National AIDS Strategy for Women in the United States

Submitted by the National Women and AIDS Collective (NWAC)

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National Women and AIDS Collective: A National AIDS Strategy for Women

History of National Women and AIDS Coalition (NWAC)

Since 1996, The Ms. Foundation has been responding to the essentially invisible impact of the AIDS epidemic on women in the United States through its Women and AIDS Fund (WAF). As the first and only national fund solely dedicated to supporting advocacy by and for women living with and affected by HIV/AIDS, the mission of WAF is to improve the lives of HIV-positive women by supporting grassroots organizations that advocate for policies and services to meet their needs. A total of approximately thirty women-led, women-serving, and allied organizations have received funding from the Ms. Foundation's Women and AIDS Fund. These organizations are located throughout the United States and the Virgin Islands.

In May 2005, having laid the foundation in a prior series of annual meetings, the Women and AIDS Fund of the Ms. Foundation sponsored a national Women and AIDS Policy Convening. This event led to the creation of the **National Women and AIDS Collective (NWAC),** a diverse network (see Appendix A) of HIV-infected and affected women working to influence the ways in which policies are determined at the federal level.

NWAC is the only national organization that advocates for women-led and women-serving organizations. NWAC represents a powerful group of HIV-positive and affected women leaders who are their communities' most consistent, resilient and reliable advocates. With informal networks and astoundingly few resources, NWAC members have been able to improve services for their communities, expand the scope of discussion of HIV/AIDS prevention and care, and widen their circle of sister advocates to include friends, family and community. With these positive changes in mind, NWAC leaders are determined to affect systemic change through policy at the national level.

Below are a few samples of NWAC's policy work.

Samples of NWAC Policy Work

- In May 2005, NWAC created and distributed their first-ever women and AIDS national policy paper, which outlined the importance of the re-authorization of the Ryan White Act and how services for the engagement, care, treatment, and support of women must be properly supported. Recommendations included the allocation of a certain amount of money to fund crucial support services which would enable women to access the medical services they need as well as the support services that serve as a bridge to medical care. Recommendations also called for mandated requirements that would ensure the participation and support of women on important Ryan White policy and planning bodies.

- In October 2007, NWAC held a congressional briefing on Women and AIDS and presented its policy position paper entitled, *Change the CDC HIV Surveillance System to More Accurately Reflect the Reality of the HIV Epidemic and the HIV Prevention Needs of Women Living in the United States.* In this paper NWAC

explains that the growing crisis of HIV infection among women in the United States can be found in the Center for Disease Control and Prevention's (CDC) national HIV-surveillance system. A system based on an outmoded understanding of the epidemic from the early 1980s and since then, has only been minimally revised once during the 1990s. As such, it does not accurately report or reflect why women are increasingly becoming infected with HIV. The paper goes further and provides key recommendations to Congress on how to address this structural defect in the nation's HIV data collection system. Recommendations include: revising the CDC transmission categories, creating an acquisition category, and increasing funding for HIV surveillance.

This action brief is a continuation of NWAC's role in ensuring the voices of women living with, affected and impacted by HIV/AIDS are heard, especially as the country moves towards the development of a National AIDS Strategy to address an epidemic that is once again spiraling out of control.

Background: Why there must be a National Response that Addresses the Specific Needs of Women Living with, Affected, and Impacted by HIV/AIDS

Over the last twenty-six years of the AIDS epidemic in the United States, women have come to represent a growing proportion of new HIV/AIDS cases, more than tripling from 8% of new cases in 1985 to 27% of new cases in 2006, according to the latest CDC incidence surveillance report. In some rural counties in the South, women represent 50% of new HIV infections. Amongst women testing positive for HIV, over 80% are women of color – mostly of African descent (67%) and Latina women (14%). About 80% contract HIV through heterosexual contact—many from a partner they believed themselves to be in a monogamous relationship with. And over one third of women testing positive for HIV are diagnosed late – presenting with AIDS within a year – leading experts to believe that women are slipping through the cracks when it comes to prevention campaigns and testing efforts.

