



POSITIVE WOMEN'S NETWORK
USA

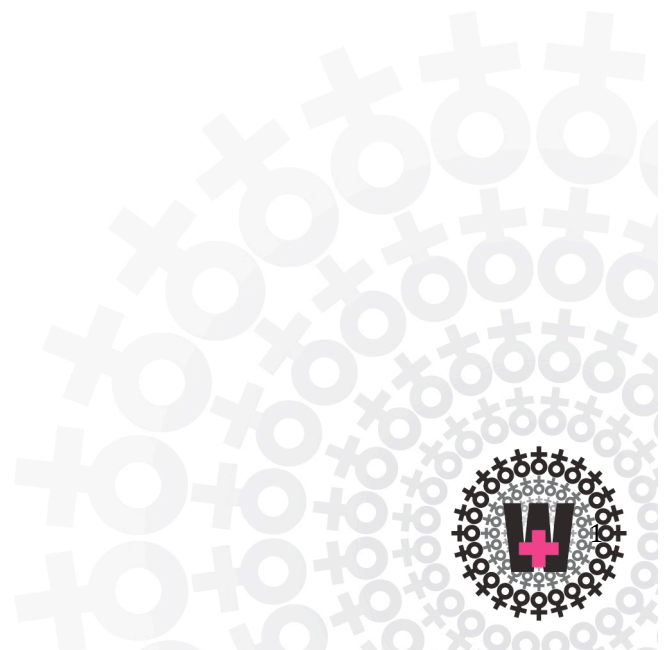
DIAGNOSIS, SEXUALITY AND CHOICE: Women living with HIV and the quest for equality, dignity and quality of life in the U.S.

ANALYSIS AND RECOMMENDATIONS FROM THE
U.S. POSITIVE WOMEN'S NETWORK 2010 HUMAN RIGHTS SURVEY
MARCH 2011

Authored by U.S. Positive Women's Network,
a project of Women Organized to Respond to Life-threatening Diseases (WORLD)

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INTRODUCTION

Current data confirms what so many women living with and affected by HIV know from experience – race, gender, geography and other structural and social variables impact health access, quality of care, and health outcomes for people living with HIV. “. . . [P]overty, intimate partner violence and food insecurity are increasingly recognized as factors significantly associated with increased high-risk sexual behaviors, decreased initiation and retention in care, and worse clinical outcomes.”¹

Related to these structural factors are societal realities that impact whether or not HIV-positive women will seek out and attain the care and treatment they need. For example, the establishment of a trusting and respectful doctor-patient and other HIV service provider relationships, and laws and policies that intentionally or unintentionally discriminate against and disparately impact people living with HIV can contribute to health outcomes.

President Obama’s National HIV/AIDS Strategy, released in July 2010, includes three priorities: 1) reducing the number of persons who become infected with HIV annually, 2) increasing access to care and optimizing health outcomes for people living with HIV, and 3) reducing HIV-related health disparities.

Reducing health disparities experienced by HIV-positive women requires a close look at gender inequality and the ways in which women’s experiences are accounted for in HIV prevention programs and care systems. A recent editorial in the *Journal of Infectious Diseases* stated that “[i]dentifying which factors are the most significant barriers to participation in care and

designing appropriate interventions are necessary to make any headway in erasing the disparities that are evident in . . . ”² health outcomes for women living with HIV.

The U.S. Positive Women’s Network conducted a survey from February 2010-January 2011. It is our hope that the below analysis of the survey results will contribute to and enrich an ongoing dialogue on the best ways to lessen existing health disparities experienced by women. In the survey, women were asked about their HIV testing experiences, provider attitudes and knowledge about their sexual health and reproductive choices as HIV-positive women, and the effects of criminal HIV exposure and transmission laws on their personal decision-making and on the HIV epidemic overall. The below themes were apparent throughout the survey as areas requiring increased attention:

The Right to Sexual and Reproductive Health and Reproductive Choice: HIV specialist and general practitioners are not adequately informed about HIV-positive women’s reproductive rights and options thereby limiting the full range of reproductive choices and options for women living with HIV.

The Right to be Free from Harmful HIV-related Stigma: HIV related stigma and lack of provider professionalism, such as inadequate confidentiality policies, or discriminatory treatment, impacts women’s decision-making when it comes to accessing care or when making decisions related to their reproductive health and choices.

The Right to Accessible and High-quality Health Care: Women often do not know they are at risk for HIV or are not encouraged to get tested for HIV. When receiving HIV-positive test results from doctors, women have experienced a range of negative experiences sometimes

¹ Armstrong, W, et al. Gender, Race, and Geography: Do They Matter in Primary Human Immunodeficiency Virus Infection? Editorial Commentary, *J Infect Dis*. 2011;203:437–438.

