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Ending the invisibility of sex workers in the US HIV/AIDS surveillance and prevention strategy

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Globally, sex workers, i.e., individuals who trade sex for money or other goods,¹ suffer a disproportionate HIV burden.² Most nations provide sex worker-specific HIV infection and risk behavior estimates routinely in the UNAIDS global epidemic reports. By contrast, sex workers remain conspicuously absent in US domestic HIV/AIDS policy. Our national surveillance system fails to disaggregate HIV risk, disease burden, and treatment outcomes for sex workers, rather, sex exchange is grouped within “high risk heterosexual sex”. The HIV/AIDS report form for case surveillance also omits sex exchange as a potential transmission mode. Our CDC website on sex work and HIV lacks both data and intervention recommendations specific to this population. This dearth of data stymies our ability to develop a national HIV response for those in sex work, and perpetuates their invisibility and marginalization in US policy and interventions.

Recent evidence confirms a robust sex industry in the US,³ and sex exchange is documented in patient populations of STI clinics,⁴ family planning clinics,⁵ and substance use treatment programs.⁶ The 2010 high-risk heterosexual wave of the National HIV Behavior Surveillance System (NHBS) reported a past-year sex exchange prevalence of 16.6% among men and women combined.⁷ Further, the HIV prevalence was significantly higher among exchangers (3.7% vs. 2.1%)⁷ suggesting profound HIV implications.

Why the lack of HIV surveillance devoted to sex work in the US?

One likely explanation is the challenge in characterizing sex exchange, as it is widely recognized that many who exchange sex do not identify as sex workers, and that some are involved against their will and/or as minors. Within the NHBS and elsewhere, we lack clarity on the nature of sex trade with regard to context, consent or exploitation, degree of formality, and resources received. An evidence-informed response to this ambiguity requires

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surveillance with a breadth of individuals who trade sex, with enhanced measures to clarify their experiences, rather than data suppression for fear of misrepresentation.

Sex worker marginalization in US HIV policy arguably has deeper roots. The contentious US global policy context likely exacerbated the reluctance to acknowledge sex work within the US. The 2003 United States President's Emergency Plan for AIDS Relief (PEPFAR) included a policy known as the anti-prostitution loyalty oath (APLO, the so-called "Prostitution Pledge"), which required beneficiaries to explicitly oppose prostitution, its legalization, and sex trafficking. By conflating sex work and sex trafficking, the APLO furthered the marginalization of sex work. Needed research and intervention efforts which might have helped evaluate risks related to HIV and violence across the spectrum of sex exchange did not occur. The 2013 US Supreme Court ruling the APLO unconstitutional should pave the way for a new era of policy, including sex industry-related research to monitor risk behavior and infection trends, and inform the extent of exploitation.

Why disaggregate sex work from other forms of high-risk sexual transmission?

Globally, sex workers face significant, unique challenges that amplify HIV risk and exacerbate exclusion from essential HIV/STI services. Criminalization leaves sex workers vulnerable to pressure for unprotected sex, condom confiscation by police as evidence of sex work, and sexual violence with impunity.^{8–11} Extensive physical and sexual violence perpetrated by clients, police and others enable HIV risk behavior and infection.^{9,11–15} The US HIV epidemic dynamics, and their social determinants, also demand exploration of exchange sex as a transmission route. As is the case globally, in the US, HIV is situated in poverty. It is heavily concentrated among African Americans; the rate among African American women is twenty times that of white women.¹⁶ The confluence of gender and racial/ethnic discrimination, and economic deprivation strongly suggest sex exchange as a mechanism through which social determinants influence HIV.

The marginalization and criminalization of sex work through policy and practice are challenges to the success of the National HIV/AIDS Strategy and to control of the US HIV epidemic. Surveillance is a cornerstone of epidemiology. Without clarity on the extent and nature of sex work in the US population, we risk an incomplete and flawed understanding of HIV dynamics. And we risk the continued exclusion of sex workers from services they urgently need. We must not let discomfort with the sex industry undermine surveillance or evidence-based prevention and interventions. The improved policy climate post the Supreme Court decision is an opportunity for urgently needed reform. It is time for the US HIV surveillance system to include sex workers as a key population, and for sex workers and their communities to come out of the shadows and into urgently needed prevention, treatment and care services.

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