

August 21, 2009

Dear Senator,

RE: Women Affected by HIV/AIDS Urgently Need Health Care Reform

We, the undersigned, are a community of advocates who represent women infected and affected by HIV/AIDS, a population that was severely overlooked, undiagnosed and untreated for the first decade of the epidemic and whose unique treatment, research and prevention needs continue to be marginalized in favor of global assumptions about who these women are, how they are infected and how they are best treated. For health care reform to be successful, Congress must concretely and specifically address the needs of all women affected by HIV/AIDS.

Women in the U.S. are increasingly affected by HIV, with women accounting for more than 25% of HIV diagnoses in 2007. Black and Latina women are disproportionately affected by the epidemic, comprising 80% of new female AIDS diagnoses; similarly the proportion of young women infected with HIV is on the rise. Women affected by HIV disproportionately live in poverty, care for children and families, and lack access to quality health care that adequately meets their needs, and their HIV status serves to only further marginalize them, in their community, in the health care setting, and in the work force. Further, in regions like the U.S. South, where HIV/AIDS rates are on the rise and the number of uninsured individuals has skyrocketed, nearly two-thirds of women delayed or cancelled medical appointments due to high costs. A plan that tackles the conditions of women living with HIV is not only a matter of individual and public health, it is a critical issue of racial, gender and economic justice.

Health care reform is necessary to serve the needs of women and families affected by HIV. We urge you to move health care reform quickly, as outlined in the below recommendations. As health care reform moves through the legislative process, we ask you to consider the following as priorities in any health care reform package. Our input is based on our own experiences with the health care system, as well as those of our constituents and clients.

1. Prohibit health insurance exclusions based on health status.

Currently insurance companies are allowed to charge higher premiums or refuse coverage related to pre-existing conditions, including HIV/AIDS. The prohibition against discrimination based on preexisting conditions in the Senate Finance Committee's Options and Health, Education, Labor and Pensions (HELP) Committee bill is a tremendous show of progress on this front, and we look forward to working with Congress to ensure that this protection exists in the final base bill.

2. Eliminate health insurance ratings based on gender and age.

The Senate's Finance Committee Options and HELP Committee bill have recognized the

importance of this issue and have rightly included elimination of health insurance ratings based on gender. However, we remain concerned about the effect ratings have on the aging population, particularly women. Any reform that truly prioritizes the affordability of and access to health care must eliminate age- and gender-based ratings. We recommend that Congress impose limits on the cost-sharing older Americans have to pay as a result of age ratings, as has been done in the HELP Committee Bill Section 2701(a)(1)(D), limiting rate variation by not more than 2 to 1.

3. Improve Medicaid and Medicare services for people living with and affected by HIV/AIDS.

Public health care programs such as Medicaid and Medicare provide crucial support to people living with and affected by HIV/AIDS, but they do not go far enough. Prohibitive health care costs and rising HIV/AIDS rates go hand-in-hand. For that reason, any health care reform effort must build on important public health programs such as Medicare and Medicaid in order to effectively address the HIV/AIDS epidemic.

In concert with other members of the HIV/AIDS community we endorse a meaningful expansion of Medicaid to 200% FPL, and we urge you to recede to the highest expansion passed through a chamber of Congress. The Senate's Finance Committee Options and HELP Committee bill rightly include Medicaid expansion. But if we are to address our nation's health care crisis in a meaningful way, Congress must go further.

Congress must allow states to provide expanded Medicaid coverage by increasing income eligibility levels. Higher income eligibility levels recognize that expanded access is necessary to maximize the benefits of early health care access to low-income, HIV-positive people who could not otherwise afford the high costs associated with HIV care and treatment. Women, who typically experience lower wages and greater childcare responsibilities than their male counterparts, are in special need of such a modification.

Additionally, the Medicaid program should be expanded to cover all individuals and families, by eliminating the categorical eligibility requirement for coverage. Categorical eligibility rules must be modified to allow for expanded, early access to Medicaid for low-income, HIV-positive individuals, remedying the current illogical requirement that persons living with HIV must progress to AIDS before qualifying as disabled. This situation often forces people living with HIV to choose between employment and health care. A change in the guidelines would ensure that Medicaid furthers federal treatment guidelines by calling for early intervention and access to care.