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² Id.



resulting from the doctor's general lack of knowledge about HIV and/or lack of knowledge about referral resources. Lack of information on the part of providers may result in late testing, poor health outcomes, and an inability to provide life-saving referrals to women-centered supportive services.

The Consequences of Criminalizing HIV-positive People's Sexuality: The majority of the respondents felt that laws criminalizing HIV transmission and exposure are not an effective HIV prevention strategy. If anything many of the respondents cited the harm that could result from such laws: laws can be used as tools of abuse; laws increase the already pervasive stigma faced by HIV-positive women; and the laws may contribute to discrimination as well as hinder testing, disclosure and treatment adherence campaigns.



SURVEY METHODOLOGY, DESIGN AND LIMITATIONS

The U.S. Positive Women’s Network released a voluntary and anonymous survey in February 2010 to assess the human rights landscape for women living with HIV in the U.S. The survey questions focused on three main areas: testing and disclosure, sexual and reproductive health, and the criminalization of HIV. While many of the questions were quantitative, seeking to identify general trends, the survey also included qualitative open-ended questions to gain a more complete idea of women’s lived experiences.

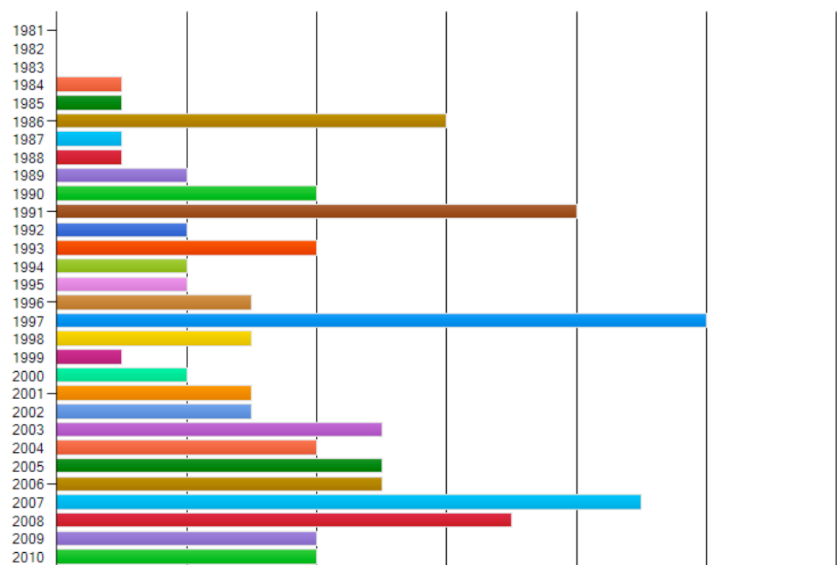
In total 160 people took the survey. A majority, 94.8%, were women, 4.5% were men, and 0.6% identified as other. Because the survey was designed to assess the experiences of HIV-positive women, analysis will focus on questions answered by women who identified themselves as living with HIV. One-hundred-and-three participants out of 160 self-identified as HIV-positive women. A majority of these respondents were between the ages of 25-44 followed by women 45-54, 55 and up, and 0-24 respectively.

About 42% of respondents identified as people of color: 30% Black, 7.8% Latina, 1% Native American, 2.9% other. The remainder, 58%, identified as Caucasian. The demographics of survey respondents are not reflective of the epidemic among women, which has disproportionately affected Black and Latina women. While this result is disappointing, some of the most poignant information gathered in the survey – personal reflections of HIV stigma and discrimination – was contributed by HIV-positive women from broad racial and ethnic backgrounds, age range, and geographical areas. The survey did not solicit data on socioeconomic status. Limitations in the survey’s ability to represent the racial and ethnic breakdown of the

epidemic may have been due to the fact that it was disseminated electronically and likely reflects the technology gap that breaks down along racial, ethnic, and socioeconomic lines. Future surveys and data collection will be conducted with the goal of proportionate participation by groups of women most affected by HIV.

The 103 respondents who identified as HIV-positive women were diagnosed with HIV/AIDS at all points during the thirty-year epidemic with

If you are HIV-positive, what year did you first test positive?



the largest number of diagnoses in 1997 followed by 2007.

