Reaching Me: Identifying Barriers to Care That May Affect Families of Color with Diverse SOGIE Experiences AND Identifying Methods to Improve their Healthcare Engagement Moving Forward

STAR TRACK Adolescent Health Program, University of Maryland School Of Medicine Dept. of Pediatrics
We Are STAR TRACK:
We Are STAR TRACK

Many of us are:

Marylanders Natives
People of Color
LGBTQ/CIS-Hete mix
Mostly under the age of 35

We have various:

Educational backgrounds
Life experiences

We reflect the communities we serve.
Mission Statement

The STAR TRACK Program mission is to provide leadership in Maryland on adolescent HIV health issues by:

• Providing comprehensive, interdisciplinary, individualized and confidential health care to HIV infected and at risk adolescents and young adults;

• Providing youth-friendly health education, prevention, and early identification services to HIV infected and at risk adolescents, young adults, and their communities;

• Training and educating professionals from a variety of disciplines regarding care, research and prevention for HIV-infected and at-risk adolescents;

• Advocating on behalf of HIV infected and at-risk adolescents and their families;

• Facilitating collaboration among the many organizations in Maryland and in the region that provide services to HIV-infected and at-risk adolescents and their families; and

• Conducting research to contribute to the knowledge leading to improvement of health, risk reduction and reduction of HIV transmission.
Vision Statement

To become Maryland’s Center for Excellence in Adolescent HIV Care by charting new territory, fostering public and private partnerships and developing effective strategies to:

• Advocate for adolescents and their families; and
• Shape and influence public policy; and
• Meet the needs of communities at local, state and regional levels
Disclosures

• Mr. Hailey, Ms. Burton and Mr. Blue are employed by the University of Maryland, Baltimore (State of MD)

• Mr. Hailey is a Howard University doctoral student; on Maryland’s Health Department’s Transgender Response Team and the Men who have Sex with Men Response Team; and a member of John Hopkins University Center for AIDS Research Community Advisory Board

• Ms. Burton is member of Maryland’s HIV Planning Group, SAMHSA National LBTQI2-S Workgroup, and a Friend of Great Kids Farm’s board member
Agenda

• Introductions
• Basic Terms
• Intersectionality
• Community Barriers
• Shifts in Practices to Improve Engagement
• Wrap—up/Q & A
Learning Objectives

• Provide attendees with a basic understanding of the theory of intersectionality

• Review examples of historic trauma to gain a better understanding of the persistence of medical mistrust in some ethnic/racial communities

• Identify and discussion the legal and ethical considerations in utilizing created families in behavioral health interventions and services.

• Review other areas for change to support engagement
Terminology
Basic Terms

• HIV-Impacted/Impacted by HIV
  • People living with HIV and people at increase vulnerability for HIV acquisition

• Behavioral Transmission
  • People who acquired HIV via typical human behaviors (sex, needle sharing, etc.)

• Perinatal Transmission
  • People who acquired HIV while in the womb
Basic Terms

• Implicit Bias
  • Subconscious snap judgements we make concerning our environment or interactions with others. Research has shown that people associate negative characteristics with certain groups over others.

• Minority Stress
  • Psychological distress caused by the tension between minority and dominant groups within the social environment (interpersonal prejudice and discrimination). When routine distal and proximal stressors become chronic they cause hyperawareness, anxiety, and poor health outcomes.

• People of Color (POC)
  • People who do not identity as white/Caucasian. The term can be used to frame common experiences of systemic racism. The term can include those who as identify Latinx.
Basic Terms

- **SOGIE**
  - Sexual Orientation, Gender Identity and Expression

- **Sexual Minorities**
  - Anyone who does not identify as heterosexual

- **Sex**
  - Biological and physiological characteristics

- **Gender**
  - Socially constructed roles, behaviors, activities, and attributes on spectrum including, but not limited to masculine and feminine identities
Intersectionality
Origins


• Intersectionality is grounded in feminist theory

• It can help explain the additive effects of systematic oppression on marginalized populations
Definition

“The interconnected nature of social categorizations such as race, class, and gender, regarded as creating overlapping and interdependent systems of discrimination or disadvantage; a theoretical approach based on such a premise.”

-Oxford Dictionary
The Premise

“Intersectionality is a lens through which you can see where power comes and collides, where it interlocks and intersects. It’s not simply that there’s a race problem here, a gender problem here, and a class or LBGTQ problem there. Many times that framework erases what happens to people who are subject to all of these things.”

