

# PrEP for Transgender Women

## Successes, Challenges & Opportunities

*A Statewide Forum Hosted by the New York State Department of Health AIDS Institute*      APRIL 10, 2018



# MEETING REPORT

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*This report was prepared by Mary Beth Hansen, MA, Project Director, Johns Hopkins University HIV Clinical Guidelines Program, July 2018*

## FOREWORD

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*Deputy Director, Office of the Medical Director, New York State Department of Health AIDS Institute*

In June 2017, the New York State Department of Health AIDS Institute convened stakeholders from across the state to discuss issues unique to engaging women in PrEP. It quickly became clear that a one-day forum would not allow the time needed to address PrEP for cisgender and transgender women, so the decision was made to host an additional meeting, in April 2018, to focus on PrEP for transgender women. This report summarizes the presentations and discussions of the April 2018 forum, *PrEP for Transgender Women*.

This forum invited PrEP providers and researchers as well as representatives of community-based organizations, family planning agencies, pharmacies, faith-based agencies, public health agencies, community advocacy groups, and consumers to contribute insights gleaned from their experiences with delivering PrEP services to transgender women in diverse settings. The day's discussion focused on identifying challenges and remedies unique to implementing PrEP for transgender women, particularly transgender women of color, and emerging best practices for engaging transgender women in PrEP statewide in support of the NYS *Ending the Epidemic by 2020* initiative.

Presentations made by invited speakers and panelists addressed research findings related to facilitators and barriers to PrEP for transgender women, detailed best practices for providing sexual healthcare and PrEP services for transgender women, and engaged attendees in thoughtful discussion about characteristics of gender-affirming clinical care for transgender women. Attendees then participated in each of three breakout sessions to address key issues in implementation of PrEP for transgender women: 1) access to PrEP; 2) PrEP retention; 3) PrEP public health program design.

Issues of social oppression, discrimination, and inadequate service delivery dominated the day's discussions. Also central to the discussion was a call to end institutionalized transphobia, to promote a "for-us-by-us" approach to service delivery, and to embrace the reality that a transgender person is entitled to the same quality of care as all other people and should not be singled out always as an "other." Epidemiological evidence and the experiences of those present highlighted the urgent need for PrEP implementation among transgender women of color, who are disproportionately affected by HIV. All agreed that improving service delivery environments, reducing stigmatization, and improving knowledge about the needs of transgender women all must be addressed in tandem to ensure New York State's success in delivering PrEP to transgender women who choose it.

Successes realized to date also were acknowledged. Representatives from agencies reported their experiences implementing PrEP and described relationship-building with transgender women patients. They also emphasized the importance of peers and navigators in service delivery. They described the value of gathering and responding to feedback from the transgender community in developing programs and policies and the success of creative community outreach activities. All had proved to be successful methods for increasing PrEP use among transgender women.

The success of this forum was made possible by the hard work of many. The people responsible for planning, logistics, materials design and production, venue coordination, registration, note taking, facilitation of and reports on breakout sessions, and transcription of notes included Rosy Galvan, Kraig Pannell, Jennifer Goldman, Nkechi Oguagha, Beth Yurchak, Joanna Palladino, Richard Cotroneo, Rob Curry, Erica Lovrin, Antia Gomez, Rachel Newport, Mary Beth Hansen, Hanna Gribble, and Laura Hatcher. Thank you all for making this day a great success. A heartfelt thanks goes to Sarit Golub, PhD, for her thoughtful guidance in preparing for this event. Special recognition and thanks goes to Laura Duggan Russell, Forum Director, who took the lead in both planning and facilitating this event.

We have made great strides in New York State in the fight against HIV and we have more to do. Sending the clear message to transgender women (and all other women) that PrEP is a proven, available, and self-controlled method of protection from HIV will be essential to ending AIDS in New York State.

## EXECUTIVE SUMMARY

### PrEP FOR TRANSGENDER WOMEN: SUCCESSES, CHALLENGES & OPPORTUNITIES

This report summarizes speaker presentations and panel and participant discussions at the first statewide forum on PrEP implementation for transgender women (transgender women) in New York. This meeting was hosted by the New York State Department of Health AIDS Institute (NYSDOH AI) on April 10, 2018.

#### Supporting the New York State Initiative to End the HIV Epidemic

This forum was a continuation of efforts to engage community and policy stakeholders in support of Governor Andrew Cuomo's plan to end the HIV/AIDS epidemic in New York State. A key component of the governor's plan is to increase access to and uptake of PrEP among people who are at high risk of acquiring HIV.

#### Fourth PrEP Implementation Forum in a Series

PrEP implementation for adults was addressed on August 26, 2015, when the NYSDOH AI convened a forum, attended by healthcare providers, consumers, community stakeholders, and state and local health officials, to discuss the use of PrEP and PrEP quality of care for adults in New York State. On November 18, 2015, a forum on implementation of adolescent PrEP was convened to address challenges and opportunities specific to the youth population. The June 18, 2017, Forum on PrEP for Women focused on identifying challenges that must be addressed to increase women's access to PrEP and their willingness to use it to protect themselves from acquiring HIV. This last forum focused on ways to increase awareness of, access to, and uptake of PrEP among transgender women in NYS who are at risk of acquiring HIV.

#### Challenges Unique to Transgender Women

Among presenters, panelists, and meeting participants, there was broad agreement that transgender women in New York State are particularly vulnerable to HIV and particularly in need of access to PrEP.

As both Johanne Morne and Oni Blackstock noted, there has been a steady increase in new diagnoses of HIV among transgender women, and particularly among transgender women of color and younger transgender women. The need is great, as are the challenges.

Transgender women face numerous barriers to PrEP, including unwelcoming and stigmatizing healthcare settings that are not gender affirming, a lack of recognition of the needs of transgender women who engage in sex work, and a general lack of knowledge about how to provide healthcare for the bodies of transgender women.

#### Key Issues and Priorities for Change

##### 1. Improve care and service delivery environments to expand access to PrEP for transgender women:

- Ensure cultural competency among all who interact with transgender women so they can expect safe, gender-affirming care always.
- Increase funding for transgender-centered services and expand the number and diversity of settings that provide PrEP and other healthcare for transgender women.
- Increase opportunities for transgender people to work in care- and service-delivery settings, and foster commitment to hiring and training transgender people for this type of work.
- Create marketing and messaging specifically designed to reach transgender women

##### 2. Reduce social oppression, discrimination, and stigmatization to increase uptake of PrEP among transgender women:

- Enforce anti-discrimination laws already in place to protect the rights of transgender people; facilitate passage of new laws that offer further protection.
- Tailor services to meet the social, economic, and healthcare needs of transgender women; PrEP will not be a priority for transgender women in need of housing and food security, transportation, and basic healthcare.
- Decriminalize sex work and protect sex workers' rights. Sex work is survival for transgender women and others who face social and structural barriers to employment.
- Focus on occupational safety in discussions of PrEP; HIV risk is an occupational hazard for sex workers.

##### 3. Improve awareness and knowledge of transgender women's healthcare needs:

- Require training in best practices in care of transgender women for all medical care providers.
- Offer non-clinical care in the same settings as clinical care, as wrap-around services.
- Promote research on PrEP efficacy in transgender women.
- Bundle hormone therapy with PrEP, always.
- Expand advertising, education, and payment options for PrEP, and ensure that all campaigns and materials are transgender inclusive.

## OPENING REMARKS

### Johanne Morne, MS

*Director, New York State Department of Health AIDS Institute*

The AIDS Institute Director opened the forum by emphasizing the importance of PrEP to New York State's (NYS) Ending the Epidemic (ETE) initiative. Ms. Morne provided an overview of ETE, describing it as a history-making collaborative effort of the community and NYS government that was sparked by community leadership and mobilization. Ms. Morne reiterated the ETE's 3-point plan to reduce the number of new HIV infections to 750 annually in NYS by the end of 2020, which includes: 1) identifying people with HIV and linking them to care, 2) retaining people with HIV in care to maximize viral suppression and reduce transmission, and 3) increase access to pre- and post-exposure prophylaxis (PrEP and PEP, respectively). She highlighted a fourth area of emphasis added to the ETE: addressing the social and structural barriers that prevent individuals from being tested and accessing healthcare, including PrEP.

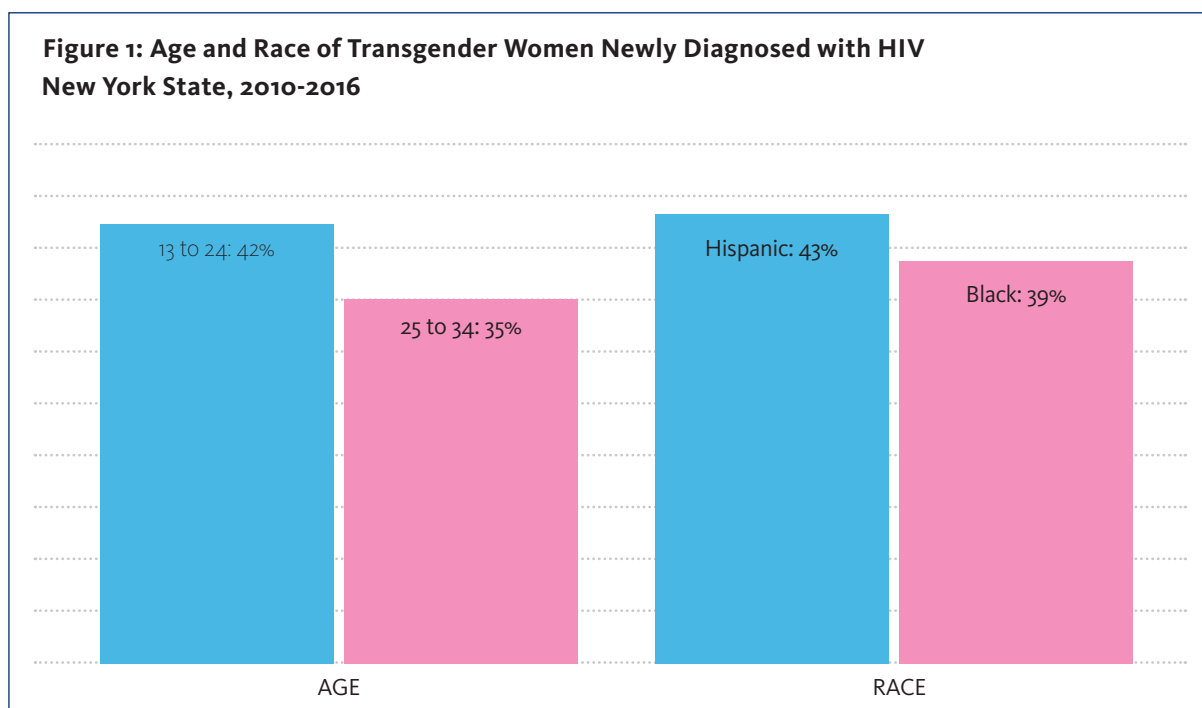
Ms. Morne then discussed the needs of specific communities of people who are disproportionately affected by HIV, including transgender and gender-non-binary individuals. She described the NYSDOH's commitment to inclusivity and to developing specialized implementation strategies to address the needs of all at risk of acquiring HIV. Toward that end, the NYSDOH has convened an advisory body to inform its work on behalf of people of transgender and non-binary experience, and the state has already passed laws to protect the rights of transgender students and state employees. Ms. Morne added that the state's HIV Special Needs Plan (SNP) now serves transgender individuals regardless of their HIV status.

