

**New York State Ending the Epidemic  
Women’s Advisory Group  
IMPLEMENTATION STRATEGIES  
January 2018**

**WOMEN’S ADVISORY GROUP**

In June 2017, the New York State AIDS Institute (NYSDOH AI) convened a women’s advisory group to address the various priority areas in the Ending the Epidemic (ETE) Blueprint. The advisory group engaged women from across the state with expertise in HIV, sexually transmitted infections (STIs) and Hepatitis C (HCV) prevention and care, consisting of decades of experience providing medical and mental health care, social services, peer services, research, community planning and policy advocacy. Our group’s work involved discussions, presentations from service providers, AIDS Institute colleagues and guest speakers, and extensive review of research, policy, epidemiological data, and all ETE Blueprint recommendations. Our group also built upon the recommendations of a prior women’s ETE workgroup. The recommendations were invaluable in assisting with the development of ETE recommendations specifically for women and girls.

Our advisory group developed a matrix tool to guide our work. It was used to direct our meeting agendas, identify guest speakers and review policy recommendations. We also examined several other ETE advisory group implementation strategies with the understanding that the issues related to women and girls intersect various key populations and issues. As such, we support our colleagues and commend their work developing their various advisory group recommendations.

Policies, strategies and resources must be directed to address the complex HIV, STI and HCV prevention and care needs of women and girls, addressing psychosocial factors, such as poor health care, poverty (i.e. inadequate housing, food insecurity, survival sex work, etc.), inequality, mental health needs, and geographic disadvantage, which amplify HIV risk. According to the NYS ETE Blueprint, **“New and innovative, as well as tried and true, evidence-based models of prevention, care and supportive services must be deployed to address these contextual issues and support women in achieving and maintaining optimal health outcomes.”**

The Women’s Advisory Group identified a series of implementation priorities, in alignment with The Blueprint’s priority areas, as being essential to ending the epidemic for diverse populations of women and girls in New York State. Included below are our recommendations.

## **WOMEN AND HIV, SEXUALLY TRANSMITTED INFECTIONS, HEPATITIS C**

The ETE Blueprint acknowledges that new infections do not happen in isolation, but rather are tied to numerous contextual factors. It further acknowledges that certain populations are disproportionately impacted by contextual factors and experience higher rates of associated health disparities, which have implications for both increasing the risk for HIV, sexually transmitted infections (STIs) and Hepatitis C (HCV) and impacting health outcomes for people living with HIV. Women, specifically women of color, were identified as a key population that requires specific interventions and implementation strategies if we are to change the trajectory of new HIV, STI and HCV infections in New York State (NYS).

### **HIV**

Approximately 112,000 people are living with diagnosed HIV/AIDS in New York State: nearly one third are female (reported by 'sex at birth'). The HIV diagnosis rate among Black females is 2.5 times higher than the rate among Latino/Hispanic females and over 13 times higher than the rate among White females. Over half of females newly diagnosed with HIV infection in New York State are Non-Hispanic Black (56%), an additional 27% are Hispanic. By age, young women and girls ages 13-24 years old comprise 11% of new diagnoses, women ages 25-39 comprise 36%, and women over age 40 comprise 53%.

While New York is making progress linking people living with HIV to care and improving viral load suppression, females overall lag somewhat behind males in timely linkage to HIV care and viral load suppression among people in HIV medical care. In 2016, 21% of females diagnosed with HIV received a concurrent AIDS diagnosis. Between 2015 and 2016, when most population subgroups experienced declines in new HIV diagnoses, the number stayed level for Black and Hispanic women (528 new diagnoses in 2015 to 519 in 2016).

### **STIs**

Women are also disproportionately impacted by sexually transmitted infections, comprising 54% of the 141,000 reported diagnoses in 2016. The majority of cases are diagnosed in young women, which is of particular concern given the potential long-term consequences of STIs such as pelvic inflammatory disease, ectopic pregnancy, infertility, and the potential for mother-to-child STI transmission. While chlamydia remains the number one most commonly reported STI in New York State, syphilis—for years an STI affecting men predominantly—is re-emerging as a concerning issue for women with the early syphilis case rate tripling between 2014 to 2016 from .5 per 100,000 to 1.4 per 100,000.

