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City Voices: New Yorkers on Health

Transgender: Speaking Out for Better Care

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"We are each other's counselors. I don't really take professionals seriously. My psychologist told me a bunch of irrelevant stuff...I feel like I trust my girlfriends better. "

– TRANSWOMAN

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ABSTRACT

In 2014, The New York Academy of Medicine and the NYC Health and Hospitals Corporation conducted an extensive community needs assessment (CNA) for several large hospital systems and their partners in the Bronx, Brooklyn, Manhattan and Queens.

The CNA findings will inform health care reform efforts and assist hospital systems, community organizations, and policymakers who are working to have a positive impact on the health and well-being of low and middle income New Yorkers.

This data brief is part of a series—City Voices: New Yorkers on Health—developed by the Academy to give a voice to the health needs of people in the city who are oftentimes invisible or unheard. "Transgender: Speaking Out for Better Health" does this by highlighting informative personal experiences from key informant interviews with LGBT service providers and two focus groups with transgender New Yorkers about their health needs, access to health services, and resources that promote good health. Participants called for more physicians and other health care providers who were more sensitive and knowledgeable about transgender health care needs, better access and coverage for transgender care, more extensive health education efforts about HIV/AIDS, and better behavioral health services.

OVERVIEW

Transgender (trans) persons, approximately 0.3% of the US population,[1] are at higher–risk for HIV,[2–3] mental distress and suicide,[4–6] substance abuse,[7] cardiovascular diseases,[8] cancer,[9] and physical violence due to their gender identity.[10–11] Trans persons have health care needs that reflect this broad array of conditions, as well as specific needs related to hormonal requirements, and surgical sex reassignment (for some), both pre and post transition. Reliable and competent health services, sensitive to these issues, are needed. Yet, trans persons continue to face difficulties accessing care, which leads to delays and underutilization of needed services. Previous research suggests that discrimination, lack of knowledge regarding trans health among health care professionals, and limited resources (e.g., referral services, insurance coverage) for trans healthcare[12–13] are likely contributors to suboptimal health among trans persons.

This report, part of a series describing findings from a comprehensive community needs assessment (CNA) conducted in four New York City (NYC) boroughs, focuses on transgender health and health care issues, with the goal of informing policies, practices, and programs that may contribute to improved health within the transgender community.

FINDINGS

Issues of special relevance to trans persons that contribute to health disparities that emerged from our research included: (1) a call for more sensitive and knowledgeable health care providers, (2) insurance coverage for trans health services, (3) HIV/AIDS, and (4) mental health concerns.

1. Need for more sensitive, knowledgeable and inclusive health care providers

A theme from study participants that cuts across all trans health issues, is the need for appropriately trained and sensitive care providers who are willing and able to see trans patients throughout various stages of transition. Key informants and focus group participants described limited specialized LGBT services, in general, and the specific challenges and repercussions of inappropriate care for trans persons.

> ***They withhold information from their providers. They're real reluctant, particularly with transgender folks, to engage in health care on so many levels. And, we could talk for hours about trans people, like getting disrobed, "What room do you go into, what's your name on the form, why doesn't this match your insurance card, why do you have breasts and a penis, can I touch this?"...just endless. (Key Informant, LGBT health service provider)***

Most focus group participants reported having regular doctors at well–known, specialized LGBT community health centers in Manhattan, regardless of where they lived.

> *The doctors, like I know my doctor is gay. The social workers there, they're either trans themselves or they're gay or bi or lesbian, or somewhere, somewhere in there. But mine, you know, he's trans. So it's, it's more comfortable because it's like you can relate to them and possibly open up with them a little better.* (transwoman)

Regular checkups for both transmen and transwomen, especially gynecological services, were reported to be underutilized, partly due to fear of mistreatment by providers at non–LGBT/non–LGBT–friendly facilities. Some transmen were refused gynecological services simply because "we [doctors] don't see men," despite their continuing need after sexual reassignment surgery. In general, there was a perception that health care providers were unaware that females transition to males, expecting only males transitioning to female.

> ***When you say "I'm trans" at the doctor they give you this look of death, like "trans?" and then I hate to explain. I'm like, female to male and they go, 'what is that?' Female to male. Meaning I'm living my life as a male now. I used to be female. This is what it is. And then they want to get loud so everyone else can hear it. (transman)***

> *I have trans men friends who, you know, have full beards and you know, they walk into OB/GYN office and everyone's staring at them. We've gotten calls and stuff from people who will, who have gotten thrown out of gynecologists' offices because they'll say, "well, we don't see men." And then they try to explain that they still have female anatomy, and the doctors are so uninformed.* (transwoman)

In addition to participants' concerns over their health care provider's inappropriate behavior and insensitive attitudes, were concerns that providers were fundamentally ill–informed about transgender health and medical care. Several described with frustration the many occasions in which they had to educate their providers about being transgender in order to receive appropriate health care. One transman commented:

> *At the end of the day you need more doctors that know. That understand. That don't have to give the question to someone else to answer it. Don't just give me the runaround and say, "You know what, I'm not too sure."* (transman)

When asked if there were enough trusted providers (e.g., primary care physicians, gynecologists, psychiatrists, endocrinologists) in NYC, most participants agreed more providers should be trained to serve the transgender community. Participants described long wait times to receive health care from a trusted provider. Across the two groups, participants agreed that having providers—physicians and other health care staff— with comprehensive knowledge of trans health was more important to them than having LGBT providers.