### The number of new diagnoses among transgender women may seem small, but the proportional increase is of great concern.

Ms. Morne, like speakers to follow, noted an increase in new HIV diagnoses among transgender women, and particularly among those of color and those who are aged 13 to 24 years [Ms. Morne, slide 3, April 10, 2018] (see Figure 1, below).

- Transgender women accounted for 1.4% of all new diagnoses in 2010; in 2016, they accounted for 2.8% of all new diagnoses.
- 42% of new HIV diagnoses among transgender women were in adolescents aged 13 to 24 years; 35% of new diagnoses were in transgender women aged 25 to 34 years.
- Between 2010 and 2016, transgender women of color, particularly Hispanics and Blacks, were disproportionately affected by HIV in NYS: 43% of new diagnoses were in Hispanic transgender women and 39% were in Black transgender women.
- 92% of transgender women newly diagnosed with HIV reported their transmission risk as sexual.

**Figure 1: Age and Race of Transgender Women Newly Diagnosed with HIV  
New York State, 2010-2016**



Ms. Morne acknowledged that the rise in new diagnoses among transgender women could be the result of increased identification of people with HIV. If so, this accomplishment in identification does not change the social and structural barriers to care faced by transgender women.

The purpose of the meeting, therefore, was to address issues of access to PrEP and linkage to care for transgender women, with the goals of 1) identifying specific and unique needs of transgender women; 2) sharing experiences to help others improve their ability to meet these needs; 3) discussing ways to create environments that are welcoming and safe for transgender women; and 4) ensuring that the conversation includes transgender women who have IV drug use as their primary transmission risk.

### When talking about PrEP, sexual risk is a crucial part of the discussion, but the risk with injection drug use must be acknowledged as well.

Ms. Morne closed by inviting participants to share their experiences, observations, and ideas about the best ways to reduce social and structural barriers that prevent transgender women from accessing available services to improve their lives, their health, and their access to PrEP.

### Oni Blackstock, MD

*Assistant Commissioner, Bureau of HIV/AIDS Prevention and Control, New York City Department of Health and Mental Hygiene*

Dr. Blackstock began with an overview of the work that the New York City Department of Health and Mental Hygiene (NYC DOHMH) does to reach groups at greatest risk of acquiring HIV and to expand access to PrEP for prevention.

Dr. Blackstock noted that transgender women in NYC are among those at great risk of acquiring HIV, as evidenced by the following data [Blackstock, slides 3-9, April 10, 2018]:

- At the end of 2016, there were approximately 1,100 people of transgender experience known to be living with HIV in NYC.
- From 2012 to 2016, new HIV diagnoses among people of transgender experience in NYC have been made:
  - Predominantly in transgender women: 232 diagnoses in transgender women compared with 4 in transgender men.
  - Disproportionately among transgender women aged 20 to 29 years.
  - Predominantly among transgender women of color.
- In 2016, 46 (2%) of all new diagnoses of HIV in NYC were in transgender women:
  - 47% were Black and 44% were Latino/Hispanic.
  - Three cases were late-stage, with AIDS diagnosed within 31 days of the HIV diagnosis.
- In NYC, HIV viral suppression rates are lower among transgender women (73%) than among cisgender men (81%).

Dr. Blackstock also described common experiences of transgender women (Figures 2 and 3, left and below) to illustrate the social and structural factors that impede access to PrEP. She noted that the numbers cited may be underestimates because care providers often do not ask about such issues as substance use, incarceration, sex work, homelessness, and sexual abuse.

After presenting evidence that underscored the need to reach people of transgender experience, Dr. Blackstock showed attendees examples of social marketing and educational campaigns from programs such as the Play Sure Network, targeted specifically to reach all women, including women of transgender experience. These examples of innovative strategies were implemented in response to recommendations of the NYC DOHMH Women's Advisory Board.

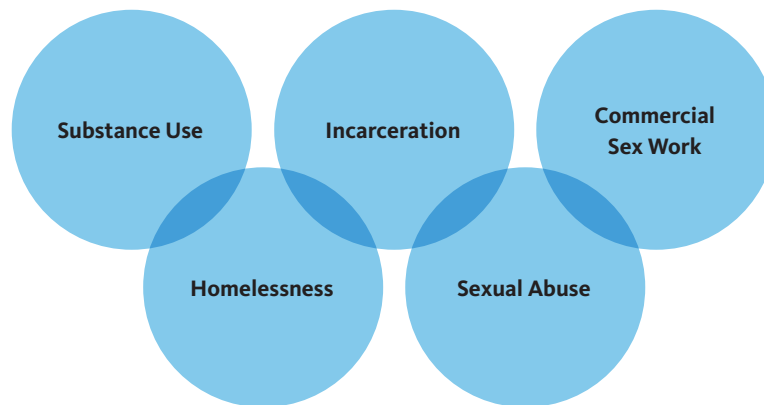
#### Figure 2: NYC transgender women with HIV who reported a history of the following (2012-2016)

[Blackstock, Slide 7, April 10, 2018]:

- Substance use: 30%.
- Incarceration: 24%
- Commercial sex work: 9%
- Homelessness: 6%
- Sexual abuse: 2%

**Figure 3: Social and Structural Barriers to PrEP Access Among Transgender Women\***

\*based on Blackstock, Slide 7, April 10, 2018



Efforts to reach transgender women are one component of the NYC DOHMH comprehensive effort to expand access to PrEP. Additional components include an emphasis on warm handoffs when referrals for PrEP are made, educational campaigns for PrEP providers and consumers, and creation of a directory and health map of LGBTQ-knowledgeable clinicians who provide gender-affirming care.

To improve services further, Blackstock informed attendees that the NYC DOHMH is participating in the National HIV Behavioral Surveillance among transgender women in 2018. National HIV Behavioral Surveillance is a CDC-funded project that is an ongoing, cyclical study taking place in 22 U.S. cities. All study activities are anonymous. Through HIV testing and structured, anonymous interviews with 200 transgender women, the agency aims to accomplish the following [Blackstock, Slide 20, April 10, 2018]:

1. Assess the prevalence of HIV and STIs
2. Assess the prevalence of risk behaviors and social determinants that increase risk of HIV acquisition and transmission
3. Describe utilization of HIV testing, linkage to care, and antiretroviral therapy
4. Assess exposure to and use of prevention services
5. Identify gaps in prevention services and missed opportunities for prevention interventions

Finally, Dr. Blackstock described NYC DOHMH support of capacity-building among four programs led by individuals of transgender experience [Blackstock, Slides 16-18, April 10, 2018]. The agency has implemented a 3-year model that funds capacity-building for 2 years and expansion for 1 year. Goals include ensuring secure, stable locations; establishment of memoranda of understanding (MOUs) with other service providers; and expansion of specific services such as rapid HIV testing. The overall goal is to promote the well-being of transgender people and lower barriers to care.

## INVITED SPEAKER PRESENTATIONS

Invited speakers addressed social and programmatic factors that impede access to and availability of PrEP for transgender women, best practices in sexual healthcare for transgender women, observations on healthcare and service delivery for transgender women, and experiences in implementing PrEP.

### Gus Klein, MSW

*Hunter HIV/AIDS Research Team*

**Facilitators and Barriers to PrEP Among Transgender Women in New York City:** Gus Klein presented study results that can be used to help facilitate the following [Klein, Slide 4, April 10, 2018]:

- **Program design:** Design and development of transgender-inclusive and gender-affirming programs to increase PrEP access and uptake.
- **Provider engagement and assistance:** Active provider engagement and assistance around PrEP to increase uptake of PrEP among members of the transgender-feminine community.
- **Sociocultural sources of risk:** Recognition of the relationship between the sociocultural experiences of transgender-feminine women and HIV risk.
- **Community mobilization and activism:** Support for existing community mobilization and activism to increase PrEP awareness and knowledge and build trust in and uptake of PrEP.

Klein's study engaged 30 transgender-feminine individuals, 15 of whom were using PrEP and 15 of whom were not, in a 60- to 90-minute in-depth, semi-structured interview that addressed their knowledge and attitudes about PrEP, use of/experience with PrEP, access to PrEP, and best practices [Klein, Slide 5, April 10, 2018]. All participants were aged 18 years or older, HIV negative, and had engaged in anal or vaginal sex with either a cisgender man or a woman of transgender experience within the 6 months prior to study recruitment. Participants were compensated for their participation. Klein reported the following participant demographics [Klein, Slide 6, April 10, 2018]:

- 93% claim a binary gender identity
- 73% person of color
- 90% not in the workforce
- 60% under age 30 years
- 87% income >\$12,000
- 57% straight/heterosexual
- 87% publicly insured

Klein focused on results related to four key themes that he found to be strongly associated with PrEP knowledge, access, and uptake: 1) program design; 2) provider engagement; 3) sociocultural sources of risk; and 4) community mobilization and activism.

**Gender affirmation is a social process that both recognizes and supports individuals in their gender identity and expression.**

**Program design:** As did most of the day's speakers, Klein noted the lack of transgender-inclusive and gender-affirming healthcare settings and reported that 90% of study participants attributed low PrEP uptake among transgender women to this program design flaw. Study participants indicated that they did not see themselves and their peers in PrEP marketing and educational materials, reported a dearth of information about the safety of PrEP when taken with hormones, and told interviewers that their care providers rarely engaged them in discussions of sexual health. As a result, Klein asserted that transgender women must choose, or not, to seek PrEP in a system that does not affirm their gender identity and offers programming that ignores their specific sexual and health needs.

Klein argued that transgender-inclusive and gender-affirming programs are key to increasing PrEP uptake among transgender women. Transgender women have to be recognized and acknowledged, which means, for instance, that the common practice of categorizing them as MSM for demographic purposes has to be stopped. It also means that educational materials, assessment tools, and prevention strategies must be created to address their needs specifically, including the primacy of hormones. One important gender-affirming strategy would be to make hormones and PrEP available at the same place, from the same care provider, on the same schedule, and accompanied by clear information about the potential interactions between hormones and PrEP.

**In medical records, transgender women should not be described as “men who have sex with men.”**



Another important strategy is to acknowledge the needs of transgender women who engage in sex work and design materials and programming to reach them. Sex workers need access to care providers and services that are available during extended hours.