-Kimberlé Crenshaw, J.D. LL.M
Framework

• People are often disadvantaged by multiple sources of oppression

• Recognizes differences between peoples’ identities and how they may hold privilege

• Deficient-based not strength-based approach

There is no such thing as a single-issue struggle because we do not live single-issue lives.

- Audre Lorde
Basic Concepts

Privilege

• A right or benefit that is given to some people and not to others and is often rooted in/apart of a reward system

Microagression

• Are incidents, statements, or actions that is indirect, subtle, or unintentional discrimination against those labeled as “other”/members of a marginalized group
Basic Concept Definitions

Structural discrimination

- A power system which is dependent on seeing marginalized people as “the other”
- Structures discrimination harms people labeled as “the other” by preventing them from meeting their basic needs at the same level as those labeled “normal/privileged”
- It normalizes whiteness, cis-gender, and heterosexuality as the standard (not norm or majority, but the “goal”)
Discussion: Let's get interactive!!!

Are there spaces where you hold more power than others because of one or more of your idents?
How do you navigate these spaces?

Are there spaces where one of your identities affords your privileges and another is oppressed?
How do you navigate these space?

Are there spaces where a majority of your identities are oppressed/stigmatized?
How do you navigate these spaces?
Discussion: Let's get interactive!!!

Do you talk to your clients about:

- navigating these spaces/experiences?
- Code switching?
- Coping strategies for minority stress?
Effects of Systematic Oppression

Queer Youth of Color

1 in 3 LGBTQ people identify themselves as people of color.

- 48% of LGBTQ students of color have experienced verbal harassment based on their sexual orientation and their race or ethnicity.
- 15% have been physically harassed or assaulted based on both of these aspects of their identity.
- 13% are more likely for Black LGBTQ youth to be sent to detention or suspended than non-Black LGBTQ youth.

In their middle or high school years...

- 79% of LGBTQ youth of color reported that they had interactions with security or law enforcement, compared to 52% of white LGBTQ youth.

College Completion Rates

- Annual percent of Bachelors: 42% LGBTQ, 42% Non-LGBTQ
- Annual percent of Black: 25%

20-40% of all homeless youth are LGBTQ.

Among them...

- 26% identify as Latino
- 44% identify as Black

For more information, go to Transformational Change.

Infographic by Landini Pan

Sponsored by:ennial Scholars, The Williams Institute, and Center for American Progress.

#LeadingChange
Community Barriers
Community Barriers

What are some barriers your clients face?
- Individual level
- Family level
- Community level
- Population level

Can you think of any negative healthcare narratives you were taught growing up?
Community Barriers

Do you see medical mistrust as a primary barrier to enrollment and engagement in care?

How might medical mistrust present itself for your clients and their families?

Can you name some notable examples of why families of color with diverse SOGIE experiences may have medical mistrust?
Historical Context

1836 & 1840-1857
- Dr. James Marion Sims
  - Fatal neonatal tetanus experiments
  - Created a medical technique for repairing real genital
    injuries
  - “There was no time that I could not, at any day, have
    had a subject for operation.”

1854
- California’s Eugenics Sterilization Program
  - This procedure was disproportionately applied to Latinos
  - Immigrants of an undesirable type were targeted
  - Increased

1920-1945
- Henryetta Lack of Native American Cell
  - No consent was obtained to culture her cells
  - Her cells were never informed of what occurred

1932-1972
- Fentanyl in NYC Children
  - Murder Sinal and OCW experiments
  - Consideration of fentanyl in
    children with a diagnosis of attention deficit and
    disorder
  - Concern over informed consent and patient
    advocacy

1951, 1953-present
- Tuskegee Syphilis Study
  - Clinical study conducted by the U.S. Public
    Health Service and Tuskegee Syphilis Study,
    in which African American men were studied.
  - Led to the creation of the Belmont Report and Office of
    Human Research Protections

1993
- Johns Hopkins Kennedy Krieger Institute
  - Test lead levels in five groups of
    young children
  - Concern over risk levels to health

1964-1996
- Dr. Levy

2016
- Dr. Levy

#LEADINGCHANGE
Current Context

• Provider bias
  • Conduct Disorder and Oppositional Defiant Disorder *versus* Attention Deficit-Hyperactivity diagnosis for black youth
    • Mood disorder(s) = Disruptive Mood Dysregulation Disorder
Current Context

• Gender Diverse and Transgender Paradox
  • To gain access to appropriate services people must be diagnosed with a mental health condition
  • Causes additional stigma and can be a barrier to some accessing services
  • However, without medical documentation their request are seen as elective procedures
Minority Stress & Health Disparities