Shortcomings in Medicaid coverage and reimbursement regulations must be rectified through comprehensive health care reform. A final reform bill must mandate prescription drug coverage and establish a comprehensive, standard Medicaid benefits package that is available in every state. Further, a health care reform bill must establish minimum provider reimbursement rates to ensure qualified provider participation. Reimbursement for routine HIV screening must be included in Medicaid coverage.

Shortcomings in the Medicare program should be remedied as well. Specifically, health care reform is an opportunity to fix the Medicare Part D “donut hole” and allow AIDS Drug Assistance Program (ADAP) costs to count toward true out-of-pocket costs (TrOOP). Without this fix, catastrophic coverage costs are essentially shifted from Medicare to ADAP, straining state programs that are often under-resourced, thus negatively impacting the scope of services provided. Additionally, Medicare’s two-year waiting period for individuals with disabilities must be eliminated as proposed in the Finance Committee’s Options. This requirement serves as a barrier to care to people living with HIV/AIDS.

4. Include a strong public health insurance option in the Health Insurance Exchange.

A public health insurance option would provide critical competition and choice for consumers purchasing health insurance in the Exchange or Gateway. This option is especially important for people affected by HIV, who are disproportionately likely to lack private insurance. We applaud the Senate’s Finance and HELP Committees for inclusion of a public or community plan option in their respective health care reform option and bill, and we are committed to working with Congress to ensure its inclusion in the final bill.

5. Protect women’s access to comprehensive reproductive health care and support HIV prevention efforts.

A majority of Americans support the inclusion of reproductive health care, including abortion, in broader health care packages, and currently most private health care plans include such coverage. Attempts by lawmakers to restrict such coverage in a health exchange would result in discriminatory, harmful, and unprecedented restrictions on women’s access to health care. Covering the full range of sexual health care is an essential element of HIV prevention and care; the epidemic in this country cannot be successfully stemmed without it. And for a woman living with HIV, already faced with judgment and coercion in her efforts to fully exercise her reproductive options, restrictions on reproductive health care impose additional hardships, for her and potentially for her family.

We support Senator Mikulski’s women’s health amendment because it addresses pertinent issues for women living with HIV. Namely, the amendment would ensure access to low-cost preventive care for women and access to essential community providers, such as community health centers, Ryan White funded health centers, and women’s health centers. Additionally, we support Senator Harkin’s plans to include preventative services such as STD screenings and CDC recommended immunizations at no cost.

6. Extend and fully fund the Ryan White HIV/AIDS Treatment Modernization Act as a stand-alone bill as requested in the Ryan White community consensus document.

As you know, health care reform efforts do not eliminate the need for important public health funding programs that serve as a critical safety net. Going forward, expanding successful programs such as Ryan White is critical if we are going to solve our nation's health care crisis, especially for women affected by HIV/AIDS.

The Ryan White program is currently set to "sunset" on September 30, 2009. Congress must act immediately to extend the Ryan White Program as a stand-alone bill for an additional three years as outlined in the Community Consensus document. Ryan White funding is funding of last resort, and as such is essential to the preservation of HIV/AIDS services across the country. Also, to meet the needs of families affected by HIV, Congress must appropriate an additional \$5 million to existing grantees under the Ryan White Part D program to serve women, youth and families affected by HIV. The current proposed funding appropriates no or limited additional funding for Ryan White Part D, which will leave thousands of women, youth and families affected by HIV with meager supportive services. This result is particularly unacceptable during these stark economic times.

We hope that the above recommendations will help to guide Congress during the final development of a historic health care reform bill. The health care needs of people living with and affected by HIV represent a microcosm of both the weaknesses and successes of our health care system. By including the needs of women affected by HIV in the development of health care reform, Congress will not only serve this community but also all Americans in need of affordable, comprehensive, and high quality health care.

Sincerely,

African Services Committee -- New York, NY
AIDS Alabama -- AL
Alliance of AIDS Services - Carolina -- Raleigh, NC
Center for HIV Law & Policy -- New York, NY and National
Community HIV/AIDS Mobilization Project (CHAMP) -- New York, NY and National
Center for Health and Gender Equity (CHANGE) -- National
HIV Law Project -- New York, NY
International Community of Women Living with HIV (ICW) -- Washington, DC and
Global
National AIDS Fund -- National
National Women and AIDS Collective (NWAC), a project of the Ms. Foundation --
National
Sisterlove, Inc. -- Atlanta, GA
The U.S. Positive Women's Network (PWN) -- National
The Women's Collective -- Washington, DC
Women Organized to Respond to Life-threatening Disease (WORLD) -- Oakland, CA