



# Breaking Barriers to Transgender Health Care



A report on health  
challenges and solutions  
for the transgender  
community



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## ★ Executive Summary

**THANKS TO ADVOCATES; COMMUNITY MEMBERS;** organizations; New York elected officials including Governor Andrew Cuomo, Senators Tom Duane and Brad Hoylman, Assemblyman Richard Gottfried, and the New York City Council LGBT Caucus; as well as media and celebrity attention, acceptance and visibility for members of the transgender community continues to increase in New York and across the country.

In New York, an estimated 25,000 transgender individuals face discrimination at every turn: from family members, at school, in the workforce, at the hands of the police, in the housing system, and in health care.

### ★ SYSTEMIC AND WIDESPREAD DISCRIMINATION IS DEVASTATING

According to surveys and data:

- 18% of people of transgender experience in New York were unemployed in 2015
- People of transgender experience are 2.4 times more likely to be living in poverty than the general population
- An estimated 40% of people of transgender experience were forced to leave school
- 61% of people of transgender experience in New York report being mistreated by the police
- 27% of people of transgender experience experienced homelessness in New York

### ★ DISCRIMINATION LEADS TO POOR HEALTH

A lack of housing, jobs, education, and high rates of violence—all considered social determinants of health—coupled with discrimination contribute to starkly worse health outcomes for the transgender community:

- Transgender women are 49 times more likely to be living with HIV
- 39% percent of transgender individuals report experiencing serious psychological distress in the past month, and, overall, 40% report having tried to commit suicide
- Nearly a third of transgender individuals report using illegal and non-medical prescription drugs

### ★ BARRIERS TO HEALTH CARE

Too often, transgender patients have to educate their doctors and medical providers about transgender health issues, including awareness about after-care and post-operative care. Private health insurance companies routinely deny coverage for procedures for transgender individuals. Furthermore, transgender individuals are often refused treatment due to their gender identity, and many individuals have been harassed in a doctor's office. Few states have adopted laws that protect individuals from discrimination, and even fewer provide Medicaid plans to transgender individuals.

### ★ SUMMARY OF RECOMMENDATIONS

In this report, we identify the contributors to poor health among members of the transgender community and the barriers to health care. We also make recommendations, including:

- Training all health providers
- Mandating coverage of comprehensive gender-affirming care services in all health insurance plans
- Implementing anti-discrimination employment policies and housing policies
- Passing the federal Equality Act

# Coverage of Gender-Affirming Health Services in the United States

## AS ACCEPTANCE AND VISIBILITY

continue to increase for transgender communities in the United States (U.S.), health care insurance coverage for services related to gender affirmation also grows. This growth in insurance coverage can partially be attributed to an increase in the following:

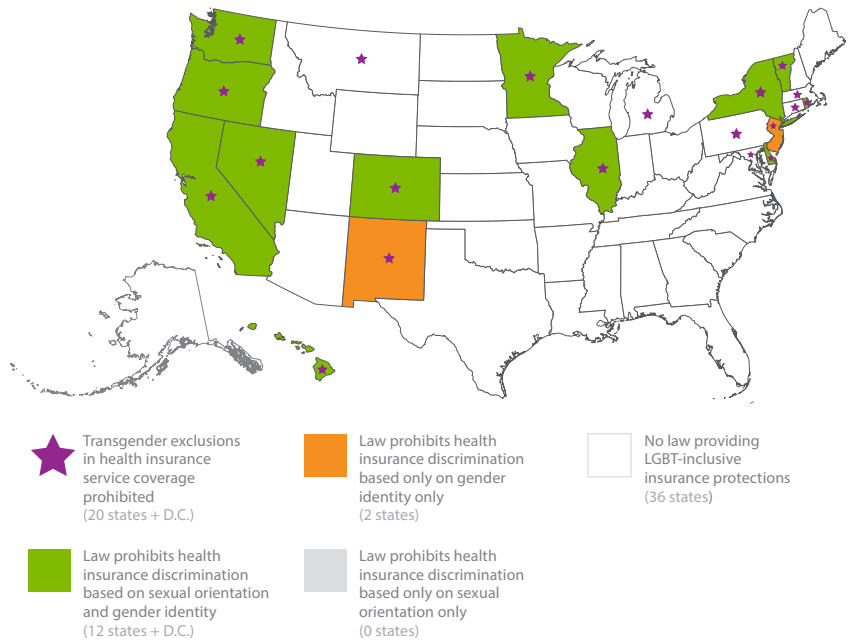
- Body of literature on transgender health
- Agreement among experts on the benefits and effectiveness of gender-affirming health care for transition as a means for transgender people to live authentically as themselves
- Patient and ally advocacy focused on improving the health, equality, and overall well-being of transgender people
- New policy interpretations that clarify non-discrimination on the basis of gender identity and/or expression
- Growing evidence about the cost-effectiveness of gender-affirming health insurance coverage

