Who we are
The U.S. Positive Women's Network (PWN) is a national membership body of more than 2,500 women living with HIV, inclusive of transgender women. Our diverse leadership team is made up of HIV-positive women who are young, mature, transgender, and coming from varying racial, ethnic and socio-economic backgrounds. We live in U.S. cities, rural areas and geographic regions hardest hit by the epidemic.

Principles
Human Rights: We believe that upholding universal human rights, striving for social justice, and a conscious effort to achieve equitable access must constitute the cornerstones of our domestic and global HIV response.

HIV is a Symptom, not the Problem: We understand that HIV does not exist in a vacuum. In fact, HIV shines a spotlight on broader structural and systemic oppression faced by marginalized communities, including but not limited to racism, sexism, homophobia, classism, and lack of commitment to social and economic equality.

Meaningful Involvement and Leadership: We believe that the people most impacted by an issue must be involved in all aspects of decision-making about how to address that issue.

Intersectionality: We believe that a successful HIV response must consider where and how HIV enters women's lives: at the intersection of poverty, gender-based violence, sexual and reproductive health, power dynamics in relationships, denial of women's bodily autonomy, and a fragmented healthcare system.

Access: We are committed to ensuring that HIV prevention tools and HIV treatment are available and accessible to all who need them, not just to the economically privileged. We further affirm that information about, and access to, all proven HIV prevention tools and strategies must be similarly universal.

“
The HIV epidemic among Black women in the U.S. mirrors the epidemic in the rest of the world.”
—Dazon Dixon Diallo, Executive Director, Sisterlove

Bringing Gender Justice to HIV Prevention: A BLUEPRINT FOR WOMEN’S ACTION

July 2012

There is an HIV prevention and care crisis in the United States. The systems for care and prevention services for women are clearly broken and insufficient.

- Over 50,000 new HIV infections occur annually in the U.S.—with no decline over the last decade.1
- Most women living with HIV in the U.S. become infected through heterosexual contact, and frequently do not see themselves to be at risk for acquiring HIV.2
- In the U.S., women living with HIV enter care later, have twice as many HIV-related illnesses, more frequent hospitalizations, and a mortality rate 20% higher than men with HIV.3
- An effective, widely accessible, affordable HIV prevention tool that women can use without her partner’s participation and consent does not yet exist.
Stakeholders

New prevention breakthroughs, including promising evidence on microbicides, and the use of Anti-Retroviral drugs (ARVs) for prevention and after HIV infection are cause for optimism. But these cannot be implemented effectively or ethically without addressing human rights issues and systemic and structural barriers that impede access to prevention and care. Voluntary, high-quality HIV care, support and treatment is still not universally accessible to people living with HIV. This cannot be achieved without substantially increased commitment and investment.

The business community must invest in ending HIV stigma, and expanding access to HIV testing, prevention, care and voluntary treatment.

Federal and state governments need to partner effectively to increase access to and affordability of non-discriminatory, culturally competent, and high quality care and treatment. This includes elimination of waiting lists for ARVs—not by decreasing eligibility criteria and reducing formularies but by creating and funding health care systems that provide HIV care, treatment and prevention services for all.

Researchers need to use their scientific credibility to speak out loudly about the foreseeable consequences of ongoing failure to invest in equitable access to HIV health care, treatment and prevention.

People Living with HIV must be at the forefront of all these discussions.

Funders concerned about the health of women in the U.S. must identify HIV as part of their portfolio.

Background

HIV prevention research break-throughs have opened the door to new possibilities in maintaining sexual health and upholding sexual rights. Women stand to benefit greatly from tools, strategies and insights acquired through recent HIV prevention research. For example, access to safe, effective microbicides will be invaluable to women who cannot always insist on condom use due to power dynamics in relationships, intimate partner violence, and personal desire for—or societal desirability of—childbearing.

The President’s Advisory Council on HIV/AIDS (PACHA) issued a resolution in May 2012 that called for revision of the U.S. National HIV/AIDS Strategy (NHAS) and its Implementation Plan to include specific progress, metrics, and goals to measure national progress on reducing new infections among women and on increasing access to care and improving health outcomes for women living with HIV. The resolution additionally calls for action to promote gender-sensitive care by integrating HIV prevention and care with sexual and reproductive health services and intimate partner violence prevention and counseling. It recommends that the President “expand and expedite” the provision of services that facilitate HIV-positive women’s access to care.

