

## Transgender Health Care in Greater Boston

### Executive Summary

The Health Equity Roundtable (“Roundtable”) is a program of the Harvard Pilgrim Health Care Foundation, designed to help Harvard Pilgrim and the health care industry tackle some of the important health disparities by soliciting input and information from those individuals most directly impacted by disparities in health and health status.

The goal of the Roundtable is to improve health care by seeking the input of representatives of the communities impacted, uncovering new information, exploring the ways in which a particular community makes meaning of important ideas, and facilitating the transfer of knowledge from communities to the health care professionals who are tasked with creating solutions. The findings from the group discussions are reported back to the Harvard Pilgrim Health Care Foundation, and are then reported more broadly through a variety of outlets.

The first Roundtable was held in Boston in March, 2016 to explore the transgender community’s experiences regarding access to and coverage of gender affirming care. The meeting was hosted by Dimock Community Health, a neutral, easy-to-access site located in a diverse community.

A total of 33 men, women, youth, parents, advocates and clinicians attended the Roundtable and contributed to the data collected. Of these, 27 identified as “trans” or “gender queer.” Among the participants:

- 24% were under 25 years of age
- 56% were between 25 and 45
- 20% were over 45 years
- 81% identified as transgender or gender queer
- 73% identified as white, non-Hispanic
- 36% identified as African American, Latino, Asian or Native American. (Participants could select more than one category.)
- Four participants identified as parents of transgender children or adolescents and four identified as spouses or partners of trans people.

The group also included four physicians, two nurses, three behavioral health clinicians and three community health outreach staff members.

## **Summary of Findings**

Based on participant feedback, 10 themes were identified. For the purposes of this report, the 10 themes have been refined to four primary subject areas:

- Insurance coverage and access to coverage
- Seeking and accessing care
- Provider/clinician knowledge/expertise
- Treatment in the health care system

### **Insurance Coverage and Access to Coverage**

Participants reported wide variation in what was covered, how one accessed gender affirming care, and the ease of understanding the insurance coverage provided.

According to participants, only two insurers provided information in an easily accessible manner — Harvard Pilgrim Health Care and Blue Cross Blue Shield of Massachusetts — clearly listing medications, treatments and procedures that were covered, as well as those that were not. Harvard Pilgrim also was praised for its use of a dedicated care manager who served as the point of contact for those seeking care related to transgender health.

There was wide variation reported in how out-of-area coverage was managed. This was especially important as presently there are only two surgeons in New England, located at Boston Medical Center, who provide gender affirming surgical services. Currently, those services are only available for trans women. Most trans individuals seeking genital surgery must travel outside of New England to Pennsylvania, California, Texas, Florida or Illinois to get the care they need. Participants described difficulty accessing care when surgical teams were out-of-state, or out-of-area for an insurer.

Participants described a lack of consistency across insurers regarding what forms and dosages of common hormones were covered. For example, while an injectable form might be covered, a gel or patch form might not be covered.

Out-of-pocket expenses were seen as disproportionately impacting trans people— who tend to be un- or under-employed—and continued to be barriers to care, especially for underserved communities and low-income people.

Some surgeons require chest binders and electrolysis as a prerequisite for gender affirming surgery. Yet a lack of coverage of chest binders for trans men, and lack of coverage of electrolysis and “gaffs” (undergarments designed to provide a smooth contour under feminine clothing) for trans women, increased out-of-pocket costs for individuals attempting to access care. In addition, electrolysis and the use of chest binders and “gaffs” were tied to reduced safety and greater vulnerability to hostility and verbal and physical assault.

Gender coding in health care systems, both in insurers' data systems and in providers' medical records, emerged as a significant problem complicating care, quality assurance and compromising patient confidentiality and safety. Most participants reported that systems of care defaulted to "male or female," which forced the patient to repeatedly "out" themselves in multiple health care encounters. As an example, one participant reported being evicted when a letter addressed to him arrived at his apartment with his natal name. The lack of nuanced gendered screens caused those who do not identify with the male-female binary to feel invisible. Physicians complained that the lack of nuanced gender screens limits research, making it impossible to describe differences within the transgender community.

### **Seeking and Accessing Care**

There is a shortage of trans-competent providers offering all aspects of care, from gender affirming care to routine medical care for trans patients. Insurers' networks may not include trans-competent providers, especially those who can provide routine, basic primary care. In addition, insurers were generally described as not offering easy to access listings of trans-competent providers.

Participants described very long waits to access providers with experience in caring for trans people. For transgender children, the situation is fraught with risk, as they must begin puberty-blocking drugs within a few months of achieving certain growth milestones. But the wait to see a competent pediatric endocrinologist can take in excess of a year. The inability to access the necessary care in a timely manner can have lifelong negative effects on the patient.

Access to trans-competent reproductive care is described as either universally difficult or non-existent, and there were perceived inequities in the way that reproductive health needs were covered by insurers. Most trans participants described negative or even hostile attitudes on the part of clinical providers, stating that these health care providers had not received any education about reproductive options before gender transition.

Emergency care emerged as a treatment setting full of risk and lacking safety. The experiences of many trans participants and the parents of trans children included poor treatment, name calling, being viewed as an "exhibit," or having care refused.