An increasing number of organizations such as the American Medical Association, the American Psychiatric Association, the World Professional Association for Transgender Health (WPATH), and the World Health Organization have stated their support of gender-affirming services. Despite this support, and increase in gender-affirming health insurance coverage, disparities across states continue. Figure 1 shows states with and without gender-affirming health insurance coverage.<sup>1</sup> Insurance coverage of transition-related care and legal protections vary from state to state.<sup>2</sup> Since 2012:

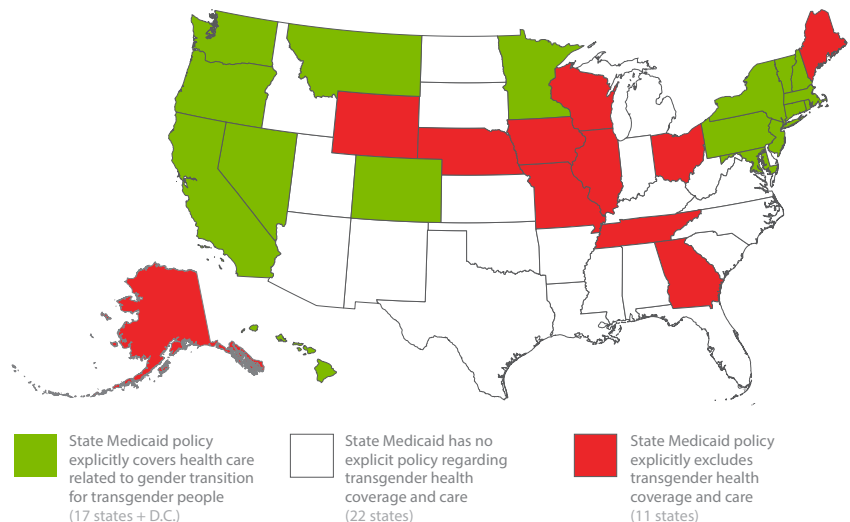
- New York and 19 other states, in addition to D.C., have adopted laws that prohibit transgender exclusions in health insurance coverage;
- New York and 11 other states, in addition to D.C., have prohibited private insurance plans from discriminating based on gender identity and/or expression; and
- New York and 16 other states, in addition to D.C., have updated their Medicaid policies to cover gender-affirming transition-related services and care.

FIGURE 1: DISPARITIES IN INSURANCE COVERAGE OF GENDER-AFFIRMING HEALTH CARE FOR TRANSGENDER PEOPLE, BY STATE

## PRIVATE INSURANCE



## MEDICAID



Source: The Movement Advancement Project (MAP)

As of October 2018, there are 36 U.S. states where it is legal for health insurance plans to exclude coverage of gender-affirming services.<sup>1,3</sup> In late 2016, the Trump administration proposed regulations to roll back key provisions of the Affordable Care Act

(ACA), which has serious consequences for health insurance coverage specific to gender-affirming health services throughout the U.S. and would subject transgender individuals to unfair discrimination in health care settings.

# Gender-Affirming Health Insurance Coverage in New York State

**IN 2014, THE ACA EXPANDED** gender-affirming health insurance coverage for transgender people throughout the U.S., including New York State. New York has adopted laws to protect against discrimination based on gender identity and expression (Table 1).<sup>1,2</sup>

In New York State, health insurance plans—including Medicaid, Medicare, and many private employer-endorsed plans—cannot discriminate and refuse covering gender-affirming care based on gender identity.

**TABLE 1: NEW YORK STATE HEALTH INSURANCE PROTECTIONS FOR GENDER-AFFIRMING HEALTH CARE SERVICES**

Non-discrimination laws prohibiting health insurance discrimination based on sexual orientation and gender identity



Insurance providers banned from excluding coverage for gender-affirming care services



New York State Medicaid began covering transition-related care, including gender-affirming surgeries in 2015



# Barriers to Gender-Affirming Health Care

**TRANSGENDER PEOPLE FACE A MULTITUDE OF BARRIERS** when seeking and obtaining health insurance and health care services. These barriers are multifaceted. Dr. Asa Radix, Senior Director of Research and Education and the Clinical Director of the Transgender Health Program at Callen-Lorde Community Health Center, notes that “the pressing issues

among transgender people include access to hormones and surgery, housing, legal issues (e.g., name change to reflect gender identity), and employment. Unless these [barriers] are addressed, any medical conditions may not be well controlled.” It is vital for insurers, policy-makers, providers, and community members to work together to address these barriers.

“Transgender people shouldn’t have to educate their providers. Providers need to work on developing their capacity to serve transgender, gender non-conforming, and non-binary clients and adhere to the WPATH Standards of Care.”

– Alicia Rubenstein, Transgender Program Coordinator, Amida Care

“The proposed rollback of ACA regulations could have an effect on “the lack of qualified surgeons who accept Medicaid, leading to longer wait times for procedures.”

