

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

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*

The Ford Foundation whose generous support made this work possible.

For background on efforts to gender monitor the U.S. National HIV/AIDS Strategy, see: [www.pwn-usa.org](http://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."<sup>1</sup> 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

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

exist, how they will be 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

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

# GENDER MONITORING REPORT CARD

GRADE	AREA OF CONCERN FOR WOMEN LIVING WITH AND AFFECTED BY HIV
	<b>Law and Policy Review</b>
<b>B</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.
	<b>Data Collection &amp; Risk Assessment</b>
<b>C</b>	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.
	<b>Meaningful Involvement of HIV-positive Women</b>
<b>C+</b>	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+.
	<b>Women Centered Service Delivery</b>
<b>C+</b>	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+.
	<b>Resource Equity</b>
<b>C</b>	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.
	<b>Research</b>
<b>B</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.
<b>C+</b>	<b>FINAL GRADE FOR THE U.S. NATIONAL HIV/AIDS STRATEGY</b>

# Analysis of the U.S. National HIV/AIDS Strategy

## ✓ LAW AND POLICY REVIEW

The issues that arise when making a review of local and national law and policy and an assessment of compliance with and enforcement of nondiscrimination laws affecting people living with HIV speak to the three pillars of the National HIV/AIDS Strategy: 1) reducing HIV incidence; 2) increasing access to care and optimizing health outcomes; and 3) reducing HIV-related health disparities. These issues increase women's vulnerability to acquiring HIV and to poor health outcomes once HIV positive.

HIV criminalization and exposure laws serve to further stigmatize already marginalized groups, dilute the public health message that all people take responsibility for their sexual health, and can lead to harassment of HIV-positive people. These laws, currently on the books in over half the U.S. States generally require no proof of intent to infect another person or actual transmission, and in some cases have been used to criminalize actions such as spitting, thereby furthering misinformation about how HIV is transmitted. In a majority of cases, conviction rests solely on the fact that the HIV-positive person was tested and knows their status. This can result in fear of testing and knowing one's HIV status and can serve as a barrier to care and treatment for HIV-positive people. For women, these laws can be further used to harass, coerce women into remaining in abusive relationships, or wrest custody of children from their mothers during divorce proceedings.

Discrimination against people living with HIV persists despite federal antidiscrimination laws like the amended Americans with Disabilities Act (ADA). In several cases local circuit courts have upheld casual contact laws that allow employers to fire HIV-positive employees in industries such as health care, meat processing, or food service despite scientific evidence showing that the transmission of HIV is unlikely in course of job-related activities. In some cases, employers are too small to be held accountable under the ADA standards. For women, who are already under-employed and underpaid, discrimination on the job as a result of HIV status can be devastating. A job loss means loss of income, and often loss of health care for women and their families.

HIV-positive women routinely face discrimination in reproductive healthcare settings despite current nondiscrimination laws that protect a woman's right to

bodily integrity and reproductive choice and health. As a result, health disparities experienced by HIV-positive women are significant. This discrimination takes many forms, including diminished standards for informed consent in prenatal testing laws, the receipt of inadequate information by healthcare providers about reproductive options, and routine discouragement of pregnancy and childbearing by HIV-positive women. Due to inadequate legal protections, transgender individuals are often unable to receive adequate and equitable preventive care and treatment.

The Strategy mentions issues of HIV transmission and exposure criminalization as well as the need for greater enforcement of existing antidiscrimination laws. However, the decriminalization of sex work and drug use, both important aspects of HIV prevention among women, were not addressed. In addition, the Strategy fails to mention that the reproductive and parenting rights of HIV-positive women are routinely violated via coerced abortions, forced sterilizations and tubal ligations, and inadequate access to fertility and reproductive counseling and technology.

