIV in the US increases, it is increasingly imperative to ensure that all aspects of the HIV care delivery system have the capacity to address the needs of women.**

Part D of the Ryan White Program targets the unique needs of women by providing access to family-centered, medical care and supportive services to women, infants, children, and youth living with HIV/AIDS throughout the country. Part D has been successful because of its comprehensive, coordinated, integrated approach—an approach that recognizes the importance of both clinical care and supportive services and the fact that women's health needs are inextricably bound up with the needs of their families.

- Part D provides coordinated, comprehensive HIV medical care that is respectful and culturally and linguistically competent. Medical services include outpatient/ambulatory care, diagnostic tests, mental health and substance abuse services, medication assistance, nutrition therapy, and oral health services.[9]

- Part D improves access to supportive services essential for women living with HIV to manage their disease and stay in care—services like transportation assistance, case management, translation, and childcare.[10]

- Part D funding goes to 116 community-based organizations, safety net and university hospitals and health departments in 39 states, Puerto Rico and the US Virgin Islands.[11] More than 90,000 women, infants, children, youth and family members use Part D funded services each year.[12] More than 37% of women receiving medical care in the Ryan White Program do so through Part D.[13]

- Part D has helped to greatly reduce vertical HIV transmission.[14] Community outreach workers help pregnant women get and stay on HIV medications and continue to support women after giving birth to ensure that infants do not contract HIV.

- While only 41% of all women living with HIV in the US are considered retained in care, 77% of female Ryan White clients stay in care.[15]

In order to ensure that the potential of the ACA and other health reforms are fulfilled for women living with HIV, implementation efforts must ensure that the services, provider expertise, and effective models of care that are the hallmark of Part D are preserved. Women-centered services are needed in all parts of the Ryan White Program and throughout the health care system.

- **Women living with HIV, and their provider and support communities, must be included in any discussions and decisions about changes to the current Ryan White Program, ACA implementation, and other health care reform efforts.**

Women living with HIV, particularly women of color and transgender women, and their providers must be part of any decision-making process that may change access to care and services. As we see a nationwide trend in laws and policies which threaten access to essential reproductive and women-focused health services, it is critical to focus efforts on ensuring that the ACA meets the care and treatment needs of women living with and at risk for HIV.

- Any administrative or legislative efforts to significantly change the Ryan White Part D program are premature, as we do not yet know the exact impact of the ACA on access to HIV care.

- Any changes must only be made after an open and transparent process that includes and incorporates women living with HIV and their providers.

- Any changes must ensure that the unique needs of women living with HIV, including access to care, treatment and supportive services that are currently provided by Part D, will continue to be effectively addressed.

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