Developing a Comprehensive Health Program for Women of Transgender Experience living with HIV/AIDS Within Medicaid Managed Care

14th Annual Iris House Women as the Face of AIDS Summit
May 6, 2019

Al Rubenstein - Transgender Program Coordinator
Monique Mackey – Transgender Health Navigator
Octavia Y. Lewis, MPA - Community Ambassador
Rachel Luscombe BSN, RN - Transgender Program Clinical Liaison

Learning Objectives

- By the end of this panel discussion, participants will be able to:

1. Describe three actions a Medicaid Managed Care Organization can take to improve the health of HIV positive transgender women
2. Explain the importance of the HIV Specials Need Plan Care Model
3. Explain the importance of pre-op and post-op surgical aftercare interventions in caring for people of transgender experience.

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THE AMIDA CARE BLUEPRINT

Dedicated to Engaging Vulnerable New Yorkers in Care

Providing Access to Medical, Surgical, and Behavioral Health Services

Amida Care

- Community-sponsored, not-for-profit Medicaid Special Needs health insurance Plan (SNP) licensed by the State of New York to operate in the five boroughs of New York City
- Provides comprehensive and coordinated medical, behavioral, pharmaceutical, and psychosocial support to populations with multiple chronic conditions
- Started by 6 non-profit multiservice providers
- Largest SNP in New York State, serving over 6,200 individuals; approximately 7% of members are transgender

Medicaid Managed Care "Special Needs Plans"

- A HIV Special Needs Plan (SNP) is a special health plan for Medicaid recipients living with HIV/AIDS and their children
- HIV SNPs were created because studies demonstrate positive health outcomes when PLWHA get their health care from providers experienced in HIV care
- New York State expanded SNP enrollment to homeless individuals regardless of HIV status in 2014
- **New York State expanded SNP enrollment to transgender individuals regardless of HIV status in November 2017**

A Snapshot: Amida Care Members

Total insured through Amida Care HSNP: 6,888 as of July 2018

- Member demographics:

Age Groups	Gender	Race	HIV Status
•0 to 21 = 2.8% •22 to 29 =8.7% **•30 to 39 = 17.2%** **•40 to 49 = 22.7%** **•50 to 59 = 37.3%** •60 to 64 = 10.3% •65+ = 0.6%	•Cis Males = 67% •Cis Females = 32% •TGNC = <7%	•AA/ Black = 62% •White = 32% •Mixed Race = 2% •Asian = 1% •American Indian/Alaskan Native = 1% •Native Hawaiian/Pacific Islander = 1% •Not Reported = 1 %	• AIDS = 19% • HIV+ = 76% • Uninfected = 5%

- 60% have had a **major mental illness** diagnosis
- 40% are active using drugs / 90% **hard drug use history**
- 40% report **experience of homelessness** since HIV diagnosis

❖ Most are **living longer** with HIV/AIDS in spite of significant and overlapping barriers to accessing care

Complex Member Needs

Top Comorbidities*

Primary Disease	Number of Unique Members by Category	Percent of Total H-SNP Population
All-Psychiatry	3,270	55%
Asthma/COPD	2,502	42%
Depression	2,093	35%
Hypertension	1,481	25%
Chronic Opioid Dependence	1,444	24%
Hepatitis	1,055	18%
Diabetes	748	12%
Cancer	466	8%

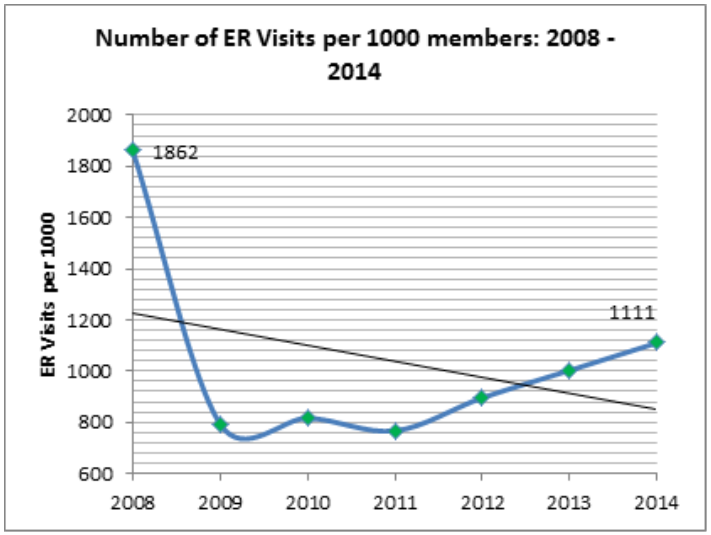
**Source- Amida Care Health Services Department Data as of March 2016*