### Does the National HIV/AIDS Strategy:

- ✓ *identify harmful local and federal laws and policies that increase the vulnerability of women living with HIV and suggest strategies to ameliorate the affects of the laws? These laws and policies include:*
  - *State laws criminalizing HIV/AIDS transmission, exposure and non-disclosure.*
  - *State & municipal laws & policies that criminalize sex work.*
  - *Criminalization of drug possession and use.*
  - *Limitations on needle exchange programs and other forms of harm reduction.*
  - *Continued federal funding for abstinence education and limited mandate for evidence based, comprehensive, age-appropriate, non-heterosexist sexuality education.*

The Strategy directly addresses the fact that state laws criminalizing HIV transmission and exposure may lead to greater fear around disclosing one's HIV status and greater risk of discrimination. The Strategy rightly questions whether these laws further the public interest

and public health,<sup>2</sup> and emphasizes the extent to which misconceptions about HIV transmission and exposure persist and damage public health goals.<sup>3</sup>

The implication of drug policies on the HIV epidemic is somewhat addressed in the Strategy, which documents the effectiveness of needle exchange programs in prevention efforts<sup>4</sup> as well as the need to better integrate substance use programs into standard HIV care.<sup>5</sup> The Strategy fails to discuss the need for alleviating those structural barriers to care and treatment that arise from the criminalization of drug use such as possible restrictions on housing, food, and social security benefits. The Strategy further failed to address the effects of the criminalization of sex work on HIV prevention and care efforts.

The Strategy recommends that sex education be included in all levels of education and that health education be based on scientifically sound information about HIV transmission and risk reduction strategies.<sup>6</sup> But abstinence education continues to be promoted as a helpful response to the HIV/AIDS epidemic.<sup>7</sup>

✓ *address laws and policies governing the diagnosis and treatment of women and girls that do not afford them the respect and autonomy identical to that afforded other populations?*

*These laws and policies include:*

- *Lowered standards for informed medical consent when pregnant.*
- *Lowered standards of voluntary and informed HIV testing and care when pregnant.*
- *Ensuring HIV-positive women's right to conceive is protected.*
- *Ensuring that HIV-positive women, including transgender women, receive adequate information to make voluntary and informed decisions about their reproductive choices.*

The Strategy addressed patient's rights and dignity by recommending that "health care that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences—should be the standard."<sup>8</sup> This recommendation speaks directly to concerns regarding the diminished standards for informed

consent and voluntary HIV testing often experienced by pregnant women.

The Strategy, however does little to address the enforcement of HIV-positive women's reproductive rights, which include the right to decide whether or not to have a child, and when and how to do so, and access to the information and services needed to make voluntary and informed decisions about pregnancy and childbirth.

✓ *prioritize the enforcement of existing anti-discrimination laws to reduce HIV-positive and affected women's vulnerability?*

- *Enforce anti-discrimination laws as they relate to race, gender, gender identity, gender expression, nationality or immigration status, disability and HIV status.*
- *Promote the expansion of federal anti-discrimination laws to protect people from discrimination, including employment discrimination, on the basis of sexual orientation, gender identity, and appearance.*

The Strategy prioritizes the enforcement of HIV-positive people's rights "to be free of discrimination on the basis of HIV status [as] both a human and a civil right. Vigorous enforcement of the Americans with Disabilities Act, the Fair Housing Act, the Rehabilitation Act, and other civil rights laws is vital to establishing an environment where people will feel safe in getting tested and seeking treatment."<sup>9</sup>

The Strategy goes so far as to insist "the Department of Justice and Federal agencies . . . enhance cooperation to facilitate enforcement of Federal antidiscrimination laws."<sup>10</sup> But the Strategy falls short of calling for the expansion of federal non-discrimination protections for gender identity and appearance to reduce stigma and discrimination, and improve health outcomes for all people living with HIV.

✓ *suggest the need to educate women living with HIV on their rights and laws and policies that affect their lives?*<sup>11</sup>

The Strategy does not address the need to educate people living with HIV as well as the people who serve them on

<sup>2</sup> Strategy pp. 36-37.

<sup>3</sup> Strategy pp. 36-37; p. 19.

<sup>4</sup> Strategy p. 6; 16-17.

<sup>5</sup> Strategy p. 25; 27.

<sup>6</sup> Strategy pp. 16; 19-20. Strategy Implementation p. 16.

<sup>7</sup> Strategy p. 16.

<sup>8</sup> Strategy p. 27.

<sup>9</sup> Strategy p. 36.

<sup>10</sup> Strategy p. 37.

<sup>11</sup> For example, utilizing the Department of Justice's resources to conduct national know-your-rights trainings for HIV-positive women and advocates.

current laws and policies, including HIV disclosure, exposure and transmission laws that may affect their lives.