“Our failure to address the epidemic among women is our failure to address it in the context of women’s lives.”
—NAINA KHANNA, COORDINATOR,POSITIVE WOMEN’S NETWORK, POLICY DIRECTOR, WORLD
Bringing Gender Justice to HIV Prevention Services

Missed Opportunities for HIV Testing and Violence Screening

Because women are often not perceived as being at risk for acquiring HIV, many women are never or rarely offered an HIV test by their provider as a routine part of their medical care. Fewer than 20% of the five million U.S. women who accessed publicly funded family planning services in 2010 received HIV tests.6 The failure to offer HIV testing endangers women’s health by leading to later testing and corresponding poorer health outcomes.

Similarly, fewer than 10% of all providers of HIV services routinely screen for intimate partner violence (IPV)7 despite evidence that, domestically, women living with HIV are twice as likely to have suffered from IPV and five times more likely than women in the general population to have Post Traumatic Stress Disorder (PTSD) related to violence.8 Gender-based, economic and other power disparities in intimate relationships render many women—particularly those experiencing IPV—unable to insist on condom use. To work for women, HIV prevention efforts must actively address the links between sexual and reproductive health (SRH), violence against women, and HIV risk. Training and funding for family planning and other SRH service providers to screen for IPV and HIV, and respond effectively to the needs detected through these screening processes, is essential to helping women reduce their HIV risk.9

Missed and Underserved Populations

Women in Communities of Color

According to the CDC, women comprise 25% of the U.S. HIV epidemic. A recent study, however, found HIV incidence (new infection) rates among African-American women in some high poverty areas that are as high as those in Congo, Kenya, and some other African countries.10 Nine of the ten urban areas with the highest HIV prevalence were located in southern states.11 In these, almost three quarters (71%) of all women newly diagnosed with HIV 2009 were African-American.12

In 2012, the U.S. government established a $44 million initiative to prevent HIV in the southern states—the region in which 80% of the states with the highest HIV-related death rates are located. This initiative is designed to expand uptake of HIV testing and participation in HIV care and prevention services. Another federal initiative, the Enhanced Comprehensive HIV Prevention Planning (or “12-Cities”) project, was launched in 2011 to address those objectives in impoverished urban areas—locations in which African-American women’s HIV risk is also tends to be high.

While useful, neither of these initiatives explicitly focuses on the structural factors that feed such disproportionate HIV spread. Poverty, lack of education, and lack of economic opportunity characterize these high-risk communities—conditions that cannot be alleviated without structural intervention. Effective HIV prevention campaigns in these communities will be those that directly address the communities’ structural realities. They will be targeted, well resourced, developed in close consultation with community partners, and closely guided by input from local women living with HIV and women at risk of acquiring HIV due to their social and/or sexual environment.

Women Who Use Drugs

Drug-using women are put at preventable risk of HIV by the U.S. government’s failure to fully fund and implement syringe exchange programs (SEP). Syringe exchange is a harm reduction strategy with proven effectiveness. To date, however, federal support for syringe exchange has been largely symbolic. Few SEPs received federal funding in 2010-2011 and those that did faced multiple barriers to actually accessing the money.13 Most SEPs continue to operate with scarce resources from state, local and private sources and can meet only a fraction of the local need for their services.

Criminalization of drug use also harms HIV prevention efforts by making it difficult for people to reduce their risk or overcome addiction without losing their jobs, children, and homes. Severe public funding short-falls
have created a drastic scarcity of residential addiction treatment and rehabilitation beds in programs designed to meet women’s needs (including programs that accommodate women with childcare responsibilities). Women’s resulting inability to get timely, targeted and adequate addiction treatment also impedes HIV prevention.14, 15, 16

Transgender Women

Although data on HIV incidence among transgender women extremely limited, CDC estimates that the transwomen’s HIV infections go undiagnosed twice as often (57% vs. 27%) as the national average.17 Providers’ lack of knowledge, comfort, and skills in transgender health, as well as lack of trans-friendly HIV testing sites and transgender-specific prevention programs contribute to this. As noted above, lack of access to these services leads to later testing and higher rates of HIV-specific illness and death.

Transgender women’s vulnerability to HIV is also exacerbated by discrimination, bias and transphobic violence; all factors that create and perpetuate barriers to employment, health care, and mental, physical and emotional well-being.

Sex Workers

Sex workers are similarly under-served and uncounted. The CDC has no survey-based estimate of HIV prevalence among female sex workers in the U.S. A recent Commentary in the Lancet stated that, globally, the dearth of data on sex workers’ HIV risk, “can be attributed in large part to the same structural conditions that increase risk of HIV and prevent engagement in interventions among female sex workers, including criminalised legal and policy environments, violence, stigma, and restrictive funding policies”.18

“Condoms as evidence” is one criminalization practice that directly thwarts HIV prevention efforts and wastes HIV prevention funding. Several cities have documented the practice of police destroying or confiscating safer sex supplies and arresting people for condom possession on the grounds that it is evidence of an intention to engage in prostitution. Police have also followed harm reduction workers, harassing them and threatening consumers trying to access their services with arrest.19 There is an immediate need for training among police, correctional staff and prosecutors regarding the human rights and HIV prevention needs of sex workers and others involved in street economies.

