A GENDER MONITORING TOOL FOR THE U.S. NATIONAL HIV/AIDS STRATEGY

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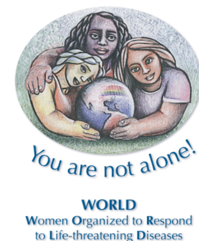

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This document is a gender monitoring tool and represents the next step by the community of women living with HIV in the United States and their allies in assuring the development and implementation of a meaningful and effective National HIV/AIDS Strategy (NHAS). The purpose of the tool is to analyze the extent to which the NHAS identifies and prioritizes ways to improve all women's, including transgender women's, access to HIV prevention, care, and treatment programs consistent with the right to nondiscrimination, dignity, bodily integrity, and ethical treatment.

Gender monitoring tools are commonly used globally to assess the extent to which the rights of women and transgender people are upheld in policy making and implementation and how gender is considered in the design, development, and implementation of laws, policies, and regulations. The community of women living with HIV and advocates in the U.S. will be able to use this gender monitoring tool to quickly assess policy strengths and gaps, and to identify the clearest path to effective advocacy. The tool will also allow policy makers to immediately see, and rectify legal, policy, and regulatory gaps that impact women living with and affected by HIV.

In 2009, a group of women and gender-focused HIV organizations compiled Recommendations for the White House Office of National AIDS Policy (ONAP) to help guide the development of the first National HIV/AIDS Strategy.[1] This set of Recommendations led to formal inquiry by the White House into the state of prevention, care, and treatment for women living with and at risk for HIV, including a White House meeting on Women and HIV held in December 2009.

Inspired by the initial Recommendations, this gender monitoring tool will serve as a mechanism for HIV-positive women, advocates for women, advocates for transgender persons, and policy-makers to gauge the extent to which the NHAS meets the unique needs of women living with and vulnerable to acquiring HIV.

Upon the release of the NHAS, a group of national HIV/AIDS organizations that advocate for the human rights of women living with and affected by HIV will use this tool along with the corresponding report card to assess how and to what extent the three goals of the NHAS, when formally articulated in the final Strategy, adequately addresses the needs of all women. The three NHAS goals are 1) reduce HIV incidence; 2) increase access to care and optimizing health outcomes; and 3) reduce HIV-related health disparities.

This initial assessment will be followed by ongoing gender monitoring of the implementation of the NHAS on a state and national level. The tool may also be adapted and utilized on a national, local, and municipal level to ensure the needs of HIV-positive and affected women are identified and addressed in all policies that impact their lives both locally and nationally.

[1] Critical Issues for Women and HIV: Health Policy and the Development of a National AIDS Strategy.

The monitoring tool identifies a discrete set of key areas where HIV-positive and affected women's rights are most clearly implicated[2]:

- **Law and Policy Review**:
  - Does the NHAS identify discriminatory and/or medically inaccurate state and federal laws and policies as harmful?
  - Does the NHAS prioritize the vigorous implementation of current nondiscrimination laws?
  - Does the NHAS 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 NHAS 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 NHAS recommend disaggregated data collection by sex, race/ethnicity, gender identity, and gender expression?
- **Meaningful Involvement of HIV-positive Women**:
  - Does the NHAS 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 NHAS recognize the importance of and recommend support for effective and inclusive women-centered HIV intervention and care programs and services?
- **Resource Equity**:
  - Does the NHAS 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 NHAS call for research into social and structural vulnerabilities and interventions, focused biomedical research, and operational research for women in the U.S.?

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[2] This tool will analyze the ways in which the National HIV/AIDS Strategy does or does not address the needs of women using the above areas as a starting point. Although the document will clarify how these different key areas fit into the ONAP's three stated goals, it is necessary to present these priorities within their own context and system of prioritization as determined by women most affected by the HIV/AIDS epidemic.

✓ 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 speaks 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; and increase HIV-positive women's vulnerability.

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 that are currently on the books in over half of the U.S. states often require no proof of intent to infect another person or actual transmission, and sometimes 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 ones status and can serve as a barrier to care and treatment for HIV-positive people. For women, these laws can be used to harass, keep women trapped in abusive relationships, or rest custody of children in divorce proceedings.

Discrimination against people living with HIV persists regardless of 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 the job circumstance. 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 not only for the individual's finances and health care access but also to her dependants who likely access health care through her employer.

HIV-positive women are routinely discriminated against in reproductive healthcare settings regardless of current nondiscrimination laws that protect all women's rights to bodily integrity and reproductive choice and health, leading to increased health disparities among HIV-positive women. Discrimination in the forms of lowered standards and incoherent testing consent laws while pregnant, or inadequate information on reproductive options, are harmful to the health of women living with HIV. In particular, transgender people are often prevented from receiving adequate and equitable treatment and preventive care, due to lack of nondiscrimination laws protecting them.

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.
    - Federal, state and municipal laws that fail to provide nondiscrimination protection on the basis of gender identity and gender expression.

- ✓ 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.

- ✓ 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.

- ✓ suggest the need to educate women living with HIV on their rights and laws and policies that affect their lives?[3]

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[3] For example, utilizing the Department of Justice's resources to conduct national know-your-rights trainings for HIV-positive women and advocates.

✓ 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.

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

✓ 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 reflective of the epidemic, including 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.

✓ 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 HIV and supportive care 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 NHAS 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 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. 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, we must coordinate and integrate sexual and reproductive health services with all aspects of HIV care—across all prevention, diagnosis, treatment, and care programs—to meet the diverse needs of women and men, regardless of HIV status.

To support women-centered HIV prevention and care services, 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?
- ✓ 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?
- ✓ suggest and provide a plan for the dismantling of funding silos for sexual and reproductive and HIV health care?
- ✓ call for HIV-specific child birthing classes?
- ✓ support programs that treat HIV-related testing and counseling as part of routinely-offered sexual health care?
- ✓ encourage states to legalize sperm washing for HIV-positive men?
- ✓ Call for increased funding and distribution for the new female condom?
- ✓ call for comprehensive, age-appropriate, non-heterosexist sexuality education throughout

the lifespan?

- ✓ call for an expansion of prevention and care services for women throughout the life span, including young women and senior women?
- ✓ reflect an understanding that HIV-positive wellness is culturally defined, and may include physical, emotional, mental, and spiritual components?
- ✓ 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?
- ✓ 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?
- ✓ call for use of peer-based and culturally relevant programs to improve linkage to and retention in care?
- ✓ propose an acceptable standard for linkage to and retention in care for HIV-positive individuals?
- ✓ call for educating HIV-positive individuals about their right to confidentiality and privacy of medical information?
- ✓ explicitly affirm that the primary goal of treatment is to improve individual health?
- ✓ explicitly affirm that all individuals have the right to counseling and information about the risks and benefits of a particular treatment recommendation prior to initiative of treatment?
- ✓ explicitly affirm that all competent individuals have the right to accept or refuse recommended treatment based on their understanding of their own best interest?

✓ 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 NHAS.

Does the National HIV/AIDS Strategy:

- ✓ call for equity and parity in funding, resources and research that specifically address gender relevant needs?
- ✓ recommend capacity building of community-based organizations that provide women-centered services?

✓ 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.

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?

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

- ✓ 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

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

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