Optimizing Linkage, Engagement, and Retention in HIV Care for Adolescents and Young Adults of Color

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Liz Salomon, EdM
Continuing Medical Education Disclosure

- **Program Faculty:** Liz Salomon, EdM
  - **Current Position:** Project Director, Community Based Research, Fenway Health
  - **Disclosure:** No relevant financial relationships. Presentation does not include discussion of off-label products.

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  - **Current Position:** Nurse Practitioner, Sidney Borum Jr Health Center
  - **Disclosure:** No relevant financial relationships. Presentation does not include discussion of off-label products.

- **Program Faculty:** Lawrence Vinson
  - **Current Position:** Youth Linkage to Care Project Manager
  - **Disclosure:** No relevant financial relationships. Presentation does not include discussion of off-label products.

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Learning Objectives

1. Summarize the state of HIV infection among youth and young adults in the US.
2. Describe the intersection of HIV infection with race, stigma, and health equity.
3. Identify best practices for linking, engaging, and retaining youth in HIV care.
4. Describe effective partnerships between program staff and clinicians in helping youth living with HIV navigate the HIV Continuum of Care.
The Continuum of HIV Care--US

Of all with HIV infection, 850,000 individuals do not have suppressed HIV RNA (72%)

African American men represented 36% of an estimated 29,800 new HIV infections among all gay and bisexual men
Of all with HIV infection, 74,500 individuals do not have suppressed HIV RNA (94%).

More new HIV infections (4,800) occurred among young African American gay and bisexual men (aged 13-24) than any other subgroup of gay and bisexual men.
Stages of HIV Care Among MSM Living with HIV/AIDS (Aged 20 to 29 Years) in Massachusetts\textsuperscript{1} by Race/Ethnicity

<table>
<thead>
<tr>
<th></th>
<th>All 20-29 MSM (408)</th>
<th>White NH (155)</th>
<th>Black NH (109)</th>
<th>Hispanic/Latino (117)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Engaged in Care\textsuperscript{*}</td>
<td>79%</td>
<td>81%</td>
<td>73%</td>
<td>81%</td>
</tr>
<tr>
<td>Retained in Care\textsuperscript{*}</td>
<td>62%</td>
<td>61%</td>
<td>61%</td>
<td>63%</td>
</tr>
<tr>
<td>Virally Suppressed in 2013\textsuperscript{*}</td>
<td>61%</td>
<td>70%</td>
<td>46%</td>
<td>62%</td>
</tr>
</tbody>
</table>

\textsuperscript{*} Lab received by MDPH

\textsuperscript{1} Includes individuals diagnosed through 2012 and living in MA as of 12/31/13, based on last known address, regardless of state of diagnosis

\textsuperscript{2} Data Source: MDPH HIV/AIDS Surveillance Program, cases reported through 1/1/14
Rate of HIV Incidence among 12-24 year old Males by Boston Zip Code, 2005-2009

Reported HIV Rate per 100,000 among 12-24 year old Males

- **Gray**: rate suppressed for confidentiality purposes (28)
- **Red**: 72 (1)
- **Black**: Boston Neighborhoods

Sources: Massachusetts Department of Public Health, 2011 & US Census Bureau, 2010

Data reflects age at diagnosis and includes individuals who may have progressed to AIDS.

Data received from Massachusetts DPH, which was organized by neighborhoods, was reorganized at zip code level to calculate infection rates. A neighborhood layer was overlaid for practical and impact purposes to identify the most at risk Boston neighborhoods.

Reported cases where no zip code was provided are not included on this map. Data does not include prisoners.

2010 Census Data

NATIONAL CENTER FOR INNOVATION IN HIV CARE

Sources: Massachusetts Department of Public Health, 2011 & US Census Bureau, 2010

Data received from Massachusetts DPH, which was organized by neighborhoods, was reorganized at zip code level to calculate infection rates. A neighborhood layer was overlaid for practical and impact purposes to identify the most at risk Boston neighborhoods.