Incarcerated Women

Women in the correctional system are put at risk of HIV by being denied access to male and female condoms and other HIV prevention tools and resources in prisons, jails and other detention settings.20 Lack of adequate investment in job training for incarcerated women, treatment for substance abuse and mental health issues and programs to maintain family and community ties to support constructive re-entry also raise women’s HIV risk, as does the lack of adequate measures to insure the continuity of health care both during incarceration and upon reentry.21

Young Women and Girls

Experts estimate that youth (between the ages of 13–24) may comprise up to 30% of all Americans living with HIV.22 Sixty percent of these are undiagnosed (do not know they are HIV positive)23 and 28% of them are female.24 But this is not representative of the impact of HIV spread among women and girls in the regions most heavily impacted by HIV. In Mississippi, for example, 39% of all HIV positive African American and Latino youth between the ages of 13 and 24 are female.25

This growing impact on girls and young women can be attributed to many of the factors listed above. One frequently missed opportunity unique to youth, however, is the provision of age-appropriate, comprehensive sex education. A 2007 study showed that 66% of the comprehensive sex education programs reviewed in the U.S. (those supporting both abstinence and the use of protection by sexually active youth) effectively reduced students’ risk behaviors.26 This was defined as delaying or reducing sexual activity, having fewer partners, and increases in reported condom and contraceptive use. None of these programs was associated with earlier initiation of sex or more frequent sexual activity.

Despite a Presidential commitment in 2009 to eliminate federal funding for “abstinence-only” sex education, $50 million was allocated in 2010 to abstinence-only programs.27 Thirty states in the U.S. received funding in 2010 for abstinence-only sex education. Fourteen of these were in the southern region (which is comprised of sixteen states total).28

“Sex worker advocates want everyone to stop seeing whores as something other than women, other than human.”

—SARAH M., ADVOCATE
**PrEP**

PrEP (Pre-exposure Prophylaxis) means taking a medicine to protect or prevent oneself from getting a disease or condition. PrEP research has shown that HIV-negative people can reduce their risk if acquiring HIV (if exposed) by taking an ARV drug on a continuous daily basis.

The current status of research on PrEP (Pre-exposure Prophylaxis) illustrates under-attention to women in HIV prevention research. Two major trials demonstrated PrEP’s effectiveness among men, while others produced conflicting data on its effect on women. The two PrEP trials devoted exclusively to women have not shown effectiveness to date. It is likely that the FDA will approve PrEP and demonstration projects to assess its introduction among U.S. men—but not among women—are planned and funded already.

"Investment in the health of women and girls is not only the right thing to do; it’s the smart thing to do."

—HILARY R. CLINTON, SECRETARY OF STATE, U.S.

Women need more data on how PrEP will work in women’s bodies with regard to effectiveness and side effects, as well as the implications of using it during pregnancy, breast-feeding, and menopause. As importantly, demonstration projects and implementation pilots focused on women in the U.S. are needed to assess PrEP’s affordability, accessibility and especially acceptability (since no data yet exist on their willingness to, or interest in, using PrEP and numerous community-based organizations have expressed concerns about this).

**Female Condoms**

International data shows that women’s and men’s uptake of this highly effective, under-used tool can be expanded substantially with appropriate community education programming and supported access. This research should be expanded upon and used to generate the political will needed to fuel investment in the education of health care providers and consumers to promote the uptake and use of female condoms in the U.S. Mathematical modeling based on recent Washington DC data showed that vigorous, well-resourced female condom promotion prevented enough infections in the first year to have saved more than $8 million in future medical costs—over and above the cost of the program.

**Microbicides**

A few candidate microbicides (products designed to be applied vaginally or rectally to reduce HIV transmission risk during sex) are now in advanced testing. If one of these is confirmed to be effective, the first microbicide could be on the market in some countries during this decade. U.S. investment has been instrumental in advancing microbicide research worldwide and needs to continue to assure that this vital prevention alternative becomes available as rapidly as possible.

Most of this investment, however, has supported the development of ARV-based microbicides (those containing small amounts of an ARV drug). The few non-ARV-based microbicides in development contain compounds that have other mechanisms for reducing HIV survival. Non-ARV-based microbicides are designed to meet the need of HIV positive women for tools to reduce their risk of transmitting HIV to a partner and their own risk of acquiring STIs and other strains of HIV. ARV-based microbicides will probably not be suitable for use by women living with HIV. At present, only one non-ARV-based candidate is in human trials, compared to several ARV-based candidates. Specific investment in non-ARV-based microbicides should increase to advance this area of development.