**Care provider engagement and assistance:** Klein emphasized that barriers to PrEP include lack of access to safe and affirming healthcare settings, lack of information about payment options, and complicated systems to secure payment. His study results suggest that the remedy is actively engaged care providers and active assistance for transgender women who need help identifying and acquiring payment options for PrEP both can make a positive difference in PrEP acceptance and uptake.

Klein defined actively engaged care providers as those who facilitate ongoing discussion of a transgender woman's sexual health and PrEP. It takes time to build rapport and trust, and it takes time to recognize and understand the benefits of PrEP and the commitment required of PrEP users. A person who turns down the offer of PrEP on a first visit may, over time and after several discussions, change that decision. A care provider who is actively engaged with a transgender woman will ask more than once and will foster understanding of sexual health as more than just avoidance of sexual risk, as attested to by study participants [Klein, Slides 12-13, April 10, 2018]:

*"He (doctor) brought it (PrEP) up almost every other time we would meet. He would say hey this is available to you it's covered by your insurance in case you want to go on it."* (on PrEP, age 28, binary, Asian/Pacific Islander).

*"PrEP was offered to me so frequently in the few interactions I had with my health clinic initially they made it so easy to get on. Plus they helped me get on insurance that covered PrEP, that's exactly the way to do it"* (on PrEP, age 29, binary, White).

Once a transgender woman decides to use PrEP, the next hurdle may be finding a way to pay for it and getting help in meeting the requirements of public payment options or private insurance. Klein reminded all that this hurdle is jumped more willingly and easily with assistance from knowledgeable navigators who can lead the way.

### Availability is not the same as access. PrEP navigation services must include payment assistance *and* help in accessing those resources.

**Sociocultural sources of risk:** Klein stressed the role of societal oppression in HIV risk for transgender women and emphasized that risk is intrinsic to survival for many. Two quotes from study participants captured this idea [Klein, Slides 16-17, April 10, 2018]:

*"If you're going to survive you might have to do those things that you don't like, and you don't like to do, and they might not be as safe as you'd like them to be, you know?"* (on PrEP, age 26, binary, Latina).

*"A lot of us transgender women of color are forced to do survival sex work. I'm not going to say we put ourselves in a risky life, but we're forced to do this. It's survival. PrEP is really important because it's helping us minimize our risk when we do what we do to survive in this cruel world"* (on PrEP, age 24, Asian/Pacific Islander).

As noted previously, most of the study participants were not in the work force. For those unable to find employment, sex work may be the only source of income. As such, HIV risk is an occupational hazard, and even more so because many commercial sex workers are subject to sexual violence, and many are powerless in negotiations about condom use.

Approaches to PrEP that focus on risky behavior and/or choosing to engage in risk ignore the reality that many people perceive no choice beyond that of survival. Perpetuating the notion that people can but don't choose otherwise may keep those who stand to benefit the most from accessing PrEP.

### Stop the narratives that shame people for their behavior.

It is crucial that PrEP is offered as another means to the end for survival—as a tool to help transgender women stay healthy while having sex. It's a harm-reduction strategy for people who may have no choice but to put themselves in harm's way. Klein found that strategies and programs that reflect this perspective will be much more effective in reaching and meeting the needs of all transgender women in general, and especially transgender women who engage in sex work.

### Transgender women and non-binary individuals experience multilevel vulnerabilities that create HIV risk; HIV risk is driven by social oppression.

**Community mobilization and activism:** Klein concluded that personal relationships and community connections among the transgender women in the study were important factors in willingness to take PrEP. Participants reported that

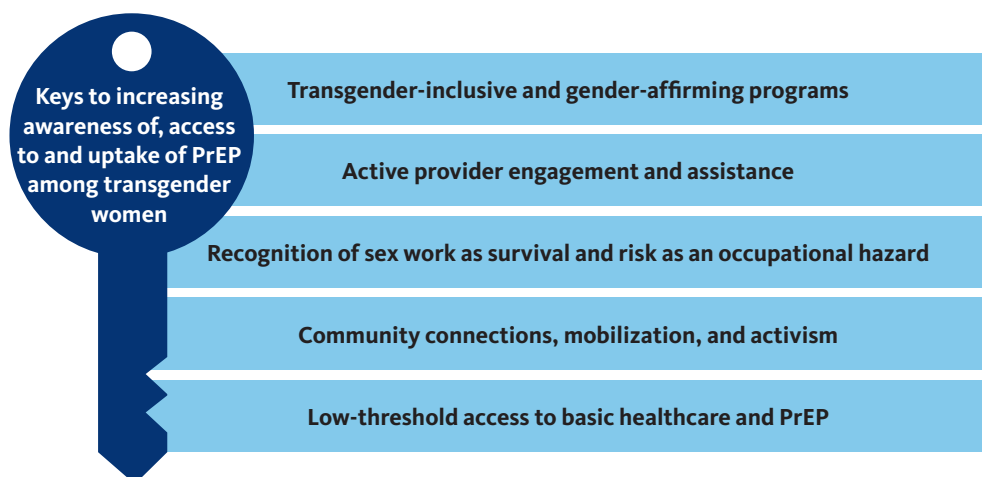
they learned about PrEP and its benefits directly from their friends and peers and that much of the knowledge about PrEP is community knowledge spread by word of mouth, including through online communities and interaction. Moreover, participants recognized the societal benefits of PrEP in protecting individuals who take it and their sex partners, which, in turn, helps protect all transgender women in the community.

*"I want my friends to be on PrEP too. I think it's important that people are on it because it helps reduce and control HIV within, not only our community, but also every persons [sic] that are having sex. I talk to my sexual partners about it too because I want them to be safe as well and also know that they are safe with me as well"*

(on PrEP, age 28, binary, Asian/Pacific Islander). [Klein, Slide 19, April 10, 2018]

Programs that respect and encourage community knowledge and support will build knowledge. Support for community mobilization and activism (including online) will not only increase awareness but also build trust and, in turn, increase uptake of PrEP among transgender women (see Figure 4, below, as summary).

**Figure 4: Keys to Increasing PrEP Engagement Among Transgender Women**



### Asa Radix, MD, MPH, FACP

Senior Director of Research and Education, Callen-Lorde Community Health Center; Clinical Associate Professor of Medicine at New York University

**Sexual Health for Transgender Women:** Dr. Radix introduced an overview of best practices gleaned from 20 years of experience providing care for transgender women, with an acknowledgment that there are no national surveillance data available on STIs in transgender women. Data are scant in general because transgender women often are categorized as MSM, as noted previously by G. Klein. He then offered the following of what is known from available data: [Radix, Slide 4, April 10, 2018; see slide for references]:

- Increased VDRL (a test for syphilis) seropositivity compared with MSM (India, Peru) and non-transgender (India)
- Increased prevalence of gonorrhea and chlamydia compared with MSM (U.S.)
- Increased rates of human papilloma virus, hepatitis B and C, and herpes simplex virus compared with MSM
- HIV risk for transgender women with neovagina not known

Also known, from the 2015 U.S. Transgender Survey, are the many fears that transgender women have about the healthcare system, such as being refused care, discriminated against in other ways, and being ridiculed or assaulted. With that backdrop, Radix suggested that care providers engage transgender women in a safe and gender-affirming assessment of HIV and other STI risk by starting with the “6 P’s”: Pronouns, partners, parts, practices, protection, and past history [Radix, Slide 4, April 10, 2018] (see Figure 5, next page).

**Figure 5: The 6 P's to Begin a Safe and Gender-Affirming Healthcare Visit with Transgender Women\***

\*Adapted from Radix, Slide 5, April 10, 2018

<b>Pronouns</b>	<ul style="list-style-type: none"> <li>• Which pronouns do you prefer?</li> </ul>
<b>Partners</b>	<ul style="list-style-type: none"> <li>• What gender(s) do your sex partner(s) claim?</li> <li>• How many sex partners have you had in the past 3 months?</li> </ul>
<b>Parts</b>	<ul style="list-style-type: none"> <li>• Which words do you prefer for your body parts?</li> <li>• Which bottom surgeries have you had?</li> </ul>
<b>Practices</b>	<ul style="list-style-type: none"> <li>• What kinds of sex are you having?</li> <li>• What behaviors might expose you to your partners' fluids?</li> </ul>
<b>Protection</b>	<ul style="list-style-type: none"> <li>• How do you protect yourself against HIV and other STIs?</li> </ul>
<b>Past History</b>	<ul style="list-style-type: none"> <li>• Have you had any STIs in the past?</li> </ul>

**Physical exams:** Radix also advised patience and sensitivity in conducting physical exams, noting that it may take more than one visit to build trust. He particularly recommended against any aspect of a physical exam performed to satisfy personal curiosity. Another example of sensitivity is use of gender-inclusive language, which can be accomplished through, for instance, use of “less-gendered” terminology. Examples provided by Radix appear below, in Figure 6, below.

**Figure 6: Sample Gendered and Less-Gendered Terminology for Gender-Inclusive Language\***

\*Reprinted from Radix, Slide 8, April 10, 2018

<b>Gendered Terms</b>	<b>Less-Gendered Terms</b>
<ul style="list-style-type: none"> <li>• Vulva, penis, testicles</li> <li>• Labia or “lips”</li> <li>• Vagina</li> <li>• Uterus, ovaries, prostate</li> <li>• Breast</li> <li>• Pap smear, prostate exam</li> <li>• Bra, panties, briefs</li> <li>• Pads, tampons</li> <li>• Period, menstruation</li> </ul>	<ul style="list-style-type: none"> <li>• External Pelvic Area, outer parts</li> <li>• Outer folds</li> <li>• Genital or frontal opening, internal canal</li> <li>• Internal organs or parts</li> <li>• Chest</li> <li>• Cancer screening, HPV screening</li> <li>• Underwear</li> <li>• Absorbant product</li> <li>• Bleeding</li> </ul>

Also important is that care providers know and care for the body parts that a person has: not all transgender people have had or will have surgery and not all will use hormones. Radix cautioned against making assumptions and advised in favor of taking an inventory of anatomy and surgeries; the inventory Radix recommends appears in Figure 7. The anatomical inventory is particularly important to ensure that all age-appropriate disease screening is performed.

An electronic medical record may prohibit a true reflection of gender and anatomy. It may not be possible, for instance, to indicate that a patient identified as “female” has a penis.

Radix described feminizing gender-affirming surgeries and focused on vaginoplasty and labiaplasty to inform attendees about post-surgical follow-up and elements of a neovaginal exam. Use of an anoscope or a small vaginal speculum may increase comfort for transgender women. Transgender women will retain a prostate after surgery, and it will be palpable through the wall of the neovagina.