– Kevin Steffens, RN, MBA, Vice President of Clinical Services and Programs, Amida Care

## Health Care Environment

### EXCLUSIONARY INSURANCE COVERAGE FOR GENDER-AFFIRMING SERVICES

**THERE ARE 36 U.S. STATES** where health insurance plans can exclude coverage of gender-affirming services.<sup>1-3</sup> Many health insurers are allowed to discriminate on the basis of gender identity and/or expression, creating obstacles for transgender people to acquire necessary health care. Additionally, some health insurance plans invoke what they deem a lack of “medical necessity” to deny coverage, based on a false argument that such care is cosmetic or experimental.<sup>4</sup> This often results in a delay in or avoidance of receiving care, which places transgender people at greater risk for other illnesses, including depression and mental health issues that can lead to suicide.

### LACK OF INSTITUTIONAL SUPPORT FOR TRANSGENDER CULTURAL COMPETENCY AMONG HEALTH CARE PROFESSIONALS

**TO CREATE A PATIENT-CENTERED ENVIRONMENT** that is welcoming and understanding of transgender patients’ health needs, institutional policies need to be adopted to ensure that health care professionals have cultural and clinical competencies and education in transgender health care.<sup>3,5-6</sup>

Owing to a lack of cultural competency, providers may rely too heavily on transgender patients to educate them about their own care.

In Lambda Legal’s 2009 Health Care Survey, 65% of transgender respondents reported encountering health care professionals and medical providers who were unaware of the specific health needs of transgender people.<sup>7</sup> In the 2015 U.S. Transgender Survey (USTS) of over 25,000 transgender respondents, about 1 in 4 respondents reported having to teach health care professionals, including medical providers, about transgender care.<sup>8</sup> In New York State, in the same survey,



32% of trans respondents who saw a health care provider in the past year reported having at least one negative health care experience due to being transgender, including having to teach the provider about transgender care.

In a study of health care providers who have interacted with transgender patients, it was revealed that some don’t have knowledge of available resources and care strategies to refer patients for gender-affirming health care and transgender specialty care.<sup>9</sup>

### LACK OF EDUCATION, TRAINING, AND AWARENESS AROUND AFTER-CARE OR POST-OPERATIVE CARE

**RESEARCHERS HAVE FOUND THAT** the number of gender-affirming surgeries are increasing and are being utilized by people from a range of demographics, particularly because some of the surgeries are now covered by Medicaid or Medicare plans.<sup>10</sup> However, there is a high rate of post-surgical complications in gender-affirming surgery, highlighting the need for greater education, training, and awareness around after-care or post-operative care.<sup>11,12</sup>

Before coverage of gender-affirming surgeries by Medicaid, gender-affirming surgery was generally only available to those with financial means. Many of these early patients had private resources to ensure their after-care maintenance, travel to appointments, and home health service needs were met.<sup>13</sup> With gender-affirming surgeries

“Transgender, gender-nonconforming, and non-binary (TGNCNB) people face significant barriers that impact the ability to access transition-related care. Widespread discrimination against transgender people has caused many TGNCNB people to distrust the health care industry and avoid seeking out care. This is compounded by a long history of health insurance companies denying coverage for transition-related care, acting as gatekeepers and preventing access to medically necessary treatment.”

– Alicia Rubenstein,  
Transgender  
Program  
Coordinator,  
Amida Care

becoming more accessible, providers must ensure that all patients have supports in place to help with recovery. These supports should include assistance for home care and next-day visits after discharge from the hospital. Social supports such as safe, stable housing and transportation to and from medical appointments are essential. Health plans that specialize in care coordination and case management have proven to be successful models of care by surrounding each patient with a team of providers, health navigators, behavioral health specialists, and social workers.

Effective after-care must be comprehensive, to include services that address co-occurring medical conditions and/or mental health issues, supportive services such as caregivers and home health aides, and assistance with continued/regular follow-up doctors' visits and physical therapy. There should be open communication between mental health, medical, and surgical team members to ensure that co-occurring conditions and health issues are addressed. For example, if the patient has a past history of substance use or depression, those issues must be discussed with the full care team prior to prescribing medication for pain management. It is also critical for care to be patient-centered, and the patient must be educated around issues including dilation in male-to-female surgery, catheter care, wound care, medication/pain management, and phallus management, and home visits are an important component to ensure better health outcomes in relation to these issues. After-care should be viewed holistically as part of the full continuum of transgender health care and services.



## Social Determinants of Health

### HOUSING INSTABILITY

**HOUSING IS A MAJOR SOCIAL DETERMINANT** of health among transgender communities. In the USTS survey, about 1 in 4 respondents experienced housing discrimination in the past year, such as being evicted from or being denied housing, due to being transgender.<sup>8</sup> About 1 in 3 respondents reported having been homeless.

Twenty-seven percent of respondents from the same survey experienced homelessness.<sup>8</sup> About 1 in 8 experienced homelessness in the past year because of being transgender, and about one-quarter (26%) of respondents avoided staying in a shelter because they feared being mistreated as a result of being transgender.