### **Provider Knowledge/Expertise**

Most health care professionals were seen as lacking even basic knowledge about trans health issues, and clinician participants reported a lack of training across all professional disciplines.

A theme that surfaced repeatedly was the burden of requiring the patient to try to educate the provider, despite the power imbalance inherent in such an interaction. Transgender youth leaving home to live independently were seen as particularly vulnerable: too young to take on the "educator role," and often having their concerns dismissed because of their youth.

Insufficient access to mental health clinicians who were competent to work with trans people was of special concern, since all insurers require evaluation by a mental health clinician before beginning gender affirming transition. The few mental health practices with competency were described as “always closed,” forcing waits of up to two years to see a competent clinician.

Participants reported being refused care by clinical providers who did not understand the difference between gender identity and sexual preference. Participants also described being pressured to endorse a “binary” (e.g., male or female) by clinicians who did not understand the spectrum of gender identity.

Participants highlighted a need for more robust research into health issues important to members of the trans community. They noted a lack of information about the long term effects of hormone treatments, and a lack of knowledge about potential interactions between hormone treatments and treatments for a number of other conditions such as cancer, heart disease and diabetes. There is little to no research available on the special issues in caring for aging trans people.

### **Treatment in the Health Care System**

Participants reported being treated poorly by both clinicians and ancillary staff (e.g., receptionists and billing administrators) in ways that expressed negative bias against transgender people and that made them wary of seeking care. Name calling, refusal of care and inappropriate curiosity were reported as common experiences. Parents expressed grave concerns about having their parenting challenged, or even being viewed as abusive and neglectful when they advocated for their transgender children.

Navigating systems of care with inconsistent information and provider systems which were considered incompetent was described as frustrating and daunting. Participants described experiencing a “stop-and-start” pattern of care when they tried to obtain information and identify systems and providers who could provide needed care.

Getting referrals proved difficult, as few providers knew which health care organizations could provide services. For children and adolescents, only families with highly literate parents who were native English speakers were seen as being able to navigate the systems needed in order to receive essential care. Ethnic minority transgender people were seen as being at an extreme disadvantage due to numerous factors such as racism, poverty and a lack of social support. For ethnic minority transgender people, the health care organizations with experience in welcoming and caring for low income and/or people of color were seen by participants as less likely to have access to trans-competent clinical providers and less likely to provide a welcoming environment for transgender people.

### **Recommendations for Action**

The following recommendations emerged from the group. These recommendations hold promise for making it easier for transgender individuals and their families to access appropriate health care with fewer barriers and less frustration and anxiety. The recommendations have the

potential to make it easier for insurers to deliver coverage with less ambiguity, to track health care status and outcomes, and to more accurately assess treatment needs and outcomes of members who are transgender.

- Develop acuity indicators to accompany the diagnosis of Gender Dysphoria. This would permit tracking and quality assessment of patients all along the gender continuum.
- Encourage provider networks to list trans-competent providers, to insure that they can collaborate to provide effective referrals for care, and that the clinical staffs are educated in the basics of trans health.
- Develop and use more precise and flexible gender screens on enrollment forms and patient records, using more inclusive language.
- Educate staff at emergency care settings, including per diems and locum tenens physicians, in the basics of caring for trans individuals. Consider pursuing disciplinary action when poor treatment or refusal of care is documented.
- Include electrolysis and coverage for medical equipment related to gender affirming medical services.
- Provide basic training on issues related to transgender health to health care providers and clinicians. Require clinicians to receive continuing education on issues related to trans health.
- Integrate basic knowledge of transgender people and their health needs into college and university training provided to health care professionals as they prepare to enter the health care professions.
- Incentivize and support more research in the area of trans health and health care that explores health issues beyond those associated with transitions.
- Hire trans people at all levels in health care organizations in order to create greater internal awareness and competence in caring for transgender individuals and their families.
- Help advocate for changes to state regulations which would allow for more flexibility in prescribing larger amounts for hormonal therapy.
- Expand coverage to include multiple forms of hormone delivery systems, e.g. patches, gels, creams, etc. and provide for the dispensing of larger amounts of the hormone being prescribed.
- Insure coverage for out-of-state, or out-of-area services for gender affirming surgical care until such care is widely available in-state or in-area.

- Insure that access to information about reproductive health options and access to reproductive care is equitable and does not require trans and same sex families to adhere to standards designed to meet the needs of heterosexual people.
- Include gender identity on in-patient admissions forms and in intake and admissions processes. Develop protocols for in-patient settings to safely accommodate transgender, gender queer and non-binary patients admitted to their services.
- Locate all information pertaining to transgender health care and coverage in one, easy-to-find location. Insure that information is accessible to those with low literacy.
- Provide clear descriptions of necessary approvals and processes required to access care. Include information relating to the timing of approvals and processes.
- Identify designated staff (e.g., navigators or care managers) who will serve as primary points of contact for individuals or family members seeking access to transgender health services.

***About the Author:** Shani Dowd serves as the Director of the Health Equity Roundtable, a program of Harvard Pilgrim Health Care Foundation. She is an experienced clinician who has practiced in a variety of health care delivery systems. She has contributed to the development of health policy at both the state and national level. She holds an appointment as an Assistant Clinical Professor of Psychiatry at Boston University Medical School.*