

# HISTORY OF THE FENWAY TRANSGENDER HEALTH PROGRAM

FENWAY  HEALTH

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# Foreword

This document is our attempt to capture the rich history of Fenway Health's work in transgender health. It's a story that spans the entire four decades of the health center's existence, particularly the 26 years since the provision of care to transgender people was added to Fenway's mission statement. There are ups and downs, along with notable milestones to mark—and in some cases, to celebrate. It's a story that continues to evolve even as this version of it has been written. But overall, we are proud to take this opportunity to share it as an important lesson for future generations.

# We would like to thank

the many people who took the time to share their memories and perspectives about different periods of time in Fenway's work with the transgender community, and their thoughts and vision for the goals and challenges we will face together in the future.

## Authors of "The Memo":

This group of people cared enough about Fenway Health to let us know about their concerns and to make suggestions for improvement.

Anderson Clark, Fenway Health Board of Visitors member, former member of the Board of Directors of Gay & Lesbian Advocates & Defenders

C.A. Miller, community member

Damian Rodriguez Lima, Education and Recruitment Specialist for Boston Gay & Lesbian Adolescent Social Services (GLASS), Chair of the Bayard Rustin Committee

Daniel O'Donoghue, former Program Manager of TransCEND at AIDS Action Committee, former member of the Steering Committee for the Massachusetts Transgender Political Coalition (MTPC)

Jesse Pack, Director of HIV Services at Brockton Area Multi-Services, Inc., former Director of Prevention and Screening at AIDS Project Worcester

Sara Schnorr, Of Counsel at Locke Lord

Bobbi Taylor, Vice Chair of the Steering Committee for the MTPC and Co-Chair of the Policy Committee, LGBTQ representative of the Massachusetts State Commission on Unaccompanied Homeless Youth

## The Cross-Department Transgender Care Working Group:

This group of employees has worked tirelessly to improve our work in transgender health.

Judy Bradford, PhD  
Michelle Bordeu, MPH  
Tim Cavanaugh, MD  
Alex Gonzalez, MD, MPH  
Chris Grasso, MPH  
Rebecca Henderson, LICSW  
Ruben Hopwood, MDiv, PhD  
Jane Powers, LICSW  
Sari Reisner, ScD, MA  
David Todisco, LICSW  
Rodney VanDerwarker, MPH  
Ralph Vettes, MD  
Shayne Zaslow

## Interviewees:

These people all took time to speak with authors of this paper so we could document our history.

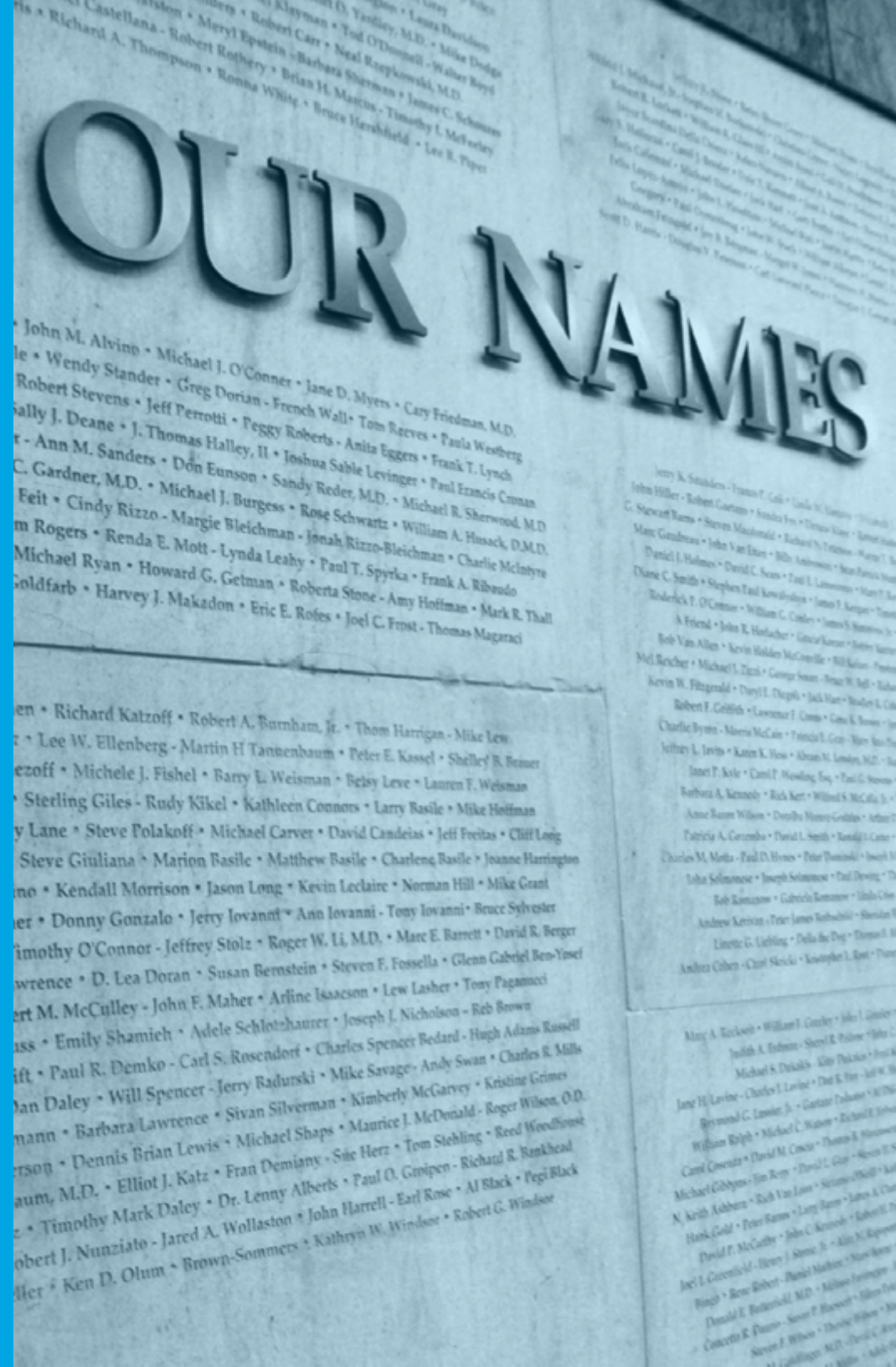
Stephen Boswell, MD, FACP  
Judy Bradford, PhD  
Anderson Clark  
Timothy Cavanaugh, MD  
Marcy Gelman, RN, MSN, MPH  
Alex Gonzalez, MD, MPH  
Joanne Herman  
Ruben Hopwood, MDiv, PhD  
Damian Rodriguez Lima  
Sari Reisner, ScD, MA