## Grade: 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

Accurate and ethical data collection and risk assessment that takes into account the unique factors that place women, including transgender women, at risk for HIV is key to 1) reducing HIV incidence; 2) increasing access to care and optimizing health outcomes; and 3) reducing HIV-related health disparities. Accurate data collection is necessary to identify the most at risk populations who are often invisible under the current data collection system and to appropriately identify and improve the unique medical and structural factors affecting women living with and vulnerable to HIV including community viral load, poverty, housing instability, violence, and mental health status.

Women face particular barriers to being effectively understood in the context of the HIV epidemic. The majority of cisgender (non-transgender) women testing positive for HIV in the United States report no “risky” behavior. Under the current hierarchical surveillance categories, women who present with no knowledge of their male partners risk factors are coded as “no identified risk.” When reporting HIV/AIDS statistics, the CDC distributes the “no identified risk” individuals into the other risk categories based on pre-determined formulas, aiming to approximate the true distribution of HIV infection among risk populations. However, this system is imperfect and especially unfair to women, who are far more likely than men to fall into the “no identified risk” category, as it may result in skewed surveillance statistics. Moreover, since funding, treatment, and prevention priorities are tied to data, inadequate data collection means that treatment and prevention resources could be inaccurately prioritized and/or distributed. Further, uniform standards are not used for the reporting of infections in transgender women, who may be incorrectly subsumed under the category of men who have sex with men, or MSM.

The adoption of the “presumed heterosexual” category will better capture women who would traditionally fall

into a non-identified risk category and therefore be missed in surveillance data. The adoption of this category would also improve resource allocation to support prevention planning efforts that better meet women’s needs.

The Strategy details women’s unique vulnerabilities for acquiring HIV, including the roles played by a partner’s risk factors, structural obstacles, and co-occurrences of infection. The Strategy calls for increased research to understand the epidemic among women and transgender women, and places a strong emphasis on the use of epidemiological and clinical data to strategically allocate resources to vulnerable communities. Acknowledging that resources to combat HIV/AIDS are finite, the Strategy argues for data-driven allocation while noting that funding and focus of prevention and care efforts have not always matched the epidemic’s disparate impact on populations in certain geographic locations, racial and gender minorities, and women. The Strategy does not, however, detail suggestions for how to better collect data, how to accurately track the epidemic among women, and how to streamline the data to understand the broader trends of the epidemic, including social and structural characteristics.

#### Does the National HIV/AIDS Strategy:

- ✓ *call for standardized, useable and non-burdensome data reporting mechanisms across agencies, including uniform and distinct reporting of infections in transgender women?*

The National HIV/AIDS Strategy does not specifically address this issue.

- ✓ *suggest a plan to revise the definition of “high risk heterosexual” to more accurately reflect characteristics of heterosexual populations acquiring HIV including a mechanism to support universal adoption of the “presumed heterosexual contact” risk category?*

The National HIV/AIDS Strategy does not specifically address this issue.

- ✓ *suggest a plan to collect and disaggregate data based on gender identity?*

The National HIV/AIDS Strategy does not specifically address this issue.

- ✓ *suggest a plan to collect and disaggregate data based on ethnicity and country of origin?*

The Strategy recognizes that targeted surveillance for gay and bisexual men, Black, Latino, Asian American, Pacific Islander, and Native American communities, and drug users is needed, given the increased impact of the

epidemic in these populations. However, there is a lack of comprehensive data collection and disaggregation planning for all ethnicities and countries of origin in addition to a lack of gender analysis.

- ✓ *suggest a mechanism for incorporating social and structural factors that increase vulnerability to HIV infection, such as community viral load, poverty, housing instability, violence, and mental health status - into prevention planning and resource allocation?*

Throughout the document, the Strategy does recognize the link between HIV infection and social determinants and calls for increased research into exploring the intersection. The Strategy calls for increased research to examine the link between heterosexual HIV transmission to women as it intersects with incarceration, violence, and injection drug use among men. In addition, the pivotal role of permanent housing and co-occurring substance use and mental health disorders is analyzed. Although the Strategy emphasizes the necessity to track community viral load, a specific mechanism to incorporate social and structural factors into risk assessment, prevention, and resource allocation is not identified.

