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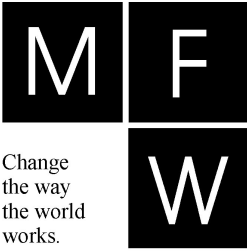
National Women and AIDS Collective

A project of the Ms. Foundation's Women and AIDS Fund

2005 Ryan White CARE Act Reauthorization Recommendations

African Services Committee (New York, NY), AIDS Services of Austin, Inc. / Women Rising Project (Austin, TX), Aniz, Inc. (Atlanta, GA), The BABES Network (Seattle, WA), Capital District African American Coalition on AIDS (Albany, NY), Christie's Place (San Diego, CA), Courage Unlimited (Las Vegas, NV), Southwest Boulevard Family Health Care/HIV University Kansas City (Kansas City, MO), Indigenous Peoples Task Force (St. Paul, MN), Mujeres Unidas Contra el SIDA (San Antonio, TX) Women's Lighthouse Project (Denver, CO), Sisterhood Mobilized for AIDS/HIV Research and Treatment (S.M.A.R.T.) (New York, NY), Virgin Islands Community AIDS Resource & Education, Inc. (Christianstead, VI), Women Alive Coalition (Los Angeles, CA), Women of Color AIDS Council (Boston, MA), The Women's Collective (Washington, DC), Women's Resource Center (Columbia, SC)

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In 2003, HIV infection was the leading cause of death for African-American women in the U.S. aged 25-34 years.¹

In the same year, HIV infection was the 4th leading cause of death among all women in the U.S. aged 35-44 years, and the 6th leading cause of death among all women aged 25-34 years.²

On May 17 and 18, 2005, grantees and colleagues of the Ms. Foundation's Women and AIDS Fund (WAF) met in Washington, D.C., to develop a policy agenda that addresses the unique and historically unmet needs of women living with HIV/AIDS. This meeting marked the first time infected and affected women from grassroots organizations across the country presented a unified front on this issue at the national level. The result was the creation of the National Women and AIDS Collective.

What follows is:

1. A history and status of women living with HIV/AIDS in the U.S.;
2. An introduction to the Ms. Foundation's Women and AIDS Fund; and
3. Two specific policy recommendations put forth by the National Women and AIDS Collective regarding the 2005 reauthorization of the Ryan White CARE Act.

History and status of women living with HIV/AIDS in the U.S.

The HIV/AIDS epidemic is devastating women in the United States. Women account for a growing share of AIDS diagnoses in the U.S. rising from 8% in 1985 to 27% in 2003.³ Women of color, particularly African-American women, have been especially hard hit and represent the majority of new AIDS cases among women. Consider these statistics:

- In 2001, the rate of AIDS diagnoses for African-American women was approximately 25 times higher than the rate for white women.⁴
- African-American and Hispanic women together represented about 25% of all U.S. women yet they account for 83% of AIDS diagnoses reported in 2003.⁵
- Of adolescents between the ages of 13-19, females represented 46% of all AIDS cases; of young people between the ages of 20-24, females represented 36% of all AIDS cases.⁶
- Of all cumulative HIV cases in women through 2003, Native-American women accounted for 311 cases, and Asian/Pacific Islander women accounted for 304 cases.⁷

It is also important to acknowledge that the CDC presents no surveillance data on woman-to-woman HIV transmission. An article posted on the CDC Web site states, "despite the considerable number of women in the United States who identify as lesbian, few data exist that address lesbian health needs."⁸

It is important to note that these statistics may be higher when taking into account the number of cases among women that go unreported.

How is HIV/AIDS different for women? Women often care for HIV-positive family members. They also navigate a complex health-care system while often dealing with child care issues, sexual and physical violence and poverty. In addition, they face the challenges of language barriers, lack of transportation, substance abuse and racism. Women living with HIV/AIDS find it difficult to build and sustain the necessary networks to organize and represent their voices and demands. Clearly, the current resources and efforts available are not equipped to address the multiple needs of women with HIV/AIDS.