**Data Disaggregation**

Improved surveillance and data collection are needed to accurately assess women’s non-behavioral risk factors for acquiring HIV. Non-behavioral (structural) factors that have been shown to affect a woman’s vulnerability to HIV throughout her lifespan include poverty, access to healthcare and housing, exposure to gender-based violence and stigma related to race and gender.

Better disaggregation of surveillance data by gender is also needed to support real-time reporting and tracking of new HIV cases to monitor trends. Sentinel surveillance and other surveys are needed to collect accurate data on HIV risk experienced among populations of women who have not been adequately or accurately counted to date, including sex workers and transgender women.
**Next Steps for Bringing Gender Justice to HIV Prevention: BLUEPRINT FOR HIGH PRIORITY ACTIONS**

### PREVENTION SERVICES

<table>
<thead>
<tr>
<th>Integating HIV Screening with Violence Screening</th>
<th>Train and fund sexual and reproductive health service providers to screen for IPV and HIV—and respond effectively to the needs detected. Train and fund IPV service providers to screen for HIV and sexual and reproductive health.</th>
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<tr>
<td>HIV Care</td>
<td>Similarly train HIV care and service providers to screen for IPV and SRH needs and respond effectively.</td>
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### Missed and Underserved Populations

<table>
<thead>
<tr>
<th>Women in Communities of Color</th>
<th>Fund structural interventions in federal initiatives to reduce HIV incidence (including violence reduction, income generation, services integration programs, etc.). Require prevention campaigns to directly address structural factors facilitating HIV risk and to be designed and implemented in close consultation with community partners including women living with HIV.</th>
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<tr>
<td>Women Who Use Drugs</td>
<td>Expedite access to federal funding for syringe exchange programs and increase support for long-term “woman-friendly” addiction treatment services.</td>
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<tr>
<td>Transgender Women</td>
<td>Require HIV clinicians and service providers to receive training in transgender health needs and fund trans-friendly HIV testing sites and prevention programming.</td>
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<td>Sex Workers</td>
<td>Stop law enforcement interference with HIV prevention, including use of “condoms as evidence” to arrest and prosecute sex workers. Mandate training for police and prosecutors regarding sex workers human and civil rights.</td>
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<tr>
<td>Incarcerated Women</td>
<td>Provide male and female condoms and other HIV prevention tools and resources to incarcerated people. Invest in gender-responsive job training, substance abuse and mental health treatment, family reunification, and other services to reduce structural factors facilitating HIV risk among women in correctional settings. For those living with HIV, ensure linkages to quality medical care and supportive services upon release to prevent treatment interruptions.</td>
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<tr>
<td>Young Women and Girls</td>
<td>Fulfill the Presidential commitment to completely eliminate federal funding for “abstinence-only” sex education.</td>
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### BRINGING GENDER JUSTICE TO PREVENTION RESEARCH

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<tr>
<th>PrEP</th>
<th>Fund and work with community organizations to create demonstration projects and implementation pilots focused to assess PrEP’s affordable, accessible and acceptable to women in the U.S. at high risk of HIV.</th>
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<tr>
<td>Female Condoms</td>
<td>Invest in domestic studies to identify best practices for promoting female condoms to health care providers and increasing their uptake and use in the U.S.</td>
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<tr>
<td>Microbicides</td>
<td>Increase targeted investment in non-ARV-based microbicides to expedite their development.</td>
</tr>
<tr>
<td>Data Disaggregation</td>
<td>Thoroughly disaggregate surveillance data by gender to support real-time tracking and monitor trends in HIV incidence. In collaboration with the relevant populations, design and conduct sentinel surveillance and other surveys to assess HIV risk and incidence among sex workers and transgender women.</td>
</tr>
</tbody>
</table>
Endnotes

20. Kramer K, Comfort M. (November 2011) Considerations in HIV Prevention for Women Affected by the Criminal Justice System. Women’s Health Issues; 2(6 Supplement); S272-S277
Acknowledgements:
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About:
The mission of the PWN is to prepare and involve HIV-positive women, including transgender women, in all levels of policy and decision-making to improve the quality of women’s lives, by:

◆ Combating HIV-related stigma and demonstrating that HIV-positive women are part of the solution;
◆ Training and supporting HIV-positive women leaders;
◆ Creating and sharing tools for women and HIV advocates; and
◆ Mobilizing for strategic campaigns to change policies

The PWN applies a gender equality and human rights lens to the HIV epidemic to achieve federal policies grounded in the reality of women’s lived experiences.

PWN is a project of WORLD (Women Organized to Respond to Life-threatening Diseases), a woman-serving HIV organization founded in 1991. WORLD is an organization by and for women living with HIV.