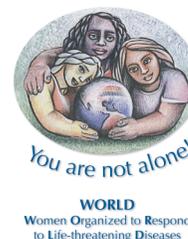


MONITORING THE U.S. NATIONAL HIV/AIDS STRATEGY FROM A GENDER PERSPECTIVE

Executive Summary

Analysis & Recommendations for Implementation
September 2010



Thank you to the many brave and brilliant HIV-positive women who shared their wisdom and personal experience to help generate the analysis and recommendations.

A special thanks to:

The Bay Area Positive Women's Network
Philadelphia Positive Women's Network
The women of Sisterhood Mobilized for AIDS/HIV Research & Treatment (SMART University)
Participants in the VOICES 2010 workshop on *Monitoring the U.S. National HIV/AIDS Strategy*

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For background on efforts to gender monitor the U.S. National HIV/AIDS Strategy, see: www.pwn-usa.org

Introduction

This document is an analysis and report card from a gender perspective of the National HIV/AIDS Strategy for the United States (National HIV/AIDS Strategy or Strategy), and lays out recommendations for the Strategy's implementation to improve all women's, including transgender women's, access to HIV prevention, care, and treatment consistent with the right to nondiscrimination, dignity, bodily integrity, and ethical treatment.

A group of national HIV/AIDS organizations that advocate for the human rights of women living with and affected by HIV have used this gender monitoring tool along with the corresponding report card to assess how and to what extent the Strategy's three goals, when formally articulated in the final Strategy, adequately address the needs of all women. The three goals are: 1) reduce HIV incidence; 2) increase access to care and optimize health outcomes for people living with HIV; and 3) reduce HIV-related health disparities. This initial assessment will be followed by ongoing community monitoring of the Strategy's implementation on a state and national level.

The U.S. National HIV/AIDS Strategy has provided a groundbreaking blueprint for tackling the HIV/AIDS epidemic in the U.S. using a more holistic and structural approach. The Strategy and Implementation Plan provide opportunities for future action but do not identify explicit next steps to improve some key issues for women living with and affected by HIV.

The impact of the HIV/AIDS epidemic on women, especially women of color, is growing: in 1985, women represented 8% of AIDS diagnoses; in 1995, this percentage rose to 20%, and in 2000, it rose again to 27%, where it remains today. Research suggests that "efforts to stem the tide of the U.S. HIV/AIDS epidemic will increasingly depend on how and to what extent its effect on women and girls is addressed."¹ Yet, when women, especially Black women, are directly identified as a hard-hit population in the HIV epidemic in the Strategy it is largely within the context of a broader at-risk population. Similarly, while the disparities in treatment and access to care for transgender individuals have been identified in the Strategy, little is mentioned about why these disparities exist, how they will be

¹ The Kaiser Family Foundation Factsheet on Women and HIV/AIDS in the U.S. Sept 2009

alleviated and how the prevention and care needs of transgender individuals differ from gay men and bisexual women and men.

The monitoring tool identifies a discrete set of key areas where HIV-positive and affected women's rights are most clearly impacted. These areas were used to analyze and grade the Strategy from a gender perspective.

Law and Policy Review:

- Does the Strategy identify as harmful discriminatory and/or medically inaccurate state and federal laws and policies?
- Does the Strategy prioritize the vigorous implementation of current nondiscrimination laws?
- Does the Strategy consider where women, including transgender women, may be victim to multiple forms of discrimination due to HIV status, gender, gender identity, gender expression, sexual orientation and/or race?

Data Collection & Risk Assessment:

- Does the Strategy prioritize accurate and ethical data collection and risk assessment that takes into account unique aspects of the HIV epidemic among women, including transgender women?
- Does the Strategy recommend disaggregated data collection by sex, race/ethnicity, gender identity, and gender expression?

Meaningful Involvement of HIV-positive Women:

- Does the Strategy identify formal mechanisms to ensure the meaningful involvement of women living with HIV, with a particular emphasis on disproportionately impacted populations, in federal, regional, and local decision making bodies?

Women Centered Service Delivery:

- Does the Strategy recognize the importance of and recommend support for effective and inclusive women-centered HIV intervention and care programs and services?

Resource Equity:

- Does the Strategy call for equity and parity in funding, resources, and research that specifically address the needs of women, including transgender women, and geographic areas where women make up a greater share of the epidemic than the national average?

Research:

- Does the Strategy call for research into social and structural vulnerabilities and interventions, focused biomedical research, and operational research for women in the U.S.?