## Hepatitis C (HCV)

One in five women living with HIV are also coinfecting with the HCV. NYSDOH surveillance has also shown a concerning increase in HCV among women of childbearing age (14-55 years). In NYS (excluding NYC), in 2016, 59% of women who were newly reported as living with HCV are of childbearing age. Injection drug use (IDU) was the most common risk reported among these new reported cases among women. Of the 1,902 women of childbearing age newly reported with HCV in 2016, 7% were pregnant. This is likely an underestimate as pregnancy status is unknown for more than half of the HCV cases among the women of child bearing age. HCV can be transmitted vertically from mother to child. Vertical transmission occurs in 5.8% of infants born to women who are infected only with HCV and in up to twice as many infants born to women who are also infected with HIV or who have high HCV viral loads. With the availability of new, more effective HCV treatments, HCV screening among women of child bearing age can act as a prevention intervention. Women identified with HCV can be treated before becoming pregnant.<sup>1</sup>

HIV, STIs, and HCV are considered by many to be “syndemics,” meaning they affect similar populations and interact with one another to facilitate transmission and exacerbate disparities within population groups. To effectively address the epidemiologic trends described above requires a response that both applies the universe of HIV, STI, and HCV prevention and care methods available within public health, and acknowledges the unique set of environmental factors unique to women that affect their sexual and overall health. The implementation strategies contained in this document are designed to achieve both aspects of this ambitious goal.

## SYSTEMIC IMPROVEMENTS

- Require state and city agencies to **report annually on the number and types of HIV/AIDS related grants** awarded (out of total grants) to fund services for women and girls at risk for and living with HIV/AIDS.
- Create a **statewide hotline**, or build the capacity of existing health-related hotlines, to ensure capacity to respond to inquiries, in multiple languages, to allow women and girls access to information on HIV prevention, testing, post-exposure prophylaxis (PEP) and pre-exposure prophylaxis (PrEP), HIV primary care and related services to support prevention and linkage to care.
- Implement comprehensive, age appropriate, culturally competent, and inclusive **sexual health education in all schools**, kindergarten through 12<sup>th</sup> grade.
- **Ensure the Interagency Taskforce on HIV/AIDS (IATF) coordinates implementation of recommendations across state agencies.** These key institutions are needed as partners to address ending the epidemic in communities of color and among women and girls.

- **Enhance the statewide ETE dashboard** to include the development of a method to track and monitor statewide uptake, adherence and retention of PrEP and PEP amongst women and girls
- **Provide support for local health departments to conduct enhanced HCV surveillance** activities for HCV-infected pregnant women and their infants to ensure appropriate and timely screening diagnosis and linkage to care and treatment.

## SERVICE INTEGRATION TO ADDRESS SOCIAL DETERMINANTS OF HEALTH

- Examine, disseminate and apply **evidence-based and –informed practices** and interventions that facilitate **HIV testing, linkage, retention, adherence, and viral load** suppression among diverse populations of women with unique needs, including but not limited to women who are Black/African-American, Latino, Transgender, currently incarcerated or transitioning from incarceration to community settings, and those living in New York State with valid immigration documentation.
- Ensure **accessibility of integrated HIV/STI/HCV testing** in community-based settings, taking into consideration location, day/time of operation, insurance coverage or provision of no/low-cost testing options, childcare coverage/access and other issues or barriers that may be specific to women and girls.
- Expand availability of services that provide an **intensive, hands-on approach to HIV primary care linkages**, including insurance and service navigation, accompaniment to appointments, peer support, practical support such as transportation to improve engagement and retention in care, and ultimately viral load suppression.
- **Support efforts (by addressing related barriers) of integration of behavioral health and primary care to allow for better on-site integration of care** to ensure access to a dynamic set of behavioral health services (ranging from preventive to psychiatric).

