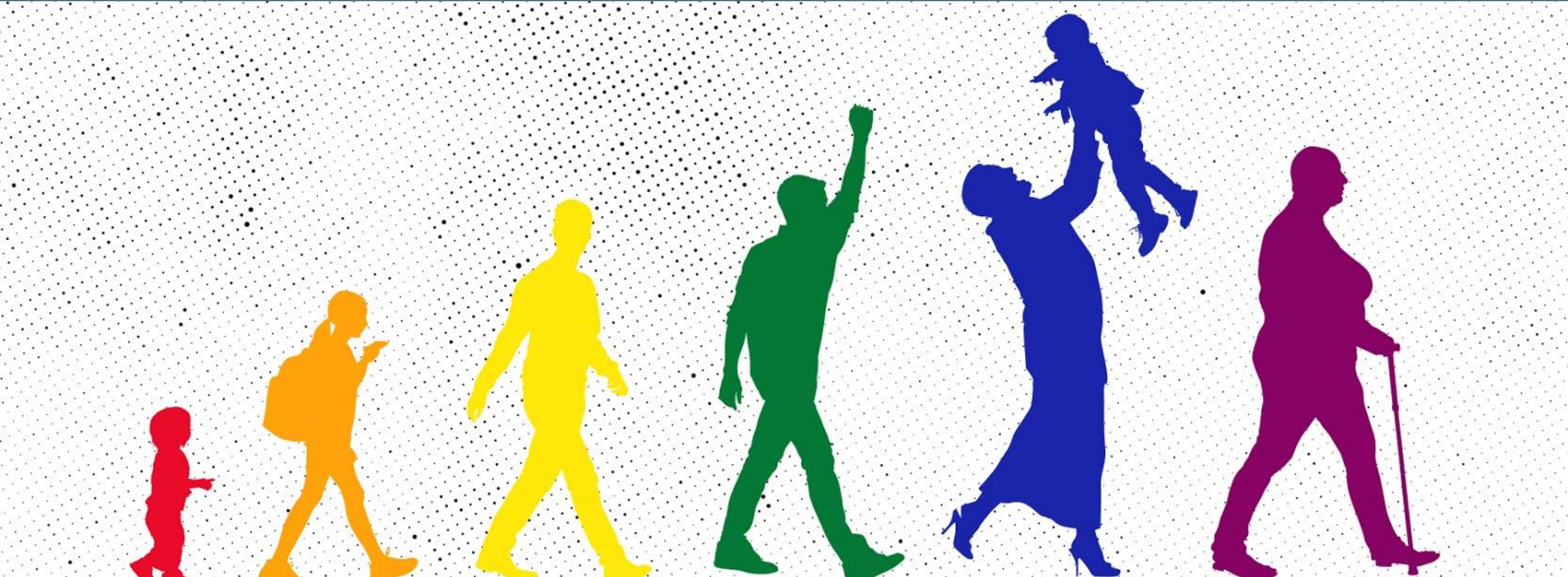
Bodies and Barriers:

Utilizing Healthcare Consumer Narratives to Improve Care for the LGBTQ Patient Population

Adrian Shanker



Decolonizing the space

We recognize that this presentation, while virtual due to COVID-19, relates to care provided in Pennsylvania -- I am joining you from Allentown, PA on the original and unceded land of the Lenape people. As this presentation is focused on health equity for LGBTQ people, we also stand in solidarity with indigenous communities who continue to fight for the unmet dream of health equity.

Bradbury-Sullivan LGBT Community Center

Provides arts, health, youth, and pride programs to celebrate and support the LGBTQ+ community across the Greater Lehigh Valley

Administers the biannual Pennsylvania LGBTQ Health Needs Assessment

Learn more: bradburysullivancenter.org

“Wellness is about surviving in a world that wasn’t made for you”

14 year old youth program participant at Whitman Walker Health Clinic, DC

“Stigma is about other people making a moral decision about your worth”

HIV activist Sean Strub

Health Equity

“The attainment of the highest quality of health for all people”

Healthy People 2020

The Problem

LGBT healthcare consumers repeatedly encounter negative experiences when accessing healthcare services.