## Grade: 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

Meaningful participation by women living with HIV in all levels of decision-making about policies that affect their lives is necessary to determine the elements that will be used to implement the three pillars of the National HIV/AIDS Strategy. Meaningful involvement means that HIV-positive women and girls, including transgender women, representative of the constituency served *and who are accountable to their constituency*, are involved in all levels of policy decision-making and program design that impact their lives. Involvement of HIV-positive women includes:

- 1) building the capacity of positive women to participate in all levels of decision making;

- 2) removing barriers for participation by women most impacted by the epidemic including background checks used to determine participation in federal advisory committees that may exclude women with criminal or drug use records; or women with trans-status, and

- 3) providing assurances that current criminalizing laws that chill the participation of sex workers and other marginalized but highly affected communities will not be used to intimidate or endanger their livelihoods if they choose to openly participate in decision making or advisory bodies.

All of these measures should include and actively cultivate involvement by marginalized women with a special emphasis on women of color, women from the South, transgender women, low literacy women, and low income women, in order to promote and secure HIV-positive women's leadership that is reflective of the epidemic. In particular, current HIV epidemiological data mandates that increased leadership by HIV-positive Black women be a national priority.

### Does the National HIV/AIDS Strategy:

- ✓ *call for and have a plan to meaningfully involve women living with HIV reflective of the epidemic in relevant federal and local advisory bodies?*  
*Federal bodies might include:*

- *Centers for Disease Control and Prevention (CDC)/Health Resources and Services Administration (HRSA) Advisory Committee (CHAC)*
- *Presidential Advisory Council on HIV/AIDS (PACHA)*
- *The NIH Office of AIDS Research Advisory Council (OARAC)*
- *Inter-agency working groups created through the National HIV/AIDS Strategy*
- *The Food and Drug Administration's Reproductive and Contraceptive Technologies Advisory Panel*
- *Title X Advisory Committees*
- *Advisory groups resulting from health care reform initiatives*
- *Advisory groups associated with the Office of Minority Health; Office of Women's Health; White House Counsel of Members; and the State Medical Care Advisory Committees*

*Local bodies might include: Ryan White Planning Councils, local and statewide community advisory boards, and prevention planning groups.*

The Strategy specifically calls for promoting public leadership of people living with HIV in order to reduce health disparities,<sup>12</sup> and tasks government and other institutions with the responsibility of building stronger relationships with people living with HIV and the people who serve them.<sup>13</sup> The Strategy does not, however, call for the institutionalization of structures to assure that people living with HIV are directly involved in and on decision making bodies and that those people are reflective of the epidemic.

## Grade: 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

Prioritizing women-centered service delivery based on human rights principles is key to the three pillars of the National HIV/AIDS Strategy: 1) reducing HIV incidence; 2) increasing access to care and optimizing health outcomes; and 3) reducing HIV-related health disparities. The medical care and supportive needs of women, including transgender women, are unique and must be met through holistic and integrated prevention and care models that respect our right to dignity, bodily autonomy, and information to make informed and voluntary medical decisions. Currently, most areas lack women-specific services leaving great disparities in access to effective and culturally appropriate care for women. To achieve the three pillars of the Strategy there must be parity and equity in access to care, which can only be accomplished by serving the unique needs of women.

Culturally relevant, comprehensive, nonjudgmental, and peer-based programs have been shown to best serve the needs of women living with HIV. A critical shortcoming of the current response to the HIV epidemic for women is the failure to fully develop programs and collaborations that reflect the interconnection between sexual and reproductive health (SRH) needs and vulnerability to HIV. Although there is broad consensus on the importance of better integration of HIV and reproductive health services, current public health funding silos and program guidance actively discourage integrated health care delivery models. Consequently many HIV-positive women receive HIV

medical care but not, for example, regular pap smears, reproductive options counseling, or general ob-gyn care. Similarly, many women presenting for family planning services who may be at risk for HIV are not offered an HIV test or counseled about HIV prevention. This disjointed approach simply does not work for women, who cannot be split into pieces to access various types of care. To effectively address the needs of women, programs must coordinate and integrate sexual and reproductive health services with all aspects of HIV care—across all testing, prevention, diagnosis, treatment, and care programs—to meet the diverse needs of women and men, regardless of HIV status.

To achieve the three pillars of the Strategy there must be parity and equality in access to care, which can only be accomplished by serving the unique needs of women. The Strategy provides a mixed response to women centered service delivery.

