2018 NATIONAL RYAN WHITE CONFERENCE ON HIV CARE & TREATMENT

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Advancing Health Equity through Community-Based Participatory Research

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Objective

- Paradigm Shifts
- Define Community Based Participatory Research (CBPR)
- Plan and implement key concepts of CBPR
- Practice positionality awareness
- Establish protocols for “full and equal engagement”
- Evaluate

Paradigm Shifts

- Overarching framework
- Epistemology, methodology, and political
- Critical
- Positivist and Post-Positivist

Agenda

Racial Disparities

- Epidemiological Data
- Care Continuum

Strategies

- Community Engagement
  - Guiding Principles
- Integration of Cultural Responsiveness Standards
- Formalizing roles of clients, grant recipients, sub-recipient, Council, community leaders

Disparities

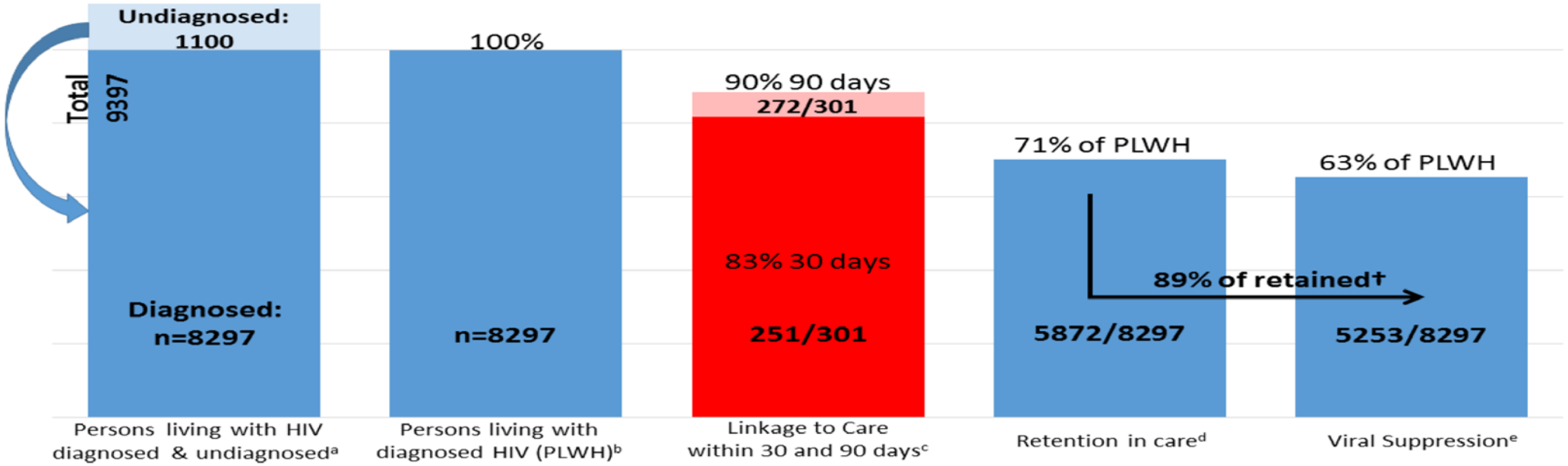
Differences in health outcomes that are linked with systematic economic, social, or environmental disadvantages based on race/ethnicity, religion, socioeconomic status, gender, age, or mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion.

Identifying Disparities

Data Source

- Populations
- Surveillance
- Care Continuum
- CLD

Percentages of Persons with HIV Engaged in Selected Stages of the Continuum of Care, 2016



[a]Defined as persons undiagnosed (estimate 1,100 (570-1,500), 95% CI) and persons diagnosed (n=8297) aged 13 or more with HIV infection (regardless of stage at diagnosis) through year end 2015, who were alive at year end 2016.

[b]Defined as persons diagnosed aged 13 or more with HIV infection (regardless of stage at diagnosis) through year end 2015, who were alive at year end 2016.