The Staff of Lifeskills

Bobbi Taylor  
David Todisco, LICSW

Additionally, we would like to thank all of our patients and community members—but especially our transgender patients and other transgender community members, who support Fenway Health in so many ways.

And thanks to Thomas Martorelli who conducted the interviews and wrote the bulk of this story and to Cameron Kirkpatrick for his work videotaping the those interviews. Thanks also to Elizabeth Gruber who designed the document.







“

What sets Fenway Health apart is the belief that transgender care is primary care, not specialty care. Transgender people are a significant portion of the population. Access to care is a problem. As medical and behavioral health providers, this is our job. But it's also a social and political act to say that you will start taking care of transgender patients. The radical part of this political act is saying that providing primary care to transgender people is really not that radical. It's something we all can do.

”

Tim Cavanaugh, MD, Medical Director,  
Fenway Health Transgender Health Program

# Today,

Fenway Health counts over 1,700 transgender individuals among its total patient population of nearly 30,000. In the past ten years, transgender people have been one of the health center's fastest-growing populations. Every Fenway provider is trained on how to care for transgender people, and transgender patients are integrated into all patient panels. All clinical and administrative staff members receive regular training in the delivery of respectful and welcoming care for transgender people. The Fenway Institute has become a national leader in transgender health research as well as in technical assistance and capacity building for providers and organiza-

tions on delivering competent transgender care and creating gender-affirming environments. While there is always more to be done, with a lot of help and input from the transgender community and their allies, Fenway Health is one of the world's leading transgender health care programs.

"Several months ago, I went to Fenway's optometry department. The head of that department saw on my form that I prefer feminine pronouns, and consistently used them. And it was clear from the way he did it that he was modeling for the other staff and students who were working with him, so everyone was clued into 'she, her, hers' for Bobbi. And that was really nice."

Bobbi Taylor,  
Fenway Health Patient

The first formal indication of Fenway's commitment to transgender health came in 1997 when, 26 years after its founding, the Board of Directors voted to add transgender people to its mission statement.

Stephen Boswell, MD, FACP, Fenway's President and CEO, remembers that time:

"Transgender patients had always come to Fenway Health for care. But in fact, in the early to mid-1980s, Fenway struggled to decide whether to even include bisexuals in its mission statement, not including them until the early 1990s. When I first got here in 1994, Fenway did not have transgender care as part of its mission, and yet we were surely taking care of transgender patients. It was clear to me that whether they were part of our mission statement or not, they were going to be part of our patient population, and we needed to provide them with competent care. They were a disadvantaged community very much like the gay, lesbian, and bisexual community was and they needed many of the same kinds of advocacy and support that these communities needed. It just made sense that the board should take an affirming vote that transgender care is part of our mission. We would learn to provide them with the very best care, and when we learned that, we would teach others, just the same as our mission with the larger gay, lesbian, and bisexual community."

# 1971–1994:

## The Early Days

Why did it take so long for Fenway Health to create a focused effort in transgender health? The answer is complicated, rooted in the history of what was then called the gay and lesbian community, and in American culture and the international medical establishment of the time.

Until the 1970s, many medical professionals and gay and lesbian organizations considered transgender people to be gay or lesbian first. The desire to dress as or become a member of the opposite sex was interpreted by some medical experts to be an extreme but secondary expression of a core homosexuality.<sup>1</sup> The terms “transvestite”, “transsexual”, “cross-dresser”, and “androgyne” were used for decades, with varying definitions. In 1965, a psychiatrist coined the term “transgenderism,” which evolved to the term as we understand it today,<sup>2</sup> but that evolution really began in 1979 when transgender pioneer Christine Jorgensen declared herself transgender, saying “gender doesn’t have to do with bed partners, it has to do with identity.”<sup>3</sup> It took another ten years or more before the term “transgender” fully entered the common vernacular in the 1980s.<sup>4</sup>

Also in 1979, the Harry Benjamin International Gender Dysphoria Association (HBIGDA) Standards of Care were first published. (The organization renamed itself the World Professional Association of Transgender Health—WPATH—in 2006.) WPATH has updated these standards several times, with the most recent Version 7 published in 2011.