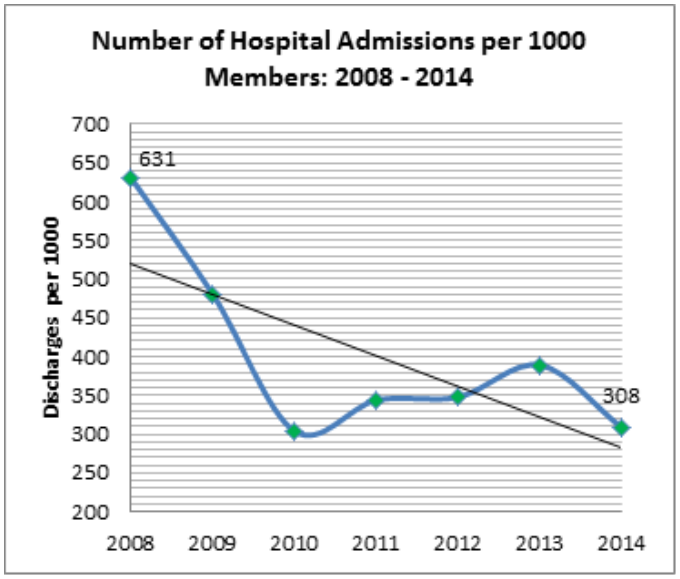
Member Risk Scores*

Mainstream Medicaid Risk per Optum
1.42

AC Average Risk Score (HSNP)
7.28

Amida Care Success with Engagement in Care





THE MODEL OF CARE
Care Coordination through Integrated Care

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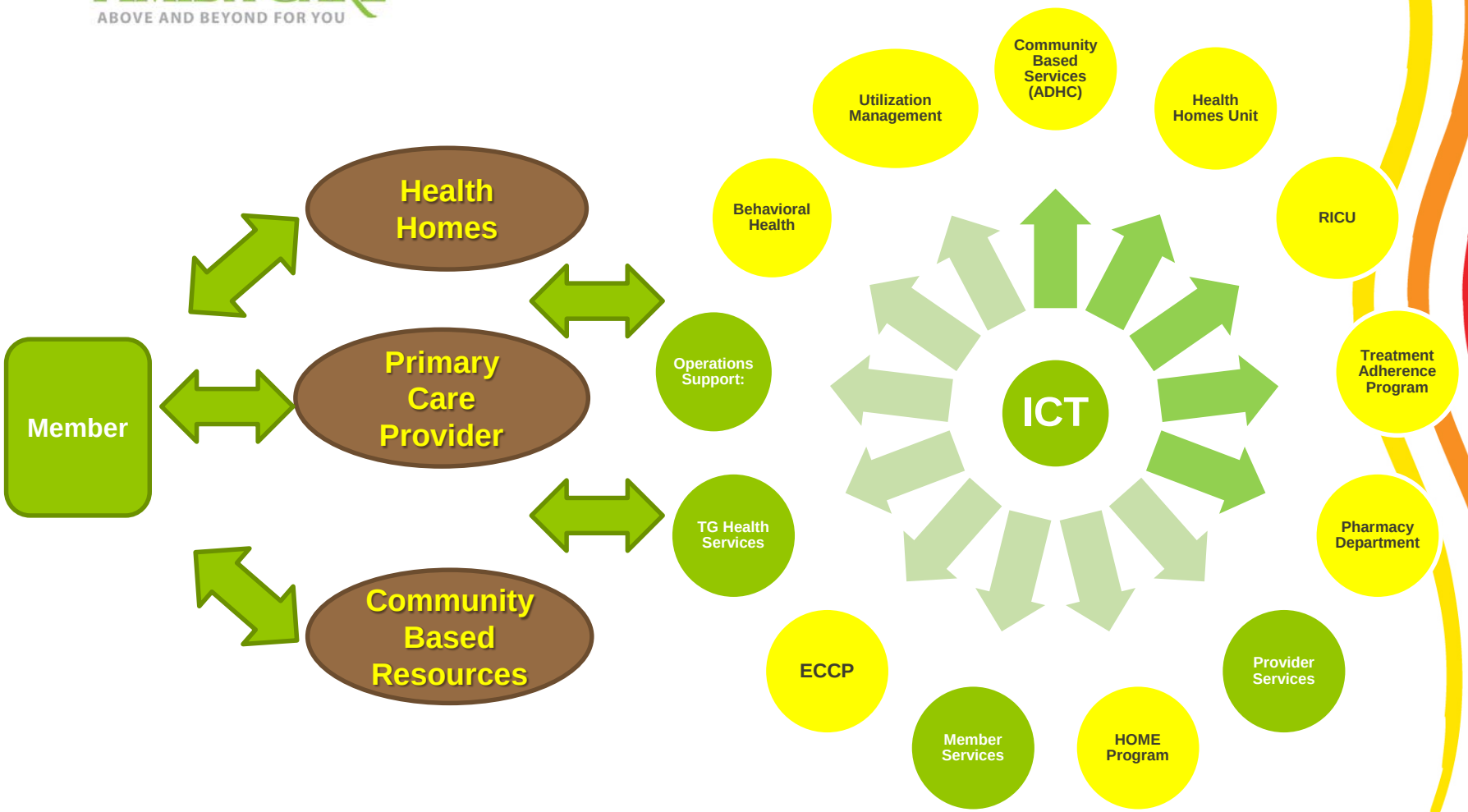

DEVELOPING A TRANSGENDER HEALTH PROGRAM

Member Feedback Improves the Member Experience

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Town Hall Meetings

- Members meet and talk directly with leadership
- Get information about new benefits and Medicaid changes
- Provide feedback on challenges faced in the delivery system
- Make recommendations to strengthen the Plan

Member Advisory Council

- Elected by Plan members; serve 2 years
- Bi-monthly meetings
- Improve existing Plan programs, suggest new programs, identify new Providers, choose health education topics and events for Plan members