### Does the National HIV/AIDS Strategy:

✓ *take steps toward the integration of sexual and reproductive health and HIV to achieve better prevention and care outcomes for women, men and/or transgender individuals?*

While HIV-positive women face extraordinary violations of their reproductive and sexual rights, including frequent coerced abortion, sterilization, and tubal ligation, integration of reproductive health care into HIV service delivery is not identified as a pressing need nor a priority. The integration of sexual and reproductive health and HIV as it pertains to men and transgender individuals is also not discussed.

The Strategy generally identifies and articulates a need to co-locate sexual and reproductive health services with HIV testing, stating that “gynecologists and family planning services can be a source of HIV prevention services for women who may or may not be engaging in high risk behaviors, but might not actively seek services from an HIV or sexually transmitted disease clinic.”<sup>14</sup> The Strategy however, falls short of articulating a care or disparities reduction goal in this important area.

✓ *suggest a plan for the co-location of sexual and reproductive health with HIV care settings, in line with U.S. foreign policy in the PEPFAR Five-Year Plan?*

The National HIV/AIDS Strategy does articulate the need for a PEPFAR -like coordinated response to the HIV/AIDS epidemic in the U.S. but does not model the

<sup>12</sup> Strategy p. 37.

<sup>13</sup> Strategy p. 37.

<sup>14</sup> Strategy pp. 26

PEPFAR response to HIV, which prioritizes the integration of reproductive and HIV/AIDS care and treatment.

- ✓ *suggest and provide a plan for the dismantling of funding silos for sexual and reproductive and HIV health care?*

The National HIV/AIDS Strategy does not specifically address this issue.

- ✓ *call for HIV-specific child birthing classes?*

The National HIV/AIDS Strategy does not specifically address this issue.

- ✓ *support programs that treat HIV-related testing and counseling as part of routinely-offered sexual health care?*

The Strategy calls for the integration of testing and counseling as part of sexual health care by suggesting that “gynecologists and family planning services can be a source of HIV prevention services for women who may or may not be engaging in high-risk behaviors, but who might not actively seek services from an HIV or sexually transmitted disease clinic.”<sup>15</sup>

- ✓ *encourage states to legalize sperm washing for HIV-positive men?*

The National HIV/AIDS Strategy does not specifically address this issue.

- ✓ *Call for increased funding and distribution for the new female condom?*

The Strategy states generally that “Federal funds should support and State and local governments should be encouraged to expand access to effective HIV prevention services with the greatest potential for population-level impact for high-risk populations.”<sup>16</sup> But the female condom - currently the only female-controlled barrier option available - is not mentioned in the Strategy.

- ✓ *call for comprehensive, age-appropriate, non-heterosexist sexuality education throughout the lifespan?*

As part of its commitment to reducing new infections by 25%, the Office of National AIDS Policy calls for age-appropriate education that extends across the lifespan and for all education to be “universally integrated into all

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<sup>15</sup> Strategy pp. 26

<sup>16</sup> Strategy pp. 19

educational environments and health and wellness initiatives”<sup>17</sup>. However, the Strategy falls short in identifying the need for sexuality education relevant to people of all genders and sexual orientations.

- ✓ *call for an expansion of prevention and care services for women throughout the life span, including young women and senior women?*

The Strategy specifically calls for expansion of community-level prevention programs to communities where HIV is most heavily concentrated, which includes Black and Latina women.<sup>18</sup> The Strategy calls for “broader HIV education . . . across the age span . . . because twenty-four percent of people living with HIV are over age 50, and 15 percent of new HIV cases occur in this age group,”<sup>19</sup> but makes no reference to the range of services HIV-positive women will require over their life span.

- ✓ *reflect an understanding that HIV-positive wellness is culturally defined, and may include physical, emotional, mental, and spiritual components?*

The Strategy recognizes the need to develop services that are “respectful of and responsive to the health beliefs, practices and cultural and linguistic needs of diverse patients” in order to improve health outcomes<sup>20</sup>. Cultural competence and provider trainings are discussed, but the Strategy does not provide recommendations or mandate the inclusion of the above components into a standard of prevention and care<sup>21</sup>.