### VIOLENCE AND TRAUMA

**TRANSGENDER PEOPLE EXPERIENCE** high levels of trauma, mistreatment, harassment, and violence. In the USTS survey, 1 in 2 respondents experienced verbal harassment, nearly 1 in 10 respondents were physically attacked, and nearly 1 in 2 respondents were sexually assaulted due to being transgender.<sup>8</sup>

Violence often leads to worse health outcomes and fatalities. Transgender people, particularly black and Latina transgender women and immigrants, are disproportionately impacted by hate crimes. The past three years have been the deadliest years on record for transgender communities in the U.S., with reports of high levels of hate crimes, including homicide.<sup>14,15</sup> Between 2008 and June 2016, at least 146 transgender people were murdered. In 2017 alone, there were 28 transgender people on record who were fatally shot or killed by other violent means. Rates of violence-related incidences continue to rise in transgender communities.

Many transgender people are reluctant to seek protection from police officers after an assault because of discrimination and mistreatment.

“One of the most pressing issues... is the lack of stable housing for our community... This [lack of housing] becomes a barrier when trying to access trans-affirming surgeries and not having a stable place to heal properly.”

– Octavia Lewis,  
MPA, Community  
Ambassador,  
Amida Care

This includes being verbally harassed, being repeatedly addressed with incorrect gender pronouns (misgendering), and/or being sexually and physical assaulted. Additionally, transgender respondents who interact with police officers and/or other law enforcement authorities are often mistaken for doing sex work, leading to many transgender people being abused or coerced into sexual activities initiated by police officers to avoid arrest. In the USTS survey, nearly 9 out of 10 respondents said they have been harassed, attacked, sexually assaulted, or mistreated by police and other law enforcement authorities.<sup>8</sup>

In New York State, among transgender people who interacted with police officers and/or other law enforcement authorities who thought or knew they were transgender, 61% said they were mistreated. The majority (57%) of transgender respondents are uncomfortable asking police for help.<sup>8</sup>

### EMPLOYMENT DISCRIMINATION

**EMPLOYMENT IS A KEY DETERMINANT** of health. However, employment discrimination is prevalent for many transgender people. In the 2015 USTS survey, transgender respondents were 2.4 times more likely to be living in poverty compared with the U.S. population (29% vs. 12% respectively).<sup>8</sup> The rate of unemployment among transgender people is three times that of the general population, and the rate of unemployment is up to four times higher for transgender people of color.

In New York State, 34% of transgender respondents from the same survey reported living in poverty, and 18% were unemployed. Additionally, 30% of transgender respondents who had jobs experienced mistreatment, including being fired and denied promotion due to being transgender.<sup>8</sup>

In January 2019, *The Gender Expression Non-Discrimination Act of 2018 (GENDA) (A.3358 Gottfried)/(S.07010 Hoylman)*, which legally codifies protections for TGNC people against discrimination in employment and health care, was passed in New York State. TGNC individuals are now guaranteed protections against discrimination in employment under New York State law.

### EDUCATION ACCESS

**BULLYING, VIOLENCE, AND MISTREATMENT** in schools disrupt the educational quality and opportunity for transgender people. In the USTS survey, 3 out of 4 transgender students in elementary and secondary schools reported being mistreated, disciplined for defending themselves, and required to dress according to their sex assigned at birth, not their gender identities.<sup>8</sup> As many as 2 out of 5 transgender people were forced to leave school or were expelled because of gender-based mistreatment. Among transgender people who made it to college and other higher education institutions, 1 in 4 experienced assault and 2 in 4 had to leave college because of mistreatment.

In New York State, 74% of transgender students in elementary, middle, and high schools (i.e., kindergarten to grade 12) reported being mistreated specifically due to being transgender.<sup>8</sup>

## Stigma and Discrimination

### HEALTH CARE

**A HUMAN RIGHTS CAMPAIGN REPORT** shows that among transgender people living with HIV in the U.S., 19% reported being refused treatment due to their gender identity, and 28% reported they have been harassed in a doctor's office. This creates a significant barrier to care and leads to care avoidance by transgender people.

### FAMILY, COMMUNITY, AND PEERS

**TRANSGENDER PEOPLE OFTEN EXPERIENCE** lack of support from family, community, and peers, which places them at greater risk for violence, homelessness, and unemployment. These consequences are long term and can have an impact on transgender people's health.