New York City/State Climate

Abbreviated timeline

- April 2002: The NYC Council passed a bill extending non-discrimination protections to transgender people in NYC
- June 2012: The NYC Police Department revises its patrol guide to better respect the gender identities of those it interacts with
- June 2014: The City Council passed a bill creating municipal identification cards on which sex can be self-designated
- **March 2015: New York State Medicaid begins to cover hormone therapy and gender affirming surgeries**
- October 2015: Governor issued state-wide regulations prohibiting harassment and discrimination on the basis of gender identity, transgender status, or gender dysphoria
- January 2016: Governor enacted ban on transgender discrimination
- **November 1, 2017, eligible transgender consumers will be able to enroll in HIV SNPs, regardless of HIV status**

Sources: New York City Council; NYSDOH

Amida Care as a Safe Haven

- Decrease stigma by staff education
- Initial limitations of fields in our database systems
- Self-disclosure by members – important health implications

Transgender Program - Elements

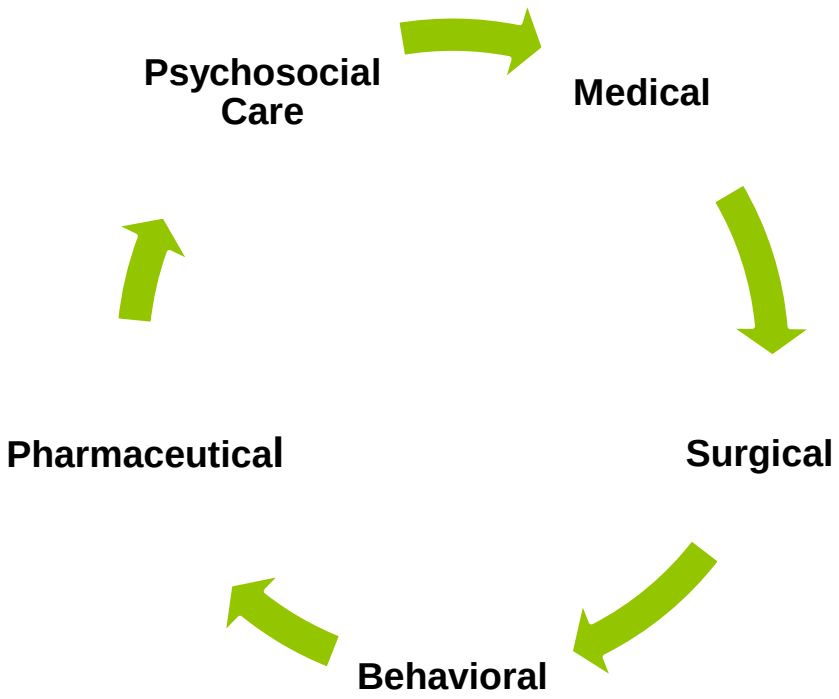
- Primary Care
- Behavioral Health Services
- Pharmaceutical monitoring
- Lab monitoring, including HIV, STI, Hep C
- STI and Hep C treatment
- Substance abuse assessment/treatment
- Vocational training and job placement

Achieving Clinical Best Practices for Transgender Membership

- Access to gender affirming surgeries, including pre- and post- care coordination
- Access to gender affirming surgeries
- Prior-authorization process in-house
- Transgender Clinical Nurse Liaison
- Transgender Health Program Coordinator
- Transgender Health Navigator

DEVELOPING CLINICAL BEST PRACTICES

Transgender Clinical Advisory Committee



- Amida Care identified a need for **clinical guidance** from **subject matter experts**
- Members of the TCAC include representation from our Provider Network that have extensive experience serving transgender people

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Clinical Guidelines and Coverage Criteria for the Treatment of Gender Dysphoria

CONTENTS

Clinical Guidelines

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8.1. GENDER AFFIRMING SURGERY AUTHORIZATION REQUIREMENTS

Service	(2) Supporting Letters*	HRT Requirement	Other Requirements	Notes
Breast Augmentation (BA)	Yes	24 months	N/A	The member has completed a minimum of 24 months of hormone therapy, during which time breast growth has been negligible; or hormone therapy is medically contraindicated; or the patient is otherwise unable to take hormones
BA Revision	Yes	No	Requires supporting documentation from surgeon that indicates the need for revision	Original supporting letters are sufficient to support diagnosis of gender dysphoria
Body contouring	Yes	No	Requires clinical documentation establishing service is medically necessary and not cosmetic	
Chest Masculinization (mastectomy)	Yes	No	N/A	
Electrolysis – Pre Op	Yes	No	N/A	
Electrolysis – Facial	Yes	No	Requires clinical documentation establishing service is medically necessary and not cosmetic	
Facial Feminization Surgery (FFS)	Yes	No	Requires supporting documentation that indicates specific type of FFS procedures requested	
Hysterectomy/ oopherectomy/ salpingectomy	Yes	No	N/A	
Metoidioplasty	Yes	12 months	N/A	
Orchiectomy	Yes	12 months	N/A	

Service	(2) Supporting Letters*	HRT Requirement	Other Requirements	Notes
Penectomy	Yes	12 months	N/A	
Phalloplasty*	Yes	12 months	Recommends completed BNA	
Phalloplasty Revision	Yes	No	Supporting documentation from surgeon that indicates the need for revision	Original supporting letters are sufficient to support diagnosis of gender dysphoria
Penile prosthesis	Yes	No	N/A	
Scrotoplasty	Yes	No	N/A	
Silicone Removal	Yes	No	N/A	
Tracheal Shave	Yes	No	N/A	
Testicular prosthesis	Yes	No	N/A	
Urethroplasty	Yes	No	N/A	
Vaginectomy	Yes	12 months	N/A	
Vaginoplasty*	Yes	12 months	Recommends completed BNA	
Labiaplasty	Yes	12 months	N/A	
Clitoroplasty	Yes	12 months	N/A	
Vaginoplasty Revision	Yes	12 months	Supporting documentation from surgeon that indicates the need for revision	Original supporting letters are sufficient to support diagnosis of gender dysphoria
Voice Modification Surgery	Yes	No	Requires supporting documentation that indicates procedures requested are medically necessary	
Voice and Communication Training	Yes	No	Requires supporting documentation that indicates procedures requested are medically necessary	

GAS Support Letters

4.2. GENDER AFFIRMING SURGERY

Gender affirming procedures shall be covered for an individual who is eighteen (18) years of age or older and has letters from two qualified New York State licensed health professionals who have independently assessed the individual and are recommending the individual for the surgery.

