

Piecing Together the Puzzle: Addressing the HIV crisis among U.S. Women and Girls

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(WORLD)*

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(Brief) Data Points

- Women are > 25% of new infections
- > 80% heterosexually infected
- > 80% women of color
- > 60% of women dx with HIV are 13-39 y.o.
- Over 64% of HIV+ women had annual incomes under \$10K (compared with 10% of men) - HCSUS
- 75% of HIV+ women had a child under 18 in their homes - HCSUS

What's the big deal?

- Numbers aren't the whole picture
- Changing epidemic; changing needs
- HIV is not just biological
- Are we asking the right questions?

30 Years? Time for a Shift

Re-think programming and service delivery

- Invest in innovation
 - Move beyond silos
 - Think outside the box
 - Diversify leadership
 - There's no silver bullet or one size fits all approach
- ... and what about the next epidemic?

Rethinking Testing

- Nobody “needs” an HIV test
- Routine testing increases access for folks in routine care
- Targeted testing is based on individual risk behavior... misses the boat on women at structural risk
- What’s a real incentive for testing?

Perspectives on Criminalization

“Without a doubt in my mind....ignorance would be bliss..If you don't know, you don't have to disclose (or get treatment)”

“why would someone even want to know, if the risk to what ever their lifestyle is, would be jeopardized by knowing...They could lose their job, their family support, friends, and tons of other life-giving opportunities”

“My close girlfriends would rather remain ignorant of their status than get tested. Ignorance equals innocence!”

Rethinking Prevention

- Missed opportunities for prevention: reproductive healthcare utilization
 - 72.7% of women aged 15-44 years of age received at least one family planning or medical service in the past 12 months
- Operationalize structural & combination prevention: housing, violence prevention, economic security, addressing gender norms
 - “Place-based” prevention?
- Sex and drugs

HIV-positive women: reproductive rights

31% of women reported a personalized discussion with their HIV provider about their own fertility desires and intentions... 64% reported initiating the conversation with their provider.

Age is a strong predictor of provider-patient communication about pregnancy

AIDS Patient Care and STDs. May 2010, 24(5): 317-323.
doi:10.1089/apc.2009.0293

HIV-positive women: reproductive rights

“my mental health issues over what to do with this HIV diagnosis and with pregnancy, both at the same time, was OVER LOADING, to say the least, and nobody gave me the option to seek deeper mental health therapy after the abortion.”

“ 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’.”

Reproductive Rights of HIV+ Men and younger women

- Fertility and reproductive intentions of HIV-positive men?
- Special needs of young HIV-positive women: transition from pediatric to adult care; negotiating intimacy, employment, health insurance, parenting, etc

Rethinking Care

- Peer-based programs improve
 - engagement in care
 - treatment adherence
 - ... and are cost-effective!
- Integrate sexual and reproductive health services with HIV services to promote seamless linkage and retention
- Barriers to care: stigma, violence, economic/food insecurity, distrust of medical system, family responsibilities, and lack of transportation



HIV-Positive Women & Girls: Life

“ 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.”

HIV-Positive Women & Girls: Life

- Co-occurring conditions - e.g. cervical cancer; effects of long-term treatment
- Violence in relationships
- Economic opportunity - job training, financial literacy
- Delivering care and support differently?
Remotely?
- **STIGMA & DISCRIMINATION**

Special Focus: Transgender Women

- 27.7% of transgender women in SF are HIV+
- 30% of transgender people interviewed had postponed care for illness or preventive care due to disrespect & discrimination
(State of Transgender California; N= 650)
- 68% of transgender AIDS cases were people of color (2003)
- Disproportionately face housing instability, violence, social isolation
- Challenges with health research & data collection

Investing in leadership... diversifying leadership

- Studies show HIV-positive women trained as advocates or peer advocates demonstrate higher levels of disclosure; treatment adherence, increased employment and community involvement.
- Diversify at all levels.

Investing in leadership... diversifying leadership

“Since the training, I am more comfortable discussing my status with my family and friends. It has also made me take good care of my overall health.”

“I disclosed my positive status on television, and also to my partner.”

“I started my own program called the "Open Hearts Program." I have a weekly support group of approximately 30 people. I have worked on setting boundaries and have gone to counseling to find balance in my own life”

Moving toward Solutions

- Stimulus funding opportunities
- Continued advocacy on healthcare reform implementation - high risk pools, workforce development
- Non-traditional partners - public/private. Leverage opportunities such as childhood obesity campaign
- Social marketing to address HIV stigma; promote sex positivity

Moving toward Solutions

- Challenge and support organizations to work differently - funding, technical assistance, capacity building
- Support innovative & collaborative work to address structural issues towards health & wellness
- Invest in and support meaningful involvement of HIV-pos in decision-making



Thank you