As US Census population data was not available for 12-24 year olds by race, rates were calculated using census data for 10-24 year olds as the denominator and DPH data for 12-24 year olds as the numerator.

Reported cases where no zip code was provided are not included on this map. Data does not include prisoners.

2010 Census Data
## Modes of Transmission Data

**2005-2009 Incidence of HIV Infection among 12-24 Year Olds**  
Data as of 01/01/11 (Prisoners Excluded)

<table>
<thead>
<tr>
<th>Boston Neighborhood</th>
<th>Presumed Reported Mode of Exposure</th>
<th>MSM</th>
<th>IDU</th>
<th>MSM/IDU</th>
<th>Het Sex</th>
<th>Other</th>
<th>Presumed Het</th>
<th>Unk</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allston</td>
<td></td>
<td>*</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
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<td>*</td>
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<tr>
<td>Brighton</td>
<td></td>
<td>*</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>*</td>
</tr>
<tr>
<td>Back Bay</td>
<td></td>
<td>5</td>
<td>*</td>
<td>*</td>
<td>0</td>
<td>0</td>
<td>*</td>
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<td>9</td>
</tr>
<tr>
<td>Charlestown</td>
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<td>0</td>
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<td>0</td>
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<tr>
<td>E Boston</td>
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<td>0</td>
<td>*</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>*</td>
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<td>Hyde Park</td>
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<td>Mattapan</td>
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<td>0</td>
<td>*</td>
<td>7</td>
</tr>
<tr>
<td><strong>N Dorchester</strong></td>
<td></td>
<td><strong>12</strong></td>
<td>0</td>
<td>*</td>
<td>*</td>
<td>0</td>
<td>*</td>
<td>*</td>
<td><strong>19</strong></td>
</tr>
<tr>
<td>S Dorchester</td>
<td></td>
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<td><strong>14</strong></td>
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<tr>
<td>Roxbury</td>
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<td>0</td>
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<td>*</td>
<td>*</td>
<td>13</td>
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<tr>
<td>S Boston</td>
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<td>0</td>
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<td>0</td>
<td>0</td>
<td>5</td>
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<tr>
<td>South End</td>
<td></td>
<td>7</td>
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<td>*</td>
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<td>0</td>
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<td>10</td>
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<tr>
<td>W Roxbury</td>
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<td>*</td>
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<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>*</td>
</tr>
<tr>
<td>N/W/Down</td>
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<td>0</td>
<td>*</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>*</td>
</tr>
<tr>
<td>Homeless</td>
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<td>0</td>
<td>*</td>
<td>0</td>
<td>*</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Unk</td>
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<td>*</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>*</td>
</tr>
</tbody>
</table>
Strategic Multisite Initiative for the Identification, Linkage and Engagement in Care of Youth with HIV Infection

A Program of The Fenway Institute

NATIONAL CENTER FOR INNOVATION IN HIV CARE
LTC- (Linked to Care) client attended first medical visit (within 42 day)

EIC- (Engaged in Care) attended 2nd medical visit (within 16 weeks of LTC appointment)

RIC- (Retained in Care) client attended 3rd medical visit (within 1 year of EIC appointment)

YLTC- Youth Linkage to Care
The SMILE Linkage to Care Program

- The SMILE Linkage to Care Program is designed to provide linkage to medical care and psychosocial support for youth who are newly diagnosed, having difficulties staying engaged in care, or new to the Boston area. This project is for Boston youth ages 12-24.

- Benefits to Youth:
  - Case Management support from the Youth Linkage to Care Project Manager and YLTC Case Management Interns
  - Transportation assistance to and from medical appointments
  - Incentives for participating in the SMILE Program
  - Access to resources from other youth-oriented programs
  - Development of steps to a solid foundation for a healthy future
“If young adults have nothing to live for, why would they care about their medical care?”