4.2.1. LETTERS OF SUPPORT FOR DIAGNOSIS OF GENDER DYSPHORIA

- One of these letters must be from a psychiatrist, psychologist, nurse practitioner, psychiatric nurse practitioner, or licensed clinical social worker with whom the member has an established and ongoing relationship.
- The other letter may be from a psychiatrist, psychologist, nurse practitioner, physician, psychiatric nurSe practitioner, or licensed clinical social worker acting within the scope of his or her practice, who has only had an evaluative role with the member.
- The *totality* of the referral letters together must establish the following and must be written within 12 months at the time of surgery request:
  - Member has persistent and well-documented gender dysphoria;
  - has received hormone therapy appropriate to the member's gender goals, which shall be for a minimum of twelve (12) months in the case of an member seeking genital surgery, unless such therapy is medically contraindicated or the member is otherwise unable to take hormones;
    - Hormone therapy is necessary if it is appropriate to the member's gender goals recommended by the member's treating provider, clinically appropriate for the type of surgery requested, not medically contraindicated, and the member is otherwise able to take hormones. Ref 18 NYCRR 505.2(l)(2); (3)(i)(b);
  - has lived for twelve (12) months in a gender role congruent with the member's gender identity, and has received mental health counseling, as deemed medically necessary, during that time; there is no requirement that mental health counseling be provided continuously for twelve (12) months prior to surgery. [Ref 18 NYCRR 505.2(l)(3)(i)(c)]
  - has no other significant medical or mental health conditions that would be a contraindication to gender affirmation surgery, or if so, that those are reasonably well-controlled prior to surgery;
  - has the capacity to make a fully informed decision and to consent to the treatment.

Preparing for Surgery

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8.2. BIOPSYCHOSOCIAL NEEDS ASSESSEMENT

Patient Name: _____ **DOB:** _____

Name on Mediciad Card, if different: _____

Primary Care Provider: _____ **PCP Location:** _____

Patient Information

Gender: ☐ Trans Woman ☐ Trans Man ☐ Non-binary ☐ Other: _____
Sex Assigned at Birth: ☐ Male ☐ Female ☐ Intersex **Sex on Insurance Card:** ☐ Male ☐ Female
Primary Language: ☐English ☐Spanish ☐Other: _____ **Language Proficiency:** ☐Oral ☐Written

Medical History: _____
Co-occurring medical conditions, medications, hospitalizations, pain management etc _____

Behavioral Health: _____
Mental Health / Substance Abuse _____

Supportive Services: _____
Case workers, friends & family, caregivers, home health aids, etc _____

Prerequisites for Surgery

☐Major medical and mental health conditions are reasonably controlled
☐ Surgery referral process explained in language patient can understand
☐ Two referral letters written by a New York State licensed physician, psychiatrist, psychologist, psychiatric nurse practitioner, physician, or clinical social worker (**LCSW**, not LMSW)
  ☐One written by a New York State licensed psychiatrist, psychologist, or psychiatric nurse practitioner who has an ongoing relationship with the patient.
  ☐The second letter written by a New York State licensed psychiatrist, psychologist, psychiatric nurse practitioner, physician, or clinical social worker (**LCSW**, not LMSW).
  ☐ Combined content of letters must establish that member:
    ☐ Has a persistent and well-documented case of gender dysphoria
    ☐ Has received hormone therapy appropriate to the individual's gender goals unless hormone therapy is medically contraindicated or not clinically appropriate for the type of surgery requested:
      ☐ 12 months for genital surgery
      ☐ 24 months with negligible breast growth for MTF breast augmentation
    ☐ Has lived for 12 months in a gender role congruent with the individual's gender identity, and has received mental health counseling, as deemed medically necessary, during that time
    ☐ Has no other significant medical or mental health conditions that would contraindicate gender reassignment surgery, or if so, that those conditions are reasonably well-controlled prior to surgery
    ☐ Has the capacity to make a fully informed decision and to consent to treatment

1. Patient Education
☐ Patient has been educated on surgical procedure in language they can understand
☐ Patient has been made aware of long term impact of genital surgery on long-term reproductive capacity
☐ Patient has realistic expectations of surgery

2. Support Systems
☐ Patient has supports in place to assist with ADLs during recovery phase.
☐ Patient has people/resources that will provide emotional and social support during recovery

3. Financial
☐ Any anticipated changes in income/ability has been accounted for, including sex work if applicable
☐ Patient has a plan to pay for food, rent, medical supplies and other expenses during recovery

4. Medical History and Care Compliance
☐ If major medical conditions are present, they are well controlled.
☐ Patient is adherent to medications with no issues to report
☐ There is clear communication between mental health, medical, and surgical members of treatment team