- This leads many LGBT patients to delay or avoid seeking care due to fear of mistreatment
- LGBT patients may be unsure which providers are welcoming in their community
- Healthcare professionals are not always aware of the negative experiences of their patients

IT IS A PATIENT SAFETY ISSUE IF LGBT PATIENTS DELAY OR AVOID CARE BECAUSE OF FEAR OF MISTREATMENT

(PA Patient Safety Authority)

Barriers to Care in Pennsylvania

LGBTQ Discrimination

1 in 3 LGBTQ Pennsylvanians fear seeking healthcare services because of past or potential negative reactions from providers

Racial/Ethnic Discrimination

1 in 5 BIPOC LGBTQ Pennsylvanians have experienced a negative reaction from a provider because of their race

Insurance Coverage

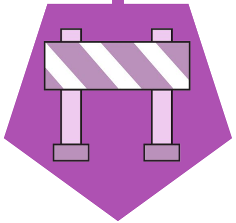
1 in 5 LGBTQ Pennsylvanians receive insurance through medical assistance & 1 in 10 are prevented from seeking care because LGBTQ-affirming providers are not covered by their insurance

Distance to Providers

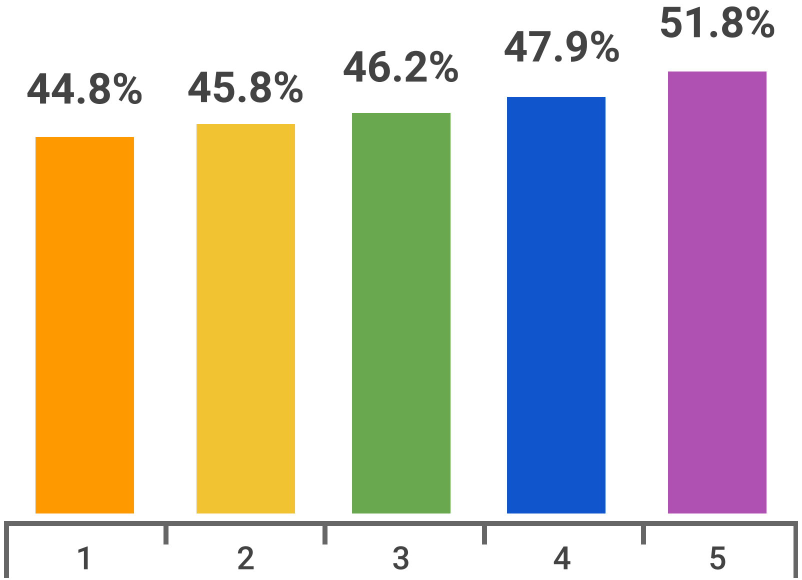
1 in 10 LGBTQ Pennsylvanians are prevented from seeking care because LGBTQ-affirming providers are too far away

Other Barriers

Other barriers to care include finances, language, transportation, time, and knowing which providers are LGBTQ-affirming



Flu Vaccines



The 2020 PA LGBTQ Health Needs Assessment asked respondents, "During the past 12 months, have you had either a flu shot or a flu vaccine that was sprayed in your nose?"

1 LGBTQ Pennylsvanians Overall

From our sample of +6,500 LGBTQ Pennsylvanians across 64/67 counties, 44.8% had **not** had a flu vaccine in the last year

2 Transgender, Nonbinary, & Genderqueer

A slightly higher percentage of transgender, nonbinary, and genderqueer respondents had not received an annual flu vaccine

3 LGBTQ People of Color

46.2% of respondents who identified as Hispanic and/or a race other than white had not received a flu vaccine in the last year

4 Barriers to Care

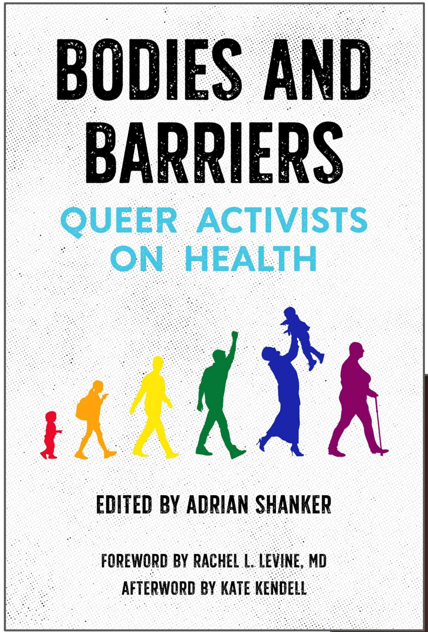
47.9% of LGBTQ Pennsylvanians indicated that they faced one or more barriers to care including distance, insurance coverage, and fear of discrimination

