



VIRTUAL
2020 NATIONAL
RYAN WHITE
CONFERENCE ON
HIV CARE & TREATMENT

Engaging Transgender Persons in HIV Primary Care: Best Practices from a Community Collaborative

Deja Lynn Alvarez, Helena Kwakwa

Overview



- Background
 - Terminology
 - Epidemiology of HIV in transgender populations
 - Barriers to care
- Systems collaborations
- Successes
- Challenges

Background

Terminology

- Gender/gender identity
 - Internal sense of self and how they fit into the world, from the perspective of gender
- Gender expression
 - The outward manner in which an individual expresses or displays their gender
- Sexual orientation
 - Describes sexual attraction only, and is not directly related to gender identity

- Transgender
 - Gender identity differs from the sex that was assigned at birth
 - Transgender man: male gender identity and a female birth assigned sex
 - Transgender woman: female gender identity and a male birth assigned sex
 - Non-transgender: may be referred to as cisgender
- Gender nonconforming
 - Gender identity differs from that which was assigned at birth, but may be more complex, fluid, multifaceted, or otherwise less clearly defined than a transgender person (genderqueer)

Epidemiology of HIV among transgender persons

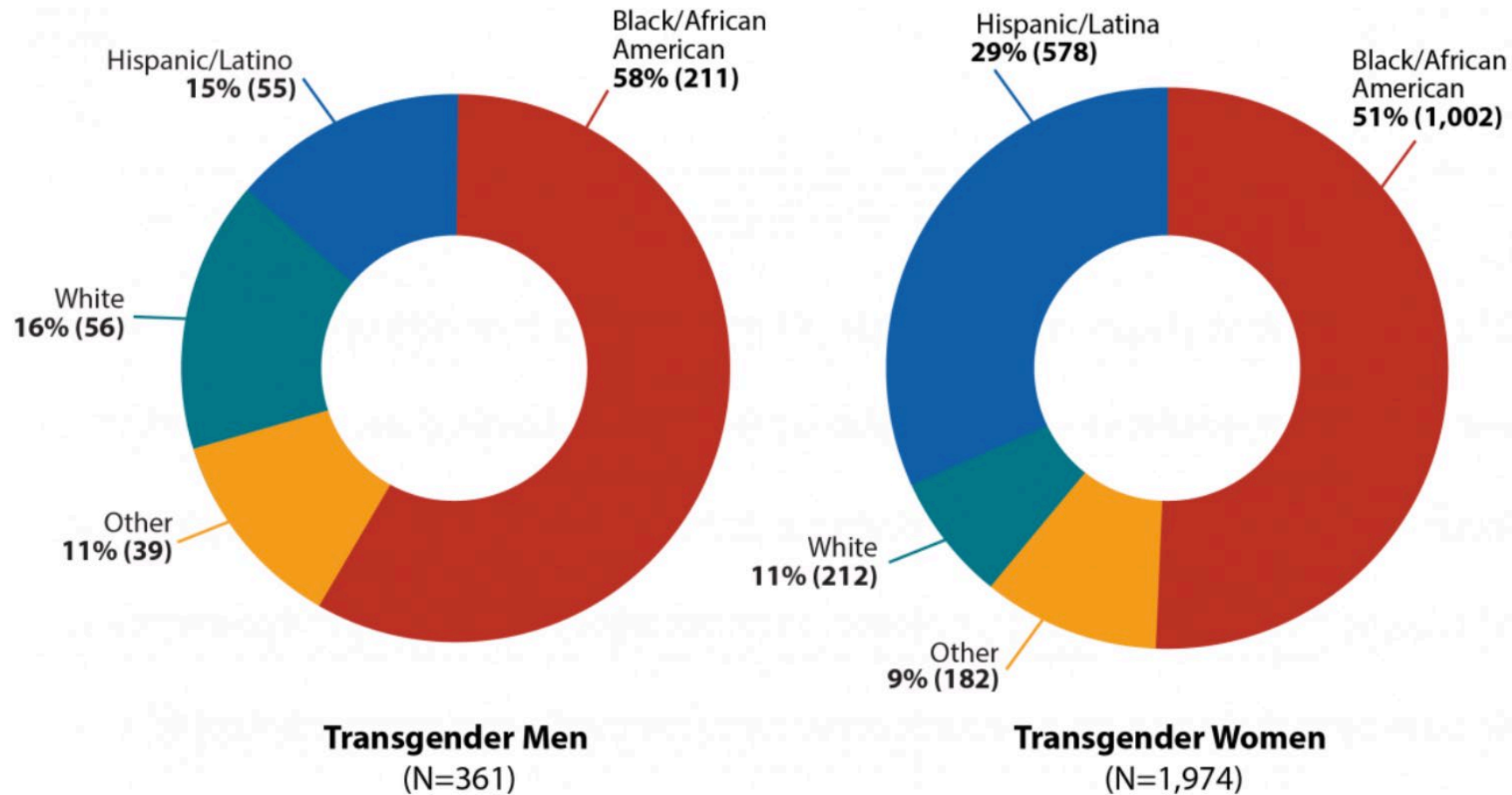


- Nearly 1 million adults in US are transgender
- 2009-2014, 2351 transgender persons were diagnosed with HIV
 - 84% women, 15% men
- 44% Black transgender women have HIV
 - 26% Latina transgender women
 - 7% White transgender women