*Trecia Mayo, SPARK Center*
Social animal

What a man can be, he must be
This level of need pertains to what a person’s full potential is and realizing that potential. For example: desire to become an ideal parent, expressed athletically, in painting, pictures, or inventions.

Self-actualization

Esteem
to be respected
to have self-esteem
desire to be accepted
valued by others

Esteem

Love and belonging

Friendship
family

Safety needs

Physical security
interpersonal security

Physiological

M A S L O W

Hierarchical needs

Frustration-regression principle:
If a higher level need remains unfulfilled,
the person might regress to lower level
needs that appear easier to satisfy

Access to the higher levels
required satisfaction in the
lower level needs
SMILE LTC
Client Distribution by Zip Code

N = 113*

Legend
- Boston Neighborhoods
- Count
  - 1-2
  - 3-5
  - 6-8

* N includes all clients in the SMILE LTC program, not just those in Boston.

NATIONAL CENTER FOR INNOVATION IN HIV CARE

NATIONAL LGBT HEALTH EDUCATION CENTER
SMILE Demographics
SMILE LTC Client Profile: Race

- Black/African American: 37%
- White: 21%
- Mixed: 12%
- Unknown: 20%
- Other: 4%
- Asian: 5%
- Native Hawaiian: 1%

N=113
SMILE LTC Client Profile: Ethnicity

- Hispanic/Latino Identified: 20%
- Unknown/Not Asked: 35%
- Non-Hispanic/Latino: 45%

N=113
SMILE Clients Mode of Transmission

- MSM: 70%
- Unknown/Not Asked: 21%
- Heterosexual: 3%
- MSM w IDU: 1%
- Perinatal: 5%

N=113
SMILE Linkage to Care Comparison Chart

- % Eligible for LTC
- % of Cases LTC
- % LTC, with EIC
- % Cases EIC, RIC

National: 88
Boston: 88 (N=1783)

National: 88
Boston: 86 (N=113)

National: 90
Boston: 89
Treatment Cascaded Comparison

SMILE National  SMILE Boston  Treatment Cascade

% of Cases LTC: 68  58  56
% LTC, with EIC: 88  86  56
% Cases EIC, RIC: 90  89  28
Barriers To Care
Services Trends

- Accepted
- Escorted
- Offered

<table>
<thead>
<tr>
<th>Service</th>
<th>Accepted</th>
<th>Escorted</th>
<th>Offered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transportation</td>
<td>80</td>
<td>20</td>
<td>60</td>
</tr>
<tr>
<td>Housing assistance</td>
<td>70</td>
<td>30</td>
<td>50</td>
</tr>
<tr>
<td>Financial Counseling</td>
<td>60</td>
<td>40</td>
<td>40</td>
</tr>
<tr>
<td>Food/meal assistance</td>
<td>50</td>
<td>30</td>
<td>30</td>
</tr>
<tr>
<td>Clothing</td>
<td>40</td>
<td>20</td>
<td>20</td>
</tr>
<tr>
<td>Insurance Assistance</td>
<td>30</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Child Care</td>
<td>20</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Other</td>
<td>10</td>
<td>5</td>
<td>5</td>
</tr>
</tbody>
</table>
Other Services Defined

Educational Support: 17
HIV 101: 2
Immigration Assistance: 4
Job/career: 5
Legal Support: 2
Relationship Assistance: 3
Identification Assistance (ID): 3
Group Support: 2
Utility Assistance: 2
Barriers To Care
Insurance by Type

- Medicaid: 30%
- Medicare: 7%
- Private Insurance: 25%
- Ryan White: 7%
- Unknown: 13%
- None: 18%
Services Trends

N=100 Encounters
Other Services Defined

- Educational Support: 43%
- Utility Assistance: 6%
- Group Support: 6%
- Identification Assistance (ID): 6%
- Relationship Assistance: 9%
- Legal Support: 9%
- Job/career: 6%
- Immigration Assistance: 6%
- HIV 101: 6%

N=40
Addressing Barriers to Care

smile
LINKAGE TO CARE

C2P BOSTON
Connect to Protect Boston
The SMILE LTC Program, while the main focus is the program, also has a research component within it. ATN 116 (Adolescent Medicine Trials Network) study seeks to utilize the existing Connect to Protect® (C2P) coalition infrastructure to address structural barriers that hinder the ability of HIV-infected youth to link to care and remain engaged-in-care.