**Figure 7: Anatomic and Surgical Inventory for Care of Transgender Individuals\*\***

\*Reprinted from Radix, Slide 9, April 10, 2018

Anatomic Inventory	Surgery Inventory	
<ul style="list-style-type: none"> <li>■ Breasts</li> <li>■ Cervix</li> <li>■ Ovaries</li> <li>■ Penis</li> <li>■ Prostate</li> <li>■ Testes</li> <li>■ Uterus</li> <li>■ Vagina</li> </ul>	<ul style="list-style-type: none"> <li>■ Bilateral breast augmentation</li> <li>■ Bilateral orchiectomy</li> <li>■ Bilateral total reduction mammoplasty</li> <li>■ Forehead reconstruction</li> <li>■ Laryngeal feminization surgery</li> <li>■ Metoidioplasty</li> <li>■ Phalloplasty</li> <li>■ Reduction thyroid chondroplasty</li> </ul>	<ul style="list-style-type: none"> <li>■ Scalp advancement</li> <li>■ Scrotoplasty</li> <li>■ Soft tissue filler injections</li> <li>■ Urethroplasty</li> <li>■ Vaginoplasty, colon graft</li> <li>■ Vaginoplasty, penile inversion</li> <li>■ Voice surgery</li> <li>■ Other unlisted surgical procedures</li> </ul>

**STI screening:** Radix reminded all that when screening for STIs, care providers should screen all body parts that could be affected, which makes the anatomic inventory and the information acquired through the “6 P’s” questions essential. Also important is to offer transgender women the option of self-swabbing for STI screening.

The microflora of a neovagina is very different from that of a vagina; therefore, a transgender woman with a neovagina is not susceptible to the same STIs as a natal woman with a vagina. STIs that do occur include condyloma acuminatum (genital warts), *Neisseria gonorrhoeae* (gonorrhea), and bacterial vaginosis. Radix noted that there have been no case reports of chlamydia, trichomoniasis, or other STIs in this population. There are, however, other conditions that can mimic an STI, including fistulae (an abnormal “tunnel” that forms, often as a result of injury), granulation tissue (tissue that forms on a wound), and folliculitis (inflammation around a retained hair). Screening should be performed with swab-based (including self-collected swab samples), not urine-based, tests for STIs.

### People may not take PrEP or ART out of fear of drug interactions with their hormones.

**Prevention:** Radix affirmed the importance of a multifaceted approach to prevention, with PrEP as an important, but just one, component of HIV prevention for transgender women because the incidence is high and uptake is low. Radix reiterated points made by Klein, noting the many barriers to PrEP for transgender women: low knowledge, lack of transgender-inclusive marketing, mistrust of the medical system, being misgendered, and concerns about PrEP interactions with hormones. Radix stressed the need for clear communication about hormones so transgender women know that the drugs used for PrEP do not interact with hormones. Fear of drug-drug interactions can lead people to stop taking PrEP.

On the other hand, Radix also noted the dearth of research on PrEP in transgender women and the lack of data on interactions between antiretrovirals and hormones. In one study, PrEP was found to be effective in transgender people who took at least four doses per week, but data in transgender women specifically are lacking.

**Steps to improve prevention:** In closing, Radix detailed the actions necessary to improve HIV prevention among transgender women [Radix, Slide 25, April 10, 2018]:

- Integrate HIV prevention into sexual health and gender-affirming services
- Provide legal services to assist transgender individuals in getting their names and gender markers changed in their health and pharmacy records
- Expand research and increase understanding of possible interactions between antiretrovirals and hormones
- Ensure the availability of and access to knowledgeable peer navigators, counselors, and HIV testers
- Develop quality of care systems to identify and correct deficits
- Ensure that all education, marketing, messaging, and assessment tools are transgender inclusive

## Zil Garner Goldstein, FNP-BC

*Assistant Professor of Medical Education; Program Director, Center for Transgender Medicine and Surgery at Mount Sinai*

**Gender-Affirming Clinical Care for Transgender Women:** In presenting her observations on PrEP and healthcare for transgender women, Zil Garner Goldstein agreed with and expanded upon many of the points made by the speakers who preceded her. Garner Goldstein's talk, which did not include slides, was organized around the following themes:

- What does it mean to provide gender-affirming care?
- Medical mistrust engenders fear of PrEP.
- Sex work must be acknowledged.
- PrEP requires ongoing discussion.

**What does it mean to provide gender-affirming care?** Garner Goldstein pointed out a central dilemma inherent to any answer to this question by noting that any attempt to make a practice “gender-affirming” relies on a view of transgender and non-binary people as “other,” as exceptional. This is indicative of institutionalized transphobia in that the only way to ensure quality care for transgender people is to call them out, to make them exceptional, when, in fact, they should be entitled to the same quality of care as everyone else. She argued that what people want is to not be the only one, the one requiring something different.

### There is no good reason why healthcare practices can't accommodate everyone.

Gender-affirming care starts with an intake form that does not make a person have to guess the consequences of ticking the wrong box for sex: “If I'm a transgender woman, and I have a penis, how will the quality of my care be affected if I check 'female'? What will happen if I check 'male'?” Questions must be phrased with the needs of all in mind and accommodate all possible answers.

Gender-affirming care responds to the identity of all individuals by, for instance, asking every person rather than just transgender patients about desired pronouns and then using them. No assumptions about identity are made, nor are assumptions made about risk. Garner Goldstein suggested that every person should be asked such questions as, “Tell me a little about your sex life,” and “How do you like to have sex?” She also suggested that conversations about sex should be nuanced and positive rather than laser-focused on risky behavior, which can be stigmatizing. These conversations acknowledge the different ways that transgender women may have sex.

### Transgender people expect to be treated poorly . . . this has to change.

Gender-affirming care includes access to hormones for transgender people. Garner Goldstein stressed that the most important thing care providers can learn is how to prescribe hormones, which she described as life-saving: “You wouldn't make a patient wait to start treatment for HIV. Why would you make a patient wait to start hormone therapy? Being transgender is life threatening, as evidenced by the rates of murder, suicide, and depression; transgender people have poor mental health outcomes and are stigmatized.” Non-stigmatized care is care that meets the needs of individuals while ensuring that every individual receives high-quality care.

Garner Goldstein described gender-affirming care as care delivered by an educated and sensitive staff. She explained that education of all staff (administrators, receptionists, medical assistants, care providers, social workers, navigators, janitors—everyone) helps assure that clients are not subject to aggression in any form—from assault or ridicule to being misgendered or subject to unnecessary questioning. In such a setting, it's understood that mistakes will be made and that they will be addressed. And, ideally, transgender people will be among the staff members. It's also crucial to post policies regarding non-discrimination and confidentiality where they are visible and accessible to all and to enforce those policies.

**Medical mistrust.** Mistrust of the healthcare system engenders fear of PrEP. One source of mistrust is a lack of clarity regarding the question of the effect of PrEP on hormones. Garner Goldstein asserted that this question is so easy to answer that it's hard to understand why it's still an issue. It's clear that PrEP does not affect hormones, and there's no reason not to state that clearly.

One of the factors at play, she believes, is community-level mistrust, which means that one answer is to work hard to get more transgender women on PrEP to build community-level trust. The more people see others using PrEP and doing well with it, the more transgender women will be willing to try it. Positive role models are essential.

An important source of community mistrust is lack of information—not just about interactions with hormones, but also about what it's like to take PrEP. Garner Goldstein called for greater effort on the part of care providers in educating patients about

side effects or PrEP—what kinds of side effects to expect, for how long, and how they can they be managed. Transgender women community connections (including online) can be strong, which means that an influencer who talks or posts on a bad day with PrEP can have a negative effect on many: “People share when they’re feeling bad, and they rarely go back and correct their impressions once the side effects stop and they’re feeling good. But what others remember is the negative.” Care providers have to acknowledge and be forthcoming about side effects and help people manage them.

## When people say they don’t want to use PrEP or take ART because the medications are toxic, I remind them that HIV is toxic.

Garner Goldstein pointed out that care providers have to take responsibility for making sure that transgender women understand that PrEP will not affect their hormones. This can mean measuring hormone levels before a person starts PrEP and then measuring them later, for reassurance. It means checking in regularly and asking a patient if she feels as though her hormones are less effective. It means reinforcing the importance of adherence to the PrEP regimen just as adherence to other medications is stressed.

Concern about the interaction of PrEP and hormones is not a good reason for transgender women to avoid PrEP. That message has to be telegraphed by care providers and by people using PrEP. Garner Goldstein suggested that increasing PrEP uptake will require, among other efforts, targeted campaigns within the transgender women community and through social media: “The message has to be clear: If you are putting dangerous things in your body, it’s safer to be on this medication.”

On the other hand, care providers must acknowledge the limitations of medical knowledge. Garner Goldstein echoed Asa Radix’s point about lack of research on PrEP in transgender people. There are no data on efficacy in people with neovaginas, for instance, which means that care providers should advise transgender women using PrEP to be conservative in their estimation of protection, given that cisgender women are advised that PrEP must be taken for 21 consecutive days (which is longer than the 7 days recommended for cisgender men) to be efficacious.

**Sex work must be acknowledged.** Garner Goldstein affirmed that any discussion of PrEP among transgender women must include discussion of sex work and that it should not be an afterthought. Sex work is a reality for many transgender women, and it should be addressed forthrightly. The way the topic is addressed is important. Rather than asking, “Have you ever traded sex for money, housing, drugs, etc.,” which can be stigmatizing, Garner Goldstein posited that questions such as “How do you support yourself?” or “What’s your hustle?” will lead more readily to a discussion that opens with “Let’s keep you safe.”

As noted earlier in the day, Garner Goldstein agreed that HIV risk is an occupational hazard for a sex worker and is no different than other occupational hazards, such as sleep apnea for long-haul truckers. She pointed out that sex work will become even more dangerous now that the *Stop Enabling Sex Traffickers Act (SESTA)*; *Allow States and Victims to Fight Online Sex Trafficking Act (FOSTA)* has passed and sex workers can no longer advertise online. PrEP is an important tool for occupational safety, but that message can be delivered only if sex work is acknowledged.

Garner Goldstein also noted the importance of outreach to men who have sex with transgender women. She described three different groups that are affected by transgender women sex workers: the transgender women themselves, the men with whom they have sex, and any other people who have sex with those men. Any discussion of risk should include discussion of the transgender woman’s transmission network.

**PrEP requires ongoing discussion.** Garner Goldstein reminded all that although PrEP can (and should) be brought up at every encounter with a transgender women, not every encounter is about PrEP. People’s lives, sexuality, sex practices, risk, and understanding of risk change over time. Affirming the identity of individuals means recognizing that each person’s story and needs change. A person who turns down PrEP once, twice, even three times, may request it when it comes up a fourth time. Garner Goldstein agreed that PrEP is a subject worth revisiting often, but it’s just one aspect of quality care.

She acknowledged that people with chaotic lives may not see HIV risk as their most important problem. People with unmet basic needs will not prioritize PrEP and will need good reasons to consider it when they don’t have housing, food, transportation, or employment.

## Don’t expect someone to come in just for PrEP. People with chaotic lives need more than one reason to seek care or services.

