



POSITIVE WOMEN'S NETWORK
USA

To: Global Commission on HIV and the Law

From: Brook Kelly, J.D. - U.S. Positive Women's Network, a project of WORLD

Re: Organizational Submission from U.S. Positive Women's Network, a project of WORLD 2011 High Income Countries Dialogue – Reproductive Rights of HIV-Positive Women

Date: August 7, 2011

Thirty years into the HIV/AIDS epidemic life-saving milestones have been reached through effective legal and public health policy reforms. Yet for women living with HIV in the U.S., barriers to leading a quality life remain. HIV-positive women experience many of the same forms of discrimination and neglect as the larger HIV community including underfunded health care systems, discrimination in the work place, discrimination in or lack of affordable housing, and HIV-specific criminalization. In addition, women living with HIV face violations of their sexual and reproductive rights to choice and information, as well as their right to parent.

The mission of the U.S. Positive Women's Network, a project of WORLD, 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. We offer a unique perspective on how U.S. law and policy affect the human rights of women living with HIV because our broad national Network allows us to keep our finger on the pulse of women's lived experiences.

This submission will focus on aspects of U.S. law and policy that uniquely affect women living with HIV in the U.S.—namely, the violations of HIV-positive women's sexual and reproductive rights in the U.S.

International Law and women's sexual and reproductive rights

The following United Nations human rights bodies have acknowledged sexual and reproductive rights as a fundamental human right: the Committee against Torture; the Committee on Economic Social and Cultural Rights; the Committee on the Elimination of Discrimination against Women; the Committee on the Elimination of Racial Discrimination; the Committee on the Rights of the Child; and the Human Rights Committee.

The 1995 Platform for Action of the Fourth World Conference on Women in Beijing, China (Beijing Platform)¹, in which governments, including the U.S., pledged to uphold the sexual and reproductive rights of women, states in Paragraph 94 that reproductive health includes the ability “to have a satisfying and safe sex life” and “have the capability to reproduce and the freedom to decide if, when and how often to do so.”² This means that both women and men have the right “to be informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice, as well as other methods of their choice for regulation of fertility which are not against the law. . . .”³

Domestic law

The U.S. Constitution protects the fundamental right to decide whether or not to have children.⁴ In 1972, the Supreme Court held that “If the right of privacy means anything, it is the right of the individual, married or single, to be free from unwarranted governmental intrusion into matters so fundamentally affecting a person as the decision to bear or beget a child.”⁵ That right has continued to be upheld by the Court and applies to all people regardless of HIV status.

¹ Beijing Declaration and the Platform for Action, Fourth World Conference on Women, Beijing, China, Sept. 4-15, 1995, U.N. Doc. A/CONF.177/20 (1995) [hereinafter Beijing Declaration and Platform for Action].

² Id. para. 94.

³ Id.

⁴ Griswold v. Connecticut, 381 U.S. 479 (1965); Eisenstadt v. Baird, 405 U.S. 438 (1972); Roe v. Wade, 410 U.S. 113 (1973); Planned Parenthood of Southeastern Pennsylvania v. Casey, 505 U.S. 883 (1992).

⁵ Eisenstadt v. Baird, 405 U.S. 438 (1972)

HIV-positive people's right to the information and care necessary to decide if and when to have a child is also protected under the amended American's with Disabilities Act (ADA),⁶ as well as the ADA's precursor, the Rehabilitation Act of 1973.⁷ The ADA prohibits the denial of medical services based solely on a person's HIV status, and the Rehabilitation Act prohibits such discrimination by the federal government or federally funded entities.

The Right to Sexual and Reproductive Health and Reproductive Choice for women living with HIV

Sexual and reproductive rights include the full spectrum of a person's right to information, education and health, and to choose when and whether to parent and be supported in that decision. Although science proves that the risk of parent to child transmission in the U.S. can be virtually eliminated with appropriate care and treatment, and although the evidence base demonstrates that heterosexual HIV-positive individuals with suppressed viral load are extremely unlikely to pass on the virus, it is well documented that HIV-positive women continue to suffer from violations of their rights to be sexual and reproductive beings.

HIV specialist and general medical practitioners routinely fail to educate HIV-positive female patients about their fertility, conception and contraception options. The lack of information provided to women living with HIV about their reproductive options limits their full range of reproductive choice and violates their sexual and reproductive rights under both international and domestic law.