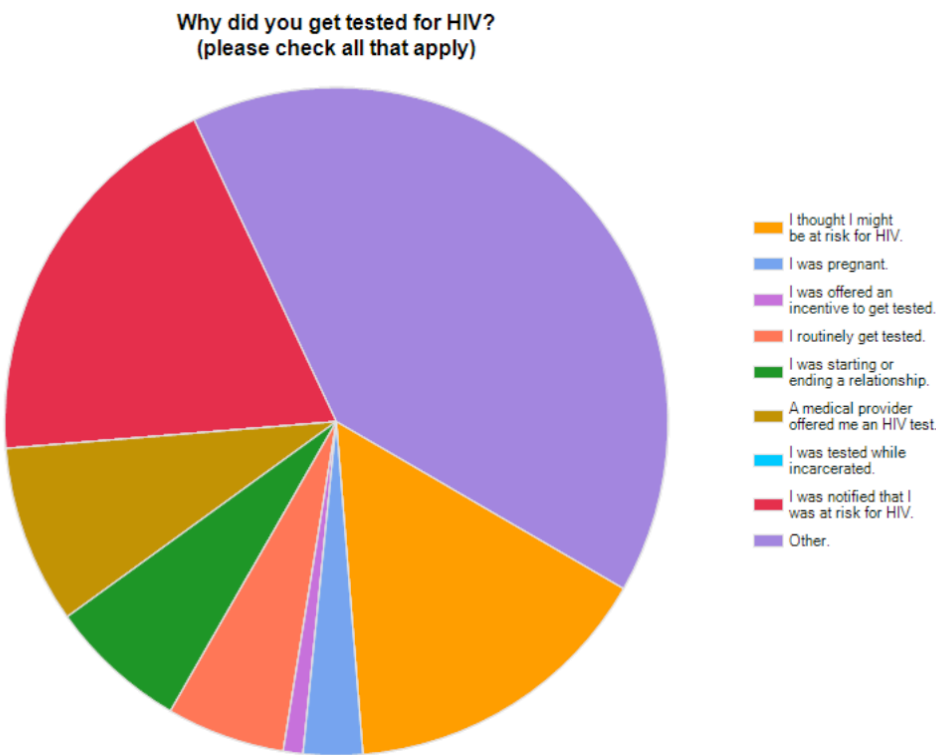
HIV TESTING, COUNSELING & DISCLOSURE EXPERIENCES

As a population, women tend to get tested later for HIV and consequently experience worse health outcomes than other groups. Research shows that this is not necessarily a result of biological differences but rather the consequence of structural factors that impact access to prevention services, care and treatment. These structural barriers can be improved by implementing universal and voluntary HIV testing and counseling that targets



women’s unique risk factors and barriers to testing; streamlining culturally appropriate, family-friendly, and holistic supportive services post-diagnosis; and improving the quality of HIV medical and service provision through ensuring professional, confidential, and respectful treatment in all medical and supportive service settings. Women’s answers to the survey questions provide some guidance on when women get tested, why it is often so late into their disease progression, and which factors help women enter and stay in care.

HIV Testing & Counseling: Why did you get tested for HIV?



The survey gave participants a number of choices to explain why they got tested for HIV including an “other” category where they could explain testing experiences that did not fall into the designated answer choices. Of the women who chose from the already formulated answers, a majority were tested when they were notified that a sex partner is HIV-positive or when they

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suspected that they were at risk for HIV. A majority, about 45%, of the participants who answered this question, however, chose the “other” category and explained their answers.

Many women stated they got tested for HIV only after experiencing symptoms from what turned out to be AIDS-related illnesses and were hospitalized for intensive care.

I was ill and hospitalized.

I was dying in the hospital and the[y] tested me there.

I was asthmatic and using an inhaler. It [stopped] work[ing]. I went to the ER. The breathing treatment didn't work [so] they took an x-ray of my lungs. They admitted me that night, [did a] lung biopsy and tested me for AIDS. My husband and I were married at this time 17 years.

I went to the emergency room because I was very sick. I found out I had bacterial spinal meningitis/encephalitis. The hospital asked me if I wanted to get a test for HIV. I agreed. I found out I was HIV positive during my hospital stay while I was being treated for the meningitis/encephalitis, which was an opportunistic infection due to the HIV.

I was in the hospital barely able to breathe from pneumocystis pneumonia (PCP). My physician



knew me and HIV was the last test she thought she needed to give. HIV didn't happen to "people like me". I had full blown AIDS and the doctor tossed a clipboard over to me that had the ELISA Western Blot info on it. No one knew what to say. I was told to go home and get my affairs in order.

Some women stated that they were tested for HIV and discovered their HIV status during routine check-ups to enroll in health or life insurance. Testing positive led to immediate rejection from the insurance plans.

I applied for health insurance with [name of health insurance company omitted] and was subsequently informed and denied coverage due to testing positive for HIV.

Other women thought they were being tested by their general practitioner or OB/GYN for HIV as part of their routine examinations and STI panel but were in fact not tested for HIV.

I thought I was tested every year, I was sexually active and told three doctors exactly that. They opted not to test me, even though my STD tests were positive. Finally a Primary Care Physician tested me. Who knows how long I have been positive. Just glad to finally have a good doctor that took the responsibility to test me.

A majority of women were tested by their primary care physician, OB/GYN, or at their local health department after their husbands or partners had already fallen ill or died from AIDS related illnesses.