5. Behavioral Health
☐ Mental health benefits of surgery outweigh the risks
☐ Necessary supports are in place to manage MH symptoms that may arise as a result of surgery
☐ Patient is not currently using substances
☐ Patient has a plan to cut down or discontinue substance use: _____

6. Housing
☐ Patient has stable housing
☐ Patient has a plan for safe discharge/shelter post-surgery
☐ Patient has a private area and access to clean water for post-surgery recovery
Please describe current living situation. Include descriptions of accessibility (steps, shower, elevator access etc):

7. Transportation
☐ Patient has planned transportation to and from surgery
☐ Patient has transportation to and from pre-op and post-op medical appointments

8. Would the member benefit from supportive services that are currently not in place? ❑ Yes ❑ No
☐ Psychosocial Case Management Referral ☐ Physical Therapy ☐ Electrolysis
☐ Support with Aftercare: ☐ Visiting Nurse Services ☐ Home Care Services (PCA)
☐ Discharge to a Skilled Nursing Facility (SNF) ☐ Other: _____

Other relevant clinical information (clinical observations, concerns, areas that still need to be addressed):

_____
_____

☐ **Patient is stable for surgery** - ☐ Medically ☐ Mentally ☐ Psychosocially

_____ _____
Primary Care Provider **Date**

_____ _____
Title **Signature**

Fax completed form to: 888-273-8296
Phone: (646) 757 – 7000, Extension 7982 • Email: TransgenderHealthServices@amidacareny.org

Post Care

- High rate of complications - support is vital to ensure better health outcomes
- Home Care
  - Next day visit after Discharge
  - Next day visit after first MD appointment to assist with dilation if indicated
  - Patient education:
    - dilation
    - catheter care
    - wound care
    - Wound - vac care
    - medication/pain management
    - phallus management
  - HHA/PT if required

RESEARCH

Transgender cohort research

Grant to Amida Care from the NYS AIDS Institute

Findings will help inform clinical programs help fill gaps in research

Background

- Transgender persons living with HIV/AIDS experience some of the highest rates of health disparities
- There are significant research gaps related to comorbidities and integrated approaches to care in this population.
- **Information about health care utilization and outcomes is needed to be able to develop effective primary and secondary HIV prevention interventions.**

Methods

- The transgender cohort was identified through comprehensive claims review
- Subject matter experts compiled a list of transgender-related ICD-9/10 codes, CPT-4 procedure codes, and pharmaceuticals.
- Amida Care has access to claims for all health resources utilized by all members of the Plan, as well as laboratory results for many Plan members.

Table 1. ***Transgender Cohort Inclusion***

Total Individuals Included = 401	
Inclusion Criteria (at least one necessary)	**N**
Gender affirming surgery prior-authorization	116
Self-reported transgender identity to Plan	156
Sex marker on insurance card Male; prescribed feminizing hormone therapy	63
Sex Marker on insurance card Female; prescribed feminizing hormones AND have >2 transgender-related ICD-9/10 codes in claims	36
Transgender-related ICD-9/10 codes in claims	30
Demographics: The transgender cohort is almost exclusively MTF (99%), with 61% of the cohort self-reporting as transgender to the Plan. The age of the cohort ranges from 21 to 66 with a mean age of 38.5. The race/ethnicity of the cohort is 63% Black, 27% Hispanic/Latino, 5% White, 2% Asian, 2% Not Reported, <1% American Indian/Alaska Native, and <1% Pacific Islander. The mean age of the transgender cohort is 7.5 years younger than the non-transgender cohort; race/ethnicity is similar to that of the non-transgender cohort.	

Conclusions

- CD4 counts and viral load suppression rates of the transgender cohort were similar when compared to the non-transgender cohort

Table 2. ***HIV Viral Load of Transgender Cohort and Non-Transgender Cohort***

Viral Load Count	Transgender Cohort N	%		Non-Transgender Cohort N	%
Suppressed 0 to 199	222	70%		2898	62%
Unsuppressed 200 to 999	44	14%		957	21%
Unsuppressed 1000 to 9999	24	8%		394	8%
Unsuppressed 10000 to 99999	19	6%		304	7%
Unsuppressed >= 100000	7	2%		98	2%
Unknown	85	21%		1798	28%
Based on most recent measure on file between 3/1/2015 – 5/16/2018; percentages are based on available data **Note: There was not a significant difference in viral load suppression rates by cohort F(1, 4965) = .276, p = 0.6**					

Table 3. ***CD4 Count of Transgender Cohort and Non-Transgender Cohort***

CD4 Count	Transgender Cohort N	%		Non-Transgender Cohort N	%
0 to 199	40	10%		648	12%
200 to 349	45	12%		736	14%
350 to 499	72	19%		877	17%
500+	227	59%		2958	57%
Unknown	17	4%		1228	19%
Based on most recent measure on file between 3/1/2015 – 5/16/2018; percentages are based on available data					

Conclusions

- results suggest that interventions for transgender people living with HIV/AIDS should **focus on substance use programs and mental health initiatives**.
- Approximately a third of the cohort demonstrated **nutritional deficiencies**, suggesting a need for nutrition services and raises concerns for food security.