GRADING

| | |
|----------|--|
| A | Identified the issue as affecting women, and proposed next steps reflecting an articulated gender analysis. |
| B | Identified the issue as affecting women, and proposed next steps but without an articulated gender analysis. |
| C | Identified the issue generally but next steps reflect limited to no gender analysis. |
| D | Identified the issue with no next steps, or gender analysis. |
| F | Failed to identify the issue entirely. |

GENDER MONITORING REPORT CARD

| GRADE | AREA OF CONCERN FOR WOMEN LIVING WITH AND AFFECTED BY HIV |
|-----------|---|
| | Law and Policy Review |
| B | Because the U.S. National HIV/AIDS Strategy makes great strides in addressing the rights and dignity of people living with HIV overall, but little mention of improving enforcement and education about laws and policies that disproportionately affect women, in Law & Policy for women living with and affected by HIV, the Strategy receives a B. |
| | Data Collection & Risk Assessment |
| C | Because the U.S. National HIV/AIDS Strategy articulates the need for targeted surveillance to better track and describe the HIV epidemic, but does not address the need to disaggregate data based on gender identity and makes no suggestion to better track social and structural determinants of women's vulnerability to acquiring HIV independently of personal risk behavior in Data Collection and Risk Assessment for women living with and affected by HIV, the Strategy receives a C. |
| | Meaningful Involvement of HIV-positive Women |
| C+ | Because the U.S. National HIV/AIDS Strategy calls for increased leadership of people living with HIV as a mechanism to reduce stigma and discrimination, but does not describe mechanisms to build capacity to promote leadership among people living with HIV reflective of the epidemic, in Meaningful Involvement of HIV-positive Women, the Strategy receives a C+. |
| | Women Centered Service Delivery |
| C+ | Because the National HIV/AIDS Strategy for the United States identifies the unique structural factors that lead to increased vulnerability of women in the HIV epidemic, reinforces the right of all HIV-positive people to voluntary, informed, and respectful HIV care and treatment but does not provide concrete recommendations for the integration of women-centered services such as sexual and reproductive healthcare into HIV care and treatment, in Women-Centered Service Delivery for women living with and affected by HIV, the Strategy receives a C+. |
| | Resource Equity |
| C | Because the U.S. National HIV/AIDS Strategy proposes no plan or campaign to address the unique needs of women beyond their roles as partners and mothers; fails to specifically recognize how women's needs and risk for HIV vary based on geographic location, and how resource allocation should reflect this variation; and has no proposal for capacity building for community based organizations (CBOs) that provide women centered services, in Resource Equity for women living with and affected by HIV, the Strategy receives a C. |
| | Research |
| B | Because the Strategy does implicate some structural drivers of the HIV/AIDS epidemic as worthy of further research but does not call for great scale up or changes in the approach to HIV/AIDS research as a whole and especially for women, in Research, the Strategy receives a B. |
| C+ | FINAL GRADE FOR THE U.S. NATIONAL HIV/AIDS STRATEGY |

Recommendations for the Implementation of the U.S. National HIV/AIDS Strategy

The following recommendations will help guide the implementation of the Strategy toward a more effective response to the HIV epidemic among women in the U.S. The recommendations are not inclusive of all aspects of HIV-positive women's health addressed in the Toolkit but do give concrete suggestions based on the priorities of the National HIV/AIDS Strategy and Implementation Plan.

REDUCING NEW HIV INFECTIONS

1. Intensify HIV prevention efforts in communities where HIV is most heavily concentrated

Recommendation: HHS, CDC, SAMHSA, HRSA, and HUD must ensure that formation of new formulas to better distribute resources in areas most affected look closely at the needs of women, transgender people, and sex workers in order to provide hospitable and nondiscriminatory prevention services.

Recommendation: CDC should direct local prevention planning bodies to prioritize and allocate HIV prevention resources considering social and structural drivers of the epidemic, rather than just behavioral risk.

Recommendation: CDC and NIH should prioritize women-centered prevention research by

- investing in women controlled prevention methods such as vaginal and rectal microbicides research in the U.S. and abroad, and female condoms; and
- ensuring women are included in pre-and post-exposure prophylaxis research.

Recommendation: In consultation with community and other stakeholders, the CDC should launch targeted and funded national initiatives to address the HIV prevention needs of Black and Latina women.

2. Expand targeted efforts to prevent HIV infection using a combination of effective, evidence-based approaches

Recommendation: To better prevent and track the epidemic among women, the CDC should uniformly adopt a “female presumed heterosexual contact,” category since many HIV cases among women cannot currently be categorized under any “risk” category.

3. Educate all Americans about the threat of HIV and how to prevent it

Recommendation: The age-appropriate HIV and STI prevention education that will be developed by the CDC should include stigma-reducing information, non-heterosexist materials, and should address partner violence, challenge gender norms and reinforce gender equity.

INCREASING ACCESS TO CARE & IMPROVING HEALTH OUTCOMES FOR PEOPLE LIVING WITH HIV

1. Establish a seamless system to immediately link people to continuous and coordinated quality care when they are diagnosed with HIV

Recommendation: The Centers on Medicare and Medicaid (CMS) should reverse policies that limit the integration of HIV/STI services for Medicaid family planning expansion patients.

Recommendation: HHS and the CDC should revise guidelines for federally-funded HIV, STI, family planning, and women's health programs to encourage integration and put guidance in place indicating which sexual and reproductive health (SRH), HIV, and STI services should be provided, and how they should be provided (either by direct service or referral).

Recommendation: HIV and STI programs should allow the purchase of contraceptives. For instance, contraception should be included in ADAP formularies.