What is the current status of women living with HIV/AIDS in the U.S.? In fiscal year 2004, U.S. federal funding for HIV/AIDS was estimated to total \$18.5 billion. Of this, 59% was to go to medical care, 16% to research, 9% to cash and housing assistance, 5% to prevention, and 10% to combat the international epidemic.⁹

Although important advances have been made in prevention, treatment, and medical care, women have not benefited at the same rate as men. Between 1993 and 1999, the number of new AIDS cases among women fell by 36%, compared to 60% for men during the same period.¹⁰ Even more alarming, the number of AIDS deaths among women has declined at a considerably slower rate than men. Between 1993 and 1998, estimated AIDS deaths among women declined by 35%, compared to a 64% reduction among men over the same period.¹¹ In many instances, these deaths have left orphaned children behind.

Similarly, women with HIV/AIDS who are in care still fare more poorly on several important access and quality measures than men. For example:

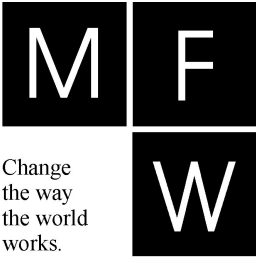
- About a quarter of women with HIV (a rate significantly higher than men) report postponing medical care due either to barriers such as sickness or lack of transportation.¹²
- Women are more likely to be hospitalized and use the emergency room than men.¹³
- Women are also less likely to have received combination antiretroviral therapy, the accepted standard of care.¹⁴

The Ms. Foundation's Women and AIDS Fund (WAF)

In response to this epidemic, the Ms. Foundation for Women created the Women and AIDS Fund in 1996. This fund is the first, and remains the only, national fund that supports advocacy and self-determination for women living with HIV/AIDS. **By funding organizations that are led by or have significant leadership of HIV-positive women, the Ms. Foundation acknowledges that these women know best what they, their families, and communities need.**

In addition to funding, a critical piece of WAF includes an annual convening of HIV-positive advocates from across the country. These convenings provide skills-building trainings and crucial networking opportunities. Nine years into existence, WAF has succeeded in seeding a national women and AIDS movement and is in the process of ensuring its growth, sustainability and impact. WAF grantees represent a powerful group of HIV-positive women leaders who are their communities' most resilient advocates. With informal networks and astoundingly few resources, they have improved services for their communities, expanded the scope of discussion of HIV/AIDS prevention and care, and widened their circle of fellow advocates to include friends, family and community. These leaders have made positive change in their communities and are determined to affect systemic change through policy at the national level.

The May 2005 National Policy Convening marked the first time WAF grantees came together to set the beginnings of a national policy agenda for women living with HIV/AIDS in the U.S.



National Women and AIDS Collective
A project of the Ms. Foundation's Women and AIDS Fund (WAF)

Ryan White CARE Act Reauthorization Recommendations

Whereas federal legislation for the Ryan White Care Act is due to expire and be reauthorized in Fall 2005, the National Women and AIDS Collective asserts the rights and needs of women living with HIV/AIDS through the following two policy recommendations.

1. Allocate 25% of all Ryan White CARE Act funds across all titles to community-based organizations that currently and historically have been led by and for HIV-positive women.

Why allocate this money to these organizations? Groups led by and for HIV-positive women address support, treatment and prevention of HIV/AIDS *through the perspective of those most affected*. They understand how crucial support services are in enabling women to access the medical services they need. Support services are the bridge to medical care, and thus eliminate disparities in access that are so prevalent today.

2. Continue, sustain, and expand consumer representation in the implementation of all titles. This includes an increase in representation of women living with HIV/AIDS on local Ryan White Planning councils and other decision-making bodies.

A fundamental component of the local HIV planning process is parity, inclusion, and representation (also know as PIR). All three concepts are intended to ensure that planning bodies include a diverse group of members who truly understand and represent those most infected and/or affected by the HIV/AIDS epidemic.