I was tested after my husband was hospitalized with an opportunistic infection caused by AIDS.

My husband received an AIDS diagnosis after a year of severe illness. That is why I got tested.

I found medication for my boyfriend and called a hotline to find out what they were for. They were AZT, and I was advised to get tested.

My husband died of AIDS-related complications . . . I was urged to get tested.

I found that my ex-husband was positive, so I got tested.

While the majority of respondents were not discouraged from testing, there were quite a few women whose doctors overlooked or discouraged them from taking an HIV test.

I was never asked, never thought I needed a test.

I thought I was being tested every year with routine STD tests. How wrong I was.

When I requested to be tested for STDs the doctor initially questioned if I wanted to go as far as getting an HIV test. I repeated ALL STDs please. She was surprised. I was the first of her patients she ever had to give a positive result to.

A few women wrote that they had been denied HIV testing.

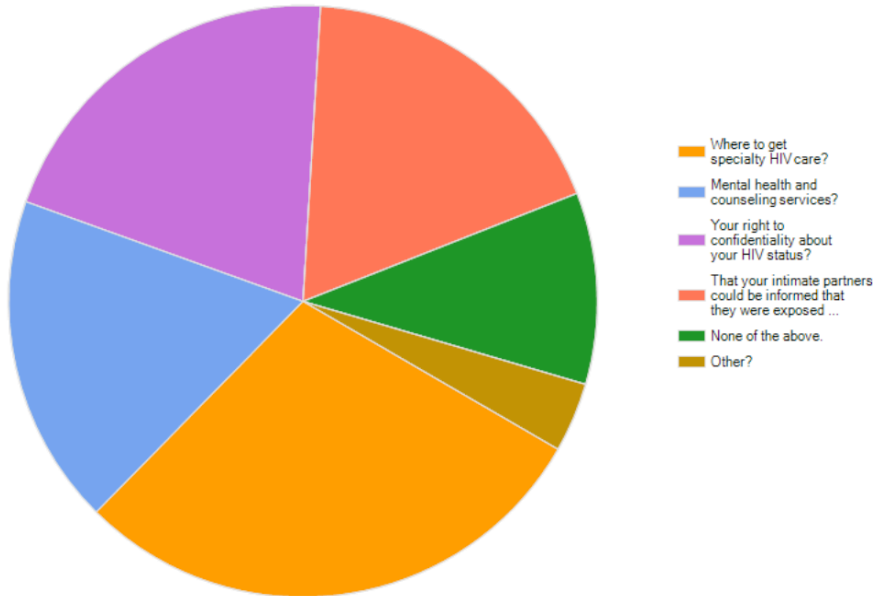
Once I requested [an HIV test] from the ER and was told no and given a handout with other agencies offering HIV testing. Actually, this happened twice at two separate ERs.



My family Dr. at the time refused to test me after a rape.

way she offered her assistance in the future.

After you received your HIV diagnosis were you given information about:
(please check all that apply)



– and negative experiences –

“My doctors were indifferent and even rude. They treated me like I had the plague and did not want to discuss any treatment options or offer any help.”

“My doctor didn't know anything, and he told me to wait a couple of weeks until I was able to have an appointment with the HIV specialist for the first time.”

After testing positive for HIV, about 64% of respondents received information about specialty medical care. Far less than half, however, received information about other essential services such as mental health care and support, their right to medical confidentiality, and partner notification policies. Almost a quarter of respondents, 23%, received none of this information when diagnosed with HIV. Explanations of HIV diagnosis experiences included both positive experiences –

The two girls who did the test did an excellent job and one of them even gave me her cell number saying I could call at 3 am or whatever if need be . . . [I called her] back . . . and I met her. She gave me all sorts of information and then walked with me several blocks to an AIDS case management place and introduced me to a worker there and along the

Confidentiality, Professionalism and HIV Disclosure: Has a medical provider or government worker ever disclosed your HIV status without your consent?

Many of the populations most affected by HIV already have a history of mistrust with the medical profession. Breaches in confidentiality, and a lack of professionalism resulting from HIV-related stigma continue to erode provider-client relationships in the HIV community, which can lead to disrupted HIV care and treatment. Respondents described multiple breaches of their medical confidentiality when their HIV status was disclosed without their consent and some of the consequences that followed.

These breaches of confidentiality were often conducted by the people clients need to trust the most: medical providers, pharmacists, and staff who work at AIDS service organizations (ASOs).



In the hospital staff were talking about me being [HIV-]positive and pregnant. It made me feel unsure of continuing with my pregnancy and I did not want to seek medical care anymore.

People in the community who worked for the ASO I was using disclosed my status without my consent. . . . It was humiliating. I had to seek ASO services and medical services more than an hour from my home.