Table 4. ***Top Ten Comorbidities of Transgender Cohort***

ICD-9/10 Diagnosis Code	N	%
Other drug dependence	206	51%
Mood disorder, depressed	170	42%
Nutritional deficiency	102	25%
Cocaine or amphetamine dependence	96	24%
Mood disorder, bipolar	92	23%
Asthma	86	21%
Infectious hepatitis	76	19%
Other infectious diseases	61	15%
Hypertension	56	14%
Other hematologic diseases	49	12%
Based on claims submitted to the Plan through 5/16/2018		

Conclusions

- There is a true demand for gender affirming surgeries, with 22% of the transgender cohort accessing procedures.
- Managed Care Organizations, with their access to claims data, have a unique opportunity to mine and analyze data for populations disproportionately affected by health disparities, which has the potential to inform primary and secondary HIV prevention strategies based on real-life data.

Table 5. ***Gender Affirming Surgery Utilization***

Gender Affirming Surgery Procedure	Number of Procedures	Percentage of Cohort
Breast Augmentation	83	21%
Vaginoplasty	47	12%
Orchiectomy	35	9%

Based on procedures covered by the Plan from 3/1/2015 – 05/16/2018
Note: The New York State Medicaid benefit for gender affirming surgery began in March of 2015. 88 unique (22%) cohort members have since had one or more procedures covered by the Plan.

HIV & TRANSGENDER WOMEN

HIV disproportionately burdens transgender women in the United States

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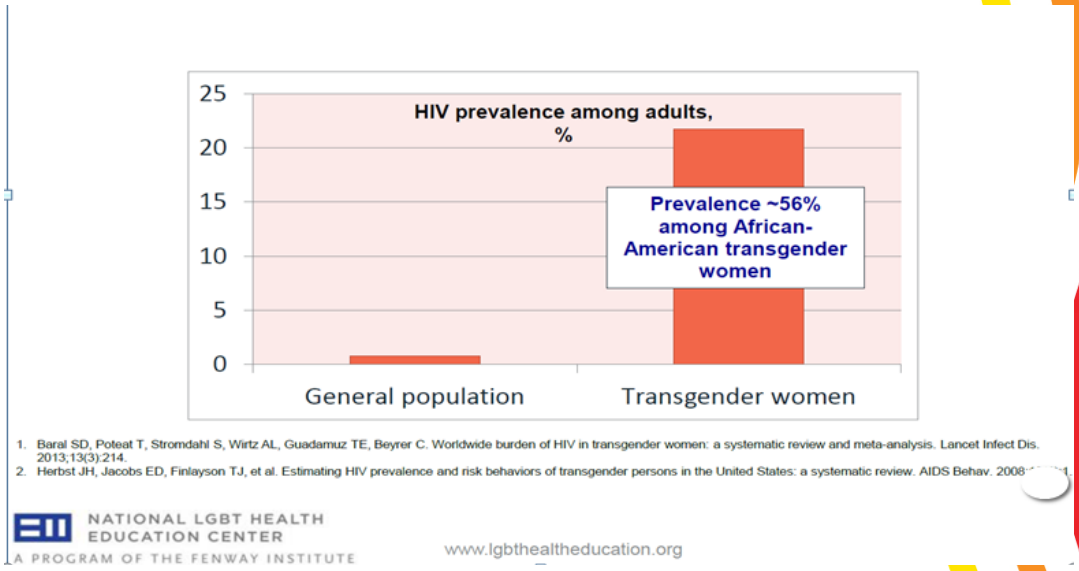
2,351 HIV Diagnoses in the US from 2009-2014

- 84% Transgender Women
- 15% Transgender Men



1. Baral SD, Poteat T, Stromdahl S, Wirtz AL, Guadamuz TE, Beyrer C. Worldwide burden of HIV in transgender women: a systematic review and meta-analysis. Lancet Infect Dis. 2013;13(3):214.
2. Herbst JH, Jacobs ED, Finlayson TJ, et al. Estimating HIV prevalence and risk behaviors of transgender persons in the United States: a systematic review. AIDS Behav. 2008

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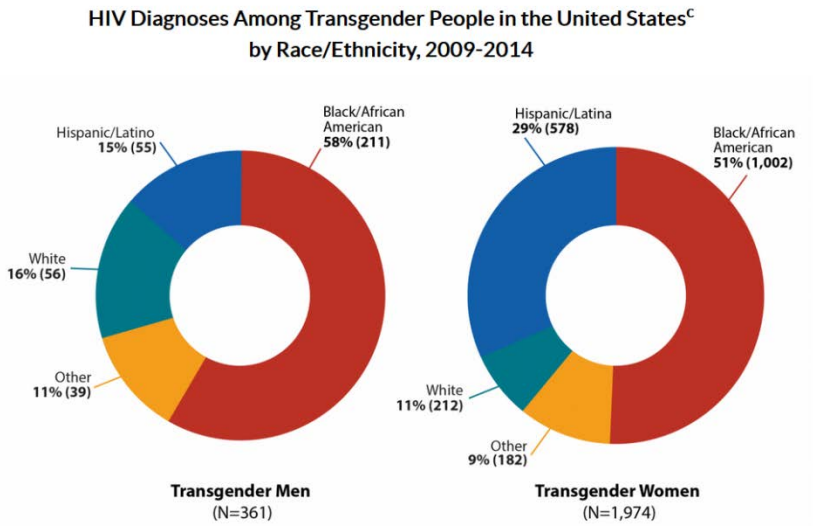


about 14% of transgender women in the US have H I V . An estimated 44% of black/African American transgender women have HIV—the highest among all transgender women

Source: Clark H, Babu AS, Wiewel EW, Opoku J, Crepaz N. Diagnosed HIV Infection in Transgender Adults and Adolescents: Results from the National HIV Surveillance System, 2009-2014. *AIDS Behav* 2017;21(9):2774-2783. Hispanics/Latinos can be of any race.