[c]Calculated as the percentage of persons linked to care within 30 and 90 days after initial HIV diagnosis during 2015. Linkage to care is based on the number of persons diagnosed during 2015 and is therefore shown in a different color than the other bars with a different denominator.

[d]Calculated as the percentage of persons who had ≥1 CD4 or viral load test results during 2016 among those diagnosed with HIV through year end 2015 and alive at year end 2016.

[e]Calculated as the percentage of persons who had suppressed viral load (≤200 copies/mL) at most recent test during 2016, among those diagnosed with HIV through year end 2015 and alive at year end 2016.

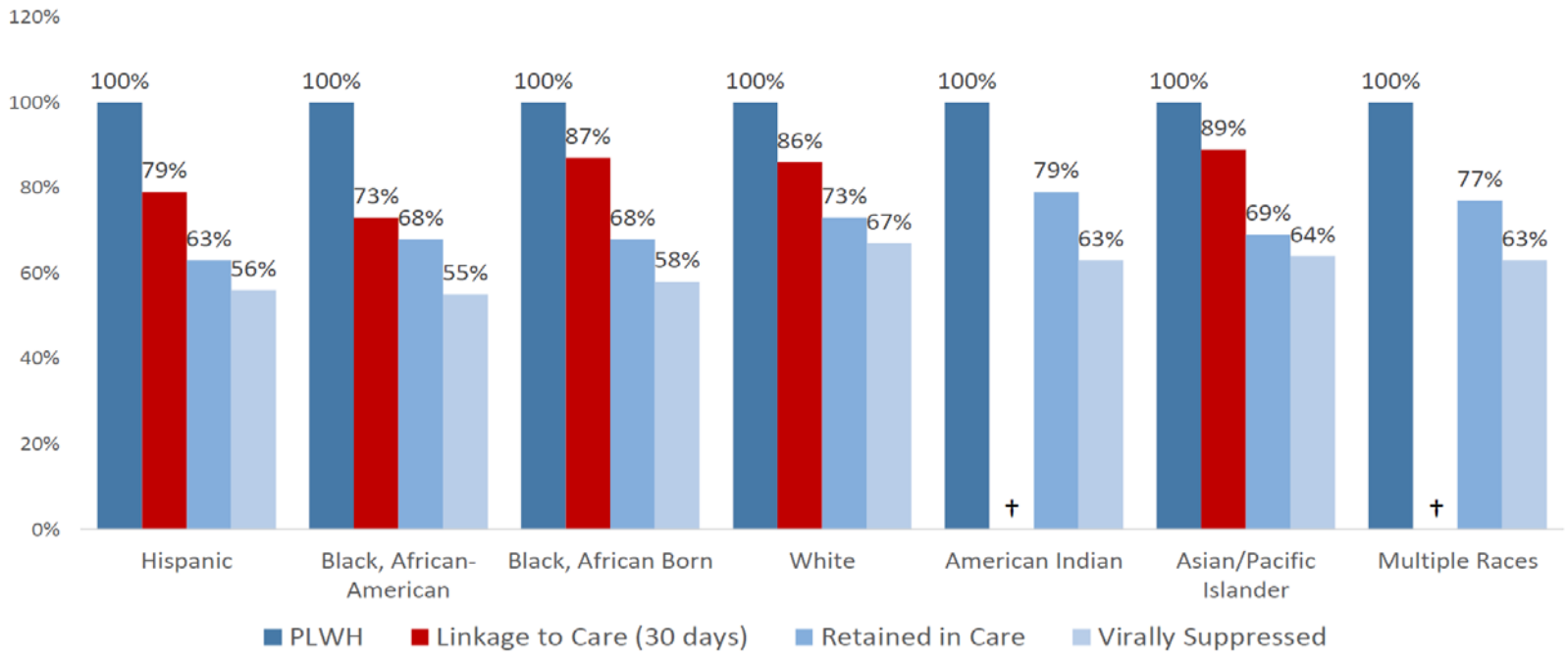
†Calculated as number of persons who had suppressed VL (≤200 copies/mL) at most recent test during 2016, among those who were retained in care during 2016 (5,253/5,872).