## ADDRESSING VIOLENCE AGAINST WOMEN

*Support the integration of **trauma-informed care models** in clinical and non-clinical settings. Integrate policies and programming that recognizes and addresses the impact of experiences of violence on HIV prevention and care outcomes.*

- Continue/Expand financial support of **trauma-informed training for clinical and non-clinical HIV prevention and care providers** with a focus on working with women and girls.

- Require clinical and non-clinical service providers to **routinely screen for Intimate Partner Violence (IPV), Post-Traumatic Stress Disorder (PTSD) and HIV risk** among patients during routine HIV testing, primary care, dental care, and reproductive healthcare appointments/encounters in order to support women’s HIV prevention, access to PEP/PrEP and HIV healthcare.
- Require AIDS Institute grantees, to **integrate IPV and PrEP/PEP screening into service delivery** and establish a process for service referral.
- Require workers, in **emergency departments** and other clinical settings, examining women who have been sexually assaulted to offer them information and access to HIV, STI, and Hepatitis C (HCV) screening and PEP/PrEP services.
- **Revise and disseminate New York State Department of Health (NYSDOH) standardized IPV protocol**, screening tool for clinical settings, to include PEP/PrEP screening. Monitor the integration of IPV screening by collecting data from health care providers on the delivery of integrated IPV/HIV screening and referrals for services; expand the Ending the Epidemic Dashboard to reflect this data.
- Ensure alignment between NYS and New York City Department of Health and Mental Hygiene (NYC DOHMH) IPV screening protocols.

#### PREP & PEP ACCESS FOR WOMEN

- Develop a NYS PrEP Center of Excellence to **review data and provide guidance to providers on PrEP/PEP awareness, accessibility, acceptability, PrEP-AP, uptake, retention and adherence for women**. Develop a clearinghouse with culturally responsive information for diverse populations women of color to better understand PEP/PrEP.
- Provide **culturally and linguistically responsive PrEP and PEP education campaigns** throughout the state specifically centering diverse populations of Black and Latina, cis and transgender women.
- **Enhance the programmatic and fiscal capacity of organizations**, that primarily serve women and girls who are at increased risk for HIV infection by providing resources in the form of funding, training and capacity building to provide HIV prevention education, with an emphasis on PrEP/PEP, and referral for testing and care to meet ETE objectives
- The NYSDOH to work with the Interagency Task Force on HIV/AIDS (and others) to **develop a dear colleague letter around sexual health, including PrEP/PEP** to be disseminated widely and strategically through a diverse variety of professional

organizations (MMA, AMA, etc.). This will help to increase awareness and allow for integration into various state agencies. It will help to ensure providers obtain information and educational opportunities for sexual health topics.

## CORRECTIONAL SETTINGS

- **Provide comprehensive sexual and reproductive healthcare services**, including HIV, STI, Hepatitis C treatment, and PrEP eligibility screening to women and girls in correctional facilities.
- **Extend availability of transitional planning services**, initiating the process earlier in one's incarceration and further beyond their post-release date to enable an adequate response to medical, social service, and health insurance needs for people living with HIV as they move from institutionalization to community settings. Explore conversations with Medicaid to minimize any lapse in insurance coverage during the transitional period.
- **Increase and expand funding and support for AIDS Institute Criminal Justice Initiative (CJI) community-based organizations** to provide discharge planning and transitional services in correctional settings. Extend the amount of time providers work with individuals post-release and provide guidance and support to ensure there are planned next steps for individuals who reach the end of their grant funded services.
- **Integrate a trauma-informed care approach into prison-based health services** provided to women living with HIV in or returning from correctional settings, including prison-based health and services provided by AIDS Institute funded programs that provide services in correctional settings.
- Require AIDS Institute **funded providers that provide services in correctional settings to offer HIV prevention, emphasizing PEP/PrEP education and referral** (at discharge), at various contact points during service delivery to women prior to, during and after discharge.