Transgender women may have to be convinced to believe a care provider over their friends and the community on which they rely. Trust is key. Garner Goldstein encouraged building a relationship that encompasses a transgender woman's whole life, not just her health, and not just her sex life. Asking patients about all aspects of their lives affirms their identities as individuals while helping to build trust and conveying compassion. A transgender woman who trusts her PrEP provider will be more likely to believe information from that provider over information from friends.

## Highlights of Discussion Following Opening Remarks and Speaker Presentations

Lively discussion among all attendees followed the speaker presentations. Key points are highlighted below.

- It's difficult to know how to manage the tension between a desire for no exceptionalism (e.g., transgender people are just like all others, integrative care is the priority) vs. acknowledgment of relevant differences that are specific to transgender people.
- The answer is cultural competency and quality care for everyone.
- Transgender people should be able to go anywhere for care, but "transgender everywhere" is aspirational. Right now, transgender people need special care, need trauma-informed care.
- Transgender people may have to deal with multifaceted stigma: they may be subject to age discrimination, xenophobia, misogyny.
- It's important to make PrEP a part of any discussion of preventive medical care.
- Providers should access other resources, such as pharmacists, who can improve treatment/access.
- Discussions about PrEP must consider context (e.g., race, immigrant status) and individual needs (e.g., age and developmental stage; young transgender-feminine individuals may be less able to plan ahead).
- It's a good idea to marry PrEP and hormone treatment, but is it practical? There is no regimented follow-up for hormone therapy. Follow-up may be similar in the long run, but initially, PrEP requires more frequent follow-up. It would be useful to find a way to align PrEP and hormone provision.
- Greater effort should be made to integrate PrEP into community events and community discussion. Meetings such as this one, while important, may be too closed a circle—we need to go to the people who need PrEP and talk with them, not just talk among ourselves.
- Part of acknowledging sex work is acknowledging the realities of life as a sex worker; services are not available during the business hours kept by most sex workers and that should change if we want more sex workers to use PrEP.
- Many transgender women who engage in sex work may be undocumented immigrants who have no rights, and no ability to access PrEP. How can they be helped?

**PANEL DISCUSSION:****REAL-WORLD EXPERIENCES IN IMPLEMENTING PrEP FOR WOMEN****PANELISTS:**

- **Melanie Dulfo, LMSW**, Director of Community Health Education, Apicha Community Health Care, New York, New York
- **Timothy Au, LMSW**, Program Manager for Support Services, Apicha CHC, New York, New York
- **La'Mia Aiken**, TransCare Advocate, In Our Own Voices, Albany, New York

Panelists were invited to discuss their experiences in implementing PrEP for transgender women in a clinical setting (Apicha CHC) and a community-based organization (CBO) setting and were asked to describe the following aspects of their programs: utilization, service model, best practices, successes, and challenges. Presentations are summarized in Figures 8 and 9, on the following pages.

**Figure 8: Overview of Panelists' PrEP Implementation Programs**

<b>Melanie Dulfo and Timothy Au, Apicha Community Health Center, New York, New York</b>	
<b>Utilization</b>	<ul style="list-style-type: none"> <li>• 90 transwomen patients on PrEP for calendar year 2017</li> <li>• 63% were people of color</li> <li>• 59% were aged 18 to 29 years</li> <li>• 41% were aged 30 years or older</li> </ul>
<b>Service Model</b>	<ul style="list-style-type: none"> <li>• Engage individuals in care through multiple channels: Media/outreach, HIV/STI screening, coordination of care/navigation, primary care/PrEP, insurance/SNAP, and pharmacy</li> <li>• Multidisciplinary staff for service delivery: Medical care providers, mental healthcare providers, nurse managers, medical assistants, patient associates/assistants, pharmacists, project coordinators in key areas (transgender care, prevention, PrEP), case managers/navigators, insurance navigators</li> <li>• "It takes a village to start someone on PrEP and keep them on PrEP"</li> <li>• Make referrals to help patients meet needs for housing, food, and clothing</li> </ul>
<b>Best Practices</b>	<ul style="list-style-type: none"> <li>• Mobilize and educate to increase awareness, access, and destigmatization of PrEP in communities</li> <li>• Every person seen at Apicha is asked to complete a sexual health survey so that needs at that point in time can be identified and so the program can be responsive to those needs (i.e., for PrEP, it's essential to "strike while the iron is hot")</li> <li>• Navigators to help with systems and payment; many young people don't know anything about getting prescriptions filled, getting medication paid for, or other requirements for PrEP</li> <li>• Many people don't understand the commitment required of them to use a biomedical intervention for HIV prevention</li> <li>• Navigators follow up with patients and remind them about appointments</li> <li>• Reinforce idea that PrEP, like contraception, is a tool for safe and healthy sex</li> </ul>
<b>Successes</b>	<ul style="list-style-type: none"> <li>• Apicha's Chief Medical Officer was identified as "PrEP Champion"</li> <li>• Awareness of offering PrEP and serving PrEP patients is high</li> <li>• All primary care patients were given sexual health screening form prior to medical visit; this is an effective tool to start the conversation about sexual health and PrEP</li> <li>• Apicha is part of NYC DOHMH's PlaySure Network and is a designated clinical site for CBO referrals</li> </ul>
<b>Challenges</b>	<ul style="list-style-type: none"> <li>• Many resources have to be coordinated to deliver PrEP</li> <li>• Patients don't know much about PrEP, so education about pros/cons, managing side effects, adherence is crucial</li> <li>• Patients have different challenges at different times, which requires attention to their needs at different stages of engagement in PrEP care</li> </ul>



**Figure 8: Overview of Panelists' PrEP Implementation Programs, continued**

La'Mia Aiken, In Our Own Voices (IOOV), Albany, New York	
<b>Utilization</b>	<ul style="list-style-type: none"> <li>• IOOV members who identify as transgender women and are using PrEP range in age from 26 to 50 years; it is a small but diverse population in upstate New York               <ul style="list-style-type: none"> <li>- 98% of linkages to care and referrals were among transgender women of color, of whom approximately:</li> <li>- 30% were active sex workers</li> <li>- 40% did not engage in sex work</li> <li>- 90% abused substances regularly</li> <li>- 100% did not engage in traditional monogamous relationships</li> </ul> </li> </ul>
<b>Service Model</b>	<ul style="list-style-type: none"> <li>• Utilized the experiences and feedback of the transgender/non-binary community in developing programs and policies</li> <li>• Services are for us and by us, dubbed "FUBU" by Ms. Aiken</li> <li>• Provide free rapid HIV and HEP C on-site testing with linkages to community partners</li> <li>• Provide easy access through walk-in services, appointments, and off site/home visits for the shut-in/homebound; go to people who need service</li> <li>• Strength-based, sex positive, harm-reduction approaches to service provision</li> <li>• Peers help provide services</li> </ul>
<b>Best Practices</b>	<ul style="list-style-type: none"> <li>• Assuring that service spaces are culturally specific, safe, and affirming and welcoming other services into that space</li> <li>• Engaging a diverse selection of community-based PrEP providers</li> <li>• Assessing individual and community health needs quarterly or annually</li> <li>• Providing transgender/non-binary-specific training and technical assistance to community partners</li> <li>• Open, ongoing conversations about sex work</li> </ul>
<b>Successes</b>	<ul style="list-style-type: none"> <li>• Providing services that are "FUBU"</li> <li>• Development of a "transgender team," instead of a token transgender person</li> <li>• Providing space for PrEP providers to deliver in-service training for the community</li> <li>• Developing educational materials to address the side effects and costs of PrEP</li> <li>• Facilitating ongoing dialog about U=U and ways to engage sex partners in PrEP</li> <li>• Training community PrEP providers, which demonstrated to the transgender community that the care providers are trusted</li> </ul>
<b>Challenges</b>	<ul style="list-style-type: none"> <li>• Developing an intimate knowledge of the dynamics, trends, behaviors, and needs of the transgender/non-binary community being served to avoid a "cookie cutter approach" to services and interactions</li> <li>• Understanding the importance of MOUs/community partnerships</li> <li>• Working with medical care providers who may not know how to work with the transgender/non-binary community</li> </ul>

PANELISTS’ SHARED SUCCESSSES, CHALLENGES, AND PRIORITIES

Figure 9: Successes, Challenges, and Priorities Shared by Two Programs Currently Implementing PrEP for Transgender Women in New York

SHARED SUCCESSSES	SHARED CHALLENGES	SHARED PRIORITIES
Engaging transgender women and care providers through multiple channels	Coordination of many services	Delivering services that are “for us and by us” (FUBU)
Helping transgender women navigate PrEP-related care and payment systems	Understanding the needs of the transgender/non-binary community	Meeting as many needs as possible for the transgender community, not just PrEP and other healthcare needs
Raising community awareness of PrEP	Educating transgender women and their care and service providers about PrEP	Avoiding a “cookie-cutter” approach to service delivery

## SUMMARY OF BREAKOUT SESSIONS AND REPORT OUT

Meeting participants were divided into three groups and invited to rotate through three breakout sessions, each of which addressed topics identified in advance as important to any discussion of PrEP implementation for transgender women. Group discussions were facilitated by AIDS Institute staff, who then reported on the groups' responses to questions about the following:

1. Access to PrEP among transgender women
2. Retention in PrEP care for transgender women
3. PrEP public health program design

Figure 10, below, presents the conclusions reached by the groups who engaged in the breakout session discussions.