DEPARTMENT OF HEALTH

www.health.state.mn.us/hiv
07/20/2017
To obtain this information in a different format, call: 651-201-5414

Identifying Disparities

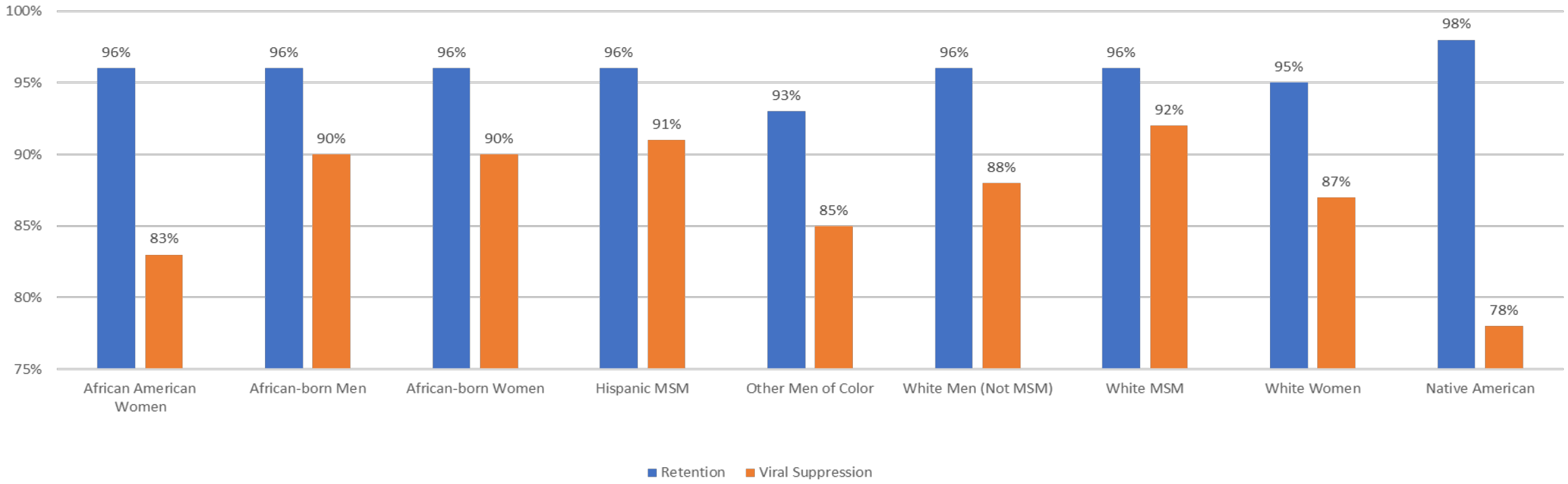
Percentage of persons diagnosed with HIV engaged in selected stages of the care continuum, by race – Minnesota (2015)



† Not reportable, <5 in population

Race	Percentage retained in care	Percentage Linked to care in 30 days	Percentage retained in care	Percentage virally suppressed.
Hispanic	63	79	63	56
Black, African American	68	73	68	55
Black, African born	68	87	68	58
White	73	86	73	67
American Indian	79	Not Reportable	79	63
Asian/Pacific Islander	69	89	69	64
Multiple races	77	Not reportable	77	63