My doctor's nurse told her daughter not to go out with [my son] because his mother – me – has AIDS.

I was hospitalized as a result of a car accident and the doctor announced that I was HIV positive in front of a friend who was visiting.

Additionally, incarceration policies that segregate HIV-positive persons result in a non-voluntary default disclosure of one's HIV status to fellow prisoners as well as to one's community as explained by one respondent:

I was segregated from the general population in prison in a building where all persons were [HIV-]positive. It is only common sense that everyone knew. People who knew me from my hometown would call and write letters saying I was on a building where people had AIDS and that I was dying. Someone even lost [their] life as a consequence of being segregated, someone called back to this persons hometown and within two weeks of her release she was murdered.

survey: 1) many women were not perceived as needing HIV testing until they began to show symptoms of AIDS-related illnesses, or demanded testing after learning their husbands were HIV-positive; 2) women fail to receive adequate linkages to non-medical supportive services such as mental health care or peer support, which help keep women healthy and in care; 3) women continue to encounter health care and HIV service settings that need strengthening to effectively provide nondiscriminatory, confidential and professional care. These themes seen together indicate that current testing, counseling, and referral services combined with a continued erosion of the doctor-patient and service provider-client relationship are barriers to attaining the highest standard of health for women living with HIV.

SEXUAL AND REPRODUCTIVE HEALTH

Women living with HIV identify non-discriminatory, quality, and appropriate sexual and reproductive health care as a gap in their health care needs. HIV-positive women are able to live long and healthy lives and give birth to healthy children. Yet frequently they suffer from judgment, discrimination, or misinformation when inquiring into their sexual and reproductive choices or attempting to exercise their sexual and reproductive rights. This is a fundamental rights violation. Like all women, HIV-positive women have the right to decide when and whether to have a child, and to access the information and services needed to make a voluntary and informed decision.

Roughly half of the survey respondents were diagnosed with HIV during their reproductive years, ages 15-44, but only 14% of respondents had a child after they were diagnosed. Of those who were of reproductive age after being diagnosed, less than a quarter, 22%, had spoken with their medical providers about their reproductive options.

A few clear themes emerged from the *HIV Testing, Counseling, & Disclosure* section of the



Seventy-six percent of respondents who did speak with their medical providers about their reproductive desires found the providers supportive.

They explained that I could choose to have a child and with proper care there was a good chance the child would be negative.

My doctor supported me with my health as well as the health of my baby while I was pregnant. They were very supportive.

My doctors have always said that pregnancy was an option and that the risk to the baby, if the mother is receiving treatment, is very tiny.

About a quarter of respondents, however, received conflicting information, had unsupportive, or extremely negative experiences.

Conflicting information on pregnancy:

My oncologist/hematologist highly encouraged me to think about having children. He was my primary HIV care provider from 1997-2005. My Primary care doctor looked at me like I was sick for even thinking of becoming pregnant. I just felt that the consensus was that I should not, that I was selfish and irresponsible for even thinking about it.

Unsupportive or uninformed medical providers:

[I was] warned against getting pregnant, but [the doctors] stated that there are treatments available if the decision was made to become pregnant.

I initiated the conversation and was deterred from becoming pregnant.

I seemed to be the educator in most of these areas. I was more up to date on any of the information than any doctor I found.

My doctor had little context or experience so it was up to me and the internet. Searching for an OB/GYN who was supportive was even more difficult. I was even offered an abortion by one OB.

[I did not receive] much of anything [information] with my first child, which resulted in him being positive. My thirst for knowledge allowed me to get the information needed to have a negative child the second time.

Stigma and discrimination resulting from reproductive choices:

I became pregnant with my son in 1991. Many doctors yelled at me and told me that I should abort the pregnancy. I finally found one doctor in all of NYC who was willing to treat me during my pregnancy. By the time I became pregnant with my daughter, there was a lot more support for HIV+ pregnant women. I was pregnant at the time of my test, and was urged to abort that child, which I did, reluctantly, but they told me that my child would be HIV+ for sure, if I carried it term.

I was told by several doctors to abort the pregnancy. I was almost in my 2nd trimester before I knew I was pregnant. I ran out of many a doctor's offices in tears after being told I was "selfish" or "if that were



my wife, I'd make her have an abortion."

Only one doctor was willing to care for me during my pregnancy with my son. With my daughter, born 6 yrs. later, it was a bit different and much more "socially" acceptable. It was pure hell with my son...not only for me but for my husband. Still I fear people finding out my status for my children's sake.

Differing reproductive choice advice based on race

Many African American respondents reported being advised to have, or choosing a tubal ligation or hysterectomy. None of the white respondents reported having a hysterectomy or tubal ligation.

I made all reproductive decisions on my own. For example, I had a tubal ligation, and have since gotten married to an HIV-negative man who has no children. Big regret.