## IMMIGRANT WOMEN

- **New York State to guarantee that regardless of immigration status women will receive sexual and reproductive health care services**, including abortion (pregnancy termination), as well as pre- and post-natal maternity care safety net services.
- **Increase awareness** among community members regarding availability of health care and social service facilities that provide services regardless of immigration status. This

can be supported by enhancing the NYS New Americans Hotline to include HIV-ETE specific information.

- AI funding to maintain (as a priority) **culturally inclusive and responsive (language and delivery type) services**; support of translated documentation and phone-based translation services.
- Require AIDS Institute grantees, to **establish partnerships and processes for immigration-related legal service referrals**.

## SUPPORT & BUILD CAPACITY OF COMMUNITY-BASED SERVICE PROVIDERS

- Support the engagement of **peer workers, trusted community members and leaders, women of color in community settings** and other stakeholders to encourage and educate women and girls about HIV/STI/HCV testing, PrEP/PEP and Anti-Retroviral Therapy (ART).
- **Continue to fund the NYS Peer Worker Certification.** Ensure women of color and girls are engaged and reflected in the demographics of participants and graduates, placements. Encourage the support of Peer Workers at a livable wage stipend.
- Establish new statewide funding to support the availability of **community-based case management and wrap-around services related social determinants of health** to address barriers to engagement and retention in care experienced by women – ability to take care of one’s family (child care and elder care), secure and maintain adequate housing, access medical and behavioral health services, address intimate partner violence, and access education/training and employment, among other needs.
- Explore how the NYS IATF on HIV/AIDS can facilitate access and engagement in prevention, care and supportive services by **fostering partnerships between HIV prevention, care and supportive service providers and other community-based organizations** that engage but do not provide direct HIV-related services to women and adolescent girls.
- Support **technical assistance and capacity building for organizations** that serve primarily HIV-positive/high-risk HIV negative women and girls, as well as transgender women by providing direct funding or encouraging financial support and resources from other state entities. This support will further develop organizations programmatic and fiscal capacity to meet the needs of women in their communities and, where applicable, integrate third party performance-based funding and value based payments within Community Based Organizations (CBO).

- Support the **development and dissemination of research** via partnerships between medical/academic institutions, community-based organizations, and service providers to increase community participation in research and development of best practices in prevention and care.
- **AIDS Institute should provide a forum for researchers and clinical providers to discuss and distribute new science (i.e. U=U campaign, PrEP efficacy with women) with a broad community of HIV prevention and care practitioners, people living with HIV/AIDS, supportive services providers and other stakeholders.** This space will bring multiple stakeholders, across disciplines, together with an emphasis on implementation and integration of science in services. AIDS Institute should work with medical and academic partners, such as the Weill Cornell Medical Center’s Clinical and Translational Science Center, to develop activities on women and ETE focused issues to facilitate relationship and knowledge sharing between CBO and academic researchers.
- Expand availability, accessibility and promotion of **training on women and girls-specific HIV prevention and care to medical and non-medical workers in healthcare settings** working in communities with high HIV incidence. Incentivize trainings by offering continuing education credits across certifications and licensures.
- Build capacity within community-based organizations and healthcare facilities to **provide stigma-free care to women who use drugs.**
- Expand capacity within Drug User Health Hubs to **provide targeted services for women who use drugs.**
- **Encourage Community based programming in partnership with medical providers** to address sexual and reproductive health.
- **NYSDOH to facilitate increased HIV/HCV/STI testing at CBO settings to align with ETE goals.** Build the capacity of established non-clinical community-based organizations to provide community-based HIV/HCV/STI testing and referral services.