Through the work of SMILE, C2P coalitions have added a focus on identifying and achieving structural change to improve linkage-to-care (LTC), engagement in care (EIC) and retention in care (RIC) outcomes for HIV infected youth.
Causes & Contributors of Risk

Macro Level
Racism, Stigma, Poverty, Gender Inequality, Homophobia, Transphobia

Structural Level
Resource Availability
Physical Environment
Organizational Systems
Laws/Policies

Community Level
Networks
Social Capital/Collective Relationships
Community Norms

Individual Level
Behavior
Attitudes
Knowledge
Perceptions
Biology

Individual Susceptibility
What is Structural Change?

- C2P defines structural change as new or modified programs, policies, and practices that are:
  - Logically linkable to HIV acquisition and transmission.
  - Can be sustained over time, even when key actors are no longer involved.
  - May directly or indirectly impact individuals.
  - Can also be changes to the physical structures of the built environment (i.e. abandoned buildings, poorly lit parking lots)
C2P Boston’s Commitment to Racial Justice and Health Equity

- Recognizing that young Black men who have sex with men and transgender-identified youth are most impacted by HIV in our city, C2P Boston committed to working through the lenses of health equity and racial justice to ensure that we address structural racism through our efforts.
Racial Justice

- Racial Justice ≠ Diversity
  - (Diversity = Variety)
- Racial Justice ≠ Equality
  - (Equality = Sameness)
- Racial Justice = Equity
  - (Equity = Fairness, Justice)
Racial Justice

**Definition:** Racial Justice is the creation and proactive reinforcement of policies, practices, attitudes and actions that produce equitable power, access, opportunities, treatment and outcomes for all.
Different Levels of Racism

MICRO LEVEL

Internalized

Interpersonal

MACRO LEVEL

Institutional

Structural
C2P Boston Mission and Goal

- The mission of C2P Boston is to identify, develop, and catalyze prevention strategies that will reduce HIV infection rates among young Black men who have sex with men and transgender-identified young people in the City of Boston. Racism (a system of advantage based on race that benefits White people) has a direct impact on these issues. We will ensure these strategies are always deliberate, inclusive, and in pursuit of racial justice through partnerships with organizations and individuals committed to our shared values and goals.

- Using a racial justice framework, our goal is to ultimately reduce HIV incidence and prevalence among Black youth and young adults in Boston, ages 12-24, through community mobilization and structural change.
So What Matters
Cut the red tape!!!
Providers are trusted

Our clients look for providers who look like them, talk like them, and someone the can trust (Eradicate the white coat syndrome.

This is were the Borum and SMILE shine
The Specialist Approach

- Every agency has a specialty. There needs to be a new cross-agency collaboration initiative to aid in our existing team approach to care.
NEWLY Diagnosed HIV+ Client

Medical Provider

Behavioral Health Clinician

Medical Case Manager

LTC Coordinator/Psychosocial Case Manager
The Sidney Borum Jr Health Center, affectionately known as the Borum, provides safe non-judgmental care for young people ages 12-29 years old who may not feel comfortable going anywhere else.
Patients Receiving Care at the Borum by U.S. Congressional District
N=1145

Legend
- Massachusetts Zip Codes
- U.S. Congressional Districts

Patients per zip code:
- 1-9
- 10-25
- 25-90
- 91-169
- 160-555
HIV+ Patients Receiving Care at the Borum by U.S. Congressional District

