## No estas sola/You are not alone

Using a family focused approach to engage and empower HIV positive women of color.

Iris House, 11<sup>th</sup> Annual Women as the Face of AIDS Summit May 3<sup>rd</sup> 2016



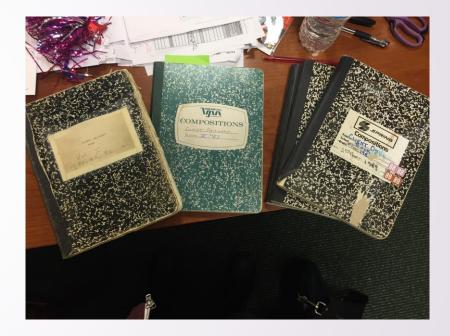
#### **Our Presenters**

- Glynis Simmons, Director of Women's Care, Prevention, and Support Services
- Nelly Melendez, Counseling Assistant, Women's Care, Prevention, and Support Services
- Christina Melendez, Outreach Data Specialist, Women's Care Prevention, and Support Services
- Katie Douglass, LCSW-R Managing Director of Mental Health & Support Services



### **GMHC** History





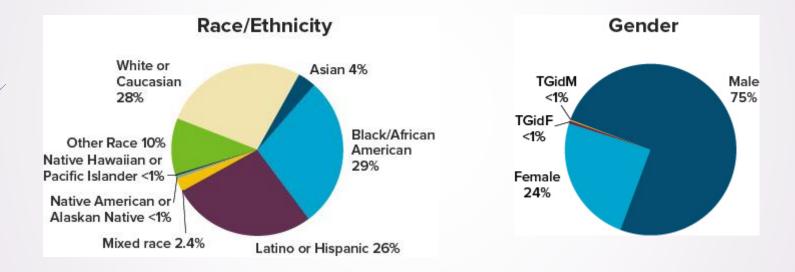
#### **GMHC** Today

Services Include:

- Food & Nutrition
- Work & Wellness
- Prevention & Outreach
- Counseling & Testing
- Mental Health
- Latex Ball
- Hotline
- Legal Services
- Care Coordination



#### **GMHC** Client Demographics



2,266 Women - 2014 Client statistic

#### Impact of HIV on Women, per CDC

- Women made up 19% (8,328) of the estimated 44,073 new HIV diagnoses in the United States in 2014. Of these, 87% (7,242) were attributed to heterosexual sex, and 13% (1,045) were attributed to injection drug use.
- Among all women diagnosed with HIV in 2014, an estimated 62% (5,128) were African American, 18% (1,483) were white, and 16% (1,350) were Hispanic/Latina.
- New HIV diagnoses declined 40% among women from 2005 to 2014. They declined 42% among African American women, 35% among Latina women, and 30% among white women.
- Of women diagnosed with HIV in 2013, 84% were linked to HIV medical care within 3 months. But only 55% of women living with HIV were retained in care (receiving continuous HIV medical care). Only 39% of women living with HIV at the end of 2012 were prescribed antiretroviral therapy (ART), the medicines used to treat HIV, and only 30% had achieved viral suppression.

Statistics gathered from : http://www.cdc.gov/hiv/group/gender/women/

### Women's Care, Prevention, and Support Services (WCPSS)

- Program is over 15 years old
- Serves over 90 women living with HIV or at high risk
- Programs include:
  - Women in Action
    - Alcohol and Other Drug Services
  - Together We Can (TWC)
    - Evidence Based Interventions
  - Community of Color
    - Sisterhood Affair

#### Women Served in WCPSS

- Are majority Latina & African American
- Range in age between 15 to 70 years old
- Majority are mothers and grandmothers
- Common themes:
  - Diverse and fluid sexualities
  - Significant trauma backgrounds
  - Active substance use issues
  - Have Not disclosed thier HIV status to significant others and family members

#### WCPSS Client HIV Wellness

- 97% of clients are prescribed ART
- Mean CD4 613
- 90% have an undetectable viral load (vs 44% overall in NYS)

# Concerns clients share about their children

- Fear their children will:
  - Hate, judge or be angry at them for contracting HIV
  - "Worry about me passing and being left alone."
  - "Act out" or misbehave in response to disclosure
  - Be stigmatized for having a mother with HIV and be put in a position having to defend their mother

#### Concerns clients share about partners

- Disclosing HIV status to husbands, spouses, sex partners could result in:
  - Physical violence
  - Being judged, ridiculed, verbally abused
  - Abandonment
  - Bringing shame to their family

# Concerns & questions children have shared about their mother's HIV status

- Death
- People judging their mother and having to "defend" mother
- Medication side effects, what are they and how harmful might they be?
- Will my mother be hospitalized?
- How can I properly help care for my mother?
- How can I emotionally support my parent?

#### WCPSS' Family Focused Model

- Program takes a "Second Family" approach
  - Supportive "no matter what," staff are loyal to the client
  - Staff are non-judgmental but do not shy away from confrontation
  - Honesty
  - Humor
  - Affection
  - Food is often incorporated into services/events

#### WCPSS' Family Focused Model cont.

- Culture is honored via:
  - Peer Providers
  - Language
  - Style of engagement
  - Values

#### WCPSS Intervention Examples

- One on one sessions with peer providers focus on creating the right environment for disclosure to happen
  - Prepping/practicing the disclosure
  - Reviewing possible consequences and benefits of disclosing
  - Encouraging disclosure to happen in a safe place (vs in the spur of the moment)
  - Ensuring back-up Mental Health support is in place
  - Bringing family member in for disclosure with peer counselor as support
- Disclosure Peer Group

#### WCPSS Intervention Examples

#### Parent/Child Disclosure Event

- Children sorted by learning needs
  - Those who knew parent's diagnosis and were well informed about HIV
  - Those who didn't know or had a negative view/misinformation about HIV
- Those who knew about parent's diagnosis
  - Spoke with two peers
  - Shared fears and concerns about their parent's diagnosis
  - Talked about when parent is not open about HIV status
  - Group focused on increasing support and decreasing isolation
- Those who did not know parent's status or had negative view
  - Spoke with HIV positive mother and daughter
  - Received HIV 101 education
  - Group focused on laying groundwork for disclosure to happen in the future

#### Questions for the audience:

- 1. What challenges do you see women face in disclosing?
- 2. What do you see as the biggest challenge to keeping women living with HIV healthy physically, emotionally, spiritually?
- 3. What kind of disclosure tools/techniques do you use in your agency?
- 4. What interventions have you learned at this conference that you will look to replicate in your agencies?

### Conclusions