- ✓ *identify the need to support integrated care and treatment programs that address concurrent factors including but not limited to housing instability, violence, substance use, and mental health status which create barriers to HIV care and treatment adherence?*

The Strategy successfully identifies the need to support integrating services to ensure care and treatment adherence and proposes recommendations to increase access to these services with the end goal of improving health outcomes. The third step of increasing access to care and improving health conditions directly dictates “support[ing] people living with HIV with co-occurring health conditions and those who have challenges meeting their basic needs, such as housing.”<sup>22</sup> A detailed analysis

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<sup>17</sup> Strategy pp. 19

<sup>18</sup> Strategy pp. 11, 32

<sup>19</sup> Strategy p. 19.

<sup>20</sup> Strategy pp. 26

<sup>21</sup> Strategy pp. 27

<sup>22</sup> Strategy pp. 27-28

of co-occurring health conditions runs the gamut from chronic diseases and co-infection to demanding a standard of patient-centered care that encompasses transportation, legal assistance, mental health counseling, child care, and especially housing.<sup>23</sup> The need for housing as a tool to achieve better outcomes in both prevention and care is particularly emphasized in the Strategy.<sup>24</sup>

✓ *call for provider competency training to assure non-judgmental and culturally appropriate care for sex workers, transgender women, HIV-positive women, and women who are currently or formerly incarcerated?*

The Strategy affirms taking purposeful steps to increase the diversity and competence of the provider workforce to assist HIV-positive patients. This goal is articulated as a need “to provide care in a non-stigmatized manner and create relationships of trust” where providers are culturally competent and communicate effectively as patients make their decisions.<sup>25</sup> For transgender clients specifically, the Strategy acknowledges existing provider stigma and calls for respectful and competent care to achieve better health outcomes.<sup>26</sup>

✓ *call for use of peer-based and culturally relevant programs to improve linkage to and retention in care?*

While not specific to women, the Strategy does recognize the value of peer-based programming in conjunction with clinical providers to keep HIV-positive clients, especially those in hard-to-reach populations, in care.<sup>27</sup> Peer-based programming, however, is not specifically mentioned in the recommended actions to diversify and expand the available provider workforce.

✓ *propose an acceptable standard for linkage to and retention in care for HIV-positive individuals?*

The Strategy defines the standard of care as patient centered, ensuring care and treatment decisions align with the patients’ wants and needs.<sup>28</sup> The Strategy, however, only recommends measuring viral load and CD4 cell counts in its recommended action<sup>29</sup>, underscoring that the Strategy does not go far beyond biomedical interventions to achieve the standard of care previously recommended.

✓ *call for educating HIV-positive individuals about their*

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<sup>23</sup> Strategy pp. 27-28  
<sup>24</sup> Strategy pp. 27-28  
<sup>25</sup> Strategy pp. 25, 27  
<sup>26</sup> Strategy pp. 26  
<sup>27</sup> Strategy pp. 25  
<sup>28</sup> Strategy pp. 28  
<sup>29</sup> Strategy pp. 35

*right to confidentiality and privacy of medical information?*

The National HIV/AIDS Strategy does not specifically address this issue.

✓ *explicitly affirm that the primary goal of treatment is to improve individual health?*

The Strategy affirms individual health as the primary goal of treatment by recommending a high standard for optimal care based on a patient centered approach.<sup>30</sup> While the Strategy acknowledges that early treatment can reduce potential transmission of the virus to others,<sup>31</sup> it also repeatedly affirms that “[d]ecisions about when to start therapies for HIV are personal.”<sup>32</sup>

✓ *explicitly affirm that all individuals have the right to counseling and information about the risks and benefits of a particular treatment recommendation prior to initiation of treatment?*

The NAS does not explicitly address the right to counseling and information about treatment but does note that “care providers should be culturally competent and able to clearly and effectively communicate to help their patients understand the benefits of following treatment plans,”<sup>33</sup> and that “when to start treatment must remain voluntary.”<sup>34</sup>

✓ *explicitly affirm that all competent individuals have the right to accept or refuse recommended treatment based on their understanding of their own best interest?*

The Strategy affirms the right of individuals to make “[d]ecisions about when to start therapies for HIV...,”<sup>35</sup> which would include the right to accept or refuse treatment. The Strategy also discusses barriers to treatment experienced by marginalized communities such as historical distrust for the mainstream health care system due to years of mistreatment, and emphasizes that positive health outcomes result from “[h]ealth care services that are respectful of and responsive to the health beliefs, practices and cultural and linguistic needs of diverse patients.”<sup>36</sup>