In 1979, Fenway Community Health Center was already almost ten years old, still tiny, and still struggling to meet the demands of its original founding constituencies of gay men, lesbian and heterosexual women, and the elderly. Little was known about transgender people among medical professionals, or by the “gay and lesbian” organizations advocating equal rights and access to health care. Some transgender people were probably coming to Fenway from its earliest days, but were likely considered part of the health center’s gay and lesbian populations.

A year later, when the first cases of HIV were diagnosed among gay men, the direction of Fenway’s programs and services shifted to focus to address this health crisis. For the next fifteen years and beyond, Fenway made a conscious decision to focus on HIV clinical care for its growing patient population. In these early days, most HIV patients who made their way to Fenway were gay or bisexual men; however, it is worth remembering that a number of transgender people also came for their HIV care.




<sup>1</sup> Zasshi SS. The history of the concept of gender disorder. Washington, DC: US National Library of Medicine, National Institutes of Health, 2012; 114(6): 673-80. Available at <http://www.ncbi.nlm.nih.gov/pubmed/22844818>.

<sup>2</sup> Oliven JF. Sexual hygiene and pathology. Philadelphia, PA, 1965; J.B. Lippincott Company, 1965

<sup>3</sup> Williams C. Christine Jorgensen: transgender woman. Cristan's Research, August 21, 2011. Available at <http://research.cristanwilliams.com/2011/08/21/christine-jorgensen-transgender-woman/>

<sup>4</sup> Williams C. 1984: transgender community = modern transgender community. Cristan's Research, March 8, 2012. Available at <http://research.cristanwilliams.com/012/03/08/1984-transgender-community-modern-transgender-community-2012/03/08/1984-transgender-community-modern-transgender-community>





Fenway's focus on HIV clinical care led to the development of integrated primary care standards that have become a hallmark of its successful model to eliminate stigma in care. This focus also included the decision to establish a research program in order to learn more about HIV, and to provide patients with access to clinical drug trials for treatment of HIV/AIDS. This research program is the foundation for what would later be called The Fenway Institute. The organizational strengths developed as a response to the AIDS crisis have become the building blocks for all of Fenway's services, including its Transgender Health Program.



# 1995–2004:

## The Transgender Task Force

Fenway Health's first organizational approach to transgender health care—the Transgender Task Force—was informal and small. Keeping structured data for the first time, it reported 11 patients in 1997

and 41 in 2000. Its staff consisted of two providers: Marcy Gelman, NP, and Randi Kaufman, PsyD. Together, they saw all of Fenway's transgender patients during this phase of the program. Services included counseling and prescription hormones, along with significant "hormone readiness" assessment time with Dr. Kaufman before hormones could be given. This was consistent with the Harry Benjamin/WPATH guidelines of the time. Fenway's providers were available for primary care, and surgery was available by referral, but it was rarely covered by medical insurance.

"In the early days, transgender people came to Fenway with a need for care, but many of them—mostly those over 40—came with long histories of discrimination and family rejection. There was a constant push and pull to earn their trust. Things moved slowly. Patients didn't get hormones right away. We wanted to get to know them, and required them to see a therapist for several months. In hindsight, this may have been too long, but we wanted to be careful. Some people were impatient; a few got really angry; but others were happy to have somewhere to go to get the care they needed."

**Marcy Gelman, NP**  
(then) The first Fenway Health medical provider serving transgender patients. (now) Director of Clinical Research, The Fenway Institute

Two providers may seem like a small number, and in fact it was, but Fenway Health was much smaller in the 1990s. There were a total of six MDs, Physician Assistants, Nurse Practitioners, and Doctoral-level professionals on Fenway's entire clinical staff in 1995.

Transgender patients came to Fenway because of the organization's reputation as a friend of the LGB community and also due to the retirement of providers seeing transgender patients at other Boston-area hospitals and health centers. Fenway staff went on outreach visits to other local organizations to listen and learn. At a time when there were no national conferences about transgender health, this was the best way to answer basic questions such as what hormones people were using and how they felt about them. During its early days, information about Fenway's Transgender Task Force was disseminated through outreach to local organizations and word of mouth.

Fenway's commitment to what was understood to be quality care had good and bad consequences. With patient safety as a primary concern, Marcy Gelman and Dr. Kaufman were careful to study best practices and adhere to existing guidelines in the medical literature for treating transgender people. Following these guidelines, Fenway's model of care included getting to know patients before prescribing hormones. Adhering to these priorities was time-consuming, and Fenway wasn't as quick to meet patients' expectations as other providers might have been, or as Fenway's new transgender patients wanted. This commitment to ensure patient safety has led to some conflicts with patients and community members.

The source of Fenway's challenges can be summarized in three areas:

## Time.

Patients coming to Fenway for transgender health services might have been convinced about the therapies they wanted, but had to move through intake interviews, giving their providers detailed life histories, and undergoing lengthy counseling and education prior to initiation of hormones. While these were not unusual aspects of transgender care at the time and were aligned with accepted clinical guidelines in the medical field, they still felt like needless “gate keeping” for many transgender people.

## Knowledge.

Transgender people have often been their own best advocates. In a world where providers were learning by doing, it was common for patients to be aware of more information about transgender care options than the doctors and nurses treating them. In the program's early days, creating a provider-patient relationship of trust and open communication in these circumstances was challenging, for both parties.

## Respect.

The majority of complaints and concerns about Fenway Health's transgender health services have been more about “gatekeeping” barriers delaying access to care, or personal interactions with health center staff (e.g. use of preferred pronouns or names or insensitive remarks) than about the quality of care provided by Fenway's clinical staff. For a number of years, Fenway's customer service training specific to transgender patients lagged behind the development of its clinical care.