**“Employment discrimination is a huge issue in the transgender community. Subsidized education, employment training, and incentive programs are needed to hire transgender people who may need more mentoring and preparation for the workplace given the amount of discrimination they experience. As such, [employment] is an important determinant of transgender health.”**

– Zil Goldstein, NP, Program Director, Center for Transgender Medicine and Surgery, Mount Sinai

In the USTS survey, 10% of transgender respondents reported that their family members were violent toward them once they disclosed their transgender identity, and 8% were kicked out of the house by their immediate family because they were transgender.<sup>8</sup>

## NAME AND GENDER MARKERS

**TRANSGENDER INDIVIDUALS OFTEN** experience difficulties and road blocks in updating their name and gender markers on identification cards and other official records to accurately reflect their gender identity. In the USTS survey, only 11% of transgender respondents have had their name and gender marker updated on all identifications (IDs) and records, 49% did not have an ID or record with the name they preferred, and 67% did not have an ID or record with the gender they identified.<sup>8</sup>

In some cases, transgender patients may be hesitant and/or embarrassed to show their IDs in settings such as a health facility or a doctor's office for fear of being interrogated by security or staff. This often results in a delay in care or complete avoidance of care. Respondents identified cost as another barrier to updating IDs and records.

Among those who have shown their ID and do not have updated markers that match their gender or name, 25% reported being verbally harassed, 16% were denied benefits or service, 9% were asked to leave, and 2% were assaulted.<sup>8</sup>

In New York State, 34% of transgender respondents who have shown an ID with a name or gender that did not match their gender identity were mistreated, including being verbally harassed, denied benefits or service, asked to leave, or assaulted.<sup>8</sup> Only 12% of transgender respondents in New York State reported having the name and gender marker that match their name and gender identities on all of their IDs.

To address this issue in New York City, the New York City Council recently passed (as of September 2018) legislation that allows people to select "X" as an option on their birth certificate. This legislation is expected to be signed into law in the near future.<sup>16</sup>

## Behavioral Health

**SOCIAL FACTORS INCLUDING** higher rates of poverty, racism, transphobia, sexism, and early life trauma for transgender individuals contribute to higher rates of behavioral health issues.

## DEPRESSION AND SERIOUS PSYCHOLOGICAL DISTRESS

**THE PREVALENCE OF SERIOUS PSYCHOLOGICAL DISTRESS** among transgender people is four times higher compared with the general U.S. population. In the USTS survey, 39% of transgender respondents reported experiencing serious psychological distress in the past month, compared with only 5% of the U.S. population.<sup>8</sup> In New York State, 40% of transgender respondents experienced serious psychological distress in the past month.



In the same survey, 40% of transgender respondents reported having attempted suicide in their lifetime.<sup>8</sup> This is nearly nine times the prevalence of the attempted suicide rate when compared with the general U.S. population attempted suicide rate of 4.6%.

## SUBSTANCE USE

**IN THE USTS SURVEY,** about one-third of the respondents (29%) reported using illicit drugs and/or non-medical prescription drugs in the past month. This is almost three times the rate of similar use of substances among the general U.S. population.<sup>8</sup>

However, while substance use is a prevalent health issue in the transgender community, health care facilities are not consistently equipped with transgender-competent providers to treat substance-use disorders.

**"There is a great need for increased community resources for transgender people, particularly for those who do not have a strong network of supportive family and friends."**

– Kevin Steffens, RN, MBA, Vice President of Clinical Services and Programs, Amida Care

**"There are not enough substance-abuse facilities that are competent enough to provide the level of care that the transgender community requires without further traumatizing them. All facilities that are licensed through the State of New York should be required to complete mandatory training on how to provide care and services to the transgender community."**

– Octavia Lewis, MPA, Community Ambassador, Amida Care

# Integrating HIV Prevention and Treatment Services in Gender-Affirming Health Care

**HIV CONTINUES TO BE** a major health issue in transgender communities in New York, the U.S., and throughout the world. In a recent finding, transgender women are 49 times more likely to be living with HIV compared with the global general population. Transgender men are also at higher risk for HIV. The Centers for Disease Control and Prevention reports that between 2009 to 2014, 2,351 transgender people were diagnosed with HIV in the U.S.: 84% were transgender women, 15% were transgender men, and 1% another gender identity.<sup>17</sup> A 2013 analysis showed that an estimated 22% to 28% of transgender women are living with HIV in the U.S., of whom 56% were black/African American.<sup>18</sup>

**“There have been several studies that demonstrate that many transgender women often prioritize their feminizing care over everything else, including HIV/sexually transmitted infections prevention. As such, it is vital that these services complement each other.”**

– Asa Radix, MD, Callen-Lorde Community Health Center

The barriers to health care, social determinants of health, economic marginalization, stigma and discrimination, and other factors described previously leave the transgender community highly vulnerable to HIV acquisition. Taken together, these findings highlight the need for solutions that holistically address the health needs of transgender individuals, including integration of HIV prevention and treatment services with gender-affirming health care.

To date, there is a lack of integration of HIV programs and gender-affirming health care

programs specifically designed for transgender people. Research has shown that transgender people prioritize gender-affirming services such as hormone therapy over other kinds of medical care, particularly if there is a perception that the treatment may potentially interfere with their gender-affirming treatment or when faced with limited resources and the choice of paying for gender affirmation vs. paying for HIV services.