With the exception of Title I, there are currently no mandatory requirements for consumer participation. Furthermore, the current guidelines regarding consumer participation are unclear.

To rectify this, we recommend the following:

- Making requirements for consumer involvement mandatory and consistent across Ryan White Titles I, II, III, and IV;
- Eliminating the “non-aligned consumer” provisions required for consumer participation on Ryan White Title I planning bodies;
- Requiring states and localities to develop a plan to ensure that representation of HIV-positive individuals includes an adequate number of HIV-positive women (i.e. representation that reflects the

national percentage of women living with HIV/AIDS). This plan should determine what barriers to participation exist and how these barriers will be addressed. This plan should also address the recruitment and selection processes and provide a mechanism for addressing grievances;

- Requiring states and localities to develop minimum standards for consumer training; and
- Requiring states and localities to take responsibility for training and preparing consumers to be informed and successful representatives.

While the two preceding recommendations list our most pressing policy demands in regard to the Ryan White CARE Act reauthorization, the following issues are also critical in addressing the needs of women living with HIV/AIDS.

- The AIDS Drug Assistance Program (ADAP) should be fully funded in each state and also pay for medications for related ailments such as medication-induced diabetes. *ADAP is one of the few entitlement programs available for undocumented women.*
- Fully fund microbicide research and develop tools that will enable women to protect themselves without having to rely on the cooperation of others.
- Increase access to both HIV-related specialty and non-HIV specialty care for women living with HIV/AIDS.
- Increase research on how HIV affects women.
- Generate research on woman-to-woman transmission of HIV.
- Ensure access to health care for women and children, including medical care with unlimited OB-GYN services
- Engage women in eliminating economic instability by providing access to educational and vocational training opportunities.

For more information on the National Women and AIDS Collective, the Women and AIDS Fund or the Ms. Foundation for Women, please call 212.742.2300.

¹ CDC, *HIV/AIDS among Women*, 2004, <http://www.cdc.gov/hiv/pubs/facts/women.htm>

² CDC, *HIV/AIDS among Women*, 2004, <http://www.cdc.gov/hiv/pubs/facts/women.htm>

³ CDC, Presentation Dr. Harold Jaffe, "HIV/AIDS in America Today," National HIV Prevention Conference, 2003.

⁴ CDC, *HIV/AIDS among Women*, 2004, <http://www.cdc.gov/hiv/pubs/facts/women.htm>

⁵ CDC, *HIV/AIDS among Women*, 2004, <http://www.cdc.gov/hiv/pubs/facts/women.htm>

⁶ CDC, *HIV/AIDS Surveillance in Adolescents*, 2003, <http://www.cdc.gov/hiv/graphics/adolesnt.htm>

⁷ CDC, 2003 Surveillance Report, <http://www.cdc.gov/hiv/stats/2003SurveillanceReport/table22.htm>

⁸ Marrazzo JM. Barriers to infectious disease care among lesbians. *Emerg Infect Dis* [Serial on the Internet]. 2004 Nov. Available from <http://www.cdc.gov/ncidod/EID/vol10no11/04-0467>

⁹ Kaiser Family Foundation, Fact Sheet: Federal Funding for HIV/AIDS: The FY 2005 Budget Request, 2004.

¹⁰ Centers for Disease Control and Prevention, *HIV/AIDS Surveillance report, Year End Editions, 1993-1999*

¹¹ Centers for Disease Control and Prevention, *HIV/AIDS Surveillance report, Year End Edition, Vol. 11, No.2, 1999.*

¹² Cunningham, et. al, "the Impacts of Competing Subsistence Needs and Barriers on Access to Medical Care for Persons with HIV Receiving Care in the United States," *Medical Care*, Vol.37, No.12, 1999.

¹³ Shapiro, et. al, "Variations in the Care of HIV-Infected Adults in the United States," *JAMA*, Vol.281, No. 1 24, 1999.

¹⁴ Shapiro, et. al, "Variations in the Care of HIV-Infected Adults in the United States," *JAMA*, Vol.281, No. 1 24, 1999.