

Recommendations for Women and Girls Infected/Affected by HIV

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Developed for the Office on Women's Policy & Initiatives - Executive Office of the Mayor

Introduction

Women and girls in the U.S. are increasingly affected by HIV. Women of color (i.e. Black and Latina women) are disproportionately affected by the epidemic, especially women living in the District of Columbia. Women and girls living in the District of Columbia are reported as having the highest prevalence of HIV and Sexually Transmitted Infections in the country. With that said, it is important that the complex medical, economic, and societal realities of those infected or vulnerable to infection are addressed and improved upon where needed in order to combat this epidemic.

The mission of The Women's Collective (TWC) is to meet the self-defined needs of women, girls and their families living with or at-risk for HIV/AIDS, reducing barriers to care and strengthening their network of support and services. Services are divided between three programs: 1.) HIV care management for women ages 18+ and families living with HIV/AIDS, 2.) HIV prevention for women, girls and families at risk for HIV/AIDS, and 3.) Policy & Advocacy to address the needs and issues of women and girls locally and nationally. TWC has a strong and proven track record in meeting the needs of women and girls of color.

The women and girls we work with face numerous structural and societal challenges in their lives that affect the health care and services available to them. As such, the recommendations presented in this document were developed within the context of our experiences as advocates and service providers, and as HIV-positive women and their allies. It is our hope that the enclosed recommendations open the way for a formal dialogue at the local level about improving the lives of women living with and affected by HIV in the District of Columbia.

The following were identified as overarching priorities for an effective district government response to the needs of women and girls infected or affected by the HIV epidemic:

- 1) Increase in care, treatment, and supportive services for HIV-positive women and girls.
- 2) Prioritize and support comprehensive, age appropriate sexuality education.
- 3) Enhance the meaningful involvement of people living with HIV, representative of the constituency served, in decision-making on policies affecting their communities.
- 4) Invest in building the capacity of community based organizations that work primarily with women and girls.

1. Increase care, treatment, and supportive services for HIV-positive women and girls.

Increase in Care

District residents living with HIV often face an acute lack of health care options. In addition, women and girls living with HIV are often unwilling to receive ongoing health care from local health clinics because of the poor quality of service and/or poor conditions of the health facility. Other female residents are often unable to reach better quality health centers and hospitals because they are not as accessible in certain wards of DC as in others. Further, existing facilities and their providers too often lack adequate training in cultural competence, such that stigma and discrimination is often perpetuated by health providers.

Recommended Action: The District Government should begin an initiative to promote city-wide programs that allow for the establishment of independent practices for physician extenders (nurse practitioners and physician's assistants) to work in underserved areas in order to expand the pool of health care resources providing services to women and girls living with HIV who need primary care.

Increase Treatment

Health care for women and girls living with or at risk for HIV/AIDS should be peer-based and must be modernized by promoting an emphasis on patient literacy and participation in health care services. The mirror image of health care provider education is patient education and empowerment. If women are aware of the full range of health care choices they are better equipped, when communicating with their providers, to find the care and treatment that best meets their needs. Additionally, health care physicians (and physician extenders) should be required to teach HIV+ patients how to read laboratory and diagnostic reports that are often distributed during doctor's appointments without explanation.

Recommended Action: Dedicate a local funding stream for agencies to hold trainings in patient literacy and participation in order to create materials such as "HIV/AIDS Patient Checklists," to be utilized by clients when attending doctor's appointments. Also create online resource guides for women and girls living with HIV that includes schematics specific to women in DC on topics such as 'How to read your laboratory reports' or 'Suggested topics to ask your provider' for those women who are not connected to agencies or who are only connected to care through their physician offices.

Increase in Supportive, Transitional, and Emergency Housing

Increasing funds for supportive housing assistance has the potential to significantly impact the quality of life for HIV-positive women and girls (and their families). For example, a large population of the women served at TWC are involved in physically, sexually, and emotionally abusive relationships. Having such factors present in a relationship limits a woman's willingness to negotiate condom usage and/or inquire about her partner's other risk behaviors for fear of violence. Having ample housing resources available that will cater to the woman (and her children) are critical in empowering women to regain control of their own physical and sexual

health. Further, present transitional and emergency housing programs are not of an adequate health standard for women with compromised immune systems.