In particular, HIV prevention tools such as pre- and post-exposure prophylaxes (PrEP and PEP) are essential to ending the epidemic. Preventing one HIV infection can save as much as \$500,000 in lifetime medical costs. Ensuring reach and coverage of HIV prevention methods to transgender populations is critical to help people of transgender experience take control of their sexual health.

Additional steps can be taken to expand access around sexual health services to people of transgender experience, including:

1. Increased outreach that educates transgender people about PrEP and PEP, using people of transgender experience in campaign material;
2. Better linkage of those interested in PrEP to treatment: most insurance plans cover PrEP, and New York also offers free or low-cost programs;
3. Promoting greater awareness around studies that have shown that PrEP is safe, no serious side effects have been reported, and PrEP does not interfere with hormones<sup>19,20</sup>; and
4. Taking a patient-centric approach to PrEP, with health care providers prepared to prompt thoughtful conversations with each individual around whether PrEP is right for them.

It is important for health insurers and public health professionals to promote integration of gender-affirming services and HIV prevention and treatment tools for transgender people. With this approach, PrEP is a promising strategy to prevent HIV acquisition among transgender people and end the HIV/AIDS epidemic.



**IN THE UNITED STATES,** it is estimated that there are more than 1.4 million transgender adults. Some 22-28% of transgender women are living with HIV.



**IN NEW YORK STATE,** there are more than 78,600 transgender residents. Between 2014 and 2016, 3,314 transgender people received HIV-related services in New York, and 2,365 transgender people were living with HIV.



**IN NEW YORK CITY,** it is estimated that there are more than 25,000 transgender people. Between 2014 and 2016, 792 were living with HIV, of whom the majority (93%) were people of color.

# Recommendations to Address Transgender Health Barriers

**AMIDA CARE RECOMMENDS THE FOLLOWING** measures to address the barriers to care outlined in this whitepaper. Our recommendations support the more expansive Ending the Epidemic recommendations outlined by the New York State AIDS Institute Ending the Epidemic Transgender and Gender Non-Conforming People Advisory Group.<sup>21</sup>

## HEALTH CARE

**TGNC INDIVIDUALS REQUIRE ACCESS TO** physical, sexual, mental, and behavioral health care that is regionally accessible, affordable, and delivered by staff that are both skilled in trans-specific care and provide services in a trans-affirming manner.

**Create a transgender-inclusive environment for transgender patients and employees at health care providers:**

- ✓ Integrate gender-affirming care in all aspects of the patient experience.
- ✓ Educate physicians and patients about after-care for gender-affirming surgeries, treatments, and other procedures.
- ✓ Implement cultural competency training for all care provider and institution staff. This includes all staff in supportive roles, such as security guards, police officers, and administrative staff.
- ✓ Hire transgender people as staff and provide career-building opportunities that nurture leadership.
- ✓ Update forms, surveys, identification, and other materials to provide options for gender markers that allow transgender people to indicate their gender identities.

**Increase access to TGNC-competent health insurance coverage:**

- ✓ Mandate coverage of comprehensive gender-affirming care services in all health insurance plans for transgender employees in the private and public sectors, including mental health screenings and hormone therapy.
- ✓ Implement TGNC cultural competency trainings for health insurance plans, surgery to change physical characteristics, speech and voice therapy, and urogenital care.
- ✓ Verify cultural competency of network providers before referring patients.

## EMPLOYMENT

**TGNC INDIVIDUALS REQUIRE ACCESS TO** living-wage employment that provides opportunities for advancement, competitive wages and benefits, and environments free of discrimination and harassment.

- ✓ Hire transgender people as staff and provide opportunities for career growth.
- ✓ Mandate health insurance coverage for gender-affirming care for all transgender employees in the private and public sectors.

# Recommendations to Address Transgender Health Barriers (cont'd)

- ✓ Implement and enforce anti-discrimination employment policies. Commit to and implement diversity readiness policies, including annual or more frequent cultural competency trainings.
- ✓ Pass legislation to end employment discrimination.
  - › *Equality Act of 2017* (H.R. 2282 Rep. Cicilline (Rhode Island)/S.1006 Sen. Merkley (Oregon)) is a federal bill that would implement protections that end discrimination on the basis of sexual orientation, gender identity, and sex in the areas of employment, housing, public accommodations, public education, federal funding, credit, and the jury system.

## HOUSING

**TGNC INDIVIDUALS NEED ACCESS TO** safe, affordable, and gender-affirming housing that is not exclusively dependent on HIV status. This includes transitional living, long-term housing, and various sheltering services.

- ✓ Welcome transgender people as residents by implementing anti-discrimination policies that comply with New York State law that prohibits housing discrimination based on gender.

## Conclusion

**THE RIGHT TO HEALTH AND HEALTH CARE** is essential to serve and care for transgender populations, particularly in the fields of public health, medicine, and health policy. As transgender communities face multi-level barriers to health care and insurance, it is critical for stakeholders including health insurers, policymakers, providers, and community members to communicate and work together to eliminate these barriers. This includes addressing critical health concerns such as HIV/AIDS and mental health among underserved communities. Providing support and adequate funding for transgender programs, as well as welcoming transgender people in the housing and employment sectors, are critical components of eliminating barriers to care and negative health outcomes.

