

CHAPTER 4

ACCESS TO QUALITY HEALTH CARE



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In a groundbreaking 2011 report, the U.S. Institute of Medicine (now known as the National Academy of Medicine) 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.¹ This report, together with the recognition of LGBT health disparities in federal efforts such as Healthy People 2020, the National Prevention Strategy, represented 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.² 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.³

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.⁴

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 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, create a dangerous gap in access to quality and affordable care for transgender people, and violate federal and state nondiscrimination laws. Federal regulations adopted in 2016—following the lead of many states—aim to sharply limit if not eliminate these practices, but it remains to be seen how quickly and fully insurance carriers will comply.

In its 2011 report, the Institute of Medicine 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.⁵ To adequately understand and meet the health needs of transgender people, systematic research and data collection on trans populations is essential. Until now, the

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

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

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

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

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

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

- The National Institutes of Health formally designated LGBT people as a health disparity population for purposes of federally-funded research. (2016)
- The Department of Health and Human Services (HHS) issued a proposed regulation requiring that hospitals accepting Medicare and Medicaid adopt LGBT-inclusive nondiscrimination policies and notify patients of these policies. (2016)
- HHS issued a proposed regulation expressly prohibiting discriminations in HHS grant programs, including on the basis of gender identity or sexual orientation.
- The Department of Health and Human Services (HHS) published landmark regulations making clear that discrimination against LGBT and intersex people in health care is prohibited by Section 1557 of the 2010 Affordable Care Act, including: discriminatory transgender exclusions or denials in most private and public health plans sold in the U.S.; denial of health services to trans people simply because they are traditionally associated with one gender; and refusal to respect a patient’s gender identity. (2016)
- The Health Resources and Services Administration added the collection of demographic data on gender identity and sexual orientation to the Uniform Data System for Federally Qualified Health Centers. (2016)
- HHS’s Medicare Appeals Council issued a ruling making clear that Medicare plans must cover transition-related surgeries on the basis of individual medical need. (2016)
- The Substance Abuse and Mental Health Services Administration (SAMHSA) published a historic report on ending harmful “conversion therapy” and affirming LGBTQ youth. (2015)
- HHS published guidance clarifying that insurance plans may not deny coverage of medically appropriate preventive services simply based on an individual’s gender identity, gender assigned at birth, or the gender listed in insurance records. (2015)
- The Office of the National Coordinator for Health Information Technology published regulations required that electronic health record systems provide for the collection of data on gender identity and sexual orientation. (2015)
- The National Institutes of Health established a Sexual & Gender Minority Research Office. (2015)
- Medicare’s long-standing exclusion for transition-related surgery was overturned. (2014)
- HHS published LGBT-inclusive National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care. (2014)
- The Department of Health and Human Services (HHS) released an updated, LGBT-inclusive

guide for substance abuse treatment providers. (2013)

- 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)

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.
- Congress should pass legislation to eliminate barriers to health coverage through Medicaid, the Children’s Health Insurance Program (CHIP), and the health insurance marketplaces for immigrants.
- Congress should fully fund the Department of Justice’s Civil Rights Division and the Department of Health and Human Services’ Office for Civil Rights.
- The Department of Health and Human Services (HHS) should issue strong federal guidance to state insurance commissioners on the enforcement of Section 1557 of the Affordable Care Act.
- The Centers for Medicare & Medicaid Services should update its qualified health plan (QHP) review and certification tools to include additional examples of discrimination, including transgender exclusions.
- The Centers for Medicare and 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 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.
- HHS should direct each of its Operating Divisions to add voluntary demographic measures on gender identity and sexual orientation into existing surveys, program applications and evaluations, and other data collection instruments.

- HHS should direct each of its Operating Divisions to issue guidance, tailored to health programs it funds, on compliance with Section 1557 of the Affordable Care Act, including basic information about cultural competence and best practices for working with LGBT people.
- HHS should update the Healthcare.gov Marketplace application to include a more accurate two-step gender question (gender identity and sex assigned at birth) and an optional demographic question on sexual orientation.
- HHS 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) should formally designate LGBT people as a health disparity population for purposes of federal grants.
- 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 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 diversity and reflect current medical science regarding gender identity.
- HHS should continue to prioritize the inclusion of demographic variables related to gender identity (sex assigned at birth and current gender) and sexual orientation in Meaningful Use and related programs introduced under MACRA, and continue to refine recommended standards for data fields, data elements, and data use related to gender identity and sexual orientation in certified EHRs

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.