### SESSION 1: ACCESS TO PrEP AMONG TRANSGENDER WOMEN

**Figure 10: Summary of Break-Out Session Discussions**

<b>QUESTIONS:</b> <ul style="list-style-type: none"> <li>• What issues and challenges related to PrEP access are unique to transgender women?</li> <li>• What are the keys to success and best practices for ensuring that transgender women have access to PrEP?</li> <li>• What policy changes are needed to increase access to PrEP for transgender women?</li> </ul>		
Issues and Challenges	Keys to Success	Needed Policy Changes
<ul style="list-style-type: none"> <li>• Cost, lack of funding, and inability of people who are not on Medicaid or who are undocumented to pay for PrEP.</li> <li>• Fear of judgment and stigma.</li> <li>• Care providers who insist on PrEP as a gateway to care when some people just want PrEP.</li> <li>• PrEP is most often available in the same settings as HIV care, which is stigmatizing.</li> <li>• The great need for wrap-around services and healthcare services and pushing PrEP before other (basic) needs are met.</li> <li>• Funding and messaging has been directed largely toward MSM, which excludes TGW.</li> <li>• PrEP and hormones are provided in different settings; transgender women prioritize hormones.</li> <li>• Needs of transgender women of color specifically are not recognized and are not being met.</li> <li>• Not enough peer role models to provide outreach and education.</li> </ul>	<ul style="list-style-type: none"> <li>• Knowledgeable assistance/ navigation to help transgender women identify payment options and satisfy the requirements of insurers and public payment programs.</li> <li>• Collaboration and partnership between medical care providers and non-medical service providers.</li> <li>• Identifying and eliminating structural barriers.</li> <li>• Ensure transportation and other services to meet basic needs for transgender women, including help with legal issues such as name and gender marker changes.</li> <li>• Advertising and education tailored to transgender women so they know where to go for healthcare in general and PrEP specifically.</li> <li>• Programming to help reduce housing instability.</li> <li>• Increased funding.</li> <li>• Welcoming, safe, and gender-affirming settings.</li> <li>• Hiring transgender women to staff healthcare and service settings.</li> <li>• Ensure access to hormone therapy along with PrEP.</li> <li>• Engaging peers to provide education and outreach.</li> </ul>	<ul style="list-style-type: none"> <li>• Decriminalize sex work.</li> <li>• Update the K-12 sexual health curriculum to be transgender inclusive and to address sexual health.</li> <li>• Ensure that PEP services are prioritized in emergency departments.</li> <li>• Hold recipients of state funding accountable for ensuring transgender-inclusive services: hiring transgender people, providing gender-affirming care, etc.</li> <li>• Require specific allocations of funding for transgender care.</li> </ul>
<b>PRIORITIES:</b> <ol style="list-style-type: none"> <li>1. Ensure a diverse array of locations for accessing PrEP, including pharmacies.</li> <li>2. Provide PrEP detailing for hormone therapy providers.</li> <li>3. Increase funding for programs designed to reach and engage transgender women.</li> <li>4. Provide wrap-around services for transgender women whose needs extend beyond PrEP.</li> <li>5. Reduce barriers to employment for transgender people.</li> </ol>		

## SESSION 2: RETENTION IN PrEP CARE FOR TRANSGENDER WOMEN

Figure 10: Summary of Break-Out Session Discussions, continued

QUESTIONS:		
<ul style="list-style-type: none"> <li>• What issues and challenges related to retention in PrEP care are unique to transgender women?</li> <li>• What are the keys to success and best practices for retaining transgender women in care?</li> <li>• What policy changes are needed to support retention in PrEP care for transgender women?</li> </ul>		
Issues and Challenges	Keys to Success	Needed Policy Changes
<ul style="list-style-type: none"> <li>• Public payment options are not well advertised and not well known.</li> <li>• Fear of interactions between hormones and PrEP.</li> <li>• Chaotic lives of many transgender women, especially those who are unemployed and/or engaged in commercial sex work.</li> <li>• Messaging is not transgender inclusive.</li> <li>• Parents of young transgender-feminine individuals may not support use of PrEP.</li> <li>• Young transgender-feminine individuals may have different social support networks if they have been kicked out of home, don't attend school, etc.</li> <li>• Care providers and transgender women may find it difficult to discuss sex, sex practices, sex history, and sexual risk of HIV, which has to be an ongoing conversation.</li> <li>• Incarceration may disrupt use of PrEP.</li> <li>• Recognizing when a person's season of risk is over and PrEP is no longer needed, but stopping PrEP shouldn't mean that other medical services are cut off.</li> </ul>	<ul style="list-style-type: none"> <li>• Make PrEP and hormone therapy available at the same place, from the same provider, and on the same schedule.</li> <li>• Clear communication about safety of PrEP with hormones.</li> <li>• Attend to assessing the mental health of transgender women and providing mental healthcare.</li> <li>• Ensure that care providers are educated: About the needs of transgender women, about PrEP, and about gender-affirming care.</li> <li>• Meeting other needs, such as housing and transportation.</li> <li>• Apply HIV retention lessons learned to PrEP retention.</li> <li>• Hire transgender people in service and care settings.</li> <li>• Maintain relationships through any means possible, e.g., reminders of appointments, social media, email.</li> <li>• Combine low-threshold mobile services with community outreach.</li> <li>• Leverage the transgender community to improve education through word of mouth.</li> <li>• Make PrEP an ongoing discussion.</li> <li>• Include transgender women in program planning.</li> <li>• Ensure that staff are culturally competent.</li> </ul>	<ul style="list-style-type: none"> <li>• Require medical schools to provide training in transgender care.</li> <li>• Ensure inclusivity through all components of work on PrEP, from program design, to messaging and education, to service delivery and outreach.</li> <li>• Reject laws that harm transgender women and pass laws that prohibit discrimination against transgender people.</li> <li>• Eliminate the requirement of a "gender dysphoria" diagnosis in order for people to have transgender-related healthcare covered.</li> <li>• Remove unnecessary and overly medicalized barriers to PrEP access: not sustainable at four required medical visits per year.</li> <li>• Decriminalize sex work.</li> <li>• Eliminate or at least reduce barriers to employment.</li> </ul>
<p><b>PRIORITIES:</b></p> <ol style="list-style-type: none"> <li>1. Effective advertising of PrEP-AP to ensure that transgender women are informed about this benefit.</li> <li>2. Eliminating the required diagnosis of "gender dysphoria" for insurance coverage for transgender women's healthcare.</li> <li>3. Decriminalize sex work.</li> </ol>		

## SESSION 3: PrEP PUBLIC HEALTH PROGRAM DESIGN

Figure 10: Summary of Break-Out Session Discussions, continued

<b>QUESTIONS:</b> <ul style="list-style-type: none"> <li>• Describe the ideal PrEP public health program for transgender women.</li> <li>• What are the keys to success and best practices for PrEP programs for transgender women?</li> <li>• What policies are needed to support effective PrEP public health programs for transgender women?</li> </ul>		
Issues and Challenges	Keys to Success	Needed Policy Changes
<ul style="list-style-type: none"> <li>• Healthcare + CBO.</li> <li>• Transgender people on staff.</li> <li>• Multiple locations and diversity of settings, statewide.</li> <li>• Include services for people recently incarcerated.</li> <li>• Include as many services as possible under the umbrella of “public health.”</li> <li>• Prioritize provision of hormone therapy, statewide.</li> <li>• Equal representation of transgender people in programming.</li> <li>• Involve transgender women in all aspects of program planning and design.</li> <li>• Patient-focused, with clinical and non-clinical providers.</li> <li>• Leadership includes transgender people.</li> <li>• Emphasis on services that are for us and by us.</li> <li>• Designed to reduce social isolation in rural settings.</li> <li>• Includes social work and legal assistance to help with name changes, changes to birth certificates, etc.</li> </ul>	<ul style="list-style-type: none"> <li>• Increasing awareness so clients know to seek PrEP.</li> <li>• Reduce barriers to employment for transgender women.</li> <li>• Normalize PrEP—build it into many aspects of care and services.</li> <li>• Ensure that all people and all services that interact with transgender women are culturally competent, sensitive to their needs, and gender-affirming.</li> <li>• Creation of spaces designed specifically with transgender women in mind—create spaces that transgender women love.</li> <li>• Active engagement of transgender people as care/service providers.</li> <li>• Focus on services for transgender women first and on PrEP second.</li> <li>• Help clients meet basic needs first: housing and food security, transportation, safety, hormone therapy.</li> <li>• Streamline the number of hand-offs to prevent people from being lost to care.</li> </ul>	<ul style="list-style-type: none"> <li>• Passage of Gender Expression Non-Discrimination Act (GENDA).</li> <li>• Elimination of healthcare exclusionary clauses.</li> <li>• Expedited approval of injectable PrEP.</li> <li>• Enforce collection of Sexual Orientation and Gender Identity (SOGI) data in electronic medical records.</li> <li>• Enforced assessment requirements to ensure culturally-sensitive and gender-affirming care; establish quality programs that address transgender care specifically.</li> <li>• Enforce policy that requires change in gender markers prior to surgery.</li> <li>• Establish a reporting mechanism for violation of existing policies that protect transgender people.</li> <li>• Require training to reduce stigma and discrimination.</li> <li>• Make sex work licensed and legal.</li> </ul>
<b>PRIORITIES:</b> <ol style="list-style-type: none"> <li>1. Increase opportunities for transgender people to provide healthcare and social services to other transgender people.</li> <li>2. Decriminalize sex work and protect sex workers' rights.</li> <li>3. Increase funding for services for transgender people.</li> <li>4. Address transgender people as whole people, with many different needs, through services that integrate clinical and non-clinical care.</li> <li>5. Train all people who interact and provide services for transgender people to build sensitivity, cultural competency, and gender-affirming awareness.</li> </ol>		

## CONCLUSIONS:

### PRIORITIES FOR CHANGE TO EXPAND ACCESS TO AND AVAILABILITY OF PrEP FOR TRANSGENDER WOMEN IN NEW YORK STATE

Transgender women in NYS are particularly vulnerable to HIV infection as a result of social, behavioral, and structural factors, including stigma and discrimination; low employment and poverty; engagement in commercial sex work for survival; and lack of recognition and acknowledgment in programming, messaging, and education related not just to PrEP, but to basic healthcare and services.

As a result, transgender women, particularly young transgender women and transgender women of color, are at great risk of acquiring HIV, and awareness of and uptake of PrEP is low among this population.

Barriers to PrEP access and uptake are formidable, but progress is being made as the needs of this group are increasingly recognized and addressed. Nonetheless, much work remains to be done to increase availability of PrEP and to ensure that transgender women have access to this important tool for preventing acquisition of HIV.

### KEY ISSUES AND PRIORITIES FOR CHANGE

This forum convened stakeholders from throughout New York to identify impediments to PrEP access and uptake among transgender women throughout the state. Many barriers and potential solutions were identified. However, several key issues emerged.

**Inadequate care and service delivery environments:** Transgender women cannot count on welcoming, safe, and gender-affirming settings to access PrEP, or other healthcare needs, or essential services. As a result, many transgender women express fear of the healthcare system and care providers, which may keep them from seeking care beyond what is needed to access hormone therapy. When they do seek care, they may be subjected to humiliation or ridicule, may be required to educate their care providers about how to provide care for transgender women, and may be misgendered or otherwise denied affirmation of their identity. There are many concrete steps that can be taken in the public and private sectors to improve this state of affairs, but education and cultural competency is needed first to foster acknowledgment of this problem and raise awareness of the needs of transgender people.

#### Priorities For Change:

- Foster “for us and by us” healthcare and service delivery and increase opportunities for transgender people to provide healthcare and social services to other transgender people.
- Increase funding for transgender-centered programs.
- Increase and diversify the settings that offer healthcare and services for transgender women.
- Train all care and service providers and all staff members to increase cultural competency and sensitivity and to ensure that gender affirmation is a given.
- Ensure that advertising, educational materials, messaging, assessment tools, and electronic medical records speak to and accommodate the needs of transgender people.