5 Fearing Healthcare Discrimination

51.8% of LGBTQ Pennsylvanians specifically reported that they often or always fear a negative reaction from a healthcare provider when they find out that they are LGBTQ

Healthcare Consumer Experiences

Adrian Shanker



BODIES AND BARRIERS

QUEER ACTIVISTS ON HEALTH

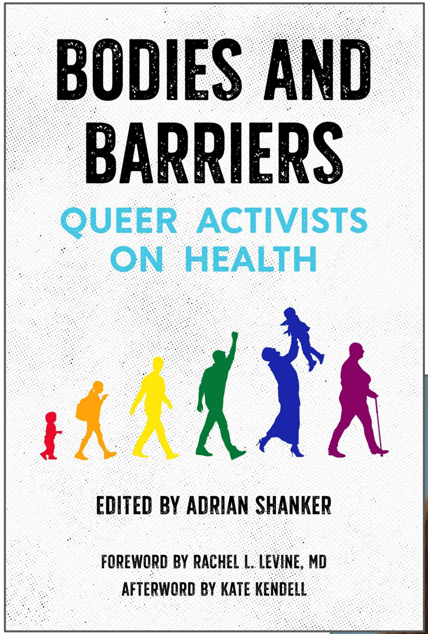
EDITED BY ADRIAN SHANKER

FOREWORD BY RACHEL L. LEVINE, MD
AFTERWORD BY KATE KENDELL

"I made an appointment with a dermatologist for a baseline screening for skin cancer. But at every turn the doctor's well-intentioned team made me question if I should be there at all. The intake forms were unnecessarily restrictive, biased news programming was on full-display in the waiting room, magazines in the waiting room did not cater to patients like me, and comments from the clinic staff displayed brazen cultural incompetence. I didn't go back for the doctor-recommended follow-up.

I'm privileged with health insurance, access to private transportation, and the ability to take time away from my job to drive a distance for a medical appointment, so I was able to find a new LGBT-inclusive dermatologist an hour away. For many other LGBT consumers of health care, the geographic barrier to accessing culturally appropriate LGBT-inclusive care from a specialist might be too great a barrier to overcome."

(excerpted from *Bodies and Barriers: Queer Activists on Health*, PM Press, 2020)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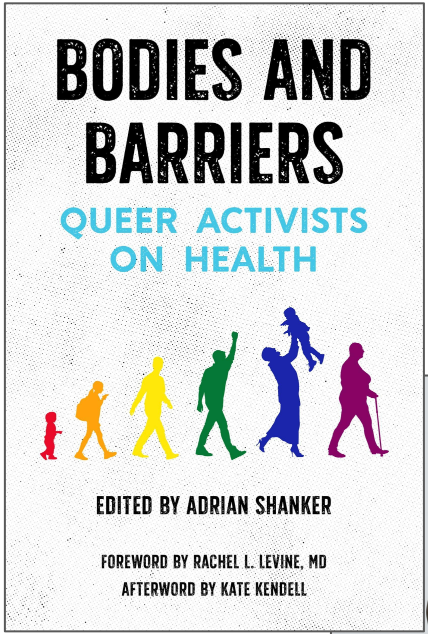
Katharine Dalke

At age six, I underwent a routine hernia operation. My surgeon and parents were shocked to discover that in place of ovaries and a uterus, my pelvis carried internal testes. A karyotype confirmed that my sex chromosomes were XY, instead of the typical female XX. My diagnosis, which would later be known as Complete Androgen Insensitivity Syndrome, reflected my body's inability to respond to the androgens that my testes had produced during fetal development, shifting me instead down a "usual" female pathway.

The next ten years were excruciating for me and my family. My physician, a well-respected pediatric endocrinologist, followed a then standard medical practice, recommending that my parents never disclose to me my diagnosis, chromosomes, or gonads. Intersex patients who knew, they feared, would question their gender identity and sexual orientation or commit suicide. And so my family adhered diligently to the prescription of total secrecy, each of us internalizing the message that there was something wrong or shameful about my natural body. It wasn't until we found the Androgen Insensitivity Syndrome-Differences of Sex Development Support Group that my family could begin to visualize a future in which I knew all the details of my condition, and I was loved and happy for being different.