#### **LEVERAGING MEDICAID & DELIVERY SYSTEM REFORM INCENTIVE PAYMENT (DSRIP) PROGRAM RESOURCES TO ACHIEVE ETE OBJECTIVES**

- **Engage and inform DSRIP activities** to incentivize practitioners and CBOs to provide testing, viral suppression/outcomes tracking.
- **Enhance HIV quality metrics in Medicaid Managed Care will improve services received by women living with HIV.** Medicaid managed care plans play a critical role in managing access to specialized HIV services, they give access to testing, treatment, and a full



continuum of care, including but not limited to case management, mental health care, substance use services, and housing services. We recommend tracking and assessing the following trends in Health plan efforts:

1. Preventive Screenings: Administration of a standard panel of preventive screenings, such as HIV testing, in the annual comprehensive Primary Care Provider (PCP) visit.
  2. Viral load (VL) testing every 6 months for HIV positive individuals.
  3. Viral Load Suppression.
  4. HIV Prevention: The number PrEP requests and prescriptions filled.
- **Allow specialist providers to bill Medicaid for multiple services provided on the same day**, to prevent clients from having to return for services over multiple days that could be provided on the same day. Removing these barriers to accessing care will aid in retention in HIV care and improved health outcomes.
  - Strengthen eligibility and recertification criteria, expectations and **accountability for Medicaid transportation services vendors** to address rampant no-show/ poor service issues, particularly in upstate regions, which create barriers to accessing care for people living with HIV/AIDS.

The numbers and rates of HCV among women of child bearing age are increasing nationally and in NYS (outside of NYC). The opioid epidemic is fueling the rise of HCV among women of child bearing age. Increased testing among pregnant women at risk for HCV and improved surveillance to track and monitor the infants at risk for vertical transmission is necessary. Additionally, community based organizations and health care facilities charged with providing services to women must ensure that those services are provided in a stigma-free environment.

## ADDRESSING THE STI EPIDEMIC

- Establish a program to **increase utilization of Expedited Partner Therapy<sup>ii</sup>** (EPT) across New York State.
- **Use data to prioritize individuals and communities for intervention.** For example, HIV-positive persons with no evidence of recent STI testing should be prioritized for STI testing. Persons with recent STIs and no evidence of HIV testing should be prioritized for HIV testing.
- **Conduct an awareness campaign** with respect to congenital syphilis targeted to laboratories (the need to conduct reverse sequence screening), providers (the need to screen all women at least once during pregnancy and more frequently for high risk women), and consumers (prevention, screening).

- Conduct a **pilot project to evaluate the feasibility and effectiveness of in-home STI testing** and scale-up as necessary.
- Establish a **monitoring system to ensure patients who are prescribed PrEP receive the full package of PrEP-related services, including regular STI screening and treatment.** This system could either be at the population level with a data source such as Medicaid, clinic level through quality improvement initiatives, or a combination of both.
- **Work with family planning providers** to make three-site STI testing (urogenital, rectal, oropharyngeal), PrEP/PEP, and other STI prevention methods available in these settings.
- **Promote comprehensive sexual health education** in all schools in New York State.
- Explore funding county health departments and family planning providers to create **comprehensive-service sexual health clinics in the rest of state** (outside of New York City).

## WOMEN'S ETE 2018 BUDGET PROPOSALS – HEALTH INVESTMENTS FOR WOMEN

### Women's ETE Connect Initiative. \$4,000,000

The Women's ETE Advisory group recommends establishing an **ETE Women's Connect Initiative** that would support women-specific supportive services for diverse that will explicitly advance PrEP, PEP, and treatment adherence, viral load suppression, linkage and retention in care for women, particularly Black and Latina women. Organizations will tailor a program that addresses barriers to care and/or contextual issues and builds a bridge to one of the service areas below. Specific services could also include (but not be limited to) supportive case management, support groups, structured socialization for children so women can attend appointments, as well as childcare/family case management.

- **Women-Focused HIV Testing & Early Treatment** – \$1 million for (5) contracts (over two years) that will reach sex workers, at-risk women who test positive for STIs, survivors/victims of domestic violence, women leaving correctional facilities. Geographic “hot spots” in the state would also be prioritized.
- **Women-Focused PrEP and PEP Uptake and Adherence** – \$1 million for (3) care coordination and treatment support contracts (over two years). Priority populations include women who have tested positive for STIs; women who rely on sex for survival immigrant women; and women re-entering community from the criminal justice system, in New York City where there was an increase in infections in 2016.
- **Upstate Women's Linkage and Retention in Care** – \$2 million for (6) contracts (over 2 years) to identify women in upstate New York who are not engaged in care or have fallen out of care and provide supports to re-engage i.e. transportation, housing subsidies, family case management, domestic violence and intimate partner violence, structured socialization for children. Priority populations include women leaving the criminal justice system and immigrant women.