Identifying Disparities



Health Equity

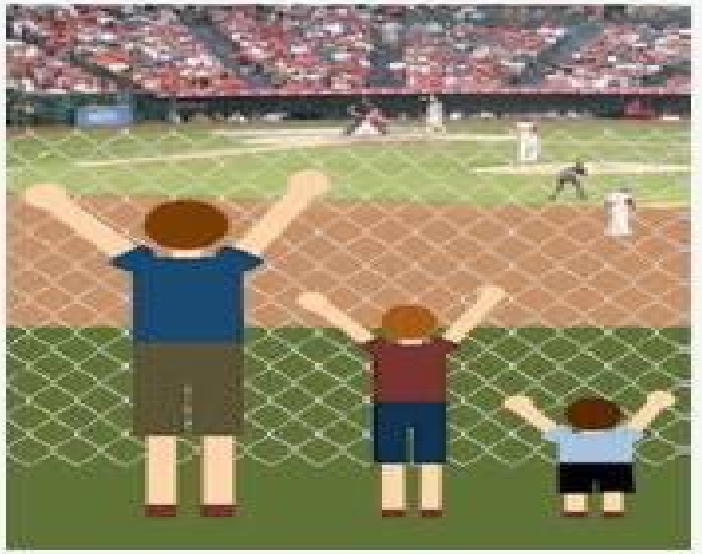
When every person has the opportunity to realize their health potential — the highest level of health possible for that person — without limits imposed by structural inequities or conditions.

Health Equity

EQUALITY VERSUS EQUITY

In the first image, it is assumed that everyone will benefit from the same supports. They are being treated equally.

In the second image, individuals are given different supports to make it possible for them to have equal access to the game. They are being treated equitably.



In the third image, all three can see the game without any supports or accommodations because the cause of the inequity was addressed. The systemic barrier has been removed.

Health

Health is the state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.

- World Health Organization

Source: http://who.int/about/definition/en/print.html

Strategies

- Community Engagement
- Integration of Cultural Responsiveness Standards
- Formalizing roles & responsibilities

Community Engagement

"Community engagement and service learning is about what we do with, not for or to, communities."

Tania Mitchell, PhD
Assistant Professor University of MN

Guiding Principles

- Community-based participatory research (CBPR) - emphasis on joining with the community as full and equal partners in all phases of the research process (Holkup et al, 2004)*
  - Positionality
  - Diversity
    - Respectful of Differences
    - Diversity- An Asset
    - Beyond Reflectiveness

Guiding Principles

CBPR Model

- Partnership
- Equitable Involvement
  - Recognizes the resources and capacity of academic and community (Hacker, 2103)
- Shared Decision Making
- Ownership
- Increase Knowledge and Understanding
- Integrate/operationalize

Preparation

- Offer Framework
- Provide Data
- Draft PH Goals and Objectives
- Manage Expectations

Guiding Principles

Positionality

- Power and Empowerment
  - Power, Privilege and Participation
  - "level the playing fields"
    (Wood & MacTeer, 2017)
- Step Back