Marcy Gelman remembers a few details from the “seat of the pants” learning involved in Fenway's pioneering work with transgender patients. Realizing that issues of respect and communication with transgender people went beyond the front desk at Fenway Health, Marcy would accompany some patients to the Department of Motor Vehicles or local banks to help them change their names and gender on official documents. She also learned by doing about how to help people get reimbursed for care from their health insurance companies, often finding success with treatment for a presenting problem of “hormone imbalance.”



Marcy Gelman, RN, MSN, MPH  
Director of Clinical Research

One of the negative outcomes from the program's early days was a failure to balance outreach with capacity. Marcy Gelman and Dr. Kaufman would reach out to transgender organizations to promote Fenway's services, and a relatively large number of new patients would soon arrive. As a result of these outreach efforts, by 2004—the year Fenway Health formalized its Transgender Health Program—the organization reported about 110 individual transgender patients. But because staff beyond the task force's two members were not trained in how to provide competent services to transgender people, some new patients would be dissatisfied with their interactions with Fenway staff, and leave the program shortly thereafter. The consequences of these incidents would linger for years; even today, some complaints that are years or decades old still stand in the way of a fully trusting relationship between Fenway and the Boston area's transgender community. As Ruben Hopwood described it in 2014, “awareness and willingness to serve isn't the same as competence.”

# 2004–2009:

## Growing the Program and Improving the Transgender Patient Experience

In 2004, Fenway created the staff position of Coordinator of Transgender Health, and designated what had been the Transgender Task Force as the Transgender Health Program. Dr. Randi Kaufman was named the first coordinator; she and Anne Marie Forth, MD, began writing a protocol to integrate the services of its medical and behavioral health programs and improved communication and training throughout the organization about transgender health. This 45-page document was released in January, 2005.

Later that year, Dr. Kaufman left as Program Coordinator, and was replaced by Ellen Rottersmann, LICSW. Supported by a grant from the Blue Cross/Blue Shield Foundation, Fenway Health hired two new staff members: Ruben Hopwood, MDiv, PhD, as the program's Training and Resources Specialist, and Alex Solange, in The Fenway Institute, as Health Navigator. Dr. Hopwood worked to provide cultural competency training in transgender issues to all Fenway staff, and Alex Solange provided advocacy and support services to at-risk Boston-area transgender people who needed assistance with medical care, housing, health insurance, and more. During the summer of 2007, Ellen Rottersmann left the program, and Dr. Hopwood was named as the third

Program Coordinator. He and Alex Gonzalez, MD, MPH, Fenway Health's Medical Director, began their work to create the multidisciplinary team that has been a hallmark of Fenway's Transgender Health Program for nearly a decade. The first few years of the program's history were a time of rapid change and intense activity. In addition to the drafting of new clinical protocols, integration of departments, and hiring of additional staff, three important events took place—all of them in 2007.

First, looking to other health centers for successful models of care, Fenway sent Dr. Hopwood to the

Mazzoni Center in Philadelphia. The Mazzoni Center was a smaller organization than Fenway Health, but it was serving 800 transgender patients, nearly four times the number at Fenway. One key to its success was the elimination of any requirement for counseling before hormones were provided. Dr. Hopwood brought this idea back to Fenway, which, under his and Dr. Gonzalez's leadership, created a hybrid informed consent model, replacing its three-month counseling requirement with a single hormone readiness assessment visit, in most cases.

Second, to prepare for the growth Fenway was planning for its Transgender Health Program, and also to eliminate the stigmatization of prospective patients, Dr. Gonzalez, decided that all Fenway providers would be trained to provide comprehensive transgender healthcare within the health center's standard definition of primary care. Like the reduction in hormone readiness counseling timelines, integrating the practice of transgender care as a part of primary care would take a concerted effort to increase staff training and change existing protocols. The model for this fully integrated care policy can be seen in the