Recommended Action: Increase funds for supportive housing for women involved in abusive relationships or situations of violence. In addition, the City Council should vote to pass a standard that would allow for a review of projects funded by Housing Opportunities for Persons with AIDS (HOPWA) to ensure that adequate allocations are being made for residents in all wards of the District. Additionally, the review should include an assessment of the conditions of such housing to ensure that they are livable and conducive for a person with a compromised immune system.

Ensure a continuum of high quality support services for formerly incarcerated women

Formerly incarcerated women who are HIV positive are likely to be lost to care upon release due to lack of consistent access to quality health care, medication, education, and the supportive services needed to navigate the system. These gaps in care create health hazards for the individual as well as for their sexual partners and children.

Recommended Action: Provide adequate access to routine health care, including sexual and reproductive health care, for women detained in DC Jail. This can be done through the creation of cross-governmental partnerships to assure a reliable continuum of high-quality confidential care, including access to appropriate medication, education, and supportive services during the period of incarceration, and ongoing for at least one year after release.

2. Prioritize and support comprehensive, age appropriate sexuality education.

There is no evidence that abstinence-only education delays sexual debut among youth yet research indicates that abstinence-only programs may reduce levels of contraceptive use. Meanwhile, studies show that comprehensive sexuality education does delay the onset of sexual activity among teens, reduces the number of sexual partners, and increases levels of contraceptive use. Women and girls need quality education about their bodies and sexuality in order to make empowered, informed decisions about their health and wellness, including their sexual health and sexual activities.

Recommended Action: Fund peer-based, age-appropriate, comprehensive, and evidence-based risk-reduction sexuality education programs, including HIV-prevention interventions that discuss abstinence, contraception, male and female condom skills, and healthy relationships. Sexuality education programs must also address the social context of sexual and reproductive health and include content on gender roles and gender equity. **Sexual education should not be limited to school-aged populations – it needs to be targeted to all women, throughout their lifespan.**

3. The meaningful involvement of people living with HIV, representative of the constituency served, in decision-making on policies affecting their communities.

HIV-positive women and girls, including transgender women, representative of the

constituency served and who are accountable to their constituency, need to be involved in all levels of policy decision-making and program design that impact their lives.

Recommended Action A: Involvement of HIV-positive women includes building the capacity of positive women to participate. All of these measures should include and actively cultivate involvement by women and girls from each of the city's eight wards in order to promote and secure HIV-positive women's leadership that is reflective of the epidemic among women.

Recommended Action B: Subsequently, female District Government leaders as well as those women in the social arena should be encouraged by the District Government, to talk more openly and candidly about the epidemic affecting women and girls in their respective constituency base and in the community. Female members of the City Council, for example, should lead city funded campaigns to encourage women to get pap smears, HIV and STI screenings, and take the lead on informing and empowering other female residents about the various resources for protecting one's sexual health.

4. Invest in building the capacity of community based organizations that work primarily with women and girls.

There are very few HIV organizations that are specifically focused on the unique needs of women and girls, and those that do exist are often poorly resourced thus, a) restricting their ability to provide a comprehensive array of HIV prevention and support services, and b) inhibiting them from moving beyond their direct, local work with women in order to weigh in on important policy issues. Providing women-led and women-focused HIV organizations with capacity building tools will result in a better informed process of developing, implementing and evaluating prevention strategies in DC. It is time to empower these organizations to gain equal footing and capacity to serve a population in need.

Recommended Action: Preferential funding should be allocated specifically for women- and girl-serving organizations. Additionally, program announcements should explicitly call for community based providers that have core competence in capacity-building activities for women-focused programming.

Conclusion

Because rates among women of color (young and elderly women) are on the rise, prevention efforts must prioritize evidence-based strategies that effectively reduce risk among women. Comprehensive sex education for people of various ages, ethnicities, cultures and genders is a start as is the increase in quality treatment and supportive services for infected women. Additionally, greater support should be given to organizations that work with HIV-positive women and above all, the city's leaders should work diligently to implement policies that will address the needs and issues of women and girls locally and improve their quality of life.