In addition, the advisory group **recommends that the AIDS Institute develop a standardized risk assessment tool that can be used to evaluate and demonstrate health outcomes related to ETE for women and girls.** This tool would help track the impact of these interventions and can lay the foundation for building organizations' capacity to address value based payment models.

The Women's Advisory Group recommends that this funding **total \$4,000,000 over two years** to allow for time to scale up and operationalize **BP1-5; BP15-20; BP22**

**Include African-American and Latina Women and Girls as a Priority Population for PEP/PrEP campaigns. \$2,000,000**

BP11 calls for a statewide education campaign on PrEP and PEP. **The Women’s ETE Advisory Group recommends that Black/African-American and Latina women and girls be named as a priority population for statewide PEP and PrEP education campaigns.** Out of \$10,000,000 total requested, \$2,000,000 should be earmarked for women-focused campaigns.

In 2015-2016, in New York City for example, new diagnoses rates **increased** for women across all racial and ethnic groups while rates continued to decline for Black, Latino/Hispanic, and White men. Women and girls, particularly Black/African-American and Latina women and girls, remain a population in need of strong HIV prevention awareness messaging across the state. Among the 735 newly diagnosed females, the majority were Black (58%), with fewer Hispanics (26%) and many fewer Whites (10%). Nearly all (94%) newly diagnosed females had heterosexual or presumed heterosexual contact transmission risk in 2014 in the state.<sup>iii</sup>

Statewide data on PrEP usage among women is lacking. However, data from Medicaid gives us a glimpse in to usage trends. During the three-year period ending June 30, 2015, the number of Medicaid recipients initiating PrEP in New York State increased more than fourfold. Those recipients initiating PrEP during this period were mostly male, aged <50 years, and, among those for whom data describing race was available, white.<sup>iv</sup> There is concern that PrEP and PEP messaging might not yet be reaching others who are appropriate for its uses. **BP11, BP25**

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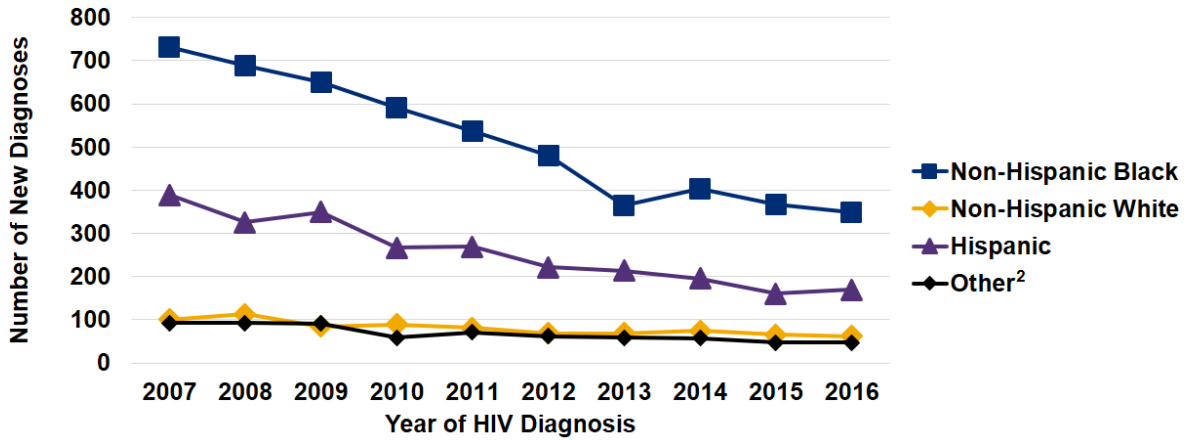
<sup>i</sup> NYSDOH. Communicable Disease Electronic Surveillance System as of August 2017.