Factors associated with HIV among transgender women

- Barriers to Healthcare
- Receptive anal intercourse
- Sex work
- Abuse, including anti-transgender violence
- Self-injection of hormones and/or silicone
- Substance abuse
- Homelessness
- Unemployment
- Mental Health Issues

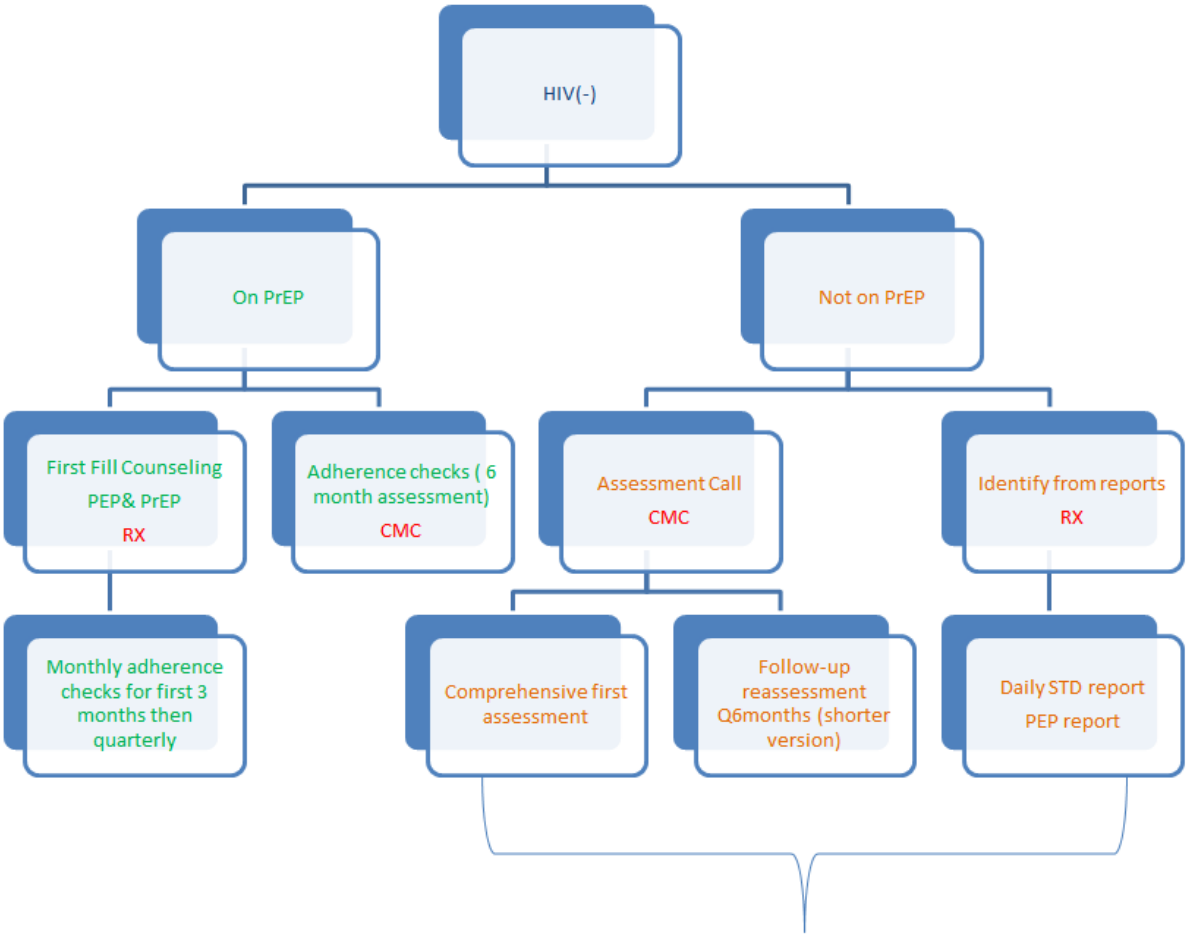
Challenges

- Socioeconomic factors
- HIV interventions are developed for other at-risk groups
- Stigma and discrimination
- Low healthcare engagement
- Lack of provider knowledge
- Transgender-specific data is limited

https://www.cdc.gov/hiv/group/gender/transgender/index.html

HIV PREVENTION

HIV Prevention Services



At risk interested in PrEP:	CC/MS make appointment for PrEP
At risk NOT interested in PrEP:	CMC provide counseling
Low risk:	CMC reassess in 6 months

A: PREP ASSESSMENT QUESTIONS

1.	In the past 6 months, have you had any condomless sex?	☐ NO	☐ YES	☐ Unsure
2.	In the past 6 months, have you had sex with someone who has HIV?	☐ NO	☐ YES	☐ Unsure
3.	Have you (or your current partner) had >1 sexual partner in the past 6 months?	☐ NO	☐ YES	☐ Unsure
4.	In the past 6 months, have you ever been diagnosed with any of the following: Syphilis, Gonorrhea, and/or Chlamydia?	☐ NO	☐ YES	☐ Unsure
5.	In the past 6 months, have you had sex for money, drugs, food, housing, or something else you needed?	☐ NO	☐ YES	☐ Unsure
6.	In the past 6 months, have you used any of the following drugs during sex: crystal meth, cocaine, poppers?	☐ NO	☐ YES	☐ Unsure
7.	In the past 6 months, have you ever shared needles (for either drugs or hormones) with other individuals?	☐ NO	☐ YES	☐ Unsure
8.	Have you been prescribed any medications for exposure to HIV (PEP) in the past 6 months?	☐ NO	☐ YES	☐ Unsure
9.	Do you think you might benefit from being on PrEP?	☐ NO	☐ YES	☐ Unsure