Reproductive options for women living with or affected by HIV and AIDS

HIV-positive women are able to live long and healthy lives and give birth to healthy children. There are a number of medical options for sero-different couples and HIV-positive mothers, greatly minimizing the risk of HIV transmission and making a healthy pregnancy and the birth of a healthy child possible. Some options for sero-different couples include sperm washing, artificial insemination, and unprotected sex when both partners have been screened and treated for any secondary sexually transmitted infections and the HIV-positive partner is on HIV treatment and has a low to undetectable viral load. Antiretroviral therapy during prenatal and postnatal care is an effective prevention strategy to protect the child. To take advantage of these options successfully requires ongoing counseling, support and treatment by well-informed medical professionals.

Despite the reproductive options available in the U.S., women living with HIV and AIDS frequently suffer from judgment, lack of, or mis-information, and discrimination when inquiring into their sexual and reproductive choices or attempting to exercise their sexual and reproductive rights. A 2007 Foundation for AIDS Research (amFAR) survey of Americans found that one-third of Americans would not support an HIV-positive woman's choice to become pregnant despite antiretroviral therapy to prevent mother to child transmission and only 14% believed HIV-positive women should be able to have children.⁸

The U.S. Positive Women's Network (PWN) conducted a survey and issued a report, *Diagnosis, Sexuality, Choice*, on HIV-positive women's experiences with reproductive health choices, and found discouraging results. The survey indicated that many doctors are either uninformed about HIV-positive women's reproductive options, choosing to forego any conversation about reproductive options or care for HIV-positive women, or are entirely unsupportive of an HIV-positive woman's right to reproductive choice, which includes the right to have a child. One woman reported that:

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.

⁶ Americans with Disabilities Act of 1990 - ADA - 42 U.S. Code Chapter 126.

⁷ Vocational Rehabilitation and Other Rehabilitation Services of 1973 - 29 US Code Chapter 16.

⁸ Women, HIV, and Stigma: Results from a National Survey, American Foundation for AIDS Research (amFAR), 2007.



Another woman reported that:

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.

Some respondents experienced outright stigma and discrimination, as in this case:

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.”

A study conducted in 2008, *Gynecologic issues in the HIV-infected woman*,⁹ of 181 HIV-positive women of reproductive age in urban health clinics, confirms some of the PWN's findings. Namely, only 31% of the women had discussed their reproductive options with health care providers. Of those 31%, 64% had initiated the conversation with the health care provider herself.¹⁰ Yet “between 25% and 45% of HIV positive individuals of reproductive age report wanting to have a baby in the future, compared with about 35% in the general population.”¹¹

On top of provider attitudes, the costs of reproduction—sperm washing, artificial insemination—are high, and are often not covered by health insurance plans. This makes safe reproduction for some HIV-positive women altogether unattainable.

Parental rights of women living with HIV

Women face abrogation of their parental rights based on HIV status. These violations include loss of child custody based solely on their HIV status—often a result of un-checked judicial attitudes and assumptions about HIV, poverty, and accompanying factors—but also result from prosecutions under HIV-specific criminalization laws. Women who are prosecuted under these laws find it difficult to impossible to regain custody of children once released from prison sentences.

Additionally, there has been a rise in cases where the custody of women's existing children is threatened by child services agencies when an HIV-positive woman becomes, or expresses the desire to become, pregnant. These instances are especially hard to document because the coercion often takes place off the record.

Conclusion

Women living with HIV in the U.S. continue to experience violations of their sexual and reproductive rights, international human rights, and domestic anti-discrimination protections when seeking to exercise their fundamental right to choose when and whether to have a child. It is our hope that the Commission will provide guidance on how the U.S. and state governments can comply with international human rights norms as well as our own domestic legal protections in order to create an environment that reflects the evidence-based advances made in HIV and sexual and reproductive healthcare for women, while taking into account the financial barriers to care faced by many women. Care systems serving women with HIV must truly adopt sexual and reproductive rights as a framework and train providers to ensure that those rights are upheld.

⁹ Cejtin, H. et al. Gynecologic issues in the HIV-infected woman. *Infectious Disease Clinics of North America* 22(4):709–739. December 2008; Finocchiaro-Kessler, S. et al. Do HIV-Infected Women Want to Discuss Reproductive Plans with Providers, and Are Those Conversations Occurring? *AIDS Patient Care STDS* 24(5): 317–323. May 2010.

¹⁰ Id.

¹¹ Leggett, H. *Becoming a Positive Parent: Reproductive Options for People with HIV*. BETA Winter/Spring 43. 2011.