> *Educating the general community so that I don't have to think "oh I have to go to this one specific doctor" in the case of an emergency. I don't have to worry about everybody getting up and wondering what's up with me.* (transman)

> ***If you don't train not only medical staff but mental medical staff at a hospital or other health care provider, transgender people may face discrimination, ignorance, and hostility. They may not even come back. So if they're not even showing up, then the medical aspects of, whatever medical experience and expertise you have is completely irrelevant. (transwoman)***

2. Access, Coverage and Quality of Transgender Health Services

From the perspective of focus group participants, access to and use of hormone therapy appeared to be the most pressing health-related issue. Most agreed that affordable, prescribed hormone therapy was accessible in NYC, although it was also accessed without a prescription from friends, illicit dealers, or online sources—despite the risk. The most commonly reported barrier to insurance reimbursement for hormone therapy was a policy requiring that the individual's gender marker and name be consistent with the gender that a particular type of hormone therapy is medically intended for (estrogen for female and testosterone for male). One transwoman described this policy to be a source of great frustration: "They [insurance company] shouldn't make people change their name. They should be able to live their life the way they want to live...That's your life."

To avoid addressing their insurer's gender marker and name discrepancy requirements, several low-income participants reported getting their hormone therapy from an LGBT community health center that allowed them to pay out of pocket and on a sliding scale. One focus group participant reported that paying out of pocket was a better option than battling with her insurance company. Furthermore, visiting the clinic as needed was less expensive than the insurance premium:

> ***Normally because I'm self-employed, I tend to have to pay somewhere around $300 to $400 per month on, just for health insurance. Versus what I spend when I go to [LGBT community health center], because of their payment scale, I tend to pay somewhere along the lines of like $50 for the actual hormones and about, anywhere between $50 to $100 for the actual doctor visits. (transwoman)***

Lack of insurance coverage plays a role in another key service used by many trans persons: breast reduction. Several transmen participating in the survey expressed frustration that "top surgery" is not covered by insurance for trans persons. Despite the fact that having breasts made these participants self-conscious about their appearance and prevented them from accessing certain male-specific services (e.g., gym locker rooms), they had to bind their breasts because the cost of top surgery was unaffordable without insurance coverage.

Beyond affordability and insurance coverage, several transmen reported difficulties getting testosterone because healthcare providers did not believe that they were transgender due to their passably masculine appearance, and questioned why they would need testosterone. One explained:

> *I'm not a girl but no one believes that I'm trans…Even with down there, they're still like "You're sure you're trans?" If I show them the top they will see a couple of scars and they would be like "You have scar."* (transman)

The amount of economic pressure: when you lose your job, then there goes the resources and increased pressure. It breaks you down. If you are a husband, there goes your manhood. Maybe there is no strong family foundation to talk to about it, no one close to tell them they are going through this, so they have to carry that. If there is no spiritual life, it eats them up inside. They become mentally ill, short- tempered. (Focus group participant, Brooklyn)

With regard to quality of care, many participants expressed concern about the standards or guidelines healthcare providers followed when prescribing hormones to trans persons. Despite frequent monitoring of their hormone levels, many feared that their providers were flying blind, and that there was no real science on how to prescribe hormones to trans persons. They were concerned that inappropriate levels might result in serious adverse effects. The metabolic effects of hormone therapy were described, including significant changes in weight.

3. HIV/AIDS

Among the most common health concerns of trans participants was HIV/AIDS. Sex work was described as a major source of HIV transmission in the trans community. The high prevalence of HIV/AIDS in the trans community was attributed both to lack of concern about the disease among some infected trans persons, and to unprotected sexual encounters between transwomen and heterosexual men. Participants described the lack of awareness of HIV risk among some of these heterosexual men. "They feel like they don't have it…I mess with women. Women do not have HIV. That comes from you guys." Others emphasized safe sex,

> *"If I'm having sex with you, I'm going to use a condom and I'm going to wrap it up."* (transwoman)

Participants called for more integrated sexual health education focusing both on cisgender (people whose biological gender matches their gender identity) and transgender persons, and more safe sex education in their community as a way to reduce the incidence of HIV/AIDS.