**Social oppression, stigmatization, and discrimination:** Gus Klein reported low employment among his study participants, a finding that mirrors that of the [2015 U.S. Transgender Survey](#), which reported low employment, low education, and high levels of poverty among the 28,000 respondents across the country. Klein also reported that study participants describe commercial sex work as a means of survival, and Aiken reported a high number of program participants engaged in sex work. Discrimination that keeps transgender people from accessing employment may force some to engage in work that exposes them to risk of violence, incarceration, and disease. These individuals are then often stigmatized for engaging in activity that ensures their economic survival. Non-stigmatizing approaches, such as offering PrEP for protection against an occupational hazard, opens access by reducing stigma and supporting empowerment. Making PrEP available with hormones further decreases stigma and expands access to both of these life-saving therapies.

**Priorities For Change:**

- Ensure and enforce anti-discrimination laws to protect the rights of transgender students and employees and reduce barriers to employment.
- Provide wrap-around services for transgender women to ensure that basic healthcare and other essential needs are met.
- Eliminate the required diagnosis of “gender dysphoria” for insurance coverage.
- Decriminalize sex work and protect sex workers' rights.
- Normalize discussions of sex work and associated risks.

**Awareness of transgender women's healthcare and other needs is lacking:** Dr. Radix made clear that there are established best practices for providing sexual healthcare for transgender women, and there are comprehensive guidelines available from sources such as the [UCSF Center of Excellence for Transgender Health](#). Yet training in medical school is not standard, so basic practices, such as taking an anatomical inventory to ensure proper care, are not standard, either. As a result, transgender women have to seek out informed care providers, and, as suggested by Zil Garner Goldstein, they mostly expect that the medical care they receive will be uninformed or poor overall.

Another important aspect of healthcare and PrEP care for transgender women that was mentioned repeatedly, is that PrEP may be low on the list of priorities for transgender women, many of whom cannot meet the most basic of needs, such as secure housing, reliable sources of food and transportation, and employment that does not threaten physical and/or psychological wellbeing. The need to meet basic needs first was stressed by many throughout the day.

Other needs that impede access to and uptake of PrEP include payment assistance. Many acknowledged that, although there are sources of payment assistance, many transgender women don't know about them, and most need help navigating the systems through which assistance is available.

Finally, many stressed the primacy of hormone therapy in the lives of transgender women and suggested that one of the most important steps that can be taken to increase PrEP use among transgender women is to ensure that hormone therapy and PrEP therapy can be accessed simultaneously. Transgender women should be able to get prescriptions and follow-up for both therapies at the same location, with the same care provider, and on the same schedule.

**Priorities For Change:**

- Educate healthcare providers to ensure promulgation of best practices in medical care of transgender women.
- Integrate clinical and non-clinical care.
- Expand research on PrEP for transgender women.
- Recognize and respond to the primacy of hormone therapy by making hormones available at the same places, from the same care providers, and on the same schedule as PrEP; train care providers to ensure they can and are comfortable providing both.
- Ensure that transgender women are informed about payment options and have assistance in accessing them.

Key issues and priorities for changes are summarized in Figure 11, next page.

Figure 11: Summary of Priorities for Increasing Access to and Uptake of PrEP Among Transgender Women in NYS

**PrEP for Transgender Women Forum attendees identified the following as priorities for change to foster expanded access to and uptake of PrEP among transgender women in New York State in the next 3 to 5 years:**

### **1. Improve care and service delivery environments:**

- Ensure cultural competency among all who interact with transgender women so they can expect safe, gender-affirming care always.
- Increase funding for transgender-centered services and expand the number and diversity of settings that provide PrEP and other healthcare for transgender women.
- Increase opportunities for transgender people to work in care- and service-delivery settings, and foster commitment to hiring and training transgender people for this type of work.
- Create marketing and messaging specifically designed to reach transgender women.

### **2. Reduce social oppression, discrimination, and stigmatization:**

- Enforce anti-discrimination laws already in place to protect the rights of transgender people; facilitate passage of new laws that offer further protection.
- Tailor services to meet the social, economic, and healthcare needs of transgender women; PrEP will not be a priority for transgender women in need of housing and food security, transportation, and basic healthcare.
- Decriminalize sex work and protect sex workers' rights. Sex work is survival for transgender women and others who face social and structural barriers to employment.
- Focus on occupational safety in discussions of PrEP; HIV risk is an occupational hazard for sex workers.

### **3. Improve awareness and knowledge of transgender women's healthcare needs:**

- Require training in best practices in care of transgender women for all medical care providers.
- Offer non-clinical care in the same settings as clinical care, as wrap-around services.
- Promote research on PrEP efficacy in transgender women.
- Bundle hormone therapy with PrEP, always.
- Expand advertising, education, and payment options for PrEP, and ensure that all campaigns and materials are transgender inclusive.



## APPENDIX A: MEETING AGENDA

- 9:30 AM–9:40 AM **Welcome and Introductions:**  
Laura Duggan Russell, MPH, Senior Program Coordinator, Office of the Medical Director, NYS DOH AIDS Institute
- 9:40 AM–9:50 AM **Opening Remarks:**  
Johanne Morne, Director, NYS DOH AIDS Institute
- 9:50 AM–10:00 AM **Opening Remarks:**  
Oni Blackstock, MD, Assistant Commissioner, Bureau of HIV/AIDS Prevention and Control, NYC DOHMH

### PART I: INVITED SPEAKERS

- 10:00 AM–10:30 AM **Facilitators and Barriers to PrEP Among Transgender Women in New York City**  
Gus Klein, MSW, Hunter HIV/AIDS Research Team
- 10:30 AM–11:00 AM **Sexual Health for Transgender Women**  
Asa Radix, MD, MPH, FACP, Senior Director of Research and Education, Callen-Lorde Community Health Center; Clinical Associate Professor of Medicine at New York University
- 11:00 AM–11:30 AM **Gender-Affirming Clinical Care for Transgender Women**  
Zil Garner Goldstein, FNP-BC, Assistant Professor of Medical Education; Program Director, Center for Transgender Medicine and Surgery at Mount Sinai
- 11:30 AM–12:00 PM **Questions & Answers**

### PART II: WORKING LUNCH WITH PANEL DISCUSSION

- 12:15 PM–1:00 PM **Real-World Experiences in Implementing PrEP for Transgender Women**
- Melanie Dulfo, LMSW, Director of Community Health Education, Apicha Community Health Center, New York, New York
  - Timothy Au, LMSW, Program Manager for Support Services, Apicha CHC, NY, NY
  - La'Mia Aiken, TransCare Advocate, In Our Own Voices, Albany, New York
- 1:00 PM–1:15 PM **Questions & Answers**

### PART III: ROUND-ROBIN BREAKOUT SESSIONS

- 1:15 PM–2:45 PM **Participant Discussions:** Attendees will circulate through three 25-minute breakout sessions to discuss their experiences with the following key topics in PrEP implementation for transgender women: 1) Access to PrEP; 2) PrEP Retention; 3) PrEP Public Health Program Design. After 25 minutes of discussion in one session, participants will be directed to the next session until everyone has had the opportunity to participate in each of the three sessions. After a short break, we will gather to report out and identify priorities for policy and change.

### PART IV: PRIORITIES FOR POLICY AND CHANGE: REPORTS FROM BREAKOUT SESSIONS

- 3:00 PM–3:45 PM **Report Out: Successes, Challenges and Priorities for Change:** Session leaders will report out to the whole group with the goal of identifying the top 3-5 items in each of the following areas:
- Issues and challenges unique to PrEP implementation
  - Keys to success, including best practices for engagement
  - Policies needed to increase PrEP uptake
  - Priorities for change to guarantee success in the next 3 years
  - Based on concerns and solutions identified are there suggested policy changes/program changes/interventions?
- 3:45 PM–4:00 PM **Next Steps and Closing Remarks:** Laura Duggan Russell

## APPENDIX B: SPEAKER BIOS

### Johanne Morne, MS

Ms. Morne currently serves as Director of the New York State Department of Health (NYS DOH) AIDS Institute. The AIDS Institute has a broad mission including hepatitis and sexually transmitted disease (STD) services, surveillance, opioid overdose prevention, and non-HIV Lesbian, Gay, Bisexual, and Transgender (LGBT) services into its structure. The AIDS Institute formulates policy related to HIV, hepatitis, STDs, drug user health, and LGBT health and human services; initiates, develops, and evaluates programs for the delivery of HIV, hepatitis, and STD prevention, healthcare and supportive services as well as drug user health and LGBT health and human services; establishes clinical standards and oversees quality management; educates healthcare providers and the public; and guides regional and statewide planning. In its more than 30-year history, the AIDS Institute has provided leadership in NYS, at the national level, and internationally. Ms. Morne's leadership advanced the State's deliberations related to Undetectable=Untransmittable and led the NYS DOH to sign on to the U=U consensus statement. New York was the first state to do so. Ms. Morne currently serves as a board member of the National Alliance of State and Territorial AIDS Directors (NASTAD). Ms. Morne is also an honoree in the 2017 POZ 100: Celebrating Women. Prior to joining the State Health Department, Ms. Morne served as quality manager of psychiatry and HIV services at a Designated AIDS Center hospital and director of community-based HIV services at a federally qualified health center. Ms. Morne's professional and clinical experience is in public health and behavioral health, particularly within communities of color.

### Oni Blackstock, MD

Dr. Blackstock is Assistant Commissioner for the New York City Department of Mental Health and Hygiene's Bureau of HIV/AIDS Prevention and Control. She is a primary care physician, HIV specialist, and researcher who has developed, implemented, and evaluated innovative community and clinic-based programs to promote HIV treatment and prevention. Dr. Blackstock is at the forefront of local efforts to increase access and uptake of biomedical HIV prevention technologies among cis and trans women who engage in transactional sex or inject drugs. She received her undergraduate and medical degrees from Harvard University, and her MHS from Yale School of Medicine in the Robert Wood Johnson Foundation Clinical Scholars Program. She trained in primary care internal medicine at Montefiore Medical Center in the Bronx and completed a fellowship in HIV medicine at Harlem Hospital.

### Gus Klein, MSW

Gus Klein is a doctoral candidate in Social Welfare at the CUNY Graduate Center and a research associate at the Hunter HIV/AIDS Research Team. He conducts community-based participatory research on health disparities in the transgender and non-binary communities. He is also a social worker who has been working with diverse communities in a variety of settings for the past 20 years.

### Asa Radix, MD, MPH, FACP

Dr. Radix is the Senior Director of Research and Education at the Callen-Lorde Community Health Center and a Clinical Associate Professor of Medicine at New York University. Dr. Radix has over 20 years of experience providing HIV care, primary care, and hormone therapy to transgender and gender non-binary people. Dr. Radix has contributed to multiple national and international guidelines in transgender health and is currently Co-Chair of the World Professional Association of Transgender Health (WPATH) Standards of Care version 8 working group and a member of the HHS Panel on Antiretroviral Guidelines for Adults and Adolescents.

### Zil Goldstein, FNP-BC

Zil Goldstein is an Assistant Professor of Medical Education at the Icahn School of Medicine and the Program Director at the Center for Transgender Medicine and Surgery at Mount Sinai. She has served as a clinical specialist in transgender and HIV health at multiple institutions, and, with over 10 years of experience in managing the healthcare of transgender individuals, has played an instrumental role in building transgender services throughout the Mount Sinai Health System.