Recommendation: Agencies should coordinate to ensure the provision of comprehensive, integrated and voluntary SRH and HIV prevention and treatment services for women who are incarcerated or recently released, commercial sex workers, immigrants, and other marginalized populations.

Recommendation: DOJ should work with HHS and medical professional associations to educate primary care physicians and obstetrician/gynecologists on HIV-positive women's reproductive rights, rights to informed and voluntary testing and medical consent when pregnant, and up-to-date information on mother-to-child transmission and risk reduction measures for serodiscordant couples.

Recommendation: HHS should investigate, document, and share best practices in integration of SRH and HIV services related to care for HIV-positive women to develop a standard of care.

Recommendation: CDC should investigate, document, and share best practices in integration of SRH and HIV services in relation to prevention and testing to develop a national standard of testing and linkage to care for women.

REDUCING HIV-RELATED HEALTH DISPARITIES

1. Reduce HIV-related mortality in communities at high risk for HIV infection

Recommendation: HHS should define a standard of care for hard-to-reach populations that includes the use of culturally relevant peer-based programs and incorporates quality of life indicators to improve outreach, linkage, and retention in care.

1. Adopt community-level approaches to reduce HIV infection in high risk communities

Recommendation: NIH can conduct research in communities with high viral loads to

- identify solutions to address structural factors like housing and economic instability, partner violence, mental health status, and drug use
- create research strategies that include community input, and that leave in place programs and services; and
- determine and alleviate barriers to women’s participation in research by providing transportation and child care, counseling and emotional support from peers and clinicians, and adequate information about risks and benefits of trials.

Recommendation: Select 15 to 25 “Health Renewal Zones”. Zones would be areas hard-hit by the epidemic that demonstrate racial and gender disparities. The purpose of designating these Zones would be to coordinate scale up and innovation of HIV testing, prevention, systems of care and support, and to institute structural or policy changes in the same Zones projected to alter the trajectory of the epidemic. Examples could include investing in HIV and health literacy campaigns, integrated health clinics with a community-based structure, in the same geographic areas where syringe exchange resources are made available and quality care is sustained for formerly and currently incarcerated individuals.

2. Reduce stigma and discrimination against people living with HIV

Recommendation: Create permanent structures to prepare and include HIV-positive people reflective of the epidemic in federal decision-making bodies. Federal agencies should partner with positive people’s networks to prepare their constituencies to become leaders in decision-making.

Recommendation: ONAP can work to remove barriers for participation of HIV-positive people in federal advisory committees by ensuring background checks do not automatically exclude those with criminal or drug history or transgender-status.

Recommendation: Prioritize and adequately fund training, advocacy and other programs that aim to quantify, monitor, and reduce stigma and discrimination based on the experiences and priorities of HIV-positive people. These programs should be informed by evidence from tools such as the People Living with HIV Stigma Index, which provides systematic information about how stigma and discrimination are experienced by HIV-positive people while building the leadership capacity of networks of HIV-positive people. These programs can be implemented at the local, state and national level.

Recommendation: HHS Offices, Congress, and other agencies can tie federal HIV funding to specific legal and HIV programming reforms that will increase safe and voluntary disclosure, and recommend repeal of HIV disclosure, exposure and transmission laws and HIV-specific sentencing laws.

Recommendation: DOJ and other agencies should review not only HIV-specific criminalization and sentencing laws, but also other laws and policies that negatively affect people living with HIV. Critical to address are policies that affect the eligibility of people with felony convictions for government benefits like housing, food assistance, and social security. Also, laws that criminalize sex work or drug use should be reviewed to determine how these laws and policies affect people’s access to HIV prevention, care, and treatment services in communities most affected by the epidemic.

Recommendation: When providing technical legal assistance to states on HIV criminalization law reform, agencies like the DOJ and CDC can conserve resources by collaborating with experts in the field and community members who are currently working creatively to alleviate the negative effects of criminalization laws.

Recommendations: DOJ/EEOC should begin legal education campaigns nationwide for people living with HIV and service providers. These “Know your Rights” campaigns will increase protections of existing non-discrimination law and flag patterns of discrimination.

ACHIEVING A MORE COORDINATED NATIONAL RESPONSE TO THE HIV EPIDEMIC IN THE UNITED STATES

1. Increase the coordination of HIV programs across the federal government

Recommendation: The oversight structure should include budget transfer authority and may consider using a designated percentage of agency funding to support inter-agency coordination, collaboration, and innovation.

Recommendation: Ensure coordination between Offices such as the CDC, HRSA, and OPA to ensure integration of SRH and HIV care for women.

Recommendation: Screening and surveillance should include standardized reporting mechanisms for all agencies that include gender identity, ethnicity, and country of origin, and structural risk factors such as community viral load, housing instability, violence, and mental health status.

2. Develop improved mechanisms to monitor, evaluate, and report progress toward achieving national goals

Recommendation: All agency implementation plans must be monitored to ensure that the needs of women and gender minorities are addressed through all programming, research, and campaign initiatives.

Recommendation: Budget reporting should include analysis of investment in programs and services geared at increasing gender equality in access to HIV prevention and care.