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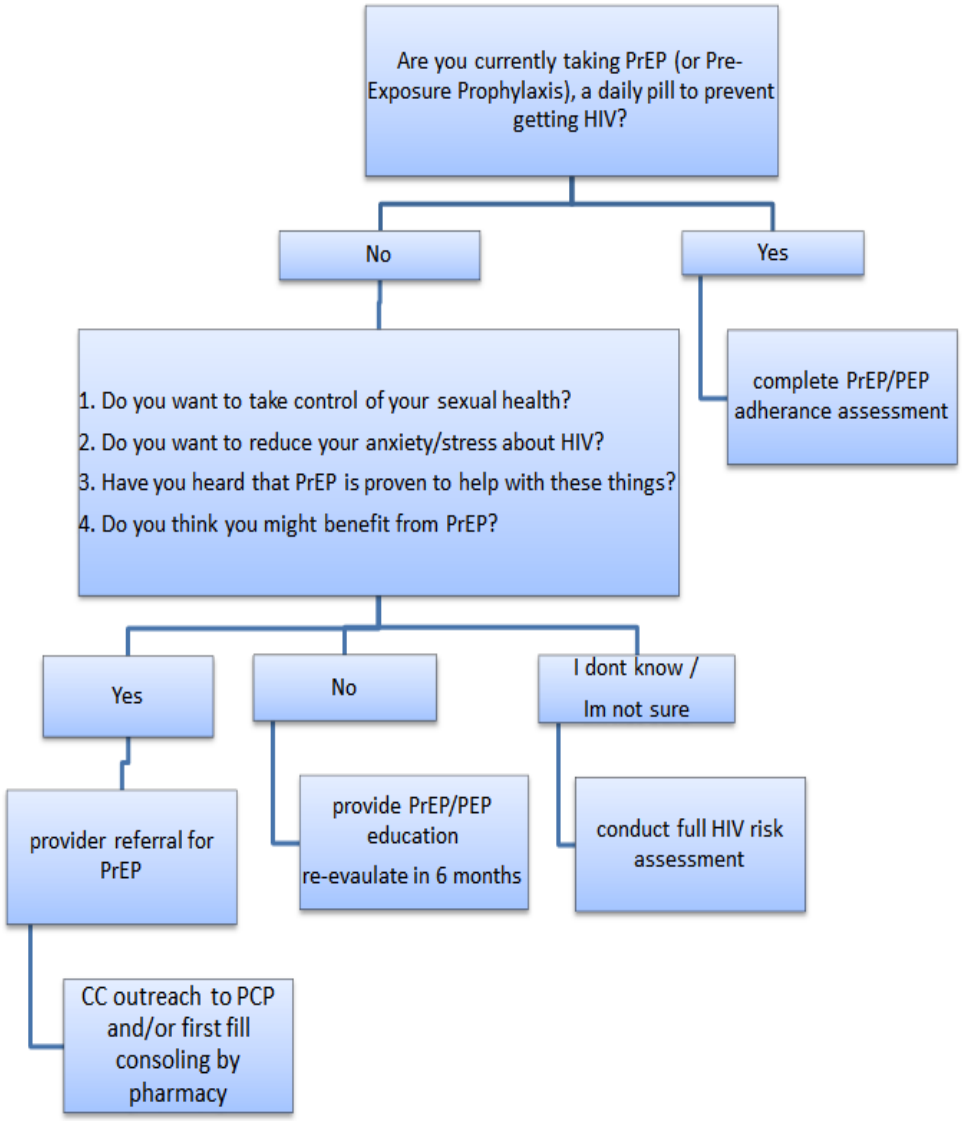

KEY ISSUES AND PRIORITIES FOR CHANGE

Key Issues and Priorities for Change

- **Improve care and service delivery to expand access to PrEP for transgender women:**
  - Ensure cultural competency
  - Increase funding for transgender-centered services
  - 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.

https://www.hivguidelines.org/prep-for-prevention/prep-implementation/prep-for-transgender-women/

Key Issues and Priorities for Change

- **Reduce social oppression, discrimination, and stigmatization to increase uptake of PrEP among transgender women:**
  - Enforce anti-discrimination laws; facilitate passage of new laws
  - Tailor services to meet the social, economic, and healthcare needs of transgender women
  - Decriminalize sex work and protect sex workers' rights
  - Focus on occupational safety in discussions of PrEP

https://www.hivguidelines.org/prep-for-prevention/prep-implementation/prep-for-transgender-women/

Key Issues and Priorities for Change

- **Improve awareness and knowledge of transgender women's healthcare needs:**
  - Require training in best practices for all medical care providers.
  - Offer non-clinical care in the same settings as clinical care
  - Promote research on PrEP efficacy in transgender women
  - Bundle hormone therapy with PrEP
  - Expand advertising, education, and payment options for PrEP and ensure that all campaigns and materials are transgender inclusive.

https://www.hivguidelines.org/prep-for-prevention/prep-implementation/prep-for-transgender-women/

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Questions?