**Melanie Dulfo, LMSW**

Melanie Dulfo started as a Peer Educator in HIV prevention and is now the Director for Community Health Education at Apicha CHC. She launched linkage and navigation services for Apicha CHC's HIV prevention projects, including linking and coordinating clients to PrEP treatment and has learned many lessons in integrating services, from outreach to retaining people in care.

**Timothy Au, LMSW**

Timothy Au, Program Manager for Support Services, assists the Support Services department in overseeing of programs implementation, including supervision of the PrEP navigation services and Trans Health Care Services. Mr. Au holds a Master's degree in Social Work and has obtained license from the New York State Board of Education as a Licensed Master Social Worker. Mr. Au has over 7 years' experience in case management of clients living with HIV/AIDS as well as managing case management services.

**La'Mia White-Revlon Aiken**

Also known as Mother, La'Mia White-Revlon is the Voice for her fellow brothers and sisters. From her humble beginning over 20 years ago in church serving as a youth Minister as a teen, leading up to her service as an Elder as an adult, La'Mia has always been determined not only to be visible but vocal for her peers' rights to be heard. Upon entering the LGBT community in 2004 she founded The House of Encore. The House of Encore would be the platform in which La'Mia would use to reach a target population desperately in need representation. With the goal of making a meaningful difference, La'Mia joined forces with In Our Own Voices, where she started off as volunteer and worked her way up to a Peer Educator, Facilitator for "T-SISTA," and Ball Promoter for our annual Black and Latino Gay Pride. Now as a full-time employee, to date La'Mia is continuing with her passion by getting involved in issues surrounding transgender equality and awareness and HIV/AIDS prevention. She is working diligently to end the HIV/AIDS epidemic by 2020 in NYS.

## APPENDIX C: PrEP PAYMENT OPTIONS

**Minor Consent:** Amendments to New York’s health regulations allow minors to consent to their own HIV treatment and HIV preventive services such as pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (PEP) without parental/guardian involvement (10 NYCRR Part 23)

<b>Payment Options for Adults and Adolescents for Pre-Exposure Prophylaxis (PrEP)</b> <i>NYSDOH AIDS Institute—Updated January 2018</i>	
<b>Commercial Insurance</b>	<ul style="list-style-type: none"> <li>• Most commercial insurance plans cover PrEP for adults and adolescents.</li> <li>• Coverage varies based on plan. There may be deductibles and co-payments.</li> <li>• Adolescents may ask that the EOB be sent to another address but parents may still receive financial information such as co-payments made. This is permitted under Insurance Law 2612(h)(2)(A) and Title 11 of NYCRR, section 23.4.</li> <li>• Co-pay coupons are available through the manufacturer regardless of income.</li> <li>• Gilead: 1-877-505-6986.</li> </ul>
<b>Fee-for-Service Medicaid</b> <b>Helpline: 1-800-541-2831</b>	<ul style="list-style-type: none"> <li>• Medicaid covers PrEP for adults and adolescents, including PrEP prescription.</li> <li>• Costs, medical appointments, and lab tests.</li> <li>• Medicaid does not issue EOBs so adolescent confidentiality is protected.</li> <li>• Prior approval is required and renewed every 3 months.</li> </ul>
<b>Medicaid Managed Care</b>	<ul style="list-style-type: none"> <li>• Medicaid Managed Care Plans (MMCPs) cover PrEP for adults and adolescents.</li> <li>• Prior authorization requirements may vary among plans.</li> <li>• MMCPs are required to send notice upon a service or claim denial, where the denial was not based on medical necessity, the enrollee already received the service, and the enrollee is not liable for the cost of the service, consistent with the Department of Health’s Policy for the Protection of Confidential Health Information for Minors Enrolled in NYS MMCPs.</li> <li>• An adolescent may work with their plan or provider to obtain consent to send notices to an alternate address.</li> </ul>
<b>PrEP Assistance Program (PrEP-AP)</b> <b>Hotline: 1-800-542-2437</b>	<ul style="list-style-type: none"> <li>• PrEP-AP serves adults and adolescents, who are residents of New York State (NYS) and are uninsured or underinsured and prescribed PrEP.</li> <li>• Financial eligibility is based on 435% of the Federal Poverty Level (FPL).</li> <li>• Covers costs of clinical visits and lab testing for uninsured and underinsured individuals. Services include HIV, STI/STD testing, counseling, and supportive primary care services consistent with clinical guidelines for PrEP.</li> <li>• PrEP medication is not covered by PrEP-AP. Manufacturer’s patient assistance programs (listed below) should be contacted for uninsured or underinsured individuals.</li> <li>• Providers that are enrolled in the NYS Medicaid Program are eligible to enroll in PrEP-AP. To become a PrEP-AP provider contact the ADAP Provider Relations Section at 1-518-459-1641 or email <a href="mailto:damarys.feliciano@health.ny.gov">damarys.feliciano@health.ny.gov</a> for more information.</li> <li>• Providers are responsible for assisting patients with the patient assistance program application to receive Truvada as PrEP.</li> </ul>
<b>New York City</b>	<ul style="list-style-type: none"> <li>• In New York City, there are other options available for low cost access to PrEP. Visit the NYC Health Map. Select “Sexual Health Services” from the services menu. Then select “PrEP and PEP” and “Sliding Scale for Uninsured” under “Cost” to find locations offering this service.</li> </ul>

<b>Payment Options for Adults and Adolescents for Pre-Exposure Prophylaxis (PrEP), continued</b> <i>NYSDOH AIDS Institute—Updated January 2018</i>	
<b>New York State</b>	<ul style="list-style-type: none"> <li>• NYSDOH-funded Adolescent/Young Adult Specialized Care Center providers can provide information and assistance navigating PrEP services and payment options for adolescents and young adults 13 -24 years old. Contact amcare@health.ny.gov to find the nearest provider.</li> </ul>
<b>Gilead Co-Pay Coupon Card</b> <b>1-877-505-6986</b>	<ul style="list-style-type: none"> <li>• Covers up to \$4,800 per year in prescription co-payments.</li> <li>• Patient must have commercial insurance.</li> <li>• Patient must NOT be enrolled in Medicare or Medicaid.</li> <li>• No income eligibility requirement.</li> <li>• For individuals under the age of 18 a patient representative will need to attest/ sign on the minor's behalf.</li> </ul>
<b>Gilead Truvada for PrEP Medication Assistance Program</b> <b>1- 855-330-5479</b>	<ul style="list-style-type: none"> <li>• Covers prescription costs.</li> <li>• Patient must be uninsured or their insurance does not cover any prescription cost.</li> <li>• Patient must have annual income less than 500% of the FPL based on household size.</li> <li>• For individuals under the age of 18 a patient representative will need to attest/ sign on the minor's behalf.</li> </ul>
<b>Patient Advocate Foundation Co-Pay Relief Program</b> <b>1-866-512-3861</b>	<ul style="list-style-type: none"> <li>• Provides financial assistance to financially and medically qualified patients for co-payments, co-insurance, and deductibles.</li> <li>• Offers grant of up to \$7,500 per year.</li> <li>• Patients, their medical providers, or their pharmacists may submit applications 24 hours a day online or via phone Monday - Friday 8:30am – 5:30pm EST.</li> <li>• Patient must be currently insured and have coverage for the medication.</li> <li>• Patient must have annual income less than 400% FPL.</li> <li>• Individuals under the age of 18 years may participate with parental/guardian consent.</li> </ul>
<b>Helpful Resources</b>	
<b>Partnership for Prescription Assistance Program</b> <b>1-888-477-2669</b>	<ul style="list-style-type: none"> <li>• Online resource that helps uninsured and underinsured patients find programs that provide prescription medicines at low or no cost.</li> <li>• Complete a brief questionnaire with basic information including prescription medicines, age, income and current prescription coverage (if any). PPA searches its database for prescription assistance programs that might be able to help and displays the results.</li> </ul>
<b>Gilead Advancing Access</b> <b>1-800-226-2056</b>	<ul style="list-style-type: none"> <li>• Helps guide patients through the process of understanding the type of insurance they have and alternative coverage if needed.</li> <li>• Can help match patients to a program that best meets their financial needs based on their particular circumstances, insurance situation and the eligibility criteria for the programs.</li> </ul>

## APPENDIX D: RESOURCES

### PrEP/PEP Directories

- NYS Department of Health PrEP/PEP Voluntary Provider Directory: [www.providerdirectory.aidsinstituteny.org](http://www.providerdirectory.aidsinstituteny.org)
- NYS Department of Health PrEP-AP Participating Provider Directory: [http://www.health.ny.gov/diseases/aids/general/pep/docs/pep-ap\\_directory.pdf](http://www.health.ny.gov/diseases/aids/general/pep/docs/pep-ap_directory.pdf)
- Please PrEP Me – National PrEP Provider Directory: <https://www.pleaseprepme.org/>

### Online Resources

- Clinical Education Initiative; In-person and online clinical training in transgender healthcare: [www.ceitraining.org](http://www.ceitraining.org)
- Ending the Epidemic: Transgender and Gender Non-Conforming Advisory Group Implementation Strategies: [www.health.ny.gov/diseases/aids/ending\\_the\\_epidemic/docs/tgnc\\_advisory\\_group\\_strategies.pdf](http://www.health.ny.gov/diseases/aids/ending_the_epidemic/docs/tgnc_advisory_group_strategies.pdf)
- HIV Education and Training Program: In-person and online non-clinical training in transgender care and support services: [www.hivtrainingny.org](http://www.hivtrainingny.org)
- National LGBT Health Education Center: “Providing Affirmative Care for Patients with Non-binary Gender Identities”: [www.lgbthealtheducation.org/publication/providing-affirmative-care-patients-non-binary-gender-identities/](http://www.lgbthealtheducation.org/publication/providing-affirmative-care-patients-non-binary-gender-identities/)
- New York State Clinical Guidelines: Inclusive of transgender and non-binary individuals: [www.hivguidelines.org](http://www.hivguidelines.org)
- Project Inform: “Transcending Barriers for Safer Pleasure”: [www.projectinform.org/pdf/pep\\_trans.pdf](http://www.projectinform.org/pdf/pep_trans.pdf)
- UCSF Center for Excellence for Transgender Health: Guidelines, articles, and online learning: <http://transhealth.ucsf.edu/protocols>

## APPENDIX E: MEETING PARTICIPANTS

**La'Mia Aiken**  
In Our Own Voice

**Niko Anderson**  
Northwell/North Shore

**Timothy Au, LMSW**  
Apicha

**Robert Beil, MD**  
Montefiore

**Uri Belkind, MD**  
Callen-Lorde

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**Constance Jones**  
Housing Works

**Aaron Kim**  
Duane Reade

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