

# The Real Deal: Context from Listening Sessions with Black Women Living with HIV

Positively Safe – National Network to End Domestic Violence Diane Granberry + Robin Pereira, Positively Safe Specialists

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# Positively Safe

- Trainings
  - National
  - In-person
  - Virtually
- Technical Assistance
- Resource Development
- Podcast Expanding the Continuum
  - Apple Podcasts
  - Spotify
  - Soundcloud



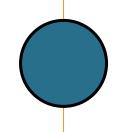


# There is no expectation that DV advocates become experts in HIV.

### After attending the session, attendees will be able to:

- 1. Understand how domestic violence impacts engagement in care and experiences of women living with HIV.
- 2. Discuss sexual health, prevention and stigma to better address the concerns of IPV survivors living with HIV and those who would benefit from HIV preventative care.
- 3. Identify areas where policies and practices can be more trauma-informed to best support survivors living with HIV and those who would benefit from HIV preventative care.





It's impossible to talk about HIV without talking about domestic and sexual violence.



# HIV Prevalence and Impact



## HIV vs. AIDS

Human Immunodeficiency Virus



Acquired
Immune
Deficiency
Syndrome



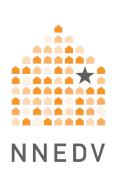
# HIV Progression

## **Acute/Primary Infection**

- Generally occurs 2-4 weeks after infection
- 70% of people will experience flu-like symptoms
- Virus reproducing, spreading quickly
- Attacking CD4 T-cells (call upon the immune system)
- Viral load is at it's highest = increased possibility of transmission

## **Clinical Latency/No Symptoms**

- People feel well with no signs/symptoms
- Can last 10+ years without medication or progress faster
- People on ART can never progress past this stage



# HIV Progression

### **AIDS**

- CD4 count below 200
  - Even if CD4 rebounds, still have a diagnosis of AIDS
- Diagnosed with an opportunistic infection
  - Examples: Kaposi sarcoma, lymphoma, tuberculosis, pneumonia
  - Greater frequency and severity in PLHIV
  - Even if infection is successfully treated, still have an HIV diagnosis



## HIV Transmission

- Sexual Contact
- Pregnancy, Childbirth, Breastfeeding
- Injection Drug Use
- Occupational Exposure
- Blood Transfusion or Organ Transplant



## Antiretroviral Therapy (ART)

- Daily Medication
- Suppresses the virus
- Side Effects
- High Costs
  - AIDS Drug Assistance Programs
  - Pharmaceutical Company Support



# U=U

Undetectable = Untransmittable



# BEING UNDETECTABLE

means people with HIV can lead long, healthy lives.





## **HIV** in the United States

In 2021, the Centers for Disease Control & Prevention found

36,136

1.2 M

87%

67%

Received an HIV diagnosis

Estimated to be living with HIV

Of those, knew they had HIV

Of all new HIV diagnoses through male-to-male sexual contact



## **HIV** in the United States

In 2019, the Centers for Disease Control & Prevention found

19%

Of new diagnoses were in women

84%

Of those new diagnoses were through heterosexual contact

54%

Of new diagnoses in women were in Black/African American women

51%

Of new diagnoses in women were in women ages 25-44



# Preventing HIV & Supporting Survivors



## What is PEP?

- Post-Exposure Prophylaxis (PEP)
- Prevent HIV after exposure
- Must be started within 72 hours
  - The sooner you begin the regimen the better
- 28 day course of ART
- Reduces chance of acquiring HIV by 80%
- Side effects
  - Nausea, cramps, bloating, headaches



## What is PrEP?

- On the market since 2012
- 99% effective in preventing HIV through sex
- Must be HIV negative before starting and while on regimen
- Requires blood tests every 3 months
- 3 FDA Approved Options



## How is PrEP Taken?

#### Pill

- Truvada generic available
- Descovy
  - Not approved for people assigned female at birth
- Taken once daily

### Injectable

- Apretude
- Newest form of PrEP (2021)
- 2 initial injections administered 1 month apart, and then every 2 months thereafter



# Accessing PrEP

### Ready, Set, PrEP - Federal Program

- ReadySetPrEP.HIV.gov
- Need a prescription from a medical provider.
- Must be uninsured or have health insurance that does not cover prescription drugs
- Taken an HIV test and received a negative result.

# **Co-pay assistance programs State PrEP Assistance Programs**

 https://nastad.org/prepcost-resources/prep-assistanceprograms



# Intimate Partner Violence and the Intersection with HIV



### The Issue

- 55% of women living with HIV have experienced IPV, for men it was found 20% have experienced IPV (Machtinger EL, et al. 2012).
- Women experiencing IPV have a 4x greater chance of acquiring STIs, including HIV (CDC, <u>Intersection</u> <u>of Intimate Partner Violence and HIV in Women</u>, February 2014.)