Guiding Principles

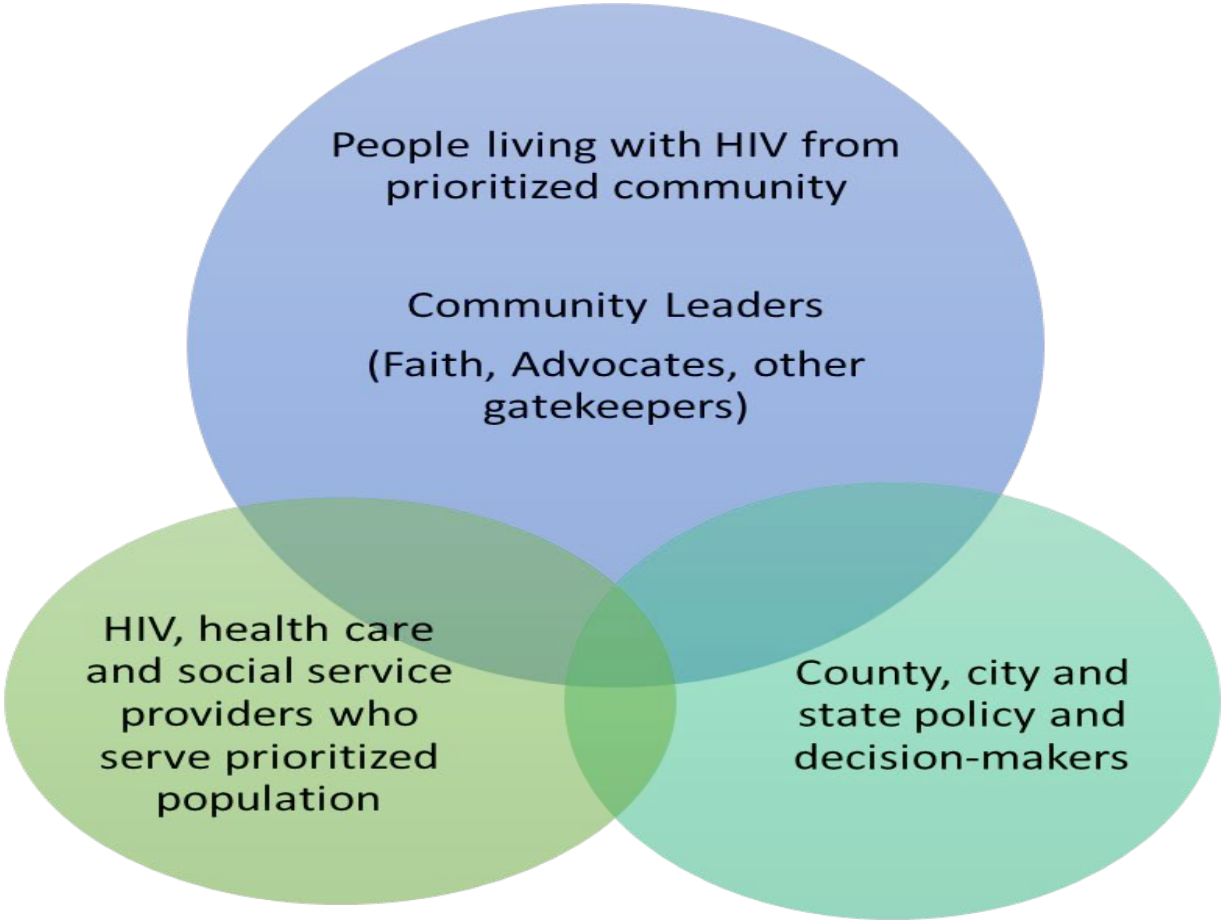
Equifinality

- End state can be reached by many potential means

Guiding Principles

- Diversity
  - Valuing of Differences
  - Diversity- An Asset
  - Beyond Reflectiveness

Community Engagement



Community Engagement

Community Engagement

African American Same Gender Loving Men

African-born Faith Leaders

West African Task Force

Latinx Gay/Bi Men and Transgender Women

Native American

African American SLG Men

Tyrie Stanley, Council Co-Chair

History

- Spring, 2016
- Began with 10. Average 15. (10-30)
- Frequency Monthly
- Tasks focused sub-groups

African American SLG Men

Accomplishments

- Strategic Plan
- Co-chairs elected
- Roles and responsibilities
- Code of conduct
- Voting Rights & Memberships

African American SLG Men

Accomplishments

- The League of Extraordinary Black/SGL Men
- Identified systems gaps
- Accomplishments
  - Council Engagement
  - Pilot Project
- Lessons Learned

African American SLG Men

Lessons learned

- Managed expectations
- Structure
- Defined timeline and milestones

African American SLG Men

Continuations

- Improve intercultural communication
- Continue partnership & community engagement
- Involved with Disparities Elimination Committee

African Faith Leaders

Culturally Responsive Sexual Health Assessment

HIV 101- Curriculum

HIV 201- Sensitive Personal Issues

- Prevention & Care
- ABCs of prevention, PEP, PrEP

HIV 301 – Eradicating Stigma

African Faith Leaders

Education exchange

- Stigma
- Spiritual writings, local sayings, beliefs about HIV
- Intersectionalities