HIV diagnoses among transgender persons by race/ethnicity, 2009-2014



VIRTUAL
2020 NATIONAL
RYAN WHITE
CONFERENCE ON
HIV CARE & TREATMENT



Clark H et al. *AIDS Behav* 2017;21(9):2774-2783

HIV in transgender persons



- Transgender women have 49 times the odds of HIV infection compared with other groups
 - Particularly pronounced for Black transgender women
- TGW with HIV less likely to receive ARV
- TGW on ARV may show lower levels of adherence
 - SF study showed VL 3 times as high in trans women as in others
- Report less confidence in ability to integrate treatment regimens into daily lives
- Report fewer positive interactions with health care providers
- Paucity of data on trans men

1. Melendez R, et al. American Journal of Public Health. 2005;95:5–7. 2. Sevelius J et al. Journal of the Association of Nurses in AIDS Care. 2010;21(3):256–264. 3. Das Met al. PLoS One. 2010;5(6):e11068.

HIV in transgender persons



- Risk of HIV is not about identity, but exposure
- Transgender men (2012-2015)
 - 6 prevalence studies
 - 1 study with self-report HIV data: 0.4%
 - 5 studies with laboratory confirmed HIV: 0.5% to 4.3%
- Transgender women (2012-2015)
 - 10 studies
 - 7 studies with self-report HIV data: 2.0% to 30%
 - 3 studies with laboratory confirmed HIV: 35% to 41%
- Transgender women who have sex with men have the highest HIV burden of any key populations
 - Rate of HIV in transgender men who have sex with men is increasing

RWHAP: Comparison of viral suppression among transgender persons

Viral Suppression among Transgender Adults and Adolescents Served by the Ryan White HIV/AIDS Program, 2018—United States and 3 Territories^a

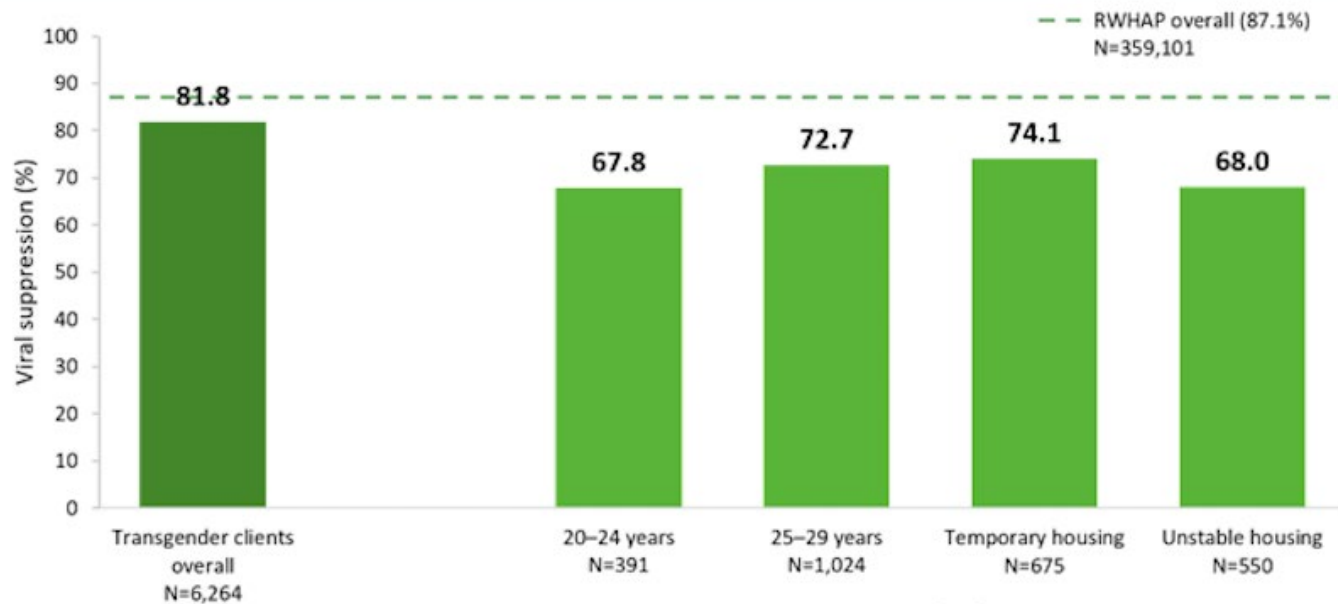


Image credit: [HRSA HIV/AIDS Bureau, RWHAP Annual Client-Level Data Report, 2018](#)