<sup>ii</sup> EPT is chlamydia treatment that medical providers prescribe to the partners of patients without needing to see them for an examination.

<sup>iii</sup> 2014 data from [https://www.health.ny.gov/diseases/aids/general/statistics/epi/docs/epi\\_profile2016.pdf](https://www.health.ny.gov/diseases/aids/general/statistics/epi/docs/epi_profile2016.pdf).

<sup>iv</sup> <https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6446a5.htm>.

## Females,<sup>1</sup> Newly Diagnosed with HIV Infection by Race/Ethnicity, NYS, 2007-2016\*



<sup>1</sup>Sex assigned at birth

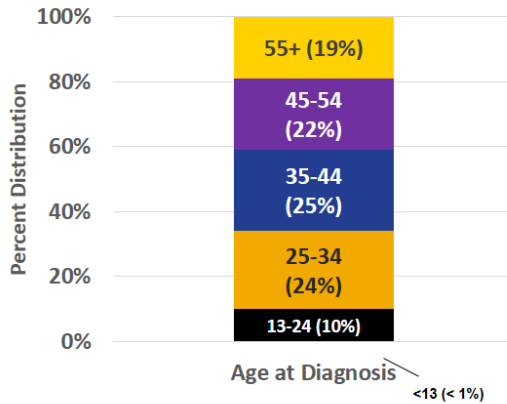
<sup>2</sup>Due to small cell size, includes: Multi-Race, Asian/Pacific Islander, Native American

\*Data as of September 2017

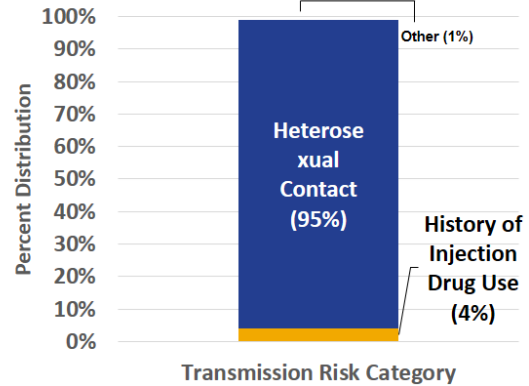


## Female Sex Assigned at Birth, Newly Diagnosed with HIV Infection by Age at Diagnosis and Transmission Risk Category, NYS, 2016\*

Age at Diagnosis



Transmission Risk Category

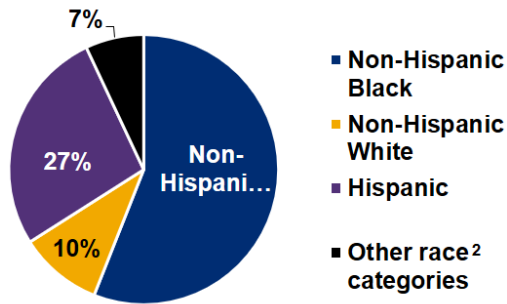


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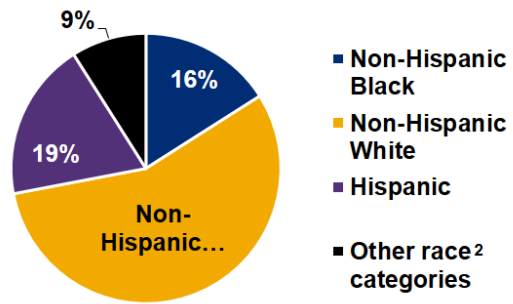


## Female Sex Assigned at Birth, Newly Diagnosed with HIV Infection by Race/Ethnicity Distribution, New Diagnoses and Population Distribution, 2016\*

*Distribution among Newly Diagnosed*



*Distribution among the NYS Population<sup>1</sup>*



\*Data as of September 2017

<sup>1</sup>National Center for Health Statistics Bridged Race Estimates for 2016

<sup>2</sup>Due to small cell size, includes: Multi-Race, Asian/Pacific Islander, Native American