Transgender people must be able to live their lives authentically and healthily, without fear, stigma, and shame. Health care environments play a critical role in supporting transgender people's lives and health. By ensuring that policies protect coverage of gender-affirming health services, expanding the number of transgender-competent providers available, creating a culturally competent environment by training staff, affirmatively hiring transgender people, and ensuring that the gender identities of transgender individuals are accurately reflected, it is possible to create an inclusive society that supports people of transgender experience in all aspects of their lives.

**“By providing critical rental assistance, New York’s HIV/AIDS Services Administration (HASA) has helped people living with HIV/AIDS to obtain safe, secure housing. But, stable housing is one of the most urgent challenges that transgender people face because of stigma, discrimination, and economic challenges, which puts them at elevated risk for HIV. Waiting until transgender people become HIV positive before helping with housing is not good enough.”**

– Lyndel Urbano,  
Director of Public  
Policy, Amida Care

# Amida Care Case Study: A Not-for-Profit Medicaid Special Needs Health Plan Serving Transgender New Yorkers

## AMIDA CARE IS A NOT-FOR-PROFIT

Medicaid Special Needs Health Plan (SNP) at the forefront of transgender advocacy efforts in New York City. Amida Care specifically tailors its services to the health needs of New Yorkers living with or at higher risk for HIV, including people of transgender experience regardless of their HIV status. Since its inception, Amida Care has made efforts to help transgender members—who comprise over 7% of its total membership—to access the full continuum of transgender health services and culturally competent care, including gender-affirming services, to live healthier, authentic lives without fear or shame.

## GENDER-AFFIRMING POLICY ADVOCACY

**AMIDA CARE HAS A HISTORY** of helping to advance gender-affirming legislation in New York City and State. New York was the first state to ban discrimination based on gender identity, and Governor Andrew Cuomo announced new regulations in January 2016 that further supports anti-discrimination in health care and insurance for transgender members.

Amida Care worked to make hormone therapy accessible for its members of transgender experience and advocated for this to be a state Medicaid benefit. As of March 2015, New York Medicaid covers hormone therapy and gender-affirming surgeries for transgender patients. This policy removes barriers to health care and insurance due to cost on many high-priced surgeries and other related care that would otherwise be difficult to attain. Medicaid coverage of gender-affirming surgery and hormones is only the first step toward making “health and health care as a human right” a reality.

## HOLISTIC CARE ADDRESSING SOCIAL DETERMINANTS OF HEALTH

**THROUGH CLOSE PARTNERSHIPS** with community-based organizations, Amida Care is able to address multiple social determinants of health and help transgender members access supportive services such as housing referrals, education programs, employment programs, and legal services. This also includes addressing factors such as mental health and substance use.

**“Amida Care’s success with the transgender community lies in their cultural competence, their willingness to learn about new innovations regarding transgender care, and their acceptance of virtually all insurance-driven claims. Amida Care has been a pioneer: they have been doing the work since before it was topical or glamorous to talk about transgender care, never mind offering transgender individuals services. Amida Care excels at meeting patients where they are without having to put patients in a category or a box.”**

– Freddy Molano, MD, Community Healthcare Network



Community Healthcare Network’s 2018 Conference on Transgender Health: TRANSforming Social Justice through Healthcare, sponsored by Amida Care and The New School

### CREATING A TRANSGENDER-INCLUSIVE ENVIRONMENT

**AMIDA CARE'S STAFF UNDERGO IN-HOUSE TRAININGS** in transgender health to improve cultural competency. Amida Care collects gender identity information and pronouns for all members, which is an important first step to establishing trust with transgender members. Amida Care's hiring process welcomes transgender people.

**"When addressing barriers to care, it is important to look at the whole person."**

– Kevin Steffens, RN, MBA, Vice President of Clinical Services and Programs

### HIV CARE AND PREVENTION

**BY ADDRESSING THE COMPREHENSIVE MEDICAL,** behavioral, and supportive needs of its members, Amida Care has proven to have a highly effective care model to help members living with HIV become virally suppressed. This means they have the chance to live longer, healthier lives and cannot transmit the virus to others. Amida Care has increased the viral load suppression rate among its HIV-positive members from 60% in 2006 to 76% in 2018, achieved by engaging 94% in regular outpatient care, which led to a 74% decrease in hospital admissions/readmissions, a 64% decrease in emergency room visits, and a 35% reduction in hospital length of stay. These improvements have resulted in Medicaid savings of \$150 million for New York State (2008-2017).