Intersectional nature of marginalization for trans persons living with HIV



- Disparities not limited to healthcare
 - Education
 - Housing
 - Employment
 - Incarceration
- Disparities exist in exposure to violence
- Lack of family support not uncommon for transgender persons
- Global transgender community in US with experiences of marginalization and terror

Top health care needs of transgender women



- Gender-affirming and non-discriminatory care
- Hormone therapy and side effects
- Mental health care, including care for trauma
- Personal care, such as nutrition
- ARV and side effect management
- If a primary care provider was a hormone prescriber, transgender women were 3 times more likely to have an
 - Undetectable viral load
 - HIV primary care visit in the previous 6 months

Barriers to care for transgender persons living with HIV



- “Siloing” of services
 - Prioritization of non-HIV-related services when offered separately from services deemed more essential
- Stigma
 - Intersectional (gender identity, race, SES, HIV . . .)
- Life instability
 - Lack of support
- Substance use

Systems Collaborations

Setting – Ambulatory Health Services



- 8 FQHC and FQHC look-alike facilities
- In the neighborhoods of Philadelphia
- Each center has an HIV Clinic
- Each center conducts HCV testing
- Each center offers MAT
- Each center has on-site Behavioral Health Counseling

Project objectives



- Improve trans friendliness of health centers
- Improve quality of care for trans persons
- Improve comprehensiveness of medical care

Establishing a task force



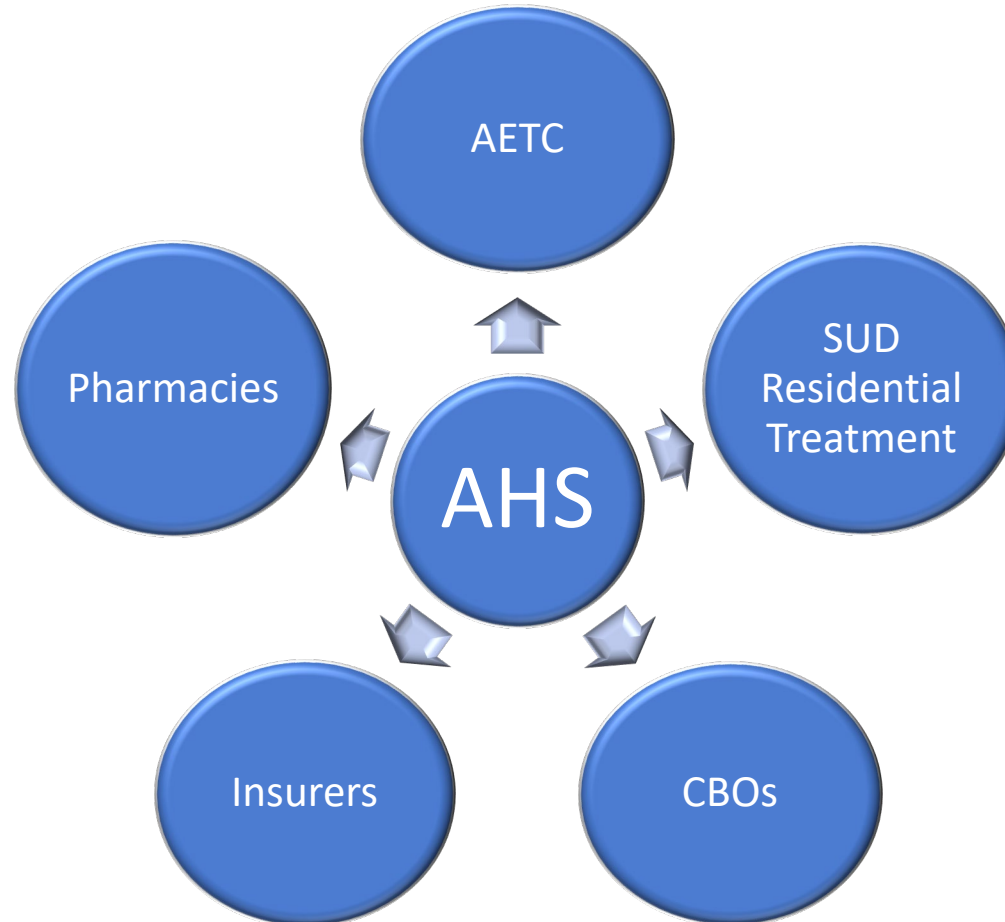
- HIV clinicians
- HIV Program outreach worker
- Medical Case Manager
- Transgender women from the community (replaced midstream due to personal circumstances)
- HIV Program Director