Legend
- Massachusetts Zip Codes
- U.S. Congressional District

Patients per zip code
- 1-3
- 4-9
- 10-16
Services Offered at the Borum

- Medical Care
- Women’s Health
- HIV testing & Counseling
- HIV Care
- Trans Health Care
- Birth Control + Emergency Contraception
- STD Testing + Treatment

Program of Fenway Health Since 2011
Clinic @ 620

In collaboration with the Sidney Borum Jr Health Center, the Clinic @620 is an RN run clinic that provides:

- Comprehensive sexual health assessment & STD counseling
- Rapid HIV Testing and 4th Generation Serum Testing
- Chlamydia, Gonorrhea, Syphilis and Hepatitis C screenings
- Referrals to behavioral health care, primary care, HIV prevention services, health insurance assistance, partner services
Youth Cultural Competency

- As providers we often ask for more training around Cultural Competency. Age is never a question. We often forget that clients 18-30 and sometimes 18-35 are in a different cultural generation from the provider.
Questions that youth may instantly ask themselves

- OMG is everyone here positive.
- I THINK that’s my cousin’s baby father’s little sister at the front desk.
- GOSH why is it taking so long?
- Will everyone know?
- What will they think of me?
- This is WAAAAY too much!
- They are going to judge me.
- I need to get out of here

"In Multicultural society like ours, the issue of belonging is especially important. One of the first issues for an adolescent walking through the door or even thinking about trying a community program is whether he or she can belong to this group of people"

-Eccles & Gootman
Location Matters

- Many clients do not feel comfortable with being exposed to well known HIV or LGBTQ facilities.
- Showing clients that they have options outside of your facilities shows clients you are truly client centered.
BAGLY is a youth-led, adult-supported social support organization committed to social justice, and creating, sustaining and advocating for programs, policies, and services for the GLBT youth community.

Leadership Development

Health Promotion

Social Support & Community Building

GLBT Youth Group Network of MA

The Clinic @620
Utilizing Existing Social Networks

- LGBTQ Youth Groups
  - BAGLY
  - MAP for Health (Mass Asian and Pacific Islanders)
- Organizations serving homeless youth
  - Youth on Fire
  - Bridge Over Troubled Waters
- Sexual exploitation survivors
  - My Life My Choice
- Ballroom Community
The Ballroom Scene

- Present in many urban cities in US
- Houses and Homes
- Family systems that provide safety and stability
  - “Nurturing Mothers” and “Fathers as Guides”
    - Setting expectations and goals for the “children”
- Events
- Prevention within Ballroom Scene
  - Sponsor categories about HIV/AIDS prevention
  - Free testing at events
  - Meeting with Mothers and Fathers of houses

Emily A Arnold and Marlon M Baily (2009)
## Statistics from The Borum

<table>
<thead>
<tr>
<th>Borum pts- HIV Outcome Measures</th>
<th>#Pts with HIV in past 3 years</th>
<th>Seroconversion in past 3 years</th>
<th>On ARVs</th>
<th>On ARVs &amp; virally suppressed</th>
<th>With an AIDS Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asian</td>
<td>* 33% 4.8%</td>
<td>* 33.3% 5.9%</td>
<td>* 66.7%</td>
<td>6.5%</td>
<td>* 66.7% 16.7%</td>
</tr>
<tr>
<td>Black or African American</td>
<td>* 57% 57.1%</td>
<td>* 57.1% 70.6%</td>
<td>* 81.0%</td>
<td>54.8%</td>
<td>* 28.6% 50.0%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>* 80% 19.0%</td>
<td>* 60.0% 17.6%</td>
<td>* 100.0%</td>
<td>16.1%</td>
<td>* 40.0% 16.7%</td>
</tr>
<tr>
<td>Unspecified</td>
<td>* 0% 0.0%</td>
<td>* 0.0% 0.0%</td>
<td>* 50.0%</td>
<td>3.2%</td>
<td>* 0.0% 0.0%</td>
</tr>
<tr>
<td>White</td>
<td>* 60% 14.3%</td>
<td>* 20.0% 5.9%</td>
<td>* 100.0%</td>
<td>16.1%</td>
<td>* 20.0% 8.3%</td>
</tr>
<tr>
<td>Multiracial</td>
<td>* 100% 4.8%</td>
<td>* 0.0% 0.0%</td>
<td>* 100.0%</td>
<td>3.2%</td>
<td>* 100.0% 8.3%</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>37 21 57%</td>
<td>17 46%</td>
<td>31 84%</td>
<td>12 32%</td>
<td>4 11%</td>
</tr>
</tbody>
</table>
Wrap Around Care at The Borum