### The Issue

- 45% of women living with HIV have experienced physical abuse as a direct consequence of disclosing their HIV status (AIDS United, 2014)
- There are higher rates of ART failure for cisgender and transgender women experiencing DV (Machtinger, 2012)



## The Impact on Black Women

- Black women, compared to white women, are 7.8 times more likely to be diagnosed with HIV, have 15 times the AIDS rate, and have three times the rate of DV-related homicide.
- Approximately 41% of Black women have experienced physical violence by an intimate partner during their lifetime compared to 31% of white women.



# Power and Control Activity

Activity: Think of tactics related to HIV an abusive individual may use as they relate to these categories.

NOTE: The abusive individual may be living with HIV, the victim may be living with HIV, or BOTH may be living with HIV

- Coercion and threats
- Emotional
- Psychological
- Medical Abuse
- Isolation

- Economic
- Spiritual
- Using children
- Sexual/reproductive
- Technology



# PHYSICAL VIOLENCE

# **HIV Power** & Control Wheel

#### Coercion & Threats

Badgering and begging for sex at an unwanted time, in an unwanted place or in a way not wanted by the victim. Threatening to "out" the victim's HIV status. Threatening to harm the victim, harm pets, or destroy property. services. Harassing, manipulating

#### **Psychological**

Playing mind games. Always changing the 'rules.' Bringing up past behaviors to place blame or quilt. Blaming the violence on the victim of the abuser's own HIV status. Giving misinformation about HIV: telling victim that they infect plates, silverware, toilets, etc.

#### **Economic Abuse**

Refusing to pay for medical care or medication. Using his/her (the abuser's) HIV status or other excuses to keep the victim from working. Not allowing access to money. Using disability money for other things instead of the victim's health needs.

Technology Abuse

Monitoring internet activities.

Restricting or prohibiting use of

technology to seek information or

or threatening victim over

social media in regards to

HIV status

#### Isolation

Moving the victim away from friends and family. Threatening to tell people the victim's HIV status without permission. Not allowing the victim to attend support groups, doctor's appointments, or use social media.

#### **Using Children**

Threatening to take the children Threatening to use HIV status of victim with the court or CPS to try show victim as an unfit parent. Using children to keep tabs on the victim. Blaming victim for child's potential HIV+ status.

### **HIV POWER** & CONTROL

#### Medical Abuse

Not allowing the victim to attend medical appointments. Interfering with medication and health routines/schedules. Withholding or disposing medicine. Not allowing the use of protection during sex. Coercing or forcing use of drugs.

#### **Emotional Abuse**

Using degrading names and humiliating the victim in public. Not keeping an HIV positive status confidential. Shaming the victim because of HIV status. Telling the victim that nobody else will want them because of an HIV+ status. Perpetuating the idea that an abusive relationship is the best they (victims)

#### Privilege

Using their (the abuser's) health status to guilt the victim into staying (how could you not stay or help someone who is sick) or to order the victim around and claim authority over decisions. (You're sick, I'll take care of this.)



Use of scripture (of any faith) as a control tactic. Imposing shame and stigma with respect to sexual behaviors/HIV status. Using the identity of an entire religion as a tool of abuse: "if you contact the police, you're exposing our entire community."



SEXUAL VIOLENCE



# Impact of Trauma



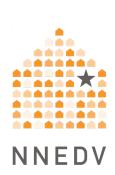
## What is trauma?

- Trauma is the unique individual experience of an event or enduring conditions, in which:
  - The individual's ability to integrate their emotional experiences is overwhelmed, or
  - The individual experiences, subjectively, a threat to life, bodily integrity, or sanity.



## Compounded Trauma

- May experience multiple traumatic events
  - A majority of women living with HIV are survivors of multiple forms of abuse. Rates of PTSD, childhood sexual abuse, and IPV are particularly high among women living with HIV. (Machtinger EL, Wilson TC, Haberer JE, Weiss DS, 2012)
- Trauma based on identity
- Trauma inflicted by services/programs
  - Power and control by advocates
  - Discrimination by service providers