Findings of task force



- Language used in intake materials not inclusive
- EMR categories not inclusive
- Gender-affirming hormones not on formulary at on-site pharmacies
- Staff not well-trained in specific nuances of serving trans populations
- No trans representation on staff

Systems engaged



Starting at home - AHS



- Staff
 - HIV Program staff
 - General health center staff
- Behavioral Health Counselors
- Medication-assisted treatment
- Existing resources (Social Work, Insurance navigation, access to manufacturers' assistance programs, legal support)
- Semi-annual data analysis to identify disparities in outcomes

Trans representation



- A transgender woman was hired as staff for a specific project
 - Other LGBTQ persons were already on staff
 - She has enduring ties with local law enforcement, advocating for trans persons and conducting training to improve quality of interactions with trans persons/communities
- She helped assess health center processes
 - Helped develop a training curriculum for health center staff
 - Helped conduct training
- Not deployed to HIV testing and prevention team

- Training conducted for staff in various roles, clinical and non-clinical
 - Smaller groups at the health center level
 - Large groups
 - LGBTQ panelists/trainers with experience as patients at the health centers or other local sites
 - CE credits provided
 - Integrated into ongoing continuing education series
 - Coordinated by local performance site of AETC
 - >90% staff participation in training series

Staff training (cont'd)



- Staff trained to ask about preferred pronouns, names
- Staff trained to
 - “See something, say something”
 - “Hear something, say something”

- Basic history and physical
- Conducting an organ inventory
- Managing hormone therapy
 - Managing patient expectations of hormone therapy
 - Asking about utilization of non-prescribed therapies, non-medical body modification
- Screening for IPV, trafficking, other violence
- Trauma-informed care
- Non-judgmental, non-voyeuristic
- 100% of clinical staff participated in training series

Supporting clinical care



- Internal protocols developed based on WPATH clinical guidelines
- List of preferred providers for gender reassignment surgery
 - From experience
 - Patient feedback
 - Direct contact at office
 - List of documents required by each provider for consultation and for procedures
- Community providers for inexpensive assistance with name change identified
- Monitoring legislative changes that may impact population

- Identified requirements of each insurer for
 - Authorization of hormone therapy
 - Authorization of gender reassignment surgery
 - Authorization of other surgical procedures

- Local pharmacies identified with HIV experience
 - Willingness to stock commonly used hormones and other meds
 - Willingness to offer meds (not on formulary at AHS) at reduced cost to uninsured patients
 - Maintain communication with care teams
 - Offer delivery services when needed

Inclusive language



- Included transgender categories on system-wide intake pages/screens
- Several iterations of including preferred names
 - Including preferred name in parentheses
 - Including preferred name on a separate line
 - Calling patients by last name (all patients)
- Asking patients preferred pronouns and documenting this information

SUD residential treatment



- Local residential treatment provider identified with new facility especially for trans persons
- Psychologists and Psychiatrist on staff
- Coordinate hormone treatment with staff
- Coordinate post-discharge medical care with staff
- Contact person helpful

Community-based organizations



- Identified local CBO with various services
 - Food bank
 - Drop-in center
 - Behavioral health
 - Immigration services
 - Weekly support group for yrans person
- Worked with them to administer hormone injections for those requesting it
 - Accept med deliveries for specified patients

Housing



- Local organization providing temporary housing for LGBTQ persons in need
- Local residential SUD treatment organization opening new facility specifically for LGBTQ persons

Outcomes



- Tripling of trans patients seen in health centers in 1 year
 - Doubling of trans patients for HIV prevention
 - Increase was greatest in the 2 centers where gender-affirming hormone therapy was offered on site
- Significant word-of-mouth referrals within community
- Satisfaction with treatment improved by 120%

- Met objectives
 - Improved trans friendliness of health centers
 - Improved quality of care for trans persons at health centers
 - Improved comprehensiveness of care for trans persons
- Improved treatment satisfaction
- Increased access to care for transgender persons with and at risk for HIV
- Identifying partner agencies willing to take this journey with us or lead us on this path . . .

Challenges



- Setback – loss of transgender woman on the task force early on in the project
- Limited data on best practices, needs of population
- Shifting deeply held paradigms
 - Both staff and patients must be prepared for well-meaning “relapses”
- Staff must be ready to take on advocacy role
- Changing legislative landscape presents a challenge



VIRTUAL
2020 NATIONAL
RYAN WHITE
CONFERENCE ON
HIV CARE & TREATMENT

Engaging Transgender Persons in HIV Primary Care: Best Practices from a Community Collaborative

Helena Kwakwa, Deja Lynn Alvarez