Ruben Hopwood, MDiv, PhD., Coordinator, Fenway Transgender Health Program

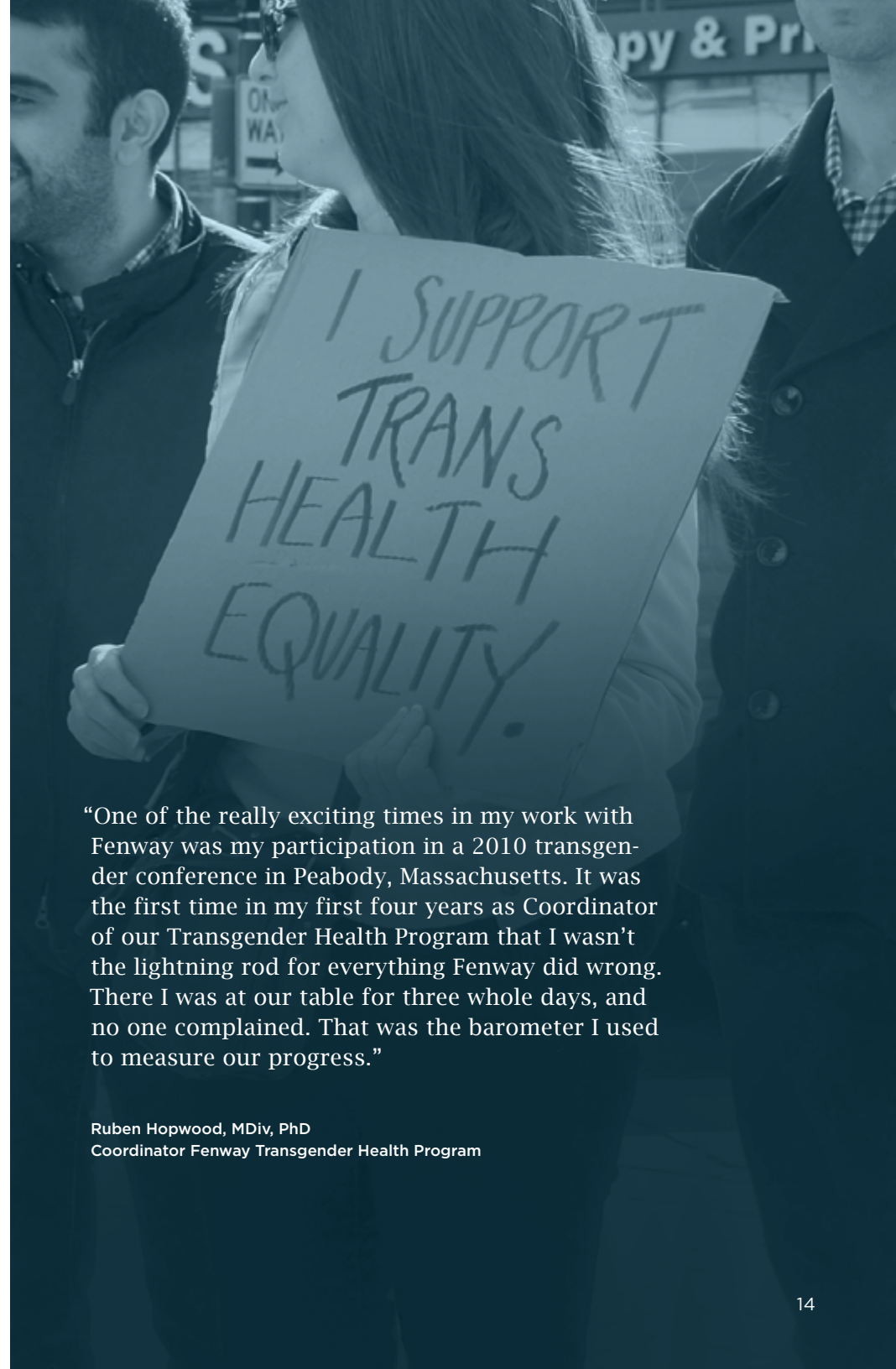


way Fenway integrated its HIV care into the health center's primary care model decades earlier, with the same goal: improving access to care and overcoming similar issues of stigmatization and discrimination.

Third, also in 2007, The Fenway Institute, in partnership with the American College of Physicians, published *The Fenway Guide to LGBT Health*, a comprehensive guide for clinicians. This book not only included transgender people in its analysis of health disparities, disease prevention, mental health, and legal issues; it also featured a groundbreaking section on "Transgender and Intersex Health." This section began with an "Introduction to Transgender Identity and Health" by Dr. Randi Kaufman, linking the rejection, ridicule, humiliation, and isolation of transgender people with the main character in Franz Kafka's *The Metamorphosis*.

Developing Fenway's transgender health program was no small challenge. Even as it was becoming New England's largest provider of transgender health services, Fenway was navigating the consequences of its earlier outreach toward transgender people, their growing demands for respect and inclusion, and a new but imperfect awareness about transgender people throughout American society.

The changes at Fenway were happening simultaneously with profound changes in standards of care for transgender people nationwide, and a corresponding explosion of information on the internet about transgender health. At times, the sheer volume of new information and literature about transgender people and ideas about their care made it a challenge for the health center to focus on the areas of improvement and growth Fenway had chosen for its Transgender Health Program.



"One of the really exciting times in my work with Fenway was my participation in a 2010 transgender conference in Peabody, Massachusetts. It was the first time in my first four years as Coordinator of our Transgender Health Program that I wasn't the lightning rod for everything Fenway did wrong. There I was at our table for three whole days, and no one complained. That was the barometer I used to measure our progress."

Ruben Hopwood, MDiv, PhD  
Coordinator Fenway Transgender Health Program

On an international level, WPATH was responding to similar demands to revise their hormone readiness and eligibility guidelines. Transgender individuals and support groups began using the internet to advocate for new treatments and protocols, with compelling anecdotes that might or might not have been rooted in sound medical science.

Fenway's search for information to help design a more integrated transgender health care program brought a wealth of data from many different sources. Expanded research and outreach also brought fresh but familiar complaints about Fenway's percep-

tion as a "gate keeper"—not an ally—standing in the way of medical treatment. The Medical Department investigated many new therapies, either through its own research or from examples brought by patients. As an organization, Fenway Health looked beyond internal concerns and apparent limitations to a larger unmet need for advocacy on behalf of transgender people at other health care facilities, insurance companies, and government agencies. A critical priority became the setting of priorities for quality improvement, first at Fenway, but with an eye toward other care facilities.

During this phase of the program's growth, Fenway staff consistently relied on six basic activities. They listened. They learned. They practiced. They taught. They stuck to evidence-based medicine. And they were patient. For some observers inside Fenway Health, the resulting changes happened with remarkable speed. For others in the transgender community outside of Fenway, progress remained painfully slow.

Patient statistics for the period show the number of Fenway's transgender patients increased from 116 to 366. During this same time, the demand

for behavioral health services for all patients exceeded available resources at Fenway; as a result, the health center changed its policies to offer these services only to its primary medical care patients. Notable exceptions to this new policy included individuals who were transgender, or who were HIV positive. For transgender people in particular, this was a decision that responded to a need for competent mental health services and the serious lack of options for transgender people to receive these services in New England.