36 Christian and 18 Muslim Faith Leaders

West African Task Force

- **Develop a West African community level action plan that**:
  - Includes culturally responsive campaigns to increase community HIV awareness and access to prevention and care services,
  - Identifies community organizations with the capacity to conduct the campaigns,
  - Determines resources needed to conduct the campaigns,
  - Reduces community and individual level HIV stigma by increasing HIV knowledge, and decreasing negative attitudes towards people living with HIV and those at risk, and
  - Increases HIV testing among West African community members.

West African Task Force

- **Preparation and stakeholder engagement**. Preparation for the conference requires the engagement of all stakeholders, both individually and collectively, to define what is to be achieved from the conference and to ensure the best desired outcomes.
- **Conference planning meetings and logistics.** Conference work groups were created to focus on the logistics which include: location, technology prep, agenda, and conference materials.

West African Task Force

- **The conference.** The meeting of community leaders and stakeholders to engage the community to reduce HIV health disparities and stigma.
- **Post-conference report and evaluation.** Develop notes and documents which reflect the outcome of the conference and the action plan for future strategic engagements developed during the conference.
- **Post-conference convening**

Latinx Gay/Bi Men

- Social Media/Grndr
  - Survey
  - Interviews
  - Analysis
  - Results

Latinx Gay/Bi Men

Grindr Survey Round One Summary:

36 people who came in for testing/PrEP linkage

22 who decided to go forward with PrEP

23 people participated in interviews

5 were linked to care through that interview

Resources

- Office of Minority Health
- Community Leaders
- Providers
- Scholars

Culturally Responsive Standards

- CLAS
- Staff Qualifications & Training
- Assessment & Evaluation

Culturally Responsive Standards

Assessment & Evaluation

4.1 Complete the provider self-assessment of cultural responsiveness as an organization every other year

4.2 Collect and maintain client utilization outcomes data that indicates:

- Numbers and demographics of clients who are receiving each funded service,
- Communities or populations that are underutilizing services,
- Disparities in HIV related client-level health outcomes
- If the population served changes, determine how the agency will adapt to be responsive to the cultural needs of the new population.

Culturally Responsive Standards

Assessment & Evaluation

4.3 Conduct annual client/community input through an anonymous survey that allows

providers to collect and evaluate client feedback to improve culturally responsive service delivery across all services

- Providers can utilize their organization's community advisory board (CAB) to review the results of the annual client survey and provide recommendations to be included in the quality improvement plan based on the responses
- If an organization does not have a CAB or is unable to utilize their CAB, providers can conduct the review of the annual client survey and provide recommendations

Culturally Responsive Standards

Assessment & Evaluation

4.4 Goals for ongoing improvement in cultural responsiveness in an annual quality improvement plan that will include as needed:

- Where the assessments indicate a deficiency in cultural responsiveness, strategies to address the deficiency,
- If the client population is not reflective of communities disproportionately affected by HIV, identify community engagement strategies to reach these populations,
- If the population served changes, determine how the agency will adapt to be responsive to the cultural needs of the new population.

Integrate (RFP example)

- **Agencies applying for Culturally Appropriate, MAI, and Disproportionately Affected Communities funds (only calculated for applicants for these funding designations)**

Total Points ___ ***(out of 50 possible)***

Target population is clearly defined.

Cultural barriers to services are clearly identified and strategies employed to mitigate such barriers are realistic.

Agency involves the target population in defining, implementing, and evaluating services.

Agency meets Additional Agency Requirements in Section D. “Proposer Qualifications”

Integrate (RFP pre-work)

- Continuous Community Engagement
- Community Assessment
- Capacity Building

Evaluate

- Engagement & Retention
- Goals & objectives
- Strategic Plans

Discussion

Thank you

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