Trans Women Living HIV: Addressing an Unjust Burden and Working to Ensure Resilience

Women as the Face of AIDS Summit, Iris House
May 8, 2017
About The Well Project

• Non-profit organization with a mission to change the course of the HIV/AIDS pandemic through a unique and comprehensive focus on women and girls
• Leverages technology to improve health outcomes and increase quality of life for women and girls living with HIV
• Provides accessible and comprehensive #information, #community support, and #advocacy building
• Access our resources and join our community at www.thewellproject.org

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Speakers

Octavia Y. Lewis, MPA Islan Nettles Community Project; board of directors, PWN-USA; Positively Trans National Advisory Board

Kiara St. James, New York Trans Advocacy Group; Positively Trans National Advisory Board

Tiommi Jenae Luckett, communications coordinator, community advisory board, A Girl Like Me, The Well Project; Positively Trans National Advisory Board

Krista Martel, executive director, The Well Project (moderator)

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Within the first four months of 2017, nine trans women of color were murdered
Mesha Caldwell, 41, Canton, MS on January 4, 2017

Jamie Lee Wounded Arrow, 28, Sioux Fall, SD on January 6, 2017

JoJo Striker, 23, Toledo, OH on February 8, 2017

Ciara McElveen, 21, New Orleans, LA on February 27, 2017

Jaquarrius Holland (Brown), 18, Monroe, LA on February 19, 2017

KeKe Collier, 24, Chicago, IL on February 21, 2017

Chyna Gibson, 33, New Orleans, LA on February 25, 2017

Alphonza Watson, 38 Baltimore, MD on March 22, 2017

Chayvis Reed, 28 Miami, FL on April 21, 2017

#SayHerName
Agenda

• Overview
• Trans Women Living with HIV
  – Overview
  – Issues Common to Trans Women Living with HIV
• Results of Positively Trans Survey
• Panelists Discuss Successful Interventions
• Q&A
Trans Women Living with HIV
Overview

- **Transgender**: A term for people whose gender identity is contrary to the sex they were assigned at birth.
- **Trans woman**: A term for a transgender individual who currently identifies as a woman.
- **Gender identity**: An individual’s internalized sense of being either male, female, or variation as well as denouncement of the gender spectrum; because gender identity is *internal*, it is not necessarily visible to others.
The Numbers Tell the Story

- Rate of HIV among trans women is 49x higher than in general adult population
- Worldwide, 19 out of 100 trans women is living with HIV
- In 2010, CDC reported that the largest percentage of new HIV diagnoses in the U.S. was among transgender women
  - 90% of newly diagnosed trans women were African-American or Latina

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The *hijra* is an ancient transgender community in India.

*Source: Seeker Stories, NPR*
Not Being Seen or Heard

- Despite these numbers, trans women historically have not been well addressed in HIV efforts.
- They are often not even ‘seen’ (or counted) because they are inadequately categorized.
- Trans women may choose not to identify as trans when seeking services due to past negative experiences and/or anticipated stigma and discrimination.
- We need to ask the right questions about sex/gender in order to count trans women appropriately.

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Global changes slowly being made

• 2014: WHO conducted discussions to understand HIV-related experiences of transgender people and incorporated those learnings into the “Consolidated Guidelines for HIV Prevention, Diagnosis, Treatment and Care for Key Populations”

• 2015: WHO issued policy brief encouraging countries to establish laws decriminalizing nonconforming gender identities, protecting against discrimination, working toward legal recognition for transgender people

• 2016: U.S. White House Office of National AIDS Policy outlined specific steps to enhance prevention and care efforts for the transgender community
Many intersecting issues can negatively affect the health outcomes of trans women living with HIV:

“Transgender and gender non-conforming people face injustice at every turn: in childhood homes, in school systems that promise to shelter and educate, in harsh and exclusionary workplaces, at the grocery store, the hotel front desk, in doctors' offices and emergency rooms, before judges and at the hands of landlords, police officers, health care workers and other service providers.”

~ National Center for Transgender Equality

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Stigma and Discrimination

Keep people from:

- Getting tested for HIV
- Getting linked to or having access to care
- Staying in care
- Getting HIV drugs
- Taking their HIV drugs correctly (adherence)
- The National Transgender Discrimination Survey found:
  - 63% reported discrimination serious enough to impact their ability to support themselves financially and emotionally
  - Trans women of color bear the heaviest burden of discrimination
    - Most likely due to the combined effect of anti-transgender bias and structural racism

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Health Issues

• Compared to cisgender people, transgender people are less likely to:
  – Be on HIV treatment
  – Be adherent when on treatment
  – Have positive experiences with healthcare providers

• Transgender people face additional health issues (NCTE survey):
  – Almost 1 in 5 may be refused medical care because of gender identity in their lifetime
  – Almost a third had at least one negative experience in a doctor’s office related to being transgendered

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Health Issues

• There are many negative consequences to poor healthcare access
  – Fewer transwomen living with HIV receive and take the HIV drugs they need to stay healthy
  – Transwomen often access feminizing hormones through underground and unregulated channels, which can result in:
    • Buying unsafe hormones and giving themselves incorrect doses
    • Infection and scarring from unsterile technique or contaminated syringes
    • Sudden death from emboli (getting an air bubble or bit of foreign material in the bloodstream)

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Despite obstacles, trans women living with HIV have shown that they can face harassment/violence with determination and grit.