# 2009–2012:

## Creating New Clinical Standards of Care

The “perfect storm” Anderson Clark describes was one of the more difficult challenges Fenway’s Transgender Health Program has faced. Obstacles to progress included mismatched beliefs about which needs were a priority for the transgender community, and a lack of effective communication channels between the community and Fenway. The most logical and basic solution—bringing Fenway Health and the transgender community together to discuss issues and plan on resolving them—took an extraordinary amount of time and effort by everyone involved. While the idea was generally supported, specific plans for how to establish these channels were not always well received on either side.

This limited and at times challenging communication damaged Fenway’s relationship with transgender people, even as the health center was designing and implementing many improvements that have become a hallmark of its Transgender Health Program’s success. One of the challenges the community brought to the attention of the program’s leadership was the amount of time that transpired between the occurrence of newsworthy events in the program and the way these changes were—or were not—communicated to the community.

In today’s “information age,” it is tempting to take it for granted that important events happen in real time, broadcast from cameras that are literally everywhere. But in many cases, it takes carefully planned and maintained communication channels for this

information to flow. Where there are no established channels, it flows slowly, or not at all. In response to the community’s requests for more regular communication, Fenway began announcing news about the Transgender Health Program, including the important story about its training of providers both within Fenway and in the greater Boston area, on its website. In November of 2012, Fenway launched a major social media release about its program, along with graphics illustrating transgender health disparities, as part of Trans Awareness Week. Still, in the eyes of some observers, the flow of information to the community remained slow and limited.

This was partly by design. Wary about negative reactions from the community in the past, when “awareness and willingness to serve [were not] the same as competence,” Fenway had decided to keep

“Fenway Health had successfully raised the standards of its program. All providers seeing transgender patients is huge. But you can never ask, ‘why isn’t this enough?’ Clinical issues might be a priority for clinicians, but let the community define what issues are important to them. Listen, and match your internal point of view with these external opinions. Understand that transgender people may fear loss of care if they give their only health provider honest but negative feedback. Realize that this reluctance, combined with Fenway’s natural discomfort in hearing bad news from people it’s dedicated to help, creates a perfect storm of miscommunication. For the program’s sake, this needs to be overcome.”

Anderson Clark, PhD, Fenway Health Board of Visitors, Massachusetts Transgender Community Advocate



many of the changes to its Transgender Health Program quiet, at least until these changes were well-established and staff were fully trained. Historically, many of the program's new policies and treatment protocols were not announced until 2007, when Fenway's significant changes to its informed consent and treatment protocols were published openly on its website for the first time. Still, for several years after this publication, some changes the transgender community has found to be noteworthy remained difficult to discover. These included multiple internal trainings for all providers in transgender health, some by such internationally known experts in transgender health care as Toby Meltzer, MD, a surgeon in Scottsdale,

**"I gave people on Fenway's Board of Directors a chance to see and work with a real transgender person. For most of them, I was the first transgender person they had ever met. During my time on the board, transgender issues didn't often come up, but when they did, I was there."**

**Joanne Herman, Board Member**

AZ; Marci Bowers, MD, a surgeon and gynecologist now practicing in San Mateo, CA; and Arlene Istar Lev, LCSW, CASAC, a family therapist and educator specializing in sexual orientation and gender identity. Other news the transgender community wanted Fenway to promote more fully included the reduction of hormone eligibility requirements for

patients, and the 2012 hiring of Dr. Tim Cavanaugh, a well-respected provider as the first dedicated Medical Director for Transgender Health.

And sometimes, the medium is the message. In 2009, Joanne Herman became Fenway Health's first member of the Board of Directors who openly identified as transgender. Author of *Transgender Explained For Those Who Are Not*, Joanne began by serving on the board's Finance and Audit Committees, choosing not to be a visible advocate for transgender issues.

But she did become the focus of discussions about important changes Fenway needed to make in serving the transgender community.

Notably, she advocated for a major reform to Fenway Health's employee health insurance program. Prior to her tenure on the Board, Fenway staff members were not covered for many gender-affirming procedures the health center advocated for through its own Transgender Health Program. When Ms. Herman brought this issue to Fenway's board, the organization responded by negotiating health insurance coverage for gender affirming mental health, hormonal, surgical and pharmacy benefits for its employees, one of the first employers—if not the first—in the state of Massachusetts to offer full transgender health coverage.

Growth in the Transgender Health Program also occurred when Fenway acquired the Sidney Borum, Jr., Health Center in July of 2010, taking responsibility for delivery of care to hundreds of Boston-area adolescents and young adults. Fifteen percent of the Borum's patients were—and are—transgender youth, who are often at risk for the consequences of bullying, substance abuse, and suicide.



Joanne Herman, Board Member

Outside of Fenway's clinical care departments, The Fenway Institute also grew its portfolio of transgender health-related work. Judy Bradford, PhD, Co-Chair of The Fenway Institute and Director, Center for Population Research in LGBT Health, led the Institute's earliest studies with transgender populations including studies on discrimination in health care and engagement in HIV medical care. Also from 2009 – 2012, The Fenway Institute brought on the first transgender identified faculty member, Scout PhD, to lead a successful health disparities initiative focused on tobacco control

2010 and co-led by Joanne Herman and Rodney VanDerwarker, MPH, Administrative Director of The Fenway Institute at the time, The Institute explicitly established strategic goals to expand its research, training and policy work to better represent transgender populations.