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<sup>30</sup> Strategy pp. 28  
<sup>31</sup> Strategy viii.  
<sup>32</sup> Strategy pp. 33  
<sup>33</sup> Strategy pp. 26-27  
<sup>34</sup> Strategy pp. 33  
<sup>35</sup> Strategy pp. 33  
<sup>36</sup> Strategy pp. 26

## Grade: 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

Because data collection and risk assessment often underestimate the population of women in the U.S. at risk for and living with HIV, resources are not equitably distributed for programs, services, and capacity building for women living with and affected by HIV, thereby implicating the three pillars of the Strategy.

While the Strategy mentions women-centered topics and calls for increased funding and resource allocation in many of the areas that the Gender Monitoring tool has highlighted, there is no specific content in the Strategy where women's unique needs intersect with prioritized programs or resources to form a cohesive plan for greater resource equity for women living with and affected by HIV. Many of the targeted programs in prevention (decreasing the rate of new infections), treatment (increasing access to care and improving health outcomes) and equal access (reduction of HIV related disparities and health inequalities) may inadvertently benefit women. However, without a specific plan and designated resources that will focus on reducing the impact of the epidemic among women, particularly women at increased risk for HIV, the process of reducing new infections and increasing access to care for women, risks being deprioritized and delayed.

#### Does the National HIV/AIDS Strategy:

- ✓ *call for equity and parity in funding, resources and research that specifically address gender relevant needs?*

While women are mentioned in the Strategy as a priority population, they are most frequently referred to as either a sub-population within a larger group, a casualty resulting from an at-risk male partner, or as childbearing vessels. The Strategy does state that, "women and men have different biological, psychological and cultural factors that increase their vulnerability to infection and disease

progression ... [which] raises complex policy and research questions."<sup>37</sup> Yet, no specific plan or campaign to address the unique needs of women beyond their roles as sexual partners and vehicles of transmission to children is proposed.

- ✓ *call for equity and parity in funding and resource allocation to address disparities in geographic areas where women make up a greater share of the epidemic?*

The Strategy does call for increased prevention efforts and resource allocation in both communities at higher risk of HIV infection and in geographic areas where HIV infection is more prevalent than the national average.<sup>38</sup> The Strategy goes so far as to call for targeted initiatives for men who have sex with men and other specific populations. Yet, it fails to specifically mention the need for targeted and funded initiatives for Black and Latina women.

In many states the face of HIV is increasingly female.<sup>39</sup> These geographic areas are thus in need of increased female-specific prevention efforts and resources to ensure women are receiving the quality of care they deserve. The Strategy, however, fails to specifically recognize how women's needs and risk for HIV vary based on geographic location, and that resource allocation should reflect this variation.

- ✓ *recommend capacity building of community-based organizations that provide women-centered services?*

There is no specific call for capacity building for community based organizations (CBOs) that provide women-centered services. Even with the recognition in the Strategy that, "women and men have different biological, psychological and cultural factors that increase their vulnerability to infection and disease progression,"<sup>40</sup> community based organizations that seek to serve the unique needs of women are not prioritized within the Strategy's plans to seek community based support and planning for prevention, care and treatment.

<sup>37</sup> Strategy p. 12

<sup>38</sup> Strategy p. 41.

<sup>39</sup> For example, an estimated 33% of individuals living with AIDS in Maryland, Connecticut, New Jersey, Delaware and the Virgin Islands are female, as compared to the national average of 24%. Additionally, the District of Columbia reports nearly 12 times the national rate of AIDS cases among women with 90.2 AIDS cases reported per 100,000 people in 2009. The Kaiser Family Foundation Factsheet on Women and HIV/AIDS in the U.S. Sept 2009

<sup>40</sup> Strategy p. 12.

## Grade: 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

Formative, community-based, social, behavioral and operational research is needed to identify and improve structural factors such as community viral load, poverty, housing instability, violence, and mental health status, which increase vulnerability for women living with and affected by HIV.