(excerpted from *Bodies and Barriers: Queer Activists on Health*, PM Press, 2020)



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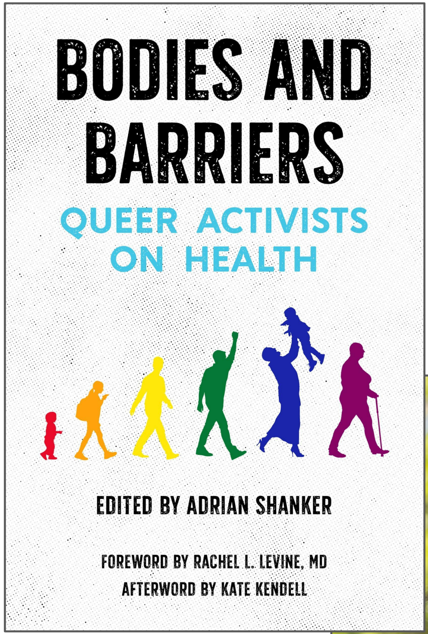
Laura Jacobs

“Laura is a transgender. Didn’t the surgeons do an amazing job? You’d never know,” said the specialist to the intern, as I sat, fully clothed, on the exam table. I heard the sanitary paper crinkle as my legs dangled over the edge, awkwardly childlike.

Every trans-identified person I’ve ever met has experienced it: a medical interaction during which we felt fetishized or insulted, when a provider used insensitive or inappropriate language, where a professional pried for information not relevant to the clinical issue. Rather than encouraging a bond, these moments only amplified the resistance.”

(excerpted from *Bodies and Barriers: Queer Activists on Health*, PM Press, 2020)



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Robyn Ochs

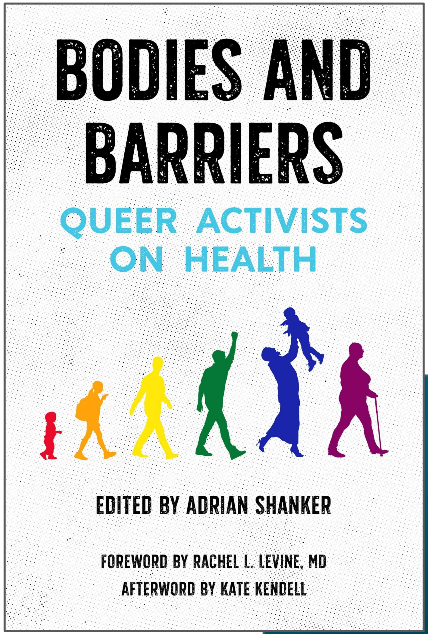
In my twenties, during an annual check-up with a new primary care physician, we had the following conversation:

Physician: “Are you sexually active?”
Me: “Yes.”
Physician: “What kind of birth control do you use?”

At the time, I was in a monogamous relationship with a woman. I wanted to reply, flippantly, “We use the lesbian method.” But I wasn’t that brave. I hemmed and hawed and squirmed uncomfortably and finally managed to state that my partner is a woman. It was awkward and uncomfortable.

A couple of years later, that relationship had ended, and I was in a new relationship with a man. I suspected there was a note in my chart saying I was a lesbian, and I finally, awkwardly, told my doctor, “I’m bisexual,” and got fitted for a diaphragm.

(excerpted from *Bodies and Barriers: Queer Activists on Health*, PM Press, 2020)



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Justin Sabia-Tanis

During my intake interview, I asked how the other members ~~of a~~ grief support group at our local hospice might respond to having a gay man in the mix. The facilitator replied, “Don’t worry ... by the second week, no one will even think twice about your being different. Grief is a great equalizer.” And it turned out to be true. For eight weeks, I was the one man, the only queer, in a roomful of straight women as we processed our grief. For most of us, our significant others had died; a couple had lost a beloved parent. Grief was, in fact, a great equalizer. [...]

My experiences and insights were part of the group dynamics and people went out of their way to ensure that I was truly included. I genuinely felt that the group members did not, in fact, see me as particularly different. I was the same as everyone else. Here lies the crux of the problem—my differences and those of queer culture were neither seen nor even acknowledged as existing. I felt that to insist on giving them space would have broken the social contract by which we were sharing our common experiences of grieving.

(excerpted from *Bodies and Barriers: Queer Activists on Health*, PM Press, 2020)

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(PA Patient Safety Authority)

If the goal is patient-centered care

- Listen to your LGBT healthcare consumers
- Focus on access to care issues
- Invest in training for healthcare professionals and support staff
- Ensure the waiting room is welcoming
- Advocate on behalf of patient needs

Questions

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