In 2011, faculty from The Fenway Institute, Drs. Judy Bradford and Harvey Makadon, participated in the publication of *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*, a report by the National Institute of Medicine written to guide studies of the health of LGBT people throughout the nation, and the development of programs improve their care.

In 2011, the Bureau of Primary Health Care (BPHC), Health Resources and Services Administration (HRSA) awarded Fenway a major grant which enabled The Fenway Institute to create the National LGBT Health Education Center. Under the direction of Harvey Makadon, MD, the Center provides educational programs, resources, and consultation to health care organizations, to increase competency in health care for LGBT people. Recent publications include “Affirmative Care for Trans-

gender and Gender Non-Conforming People: Best Practices for Front-line Health Care Staff” (2013), and “Why gather data on sexual orientation and gender identity in clinical settings” (2012).

In 2012, The Fenway Institute was funded by NIH to conduct a multi-city HIV-prevention intervention focused on young transgender women. Based on this intervention's success, The Fenway Institute was awarded a supplement to adapt it for young transgender men who have sex with other men. This became the launching pad for the work of Dr. Sari Reisner, who now leads national and international transgender research projects for The Fenway Institute. These projects include efforts to improve data collection about the health of transgender people and expanded evaluation of programs designed to improve the lives of transgender people in other countries. One example of this international work is a program based on components of Fenway Health's Violence Recovery Program (VRP) that seeks to increase Peru's capacity to effectively respond sexual violence, hate crimes, and other risks faced by its transgender population.

One of the most important recent events in the Transgender Health Program's history is the 2012 hiring of Dr. Timothy Cavanaugh as the first dedicated Medical Director of Transgender Health at Fenway. Dr. Cavanaugh's history with Fenway's Transgender Health Program actually goes back to 2008, when he brought a team of Rhode Island medical providers to Fenway to consult on transgender care protocols, and then used this information to develop a healthcare system for that state's transgender population. His long-standing experience providing care to transgender people and his belief that transgender care is an integral part of primary care, have helped support the Program's increasingly rapid development and growth.

Service statistics show dramatic growth in Fenway's transgender patient population, which increased from 366 in 2009 to 1,500 in 2014, and is over 1,700 as of July 2015.



# 2012–2015:

## Community Partnership and Improvement

In January 2013, Anderson Clark and Joanne Herman, supported by Fenway’s Development Office and the health center’s President and CEO, Dr. Stephen Boswell, began discussions about holding community forums to highlight the Transgender Health Program and to involve transgender ambassadors in the health center’s ongoing improvements to its transgender health care. After much conversation and organization, Fenway hosted a dinner conversation on March 20, 2013, where several stakeholders from the community and Fenway’s Transgender Health Program leaders met for the first time. Dr. Cavanaugh was introduced to participants at this meeting, and he shared his vision for transgender health care at Fenway, along with summaries of the work being done with the transgender community in all departments of the health center.

The meeting lasted well into the evening and included discussions about cultural competency, differences in the treatment of transgender patients vs. cisgender (non-transgender) patients, WPATH Standards of Care and their relation to Fenway’s transgender treatment protocols; explanations of Fenway’s informed consent models of care; inclusion of transgender patients in program planning; the creation of a multidisciplinary medical team in transgender health; transgender research at The Fenway Institute; and the expansion of outreach to the transgender community.

Fenway representatives at the meeting knew these were important issues; they had been working on many of them quietly for years before the meeting took place. But the pace of these changes has accelerated in the time since March of 2013. A constructive dialogue between community stakeholders and

“When Anderson Clark came to me with the idea for the community meeting, I agreed to help. That meeting was a turning point, a springboard for many steps that have changed the way the transgender community now sees Fenway Health.”

Joanne Herman, Board Member

Fenway representatives has continued after this meeting, and many identified concerns have been matched with solutions that are more responsive to the needs of Fenway’s transgender patients. As Joanne Herman noted, the meeting was a true turning point.

Several community members and patients\* followed up the meeting with a written memo providing a list of suggestions for Fenway to address specific issues they identified. As a result, the health center formed its Cross-Department

Transgender Care Working Group\* to identify specific quality improvement efforts and to work collaboratively with the community in maintaining an ongoing dialogue (\*membership noted in Foreword).

Extensive changes in Fenway’s Transgender Health Program ensued. Addressing concerns that commercial electronic medical records (EMRs) did not adequately track gender markers or preferred pronouns and names for Fenway’s transgender patients,

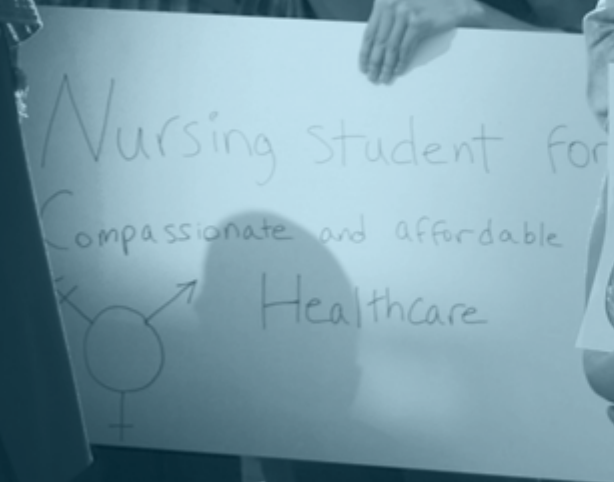


the health center's EMRs. Additionally, the health center has created new support systems and expanded staff training to significantly improve customer service for transgender patients. These changes are now being shared with other health care organizations to help improve their systems as well.