Women at risk for and living with HIV have unique needs – from basic biological differences, to family structure considerations, gender inequality and socio-economic circumstances – which must be considered for any National Response to be effective. When it comes to prevention options, a female-controlled HIV prevention mechanism is still lacking. Additionally, women are statistically more likely than men to be living at or below the federal poverty level at the time they test positive for HIV. According to the HIV Services Cost and Utilization Study (HSCUS), the only nationally representative study of people with HIV receiving regular or ongoing medical care, 64% of women living with HIV had annual incomes below $10,000, compared with 41% of men living with HIV. Also, according to HSCUS, 76% of women living with HIV have at least one child under 18 living in their homes, a factor which may strongly impact the way a woman manages her diagnosis. Women were much more likely than men to cite lack of transportation as a reason for postponing medical appointments (26% compared with 12%). Without an approach to prevention that truly takes into account the realities of women's lives, there will never halt this epidemic.

Although, it is apparent that an individual's behavior can put them at risk for HIV/AIDS, as demonstrated above there are additional factors that put women at a disproportionate risk such as racism, poverty, being the sole provider for her family or simply not having access to transportation, especially in the more rural parts of the country.

Recommendations: NWAC's Vision for a National Response

NWAC recognizes and applauds the high level of commitment and bipartisan support that was involved in the recent passage of PEPFAR legislation. NWAC believes that the same intensity of commitment and support must be shown in the fight against HIV domestically, particularly in light of the new CDC statistics. The following recommendations will help inform a renewed, effective HIV prevention effort in regard to women in the UNITED STATES.

Recommendations:

1. Expand Strategies Focusing on Women and HIV/AIDS

NWAC believes that part of the explanation for the growing crisis of HIV infection among United States women can be found in the national HIV-surveillance system. Although, NWAC acknowledges the presumed heterosexual contact category recommended by the Council for State and Territorial Epidemiologists as an interim step, ultimately the solution must go beyond the addition of this category.

The current HIV-surveillance system does not accurately report why the HIV-infection rate is rising among women because it does not capture their risk, but instead the risk of their partners. If she does not know her partner's risk which is the case the majority of the time, for the purposes of surveillance she is placed in a "no-identified risk" category. As part of the hierarchy of categories currently in place, this would place the majority of women at the bottom. Since funding streams are based on this hierarchy and because the surveillance data are skewed, there have been inadequate resources directed toward women. Nor do the surveillance data reflect the reality of why women living in the United States are increasingly becoming infected with HIV. Therefore, it is necessary to revise the CDC HIV/AIDS Surveillance System's transmission categories in order to capture HIV incidence and prevalence data on women more accurately.

NWAC further believes that women are increasingly becoming infected with HIV, partly due to the current system because its primary focus on behaviors does not take into consideration gender, socioeconomic, racial and ethnic disparities. The development of a model that focuses on women who lack knowledge of their male sexual partner's HIV status and/or behavioral risk factors (i.e. a partner who is HIV-positive, has sex with other men, injects drugs and/or other substances, engages in sex work, and/or is transgender) is also needed.

Finally, NWAC believes the CDC should make women a priority population and eliminate the current financial disincentive to test individuals who are perceived as low risk (since this has the potential to disproportionately impact women). If there is an inadequate system for testing women, then the surveillance will also be inadequate. NWAC recognizes that there is currently an effort underway to have a heightened response to African American women, however, racializing this epidemic communicates to women in other racial and ethnic groups as well as providers serving and counselors testing those women that they are not at risk.

2. Advance the meaningful participation and leadership in policy development and implementation among women who are infected and affected by HIV in the United States.

Twenty-six years into the HIV epidemic in the United States, there is still a scarcity of women living with HIV and allies who work directly with them sitting at policy decision-making tables. Despite global declarations and conventions urging greater gender equality and leadership among women within the epidemic, progress has been slow and inadequate. Women are often overlooked as key stakeholders in this epidemic. NWAC believes that the absence of these women in critical decision-making circles leads to ineffective and misguided HIV testing and prevention policies and initiatives. The United States will not see significant inroads in the fight against HIV among women, particularly women of color, until women who are on the ground doing the work, living with HIV and experiencing the impact of policies, typically developed by men or male dominated organizations, are themselves influencing policies.