In addition, women, including transgender women, are disproportionately underrepresented in biomedical research trials. Without adequate representation in trials, researchers are unable to draw conclusions about gender differences or the efficacy of interventions for women, and interventions that are developed and disseminated to the public may be unavailable to women because they were not included in the original research. Inclusion of women in research and an emphasis on developing women-specific research trials addresses this problem and would indicate that women are a highly-prioritized population in HIV prevention research.

The Strategy does not call for a great scale up or changes in the approach to HIV/AIDS research as a whole. But, generally, there is a call for increased biomedical, health services, behavioral, and operations research,<sup>41</sup> and specifically research into a variety of factors that place women at unique risk for HIV such as emotional and economic dependence, race, risk behaviors of partners, and the destabilizing effects of high rates of incarceration in communities.<sup>42</sup>

#### Does the National HIV/AIDS Strategy:

- ✓ *call for research to identify & improve structural factors like community viral load, poverty, housing instability, violence, and mental health status that play a key role in the U.S. epidemic?*

<sup>41</sup> Strategy p. 45.

<sup>42</sup> Strategy p. 12.

The Strategy generally identifies many of the most pressing structural factors that lead to higher rates of HIV within priority populations – poverty, unemployment, domestic violence, homelessness, hunger, lack of access to transportation<sup>43</sup> – and specifically calls for research into a variety of factors that place women at unique risk for HIV such as emotional and economic dependence, race, risk behaviors of partners, and the destabilizing effects of high rates of incarceration in communities.

- ✓ *identify and propose solutions to mitigate barriers to women's participation in research?*

The Strategy does not adequately address barriers to women's participation in research. The Strategy generally states that “[m]ore work is . . . needed to understand difference in treatment response between women and men and among racial and ethnic minorities,”<sup>44</sup> but no recognition of, or solutions to the barriers to researching these differences is stated.

The historical and present day mistrust sown between communities marginalized by race and gender, and the medical and health care community is mentioned in the Strategy.<sup>45</sup> But while many of the historical lessons learned and current day understanding of the importance of cultural competency, which are mentioned in the Strategy, can also be translated into initiatives to remove barriers to women's participation in HIV research, the Strategy does not expressly push for changes in approaches to research participation.<sup>46</sup>

- ✓ *prioritize a variety of women-centered research strategies to address HIV acquisition by women through including women in pre-exposure prophylaxis research, and by ensuring that transgender women are both integrated into women-specific trials and recruited for specific research on the transgender women-specific strategies?*

*Biomedical research on female-controlled prevention methods include:*

- *Antiretrovirals*
- *New female condom products*
- *Vaginal and rectal microbicides*

The Strategy calls for continued research into safe and effective vaccines and microbicides but makes no mention of female condoms and minimal gender specific

<sup>43</sup> Strategy p. 22.

<sup>44</sup> Strategy p. 24.

<sup>45</sup> Strategy p. 26-27.

<sup>46</sup> The GRACE study has identified several structural factors that can lead to greater participation by women in HIV related research trials: transportation and child care; counseling and emotional support from both peers and clinicians; adequate information about risks and benefits of the trial; additional assistance to stay involved.

recommendations about the need for women to be able to access female controlled prevention tools.<sup>47</sup> While differentials in the way treatment affects men and women is mentioned, the unique experiences and research needs of trans women is left unaddressed. In addition, while the need for increased research on the aging population is mentioned, there is no specific mention of the need to study the specific effects of menopause and women-specific aging characteristics as they relate to HIV acquisition and disease progression.

✓ *call for research on affected families with an eye toward providing services for the affected community?*

The Strategy did not directly address the need for research on affected families and for the need of all HIV/AIDS research initiatives to provide services for the affected community.

✓ *encourage research conducted with meaningful community input and participation that leaves concretely positive programs behind?*

Although the Strategy states that communities are often best suited to set priorities and allocate resources<sup>48</sup> and states the need for community level interventions, there is no mention of the importance of the community's input in and participation in research. Nor is there mention of the ways in which research projects such as the current large scale studies in Washington, DC, and the Bronx, NY, can also be used to leave behind programs that serve the community.

## **Grade: 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.

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<sup>47</sup> Strategy p. 18.

<sup>48</sup> Strategy p. 45.

# 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 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 encourage safe and voluntary disclosure, and that repeal HIV-specific transmission, exposure and sentence-enhancement 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:** To supplement the efforts to bring HIV specific laws in line with public health goals, DOJ/EEOC can 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.