Specific improvements to Fenway's staff training programs include expanding the depth, duration, and frequency of training in culturally competent transgender care for all front-line staff, including providers and front desk representatives.

Additionally, in order to support an ongoing dialogue with Fenway's transgender patients regarding their experiences while receiving care, a customer satisfaction survey was developed, along with a system for administering it and integrating its findings into the Transgender Health Program. In 2014, all of Fenway's transgender patients were sent a link to a 15-minute survey. Four hundred of the 1,200 receiving this survey responded; in addition to reporting a high degree of satisfaction with the care they receive at Fenway, they have also provided excellent feedback to inform continuing programmatic improvements.

Through a collaborative effort between Medical, Behavioral Health, and Senior Management, a revised hormone treatment protocol was developed and integrated into Fenway's primary care model in May 2015. With this change, as Dr. Cavanaugh puts it, "transgender health care is now handled in the same way our providers handle conditions like high blood pressure, diabetes, or many other matters."



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# 2015 and Beyond:

## The Challenges and Opportunities That Remain

The evolution of Fenway's Transgender Health Program never stops. Its revised informed consent model of care has solved many problems, but also presents the program with a number of new issues. One of them is illustrated by Damian Rodriguez's description of the choices he wants to make in the care he receives, and how he weighs the health risks associated with therapies available to him. As he

"I believe my provider and I have different goals. Two of my goals are my own comfort, and my emotional peace. On the other hand, my primary care provider's main goal is my physical health. I know my decision to undergo hormone replacement therapy means a higher chance of heart disease and high blood pressure, and I accept that. So maybe I am willing to take some risks that my doctor is not."

Damian Lima Rodriguez, Fenway Health Patient

notes, he may be more willing to accept the risks involved with some treatments than his provider might be. What does this mean for a clinician treating patients like Mr. Rodriguez? How does a health care institution find the balance between empowering patients and advocating for the best management of their overall health?

This is only one challenge Fenway's Transgender Health Program will face in the coming years, even as it continues to work on overcoming barriers that have already been identified, and others that have yet to emerge, in meeting the evolving health care needs of the transgender and gender-nonconforming community.

Other significant challenges include the role of research and its relationship to care. There is also a need that researchers understand about the health of underserved populations needing to be counted in order to obtain resources needed for the development of new health care and education programs.

As Judy Bradford, PhD, Co-Chair of the Fenway

Institute puts it, "if you're not counted, you don't count" when it comes to the development of new health care programs. And the risks that transgender people face every day are still far too great.

Beyond these challenges and threats, there are also many opportunities. A growing number of transgender people, particularly youth, are finding acceptance among family, friends, and their communities. As is the case with transgender health programs throughout the country, Fenway providers are finding patients who are increasingly comfortable defining their gender identity as a unique point on a broad spectrum of possibilities, rather than choosing "male" or "female" on a binary scale.

"Research doesn't equal clinical care. Some care is part of research. For example, people enrolled in Life Skills [a transgender research study conducted by The Fenway Institute] get regular HIV tests...But they still need primary care."

Dr. Sari Reisner, Research Scientist, The Fenway Institute





“At a recent transgender health conference, one of the presenters talked about the concept of ‘micro-aggression.’ He suggested we ask our clients to talk about the simple experience of getting from home to our offices. How many odd looks or stares did they get from people along the way? How many times did they feel uncomfortable or threatened? Feeling safe while navigating through the world is no simple task for a transgender person.”

David Todisco, LICSW, Fenway Associate  
Director of Behavioral Health



# Conclusion:

Another opportunity is the chance for Fenway to share what it has learned. Dr. Tim Cavanaugh notes that for a while, the program has been inwardly focused, working to make Fenway more successful in providing quality care, and more welcoming and trustworthy for its patients. Now, he believes the time is right to turn the program's attention outward, to train and educate providers and patients based on Fenway's experience and its long history of navigating the high risks and great rewards of working with transgender people.

In the current phase of its Transgender Health Program, Fenway has learned to listen more thoroughly to the voices of the people it serves. Having opened communication channels to sustain a constructive dialogue, Fenway and the transgender community can look forward to even more collaboration, using their partnership as an example to expand everyone's concept of primary care. Fenway's existing channels for consumer feedback, including website links, regular informational events, and its patient advocates, are open to everyone, including the health center's transgender patients. As Fenway's model of transgender care becomes increasingly integrated with the delivery of primary care by all providers, these systems will need to keep pace with the needs of transgender individuals. But the commitment—and the framework—is there.

"It's not a question of inviting people into our party. We need to go to their party. We need to show up not as professionals or community advocates, but to simply go in and hear what's being said. Don't go in with 'we've got an answer,' but just ask 'what are the issues? What do things look like from your position?'"

Bobbi Taylor, Fenway Health Patient

The pace of progress in the long development of Fenway's Transgender Health Program may have been uneven, but the good news is that this pace is accelerating. Fenway providers are working toward the day when transgender care will be fully seen by patients and providers alike as another element of primary care, subject to the same standards of excellence in clinical and customer service—not just at Fenway, but in every health care organization.



**“We’re not perfect. We will never be perfect.  
All we can do is strive to be less imperfect.  
And we will always rely on feedback from  
the transgender community to do that.”**

Dr. Alex Gonzalez, Medical Director, Fenway Health