- Behavioral Health
  - Psychiatry
  - Sexual health grant
  - Long term therapy
- Groups
  - Shades of Black
  - Substance Abuse
- Violence Recovery Program
Wrap Around Care at The Borum

- Medical
  - Transgender focused care including hormones
  - Sexual Health Care
  - High Resolution Anoscopy (Fenway Health)
- Patient Care Navigator
  - Insurance assistance
- Dental (Fenway Health)
- Eye (Fenway Health)
- SMILE
"Farmer said, 'The only non-compliant people are physicians. If the patient doesn't get better, it's your own fault. Fix it.'"

Tracy Kidder, Mountains Beyond Mountains.

Syndemic Theory

- Syndemic - The aggregation of two or more diseases in a population in which there is some level of positive biological interaction that exacerbates the negative health effects of any or all of the diseases.

- The crisis of HIV/AIDS currently affecting Black and Latino men is shaped by epidemics of substance abuse, trauma, incarceration, and poverty. These epidemics of disease and social conditions interact and propagate in a synergistic fashion; however, understanding the dynamic nature of these epidemics first requires considering their individual contributions to poor health outcomes among Black and Latino men.
Syndemic Theory

- “For many black and Latino men, substance use and sexual risk behavior may serve as a method for coping with the very social conditions that in par constitute the Syndemic (such as poverty or incarceration). For example, substance use and sexual risk taking behaviors among MSM have been describes as potentially serving adaptive functions through promoting cognitive escape.”

- “Psychological resilience is an important personal factor that can serve to protect Black and Latino MSM from the negative health outcomes associate with a Syndemic”
Syndemic Theory

- “Taken together, studies have suggested that in order to effectively reduce HIV among MSM, interventions need to address the multitude of Syndemic factors that affect different populations of MSM. These include social factors, such as forms of marginalization, which may contribute to excess disease burden among Black and Latino men compared to other populations.”

- “The Life experiences of Black and Latino men are shaped by the legacy of racism in the USA. Experiences of racism are related to health risk through a variety of physiological, psychosocial, and behavioral mediators”
Syndemic Theory

“There are many institutional and cultural practices shaped by the USA’s history of racism that perpetuate the marginalization of Black and Latino men and have been associated with other factors that serve to enhance the poor social conditions that make Black and Latino men disproportionately vulnerable to poverty, violence, incarceration, and trauma compared to other populations. Moreover, historical and contemporary racism and other forms of stigma reinforce societal notions that the negative outcomes experienced by Black and Latino men are consequences of personal choices and individual deficits, thereby limiting social and political capital to effectively intervene to change social conditions.”
LTC Case Scenario 1

- 22 year old black MSM w/recent syphilis diagnosis and AIDS diagnosis.
- Client is already receiving case management from an outside ASO.
- Mass DIS are now investigating the client.
- Client has a history of substance abuse.
What did we do?
LTC Case Scenario 1

- 18 year old black Hispanic transgender female from DR
- Presents seeking estrogen for medical gender transition
- Sex with men only
- Documentation is dependent on marriage to a female
- Housing and employment stable
- Baseline blood work for hormones reveals HIV positive status
What did we do?