These women bring a gender analysis that provides a framework for understanding what is fueling this epidemic in their communities. Until those who create policies understand this and incorporate the contributions of HIV-positive women, the United States will not succeed in stopping HIV in its tracks. In concrete terms, a commitment to this principle would result in women with HIV and their allies from women-focused HIV organizations taking a leadership role in the development and implementation of a National AIDS Strategy, advising the Centers for Disease Control on reality-based prevention and testing needs of women, and serving as advisors to provide expertise wherever prevention and care are being examined. Only women living with and/or working in the field of women and HIV/AIDS can definitively represent the needs of women in discussions that have policy and resource implications. While consultations are one way to implement this objective, NWAC further recommends that these women be involved and integrated into the system of decision-making in an ongoing and meaningful way. NWAC member organizations have a long history of experience involving directly impacted women in decision-making and is happy to share its best practices.

NWAC is the leading organization comprised of HIV infected and affected women in the United States and is ready to partner with decision-makers in understanding the impact that gender disparities have in fueling the epidemic among women in the United States.

3. Create best practices for recognizing and supporting the capacity of women-focused HIV organizations in the United States.

Gender disparities have clearly played a huge role in the ever-growing HIV epidemic among women and girls across the globe. These disparities have also played a role in the HIV prevention and care landscape for women in the United States. There are very few HIV organizations that are specifically focused on the unique needs of women 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. This has created a

dynamic whereby policy at the national level is informed without an adequate representation of women thus negating the role that gender plays in the vulnerability of HIV infection.

NWAC believes that 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 the United States. In the United States, this often manifests as a power imbalance between traditionally male-led organizations and those that specialize in serving women. Until this imbalance is addressed the quality of community input and partnership with government bodies will be flawed and women will continue to be at increased risk of contracting HIV. It is time to empower these organizations to gain equal footing and capacity to serve a population in need and to weigh in on critical prevention issues.

4. Support an environment that promotes open and honest dialogue thereby allowing for the full acknowledgement and recognition of the socioeconomic, biomedical, and behavioral factors that lead to HIV vulnerability among women.

NWAC supports an approach that encourages integration of policies and actions among government agencies and between government and private sectors. Ultimately, a truly integrated effort among various national, state, and local governmental entities will lead to the development of a comprehensive social and economic approach to addressing the multiple and complex factors that contribute to the growing HIV/AIDS epidemic among women.

Conclusion

In summary, NWAC is the leading organization comprised of HIV infected and affected women in the United States and is ready to partner with decision-makers in understanding the impact that gender disparities have in fueling the epidemic among women in the United States. NWAC recommends that this be done by: 1) expanding current strategies focusing on women, 2) meaningfully involving women in decision-making, 3) building the capacity of women-led organizations, and 4) examining and working to address socioeconomic factors driving the epidemic.

NWAC would welcome any additional questions and further dialogue in regard to the needs of women living, affected, or impacted by HIV/AIDS in the United States.

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Appendix A – National Women and AIDS Collective Partner Organizations

AIDS Services of Austin, Inc. /Women Rising Project, **Austin, Texas**
Mujeres Unidas Contra El SIDA, **San Antonio, Texas**
Sisterhood Mobilized for AIDS Research and Treatment (SMART), **New York, New York**
Women Alive Coalition, **Los Angeles, California**
Center for Health Justice, **West Hollywood, California**
Women Organized to Respond to Life-Threatening Diseases (WORLD), **Oakland, California**
African Services Committee, **New York, New York**
Aniz, Inc., **Atlanta, Georgia/Baton Rouge, Louisiana**
Courage Unlimited, **Las Vegas, Nevada**
Christie's Place, **San Diego, California**
Southwest Boulevard Family Health Care, **Kansas City, Kansas**
Virgin Islands Community AIDS Resource and Education, Inc (VICARE), **Christianstead, Virgin Islands**
New Jersey Women and AIDS Network, **New Brunswick, New Jersey**
Women's Lighthouse Project, **Denver, Colorado**
BABES Network, **Seattle, Washington**
The Women's Collective, **Washington, District of Columbia**
Twin States Network, **Bellows Falls, Vermont/Gilsum, New Hampshire**
Indigenous People's Task Force, **Minneapolis, Minnesota**
National Association of People with AIDS, **Washington, District of Columbia**
Capital District African American Coalition on AIDS (CDAACA), **Albany, New York**
HIV Law Project, **New York, New York**
Women's HIV Collaborative of New York**, New York, NY**