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**CHAPTER 4:**  
**ACCESS TO QUALITY HEALTH CARE**



## ACCESS TO QUALITY HEALTH CARE

In a groundbreaking 2011 report, the U.S. Institute of Medicine (IOM) found that transgender people in the United States face serious health disparities and systemic barriers to care. These disparities are particularly acute for transgender people of color. At the same time, transgender people are more likely to be uninsured, to be unable to afford to pay for health care out of pocket, and to delay seeking health care because of cost or fear of discrimination.<sup>1</sup> The IOM report, together with the recognition of LGBT health disparities in federal efforts such as Healthy People 2020 and the National Prevention Strategy, represent important steps toward integrating these issues into broader efforts to improve the nation's health and combat all disparities. Still, federal efforts to address the health of transgender people have only just begun.

Discrimination against transgender people seeking health care is an urgent and widespread problem. For example, one-fifth of respondents in the National Transgender Discrimination Survey (NTDS) reported being turned away outright by a health care provider due to bias.<sup>2</sup> Twenty-eight percent (28%) postponed or avoided medical treatment when they were sick or injured and 33% delayed or did not try to get preventive health care because they feared discrimination.<sup>3</sup>

Building the cultural competency of health care providers is critically important to the health of transgender people and is a vital corollary to nondiscrimination protections. Health care providers and support staff must become more knowledgeable about trans people's health care needs and how to best address these needs. They must be able to communicate with trans people respectfully and sensitively, and treat information about a patient's transgender status as confidential. Fifty percent of NTDS respondents reported having to teach providers about their health needs.<sup>4</sup>

Difficulties in accessing health care arise for many transgender people even before they get to a doctor's office or hospital. Despite strides in expanding the number of people in the United States who are able to secure adequate health insurance, plans still frequently exclude coverage of any services for a transition-related medical purpose, even when the same or comparable services are routinely covered for other medical indications. These arbitrary exclusions have no scientific basis and create a dangerous gap in access to quality and affordable care for transgender people. Leading employers, universities, and city and state governments are rapidly expanding employment-based coverage for transition related care, yet discrimination exclusions remain in most insurance plans. While 9 states and the District of Columbia have so far issued bulletins directing insurance plans to eliminate exclusions, there has been no guidance from the federal government.

The Institute of Medicine has recommended that data on gender identity and sexual orientation be routinely collected in electronic health records and in federally funded health surveys, and that the federal government provide expanded support for health research on transgender people.<sup>5</sup> To adequately understand and meet the health needs of transgender people, systematic research and data collection on our population is essential. Until now, the absence of even the most basic demographic and health data on transgender people has been a major roadblock to improving health and eliminating disparities for trans people.

### Policy Advances

- Medicare's long-standing exclusion for transition-related surgery was overturned. (2014)
- The Department of Health and Human Services (HHS) published LGBT-inclusive National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care. (2014)

<sup>1</sup> Injustice at Every Turn: A Report of the National Transgender Discrimination Survey, at 76.

<sup>2</sup> Injustice at Every Turn: A Report of the National Transgender Discrimination Survey, at 75.

<sup>3</sup> Injustice at Every Turn: A Report of the National Transgender Discrimination Survey, at 76.

<sup>4</sup> Injustice at Every Turn: A Report of the National Transgender Discrimination Survey, at 76.

<sup>5</sup> IOM, *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*, p. 299-304 (2011).

- The Department of Health and Human Services (HHS) released an updated, LGBT-inclusive guide for substance abuse treatment providers. (2013)
- HHS said, in a letter to advocacy organizations, that the Affordable Care Act's sex discrimination provision prohibits anti-transgender bias in health care settings. (2012)
- HHS issued regulations prohibiting anti-LGBT bias in state insurance marketplaces. (2012)
- The Joint Commission made LGBT nondiscrimination policies a requirement for hospital accreditation. (2011)
- HHS issued regulations that prohibit discrimination against LGBT people in hospital visitation. (2011)
- The Department of Health and Human Services (HHS) issued guidance outlining consumers' rights to coverage of preventive services, making clear that plans may not deny routine screenings or other services solely because of a person's gender identity, gender assigned at birth, or the gender in their insurance record. (2015)

#### **Needed Policy Changes**

- Congress should pass the Health Equity and Accountability Act, which would strengthen federal action to combat health disparities, including those correlated to gender identity and sexual orientation.
- Congress should pass legislation prohibiting deceptive and harmful "conversion therapies" that attempt to change a person's gender identity or sexual orientation.
- The Department of Health and Human Services should promulgate regulations prohibiting discrimination on the basis of gender identity and sexual orientation by health care providers and programs, both as a condition of Medicare and Medicaid participation and for all recipients of federal financial assistance pursuant to Section 1557 of the Affordable Care Act.
- The Department of Health and Human Services should issue strong federal guidance on discrimination in essential health benefits under the Affordable Care Act, including clarifying that arbitrary transgender exclusions constitute a form of prohibited discrimination.
- The Departments of Justice and HHS should aggressively pursue Section 1557, HIPAA and other complaints and litigation to advance the rights of LGBT people in health care settings, and publicize positive resolutions.
- The Center for Medicare Services should ensure that Medicare and its contractors cover all medically necessary care for gender dysphoria as provided in the WPATH Standards of Care, without unfounded restrictions.
- The Office of the National Coordinator for Health Information Technology should require the collection of data on gender identity and sexual orientation within its meaningful use standards for electronic health records, together with strong privacy protections.
- The Department of Health and Human Services should allow federally qualified health centers (FQHCs) to use local data to determine the health needs of LGBT people and people living with HIV/ AIDS in their areas and should provide support to FQHCs specifically serving these populations.
- The Agency for Healthcare Research and Quality (AHRQ) and the National Institutes of Health should formally designate LGBT people as a health disparity population for purposes of federal grants and research.
- The National Institutes of Health should establish and implement a robust LGBT health research agenda that includes a specific focus on the health and health care needs of transgender people, according to the recommendation of the 2011 Institute of Medicine report on LGBT health.

- The Food and Drug Administration should lift the ban on blood donation by men who have sex with men, which has also been used to exclude transgender donors regardless of their gender or sexual orientation.
- The Department of Health and Human Services should identify and promote best practices for providing effective, culturally competent, and nondiscriminatory care to LGBT patients in Title X Family Planning Clinics.
- The Centers for Medicare & Medicaid Services should issue guidance to state Medicaid directors clarifying that the arbitrary exclusion of medically necessary, transition-related care is inconsistent with federal law.
- The Office of Global Affairs should engage with the World Health Organization (WHO) to support appropriate revisions to the International Classification of Diseases (ICD) to de-pathologize gender variance and reflect current medical science regarding gender identity.

*See Improving the Lives of Trans Older Adults for more on Medicare and long-term care.*

*See Honor Our Veterans for more on veterans' health care.*

*See Counting Trans People in Federal Surveys for more on federal health surveys.*

*See Fighting HIV/AIDS for more on HIV/AIDS policy.*