- Increased tobacco use
- Delayed or missed benchmark health screenings
- Lack of affirming substance abuse programs
- Am I a guinea pig?
Youth Developmental Task Can Be Impacted By Minority Stress

- Create meaningful peer relationship
- Develop new coping skills in decision making, problem solving, and conflict resolution
- Identify meaningful moral standards, values, and belief systems
- Adjust to sexually maturing bodies and feelings
- Understand and express more complex emotional experiences
- Establish key aspects of identity
- Establish autonomy and renegotiate relationships with adults in parenting roles
Shifts in Practices to Improve Engagement
But, I’m not racist or LGBT-phobic

Groups who frequently experience discrimination are reasonably suspicious of service providers

- Some clinicians are prejudiced.
- Some providers are ignorant to the unique needs of different populations.
- The healthcare field has a known history of abusing people of color, LGBTQ folks, women, people with disabilities, youth and other marginalized groups.
- It’s especially hard to brave when navigating an intimidating care system if you are sick, worried about your health, or distress.
- Anticipating and accommodating extra sensitivity to slights (even perceived slights) is best practice as a provider.
Create LGBTQ Friendly Spaces

• Ask for gender pronouns
• Promote gender neutral bathrooms
• Accommodate fluidity of gender and sexuality in paperwork
• Build and maintain partnerships with LGBTQ organizations
• Broaden your viewpoint and educate others
Create POC LGBTQ Friendly Spaces

Understand:

- Images of diverse families
- Create policies to engage with created/nontraditional families
  - LGBT families
  - Non-guardian caregivers
- Know culturally affirming resources in your community (& the web)
- Recognize Juneteenth (& other holidays/celebrations POC may have)

Have:

- Images of diverse families
- Create policies to engage with created/nontraditional families
  - LGBT families
  - Non-guardian caregivers
- Know culturally affirming resources in your community (& the web)
- Recognize Juneteenth (& other holidays/celebrations POC may have)
Rules to Engaging Created Families in Care

• Use traditional enrolment practices (legal guardian)
• After screening family member(s) affirm that consumer has the right to CHOOSE what is shared
  • Encourage allowing access to show rates for clinic
  • Clinical show rates vs. prescriptions
  • Prescription directions vs. treatment plans
Rules to Engaging Created Families in Care

• Make sure that ALL staff (front desk staff, clinicians, etc) are informed about the involvement of the created family in the consumer’s life

• Have methods of engagement that do not include disclosing mental health status
  • Advertise game or movie nights
  • Health insurance information center/community service fair
  • Legal advice night
  • Job services/navigation night
Documentation

• Release of information forms
  • Who, what, how?
  • Face-sheet for chart

• Clear boundaries
  • HIPAA
  • Initially only show rate

• Bi-annual updates
  • Plans for how to inform clinic of changes
  • Reassess who has access

• Documentations/Chart
  • Information shared with families should have its own section in charts
Additional Advice for making your clinic more POC friendly

• Some of the staff members should look like the communities you serve (not just housekeeping)

• Engage all staff in cultural competency training, especially around effective communication

• If you don’t understand something, ASK RESPECTFULLY

• RESPECT, RESPECT, RESPECT
Making your clinic more youth friendly

• Employ young people as a part of your Community Advisory Board (CAB)
  • Creates opportunities for youth development (on resumes)
    • Use Youth MOVE National’s stipend guidelines
  • CABs can:
    • Think of social marking ideas
    • Tell you wants turns them off
Embrace Good Community Practices

• Develop a statement of affirming polices and procedures
• Align your organization with other affirming agencies
• SHOW UP
  • At other agencies events
  • At community driven events
  • Non-traditional work hour events (don’t complain when things start late)
• Support legislative change
  • Encourage clients to vote
• Support client development beyond your services
Always keep in mind.

- Members of these communities have been marginalized and powerless in our society for as long as they can remember
- Seek to re-empower youth by allowing them to make choices about their care whenever possible
- Always make it clear that the consumer’s needs are the utmost priority, and they are leading their care and treatment
Remember: Intent vs. Impact
Reference List


Reference List


Questions, Comments, Ah-ha?!

Whitney Burton, M.S.W, M.P.H,C.P.H  
Program Manager  
Wburton@som.umaryland.edu

Jamal Hailey, M.A.  
Director of Programs  
Jhailey@som.umaryland.edu

Alex Blue, B.A  
EIS Coordinator  
Ablue@som.umaryland.edu

STAR TRACK Adolescent Health Program  
University of Maryland School of Medicine