## Trauma + HIV

- Diagnosis
- Acquired
- Survivor
- Discrimination





# Impact of trauma

- Severe depression
- Anxiety
- PTSD
- Guilt
- Flashbacks & Nightmares

- Difficulty Sleeping
- Memory Problems
- Lack of Interest
- Mood Swings



# Trauma & Women Living with HIV

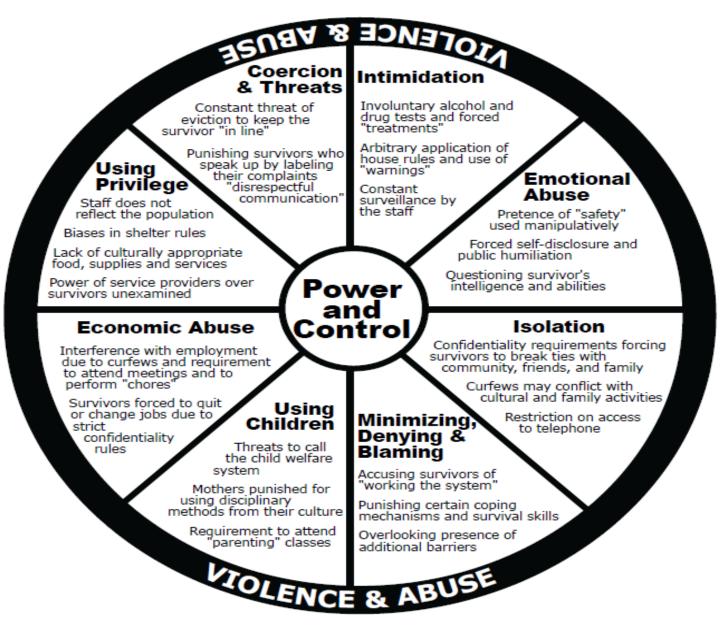
- 61.1% have experienced sexual assault during their lifetime.
- 55.3% have experienced intimate partner violence (IPV)
- 39% have experienced childhood sexual abuse (CSA) and 42% experienced childhood physical abuse.
- The estimated rate of lifetime abuse (type unspecified) is 71.6%.



# How as service providers can we cause trauma?



# Abusive Power and Control within the Domestic Violence Shelter



2002 Emi Koyama

& Lauren Martin



# What We Heard from Black Women Survivors Living with HIV



# Listening session comprised of Black women survivors living with HIV....

Because you would seclude my kids, they could not invite their friends over.

You are living with other people and their unruly kids

You don't have the feeling that the place you're staying is your.

# Listening session of Black women survivors living with HIV....

Afraid of having to disclose their HIV status

I don't have anywhere to go; shelters are always filled. No help to go nowhere.

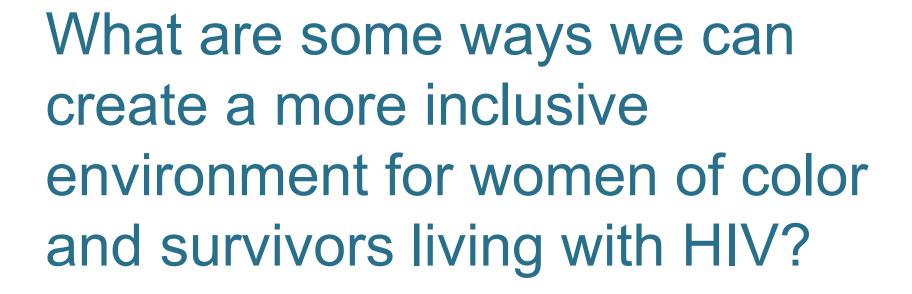
Even though you don't want to go back to him, you don't like the set-up in the system.

# Listening session of Black women survivors living with HIV....

It's like an institution, you want to live in your own space.

Shelter programs and services lack creating a more inclusive environment for women of color.

Medical mistrust and lack of best practices.





# Implementing Trauma Informed Care



## Trauma Informed Care

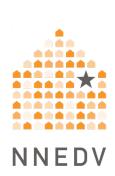
- What is traumatic for one person may not be traumatic for another.
- We must, therefore, consider carefully not only the EVENT but the individual's PERCEPTION of the event.
- Shifts the question from 'What's wrong with You?' to 'What happened to You?'



## TIC Principles

- Empowerment choices & autonomy
- Collaboration internal, external
- Trust & Relationships
- Transparency
- Cultural/Historical/Gender Issues
- Safety

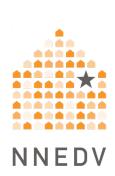
\*\*Address Barriers to Care



# Implementing TIC

- Review
- Evaluate
- Feedback
- Knowledge
- Engage
- Practice!

Be ok with being uncomfortable!



# Creating Affirming Spaces

#### Paperwork/Materials

- Asking for pronouns?
- Does it reflect that you serve everyone regardless of gender identity or sexual orientation?
- Who is displayed in organizational materials?

#### Language

- Do you have bilingual staff?
- Do you have access to an interpretation line?
- Materials in multiple languages?
- Do staff know your language access policy?

#### **Physical Space**

- Is it inviting?
- How are your bathrooms labeled? Private bathrooms?
- Accessible?



## Questions?



- To Learn More: nnedv.org/dvhiv
- Expanding the Continuum Podcast Spotify, Apple Podcasts, SoundCloud