**"In order to best understand the needs of our transgender members, Amida Care works directly with our members and involves TGNCNB people in the work. We host town halls informed by our members, and collaborate with trans-identified providers as well as community-based organizations that provide services to the TGNCNB community to develop benefits that align with the community's needs."**

– Alicia Rubenstein, Transgender Program Coordinator, Amida Care



On November 1, 2017, New York State Medicaid SNPs, including Amida Care, expanded to serve all transgender individuals who qualify, regardless of their HIV status. This helps to break down the barriers faced by transgender communities in accessing sexual health services and HIV prevention methods such as PrEP. Improving access to PrEP is crucial to empower transgender people to take control of their health and to end the HIV/AIDS epidemic. Amida Care has enrolled more than 230 HIV-negative members of transgender experience since November 2017; all have been screened for HIV risk, and nearly 25% are now on PrEP.

### CARE COORDINATION

**AMIDA CARE WORKS CLOSELY** with each transgender member and surrounds them with a dedicated integrated care team of providers, social workers, health navigators, and behavioral health specialists. Care coordination and a focus on wraparound supportive services ensures hormone therapy and other services are well integrated.



**“Amida Care follows the lead of its members. Initiatives that were created and followed through by Amida Care have been led by transgender members.”**

– Julian Cabezas, LMSW,  
Manager of Outreach  
Programs, Amida Care

Gender-affirming services often require procedures and processes for approvals, which can be difficult and costly to obtain separately. For example, for gender-affirming surgery, a patient needs to 1) provide two letters, including one from a psychologist/psychiatrist; 2) demonstrate well-documented gender dysphoria; 3) undergo 12 months of mental health counseling; 4) undergo 12 months of hormone therapy for some surgeries such as genital surgery and transgender feminine top surgery (breast augmentation); and 5) demonstrate no significant medical/mental health conditions. Amida Care works to ensure that any prior authorizations needed for providing gender-affirming care can be done in-house. This strategy reduces time, cost, and multiple travels, and allows for better care coordination.

### RELATIONSHIPS BETWEEN MEMBERS, HEALTH CARE PROVIDERS, AND INSURERS

#### DOCTOR-PATIENT RELATIONSHIPS

are a critical part of transgender people's health care experience. Amida Care works to ensure that any new and current providers and staff are equipped with expertise in transgender health.

It is important that network providers and staff are culturally competent in delivering gender-affirming services and understand the lived realities and complex health issues among transgender communities. Amida Care fosters connections with providers who are leading the field of community health for transgender people in New York City, such as Callen-Lorde Community Health Center, Community Healthcare Network (CHN), Mount Sinai Center for Transgender Medicine and Surgery, and New York University. For example, CHN serves hundreds of transgender individuals and has mobile units that are staffed with health outreach workers to meet people where they are and provide HIV testing, PrEP education, and linkage to other social services. Amida Care is a lead sponsor in CHN's annual Conference on Transgender Health in New York City, which is designed to improve understanding and build cultural competency around transgender health issues. ★

**“Amida Care was the first insurance program to include hormone therapy on the formulary when other Medicaid programs still had an active exclusion. They also provided support for people who are having surgery, created surgery checklists, and trained nurses to provide at home services for people post-operation.”**

– Asa Radix, MD,  
Callen-Lorde  
Community  
Health Center

# Message from Amida Care President and CEO Doug Wirth

**HEALTH CARE IS A RIGHT**, not a privilege. People of transgender experience need and deserve access to comprehensive, culturally competent, gender-affirming health care. As President and CEO of Amida Care, a not-for-profit Medicaid Managed Care SNP serving people living with HIV and at higher risk for acquiring HIV, I've seen firsthand that providing a high-touch model of care is highly effective in addressing the complex health needs of transgender individuals.

Amida Care strives to be a safe haven for people of transgender experience, who are eligible to join the plan regardless of HIV status. As a specialized health plan that has a history of supporting the transgender community, Amida Care is nimble, attentive, and aware of our members' needs. People of transgender experience are an integral part of our staff and health care team. We know that services and care are better when we listen first. We work closely with our members and surround them with a dedicated, integrated care team of providers, social workers, health navigators, behavioral health specialists, and a designated health home.

Our transgender program aims to take care of the whole person, including primary care, hormone therapy, gender-affirming surgeries, sexual health services, HIV treatment and prevention, substance abuse treatment,

and mental health services. In developing our transgender health program, we held trainings for staff and modified our systems and operations, including adding gender identity and pronouns to our member database, hiring staff of transgender experience, creating a Transgender Clinical Advisory Committee, and developing a culturally competent and robust provider network.

To improve health outcomes, we need to break down the barriers that keep health care out of reach for many in the transgender community, including violence, lack of employment opportunities, housing instability, and discrimination. Amida Care is committed to being an innovator in advancing access to the full continuum of care and services for transgender individuals. Amida Care works with community-based organizations to help members access support for housing, employment, and legal issues. We're proud to help our 500+ transgender members—who comprise 7% of our total membership—access respectful, culturally competent care to live healthier, authentic lives.



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## SERVICES AND SUPPORT

For information about transgender health resources, visit the Amida Care website at:  
<https://www.amidacareny.org/health-resources/trans-health-resources/>

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