The Right to Quality Reproductive Health Care

Once women broached the topic of reproductive healthcare, most respondents felt that their doctor was adequately trained to address their reproductive needs, or was able to refer them to a specialist who had more training to address their needs as an HIV-positive woman.

My doctor referred me to an HIV OB/GYN. I was my normal doctor's first HIV patient and she gave me the option to stay with her or to leave for a specialist.

The first doctor I discussed pregnancy with had started a clinic

for women with HIV, so I really trusted her.

There were, however, respondents who felt that their doctors were not adequately trained to provide accurate information and quality reproductive health care.

The doctor I ended up with was after relocating and meeting her at 6 months pregnant. She was anxious but very eager to learn. She made some mistakes (she didn't know any better) like telling me she would only single stitch the wound "less exposure to blood and needles" was her reasoning but she just doesn't realize I could have sued for discrimination. You can't treat people differently when it comes to health care.

The Right to Parent

Parenting rights are a component of reproductive rights. The survey asked whether respondents' HIV status had ever affected their ability to retain custody of a child, or been a factor in an adoption, foster care, or surrogacy decision-making process. Some respondents explained that they simply do not reveal their HIV status for fear of the repercussions – one woman stated simply, "I do not tell anyone I have HIV." Other respondents told stories of experiencing great stigma in the judicial systems and with child welfare agencies due to HIV status.

My ex-husband who was physically, psychologically, and emotionally abusive to me and my children was given sole custody even though he almost killed my eleven year old son by strangling him prior to the custody judgment. I strongly believe that the judge simply did not think I had the energy to care for



children because I was HIV-positive even though I cared for them alone since their births. I also think the judge did not think I would live long enough to care for my children.

I have been trying to regain custody of my twins for years and my HIV status is an issue with getting them back. They are 14 and HIV-negative.

Overall, the health outcomes of HIV-positive women may be improved by regular conversations with their doctors about their reproductive options at every stage of their reproductive lives. Women with HIV are living longer and healthier lives and vertical transmission is almost entirely avoidable with appropriate care, treatment and support. The right to information about and the right to choose one's reproductive options is a fundamental aspect of all women's reproductive health rights. For women living with HIV, access to up-to-date information and quality reproductive health care is vital to their physical health and essential to making informed decisions about family planning and risk reduction in relationships. Women in the survey articulated myriad examples of the way in which their reproductive health care needs are not being met. Only half of women who took the survey have had conversations about their reproductive options with their doctors. Many have experienced stigma and discrimination when expressing their reproductive desires. This can erode provider-patient relationships and lead to poorer health outcomes for women. In future surveys the PWN will inquire into the myriad other areas of reproductive health that affect women living with HIV such as access to family services like birth control, sexual health education on how to have safer sex, and sexual and reproductive health care and rights for incarcerated women.

THE CRIMINALIZATION OF HIV

As women and men living with HIV know too well, the HIV epidemic is fueled in part by fear, stigma, and a lack of accurate information. When laws exist that codify these destructive elements, the state becomes directly involved in exacerbating and legitimizing discriminatory and stigmatizing behaviors.

In the U.S. alone, thirty-six states and territories have laws that criminalize HIV exposure and transmission through consensual sex, needle sharing, or through spitting and biting, which has not been shown to transmit HIV. Some states do not have HIV-specific laws but people living with HIV have been prosecuted under general criminal laws for murder, assault, and in some cases bio-terrorism. While the intention to expose someone to or transmit HIV is an unacceptable act, it is also rare. Yet, a majority of these laws lack a requirement to show intent to transmit HIV and charges are often based on he-said-she-said accusations. Consequently, some HIV-positive people find themselves being prosecuted and sentenced to prison merely for knowing their HIV status.

Because women experience high levels of intimate partner abuse and may face economic disadvantages in relationships that lead to significant power differentials, criminalizing HIV exposure and transmission is sometimes cited as a way to protect women's health and safety. HIV-positive women are, however, also criminally prosecuted for HIV exposure and transmission. The PWN was interested in gauging the current views of HIV-positive women on the subject.

A majority of women were aware of HIV exposure and transmission laws but were not sure if their state had a law on the books and how the laws could be used. A majority of women thought HIV exposure and transmission laws were harmful to women living with HIV or they were not sure how they might be affected.



about 46% of respondents thought HIV criminalization laws could be harmful, and about 27% were unsure about how these laws would affect women. Almost 56% of respondents thought HIV criminalization laws could prevent people from getting tested for HIV for fear of punishment. Respondents explained their concerns:

Increasing stigma against people with HIV:

I refuse to be judged by this disease for I am much, much more than the disease. So, I keep this a secret. As a teacher I could lose my job. Not disclosing could get me jail time. Therefore, I no longer date. It's difficult being a leper of the 21st century.