4. Mental Health Concerns

Mental health issues were considered common within the trans community, specifically depression, dysphoria (discomfort in one's body), and anxiety, attributed to gender identity and appearance issues, as well as stigmatization, poverty, and unstable living conditions. One transman recalled his difficult experience being forced to leave his home after he started strapping his breasts and wearing his hair short, and having to sleep in his friend's car. Another transwoman described her experience living in fear in a shelter in the Bronx:

> ***In shelters they discriminate against you. I was attacked last Thursday and they threw my clothes off my back and threw them outside with the bag. If I go off and attack them, I'm gonna get in jail because I'm a man. (transwoman)***

Participants with insurance reported receiving mental health services. Many expressed a preference for LGBT mental health professionals, because they believed that personal experience enhanced their competence. However, there was general consensus that few mental health professionals understood their circumstances and/or gave appropriate advice.

> *With my regular therapist that I'm now seeing once a month ... she doesn't get many trans clients. She has like maybe one or two other LGBT clients, but you know, a lot of the time I find myself actually educating her, and not really reaping the benefits of it.* (transman)

Given the dissatisfaction with mental health services, most focus group participants relied on transgender peers as their main source of support.

They withhold information from their providers. They're real reluctant, particularly with transgender folks, to engage in health care on so many levels. And, we could talk for hours about trans people, like getting disrobed, "What room do you go into, what's your name on the form, why doesn't this match your insurance card, why do you have breasts and a penis, can I touch this?"...just endless.

– KEY INFORMANT, LGBT HEALTH SERVICE PROVIDER

CONCLUSION

Transgender New Yorkers continue to face difficulties accessing the health care they need. The most commonly reported barriers include shortages of providers with appropriate knowledge and sensitivity, reimbursement restrictions set forth by insurers, and long wait times for the health care providers they trust. HIV/AIDS was among the most common health concern among trans New Yorkers. High incidence of HIV/AIDS in the trans community was attributed mainly to unsafe sexual practices, especially among sex workers. Mental health issues were also common. Sources of distress were discrimination, stigmatization, and violence against trans persons, as well as poor living conditions resulting from poverty and limited choices. Lack of trust in providers and previous experiences of mistreatment contribute to underutilization of medical and behavioral health services. Continuing training for multidisciplinary health care providers on trans health and culturally sensitive health care to promote health, safety, dignity, and the human rights of trans persons—consistent with the recommendations put forth by the New York State Department of Health Ending the Epidemic Task Force14 —is necessary to facilitate more welcoming care environments and opportunities for optimizing care for trans persons.

Findings from our CNA highlight only some of the health needs and health care access issues of transgender New Yorkers. More research is needed to expand our understanding and to explore ways to incorporate this knowledge into policy and programs to alleviate health disparities among this population.

This collection of voices provides a direct glimpse inside the health issues and needs of New Yorkers to help inform the many decisions that are being made on a daily basis by community service and health care providers, and policy makers. For more insights and perspectives directly from those in need, visit nyam.org to download the complete City Voices: New Yorkers on Health series of reports.

METHODOLOGY

The New York Academy of Medicine led a four-borough CNA* during the summer and fall of 2014. The CNA included 41 key informant interviews and 81 focus groups, including two focus groups explicitly targeting trans persons residing in NYC. Our goal was to better understand trans persons' health issues, access to resources to promote health, use of medical and behavioral services, and their recommendations for improved service delivery. Key informants were selected for their expertise across a broad range of issues including LGBT health, aging, immigrant health, behavioral health, homelessness, incarceration, disabilities, and environmental health. The CNA was conducted to inform the design of health care service transformation through the Delivery System Reform Incentive Payment (DSRIP) programs. For more information, please refer to "Finding from A New York City Community Needs Assessment: An Overview" (November, 2015).

Trans persons 18 years or older residing in NYC were recruited through LGBT clinics and community health centers, trans support and social groups, social media, and word of mouth. Focus group participants included 15 transwomen (born as male, transitioned to female) and six transmen (born as female, transitioning to male). Of the 21 participants, 18 were receiving hormone therapy for a length of time ranging from less than one week to 44 years. The average age of participants was 33. Approximately one-third were African American and 38% were Hispanic/Latino; 55% graduated from high school and 35% graduated from either two- or four-year colleges. Eighty percent of participants were insured; 75% of the insured were enrolled in Medicaid. English was the primary language for all participants.

* The CNA was conducted to inform the design of health care service transformation through the Delivery System Reform Incentive Payment (DSRIP) programs. For more information, please refer to "Findings from a New York City Community Needs Assessment: An Overview." New York, NY: The New York Academy of Medicine. 2015.[15]

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