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Results of the Positively Trans Survey

Tiommi Luckett
Postively Trans
The Well Project

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Positively Trans

- Organize and mobilize transgender people living with HIV
- Form network of trans people living with HIV
- Fill the leadership gap in the trans community
- Develop a cadre of trans people living with HIV who will address community’s experience of the HIV epidemic through lenses of intersectionality
- Constituents led
- Evidence based advocacy
Survey Demographics

Gender Identity

Race & Ethnicity

https://transgenderlawcenter.org/programs/positively-trans
TOP 5 HEALTH CONCERNS

1. Gender affirming and non-discriminatory healthcare: 59%
2. Hormone therapy and side effects: 53%
3. Mental health care, including trauma recovery: 49%
4. Personal care (nutrition, healthy living, etc.): 47%
5. Antiretroviral therapy and side effects: 46%
History of Incarceration

- 59%: None
- 41%: Prison, Jail, or ICE detention
HAS A HEALTH CARE PROVIDER EVER REFUSED YOU CARE BECAUSE OF YOUR...

<table>
<thead>
<tr>
<th>Gender</th>
<th>Yes (31%)</th>
<th>Not sure (13%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV Status</td>
<td>Yes (20%)</td>
<td>Not sure (11%)</td>
</tr>
</tbody>
</table>

https://transgenderlawcenter.org/programs/positively-trans
Have you ever gone more than six months without medical care since your HIV diagnosis?

No: 59%
Yes: 41%

https://transgenderlawcenter.org/programs/positively-trans
How confident are you that you know your rights...

- Mostly or completely unsure
  - As a transgender person: 44%
  - As a person living with HIV: 40%

- Mostly or completely confident
  - As a transgender person: 55%
  - As a person living with HIV: 58%
Health care barriers

- Currently Uninsured
  - Rest of U.S.: 5%
  - South: 10%

- Attitude of doctor for HIV care is "hostile" or "neutral"
  - Rest of U.S.: 15%
  - South: 30%

- Accessing hormones is somewhat or very difficult
  - Rest of U.S.: 20%
  - South: 50%

https://transgenderlawcenter.org/programs/positively-trans
What was the result of your most recent viral load test?

- **Undetectable or less than 50 copies**: 71% (South) 81% (Rest of U.S.)
- **More than 50 but less than 10,000 copies**: 11% (South) 11% (Rest of U.S.)
- **Between 10,000 and 100,000 copies**: 2% (South) 3% (Rest of U.S.)
- **More than 100,000 copies**: 0% (South) 3% (Rest of U.S.)
- **I have never had a viral load test done**: 8% (South) 0% (Rest of U.S.)
- **I don't know**: 8% (South) 2% (Rest of U.S.)

Source: [https://transgenderlawcenter.org/programs/positively-trans](https://transgenderlawcenter.org/programs/positively-trans)
Panel Discussion

- What are some programs and interventions you see working best? What can we learn from them
- What do you see as the top priorities that need to be addressed in regards to trans women in HIV care/treatment? Prevention?
- Additional comments
- Q&A

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New York Trans Advocacy Group (NYTAG)

Today
I receive health, wealth, intelligence, possibilities, and opportunities in abundance in my life right now.

NYTAG
New York Trans Advocacy Group

Contact: NYTransAdvocacy@gmail.com
https://www.facebook.com/groups/OfficialNYTAG
Additional Resources on www.thewellproject.org

- To learn more:
  - Trans Women Living with HIV
  - Transgender Women: HIV Prevention as a Priority
- For a full list of topic-specific resources:
  - Resources for Trans Women
- For more fact sheets and to connect to our community of women living with HIV:
  - www.thewellproject.org
  - www.facebook.com/thewellproject
  - www.twitter.com/thewellproject
Additional Resources

• Positively Trans (T+) (Transgender Law Center)
• The Center of Excellence for Transgender Health
• National Center for Transgender Equality (NCTE)
• TransLatin@ Coalition
• Arianna’s Center
• Trans Women of Color
• Transgender Europe
• National LGBTQ Task Force
• Trans Lifeline
• Positive Women’s Network - USA