I don't even want to try to have a relationship because I am afraid of the consequences of rejection and criminalization.

HIV criminalization laws hurt everyone with HIV because it's hard enough to feel okay about being sexual without feeling like your body is a deadly weapon . . . Safe sex should always be both person's responsibility.

There are so many myths and legends attached to being HIV positive that many people would prefer other people didn't know their status. Criminalization just adds another slap to the face. Why should we be locked up because we are ill?

Using criminalization laws as a weapon of abuse:

[The laws] could be used as a weapon even if you have disclosed

[your HIV status] to someone who then says you didn't.

I believe the laws hurt women by assuming a woman wouldn't disclose her status to a partner. A scenario that frightens me would be one where a partner would accuse me of not disclosing when in fact I had. Some of the laws assume that a person with HIV is a criminal already.

Yes because someone could know because you told them and get angry with you or want to take revenge and lie and say they never knew and you could be charged. This happened to one of the women who was incarcerated with me.

In an abusive relationship the man can use these laws against you. You almost need written consent to protect yourself.

Hindering HIV testing, disclosure and treatment campaigns:

[I think it will] will inhibit a lot of people from getting tested. Some think it will be better to remain ignorant of their own health to stay out of the prison system (I don't blame them).

The laws would encourage positive women not to disclose their status to their partners, or other people they are involved with.

HIV criminalization will be hurtful to all...it will undermine testing. People will not take the test, will progress and be very infectious, which will cause more transmission. It is stupid...



Criminalization hurts all people living with HIV, because it further contributes to stigma. It also deters people from getting tested, and when people don't know their status, they will more than likely transmit it to others, and women are particularly vulnerable.

I think it makes people just go underground with their status and avoid testing or treatment when they suspect they may be infected.

People are afraid enough as it is to get tested, and know their status. The criminalization further deters people from getting tested, and actually contributes to the spread of the virus, rather than control it.

Women who believed HIV criminalization laws are not harmful to people living with HIV, about 27%, tended to express the belief that the sole responsibility to prevent HIV is with the HIV-positive person. While there may be a moral and ethical obligation to disclose one's status to sexual partners, the clear public health message from all sectors is that every person should take responsibility for her sexual health.

Women who answered the survey questions expressed nuanced and thoughtful views on how criminal HIV exposure and transmission laws can affect women and echoed some of the concerns voiced in the advocacy community as well as in the U.S. National HIV/AIDS Strategy. The Strategy has called for a review of current HIV criminalization laws with an eye toward assisting in amending or repealing these laws in the states. Hearing women's viewpoint will be helpful in assessing the way in which these laws play out for those they were intended to help.

CONCLUSION

The U.S. Positive Women's Network 2010 Human Rights Survey begins a critical process of documenting the needs of women living with HIV and next steps to incorporate those needs into current policy and health initiatives on a federal and local level. The themes that emerged through this survey are noteworthy because they include issues both unique to women and the broader population that continue to be largely unaddressed by current U.S. domestic HIV policies and practices.

The Right to Sexual and Reproductive Health and Reproductive Choice: HIV specialist and general practitioners are not adequately informed about HIV-positive women's reproductive rights and options thereby limiting the full range of reproductive choices and options for women living with HIV.

The Right to be Free from Harmful HIV-related Stigma: HIV related stigma and lack of provider professionalism, such as inadequate confidentiality policies, or discriminatory treatment, impacts women's decision-making when it comes to accessing care or when making decisions related to their reproductive health and choices.

The Right to Accessible and High-quality Health Care: Women often do not know they are at risk for HIV or are not encouraged to get tested for HIV. When receiving HIV-positive test results from doctors, women have experienced a range of negative experiences sometimes resulting from the doctor's general lack of knowledge about HIV and/or lack of knowledge about referral resources. Lack of information on the part of providers may result in late testing, poor health outcomes, and an inability to provide life-saving referrals to women-centered supportive services.



The Consequences of Criminalizing HIV-positive People's Sexuality: The majority of the respondents felt that laws criminalizing HIV transmission and exposure are not an effective HIV prevention strategy. If anything many of the respondents cited the harm that could result from such laws: laws can be used as tools of abuse; laws increase the already pervasive stigma faced by HIV-positive women; and the laws may contribute to discrimination as well as hinder testing, disclosure and treatment adherence campaigns.

NEXT STEPS

The U.S. PWN will use this initial survey as a starting place to assess the needs of women living with HIV. Follow-up surveys will target precise issue areas that emerged from the survey answers and will be disseminated in a method that will reach the women most affected by the HIV epidemic.

