**Report:** Identification and Reporting of Gender Identity Among Individuals Diagnosed with HIV in the Deep South

**Presenters:**
- Susan Reif, Duke Center for Health Policy & Inequalities Research
- Carolyn McAllaster, Emerita Duke Law
- Marissa Miller, TransSolutions LLC
Why this Research?

- Underreporting gender identity in HIV Surveillance
- Importance of accurate gender identity data in HIV surveillance
- HIV epidemic in the transgender community in the US/Deep South
Study of gender identity data collection in HIV surveillance in the Deep South

- **Interviewed** leadership staff at Deep South state offices of epidemiology

- **Reviewed** state HIV surveillance reports & literature

- **Interviewed** CDC HIV surveillance leadership
Research Findings

• CDC had not reported gender identity in HIV surveillance data due to incomplete reporting from states until the most recent report.

• States inconsistently collecting and reporting gender identity in state surveillance data:
  • Data not consistently presented across states
  • Less than 1% of individuals diagnosed with HIV reported as transgender in most states
Research Findings

Substantial barriers reported to the accurate collection of gender identity data:

• Inconsistent collection of information at testing

• Lack of consistent data collection methods

• Lack of gender identity information in medical records

• Lack of cultural sensitivity and knowledge around gender identity care and testing providers

• Discomfort in revealing gender identity
Diagnoses - 2018:
- Transgender MTF accounted for slightly more than 1% of annual HIV diagnoses
- Transgender FTM accounted for less than 1% of annual diagnoses

Prevalence 2014 through 2018:
- The largest increase (24%) in the number of PLWH was among transgender MTF.
- Transgender MTF, transgender FTM, and Additional Gender Identity (AGI) each accounted for less than 1% (10,535 total in 2018) of PLWH

CDC Caveat: Please use caution when interpreting data for FTM and AGI, as the numbers are small.
• Federal Government should provide TA & financial help to states to improve data collection mechanisms;
• Increased federal funding to support gender identity cultural sensitivity training for health department staff and other providers;
• CDC should develop formal guidance and TA targeting labs and other medical systems to develop systems to collect gender identity data;
• CDC should establish benchmarks for completion of gender identity information in national reporting no later than 2023.
Intersection of racial inequalities and gender identity reporting

- Layered stigmas of race and gender identity

- HIV prevalence higher in black community of transgender experience

- Lack of identification and documentation of HIV in these communities leads to inaction to address the needs for care and prevention
Barriers/Advocacy

• Marissa Miller:
  • Barriers in the trans community to accurate reporting of gender identity information.

• Carolyn McAllaster:
  • Discussion of advocacy and next steps
Questions/Feedback?

• Susan Reif: reif@duke.edu
• Marissa Miller: marissamiller81@yahoo.com
• Carolyn McAllaster: mcallaster@law.duke.edu

• Find the Report at: https://southernaidsstrategy.org/HIVPolicy/