The National HIV/AIDS Strategy, the U.S.'s most recent and visionary HIV policy document has the three goals of 1) reducing the number of persons who become infected with HIV, 2) increasing access to care and optimizing health outcomes for people living with HIV, and 3) reducing HIV-related health disparities. Women's unique needs, however, were largely absent from the Strategy's description of the HIV epidemic and few, if any, solutions to address them, were articulated in the Implementation Plan and resulting initiatives. With enormous energy, time, and resources being spent federally and locally to comply with and implement the Strategy, women cannot be left out of the equation.

RECOMMENDATIONS

1. Policies and programs must take into account the myriad social and structural factors beyond behavior that place women at risk for HIV – including being married or in long-term relationships,

gender based violence, and poverty – and incorporate this knowledge into prevention campaigns, voluntary HIV testing and counseling, and high quality and respectful care.

2. Policies and programs must account for the factors that create barriers for women to enter into and stay in care. Replicate community-based models that HIV-positive women say work for them. Expand peer support programs with staff who understand the challenges faced by their clients and walk women through the transition of receiving an HIV test to entering into care and navigating the complex care and treatment system.
3. Policies and programs must work to integrate sexual and reproductive health care with HIV care in order to ensure providers have the most up-to-date and comprehensive information to meet the needs of women and to ensure that HIV-positive women's health is addressed as a whole.
4. People living with HIV must be informed about laws and policies that affect their lives and must be consulted in the development and review of any HIV related laws and their enforcement. Expand civil and criminal legal services for people living with HIV to expand access to justice.
5. Laws, policies and programs must support human rights solutions to increase voluntary HIV disclosure rather than criminal prosecutions. Research must focus on why people are not comfortable disclosing their HIV status. Program efforts should be geared toward alleviating these barriers and supporting counseling and testing for couples, voluntary disclosure and ethical partner notification.



REFERENCES & RESOURCES

Armstrong, W, et al. Gender, Race, and Geography: Do They Matter in Primary Human Immunodeficiency Virus Infection? Editorial Commentary, *J Infect Dis*. 2011;203:437–438.

Burke, Ryan C, et al. Why don't physicians test for HIV? A review of the US literature. *AIDS* 2007, 21:1617–1624.

Burris, S and Cameron, E. The Case Against Criminalization of HIV Transmission. *JAMA*. 2008;300(5):578-581. doi: 10.1001/jama.300.5.578.

Campsmith, M, Rhodes PH, Hall HI, et al. Undiagnosed HIV prevalence among adults and adolescents in the United States at the end of 2006. *J Acquir Immune Defic Syndr*. 2010;53:619–624.

El-Bassel N, Caldeira N, Ruglass L, et al. Addressing the unique needs of African American women in HIV prevention. *Am J Public Health*. 2009; 99:996–1001. doi: 10.2105/AJPH.2008.140541.

El-Sadr WM, Mayer KH, Hodder SL. AIDS in America—forgotten but not gone. *N Engl J Med*. 2010;362:967–970.

Farr SL, Kraft JM, Warner L, et al. The integration of STD/HIV services with contraceptive services :442-51.

for young women in the United States. *Am J Obstet Gynecol* 2009;201:142.e1-8.

Felix, Holly C, et al. Referral and Referral Facilitation Behavior of Family Planning Providers for Women with HIV Infection in the Southern United States. *Journal of Women's Health*, July 2010, 19(7): 1385-1391.

Finocchario-Kessler, S, et al. Do HIV-Infected Women Want to Discuss Reproductive Plans with Providers, and Are Those Conversations Occurring? *AIDS Patient Care and STDs*. May 2010, 24(5): 317-323. doi:10.1089/apc.2009.0293.

Guidance for People Living with HIV Who Are At Risk of, or Are Facing, Criminal Prosecution for HIV Nondisclosure or Exposure. The Positive Justice Project at the Center for HIV Law & Policy available at <http://www.hivlawandpolicy.org/public/initiatives/positivejusticeproject>.

Hodder, SL, et al. Challenges of a Hidden Epidemic: HIV Prevention Among Women in the United States. *J Acquir Immune Defic Syndr* 2010;55:S69–S73.

Meditz, AL, et al. Sex, race, and geographic region influence clinical outcomes following primary HIV-1 infection. *J Infect Dis*. 2011 Feb 15;203(4)



U.S. Positive Women's Network

The U.S. Positive Women's Network, a project of WORLD, is a network of HIV-positive women, inclusive of transgender women, organizing and advocating for our rights.

PWN's **mission** 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.

WORLD (Women Organized to Respond to Life-threatening Diseases)

Founded in 1991, WORLD is a diverse organization for, by, and about women living with, and at risk for, HIV/AIDS.

WORLD's **mission** is to connect HIV-positive women, their families, allies, and communities to one another through peer-based education, support, advocacy, and leadership development.

For more information please visit www.womenhiv.org and www.pwn-usa.org.

