

# Promoting an Integrated Approach to Ensuring Access to Gender Incongruent Health Care

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## I. INTRODUCTION

Many transgender<sup>1</sup> and gender nonconforming<sup>2</sup> individuals are denied

1. GLAAD defines “transgender” as

[a]n umbrella term for people whose gender identity and/or gender expression differs from what is typically associated with the sex they were assigned at birth. People under the transgender umbrella may describe themselves using one or more of a wide variety of terms . . . . Many transgender people are prescribed hormones by their doctors to change their bodies. Some undergo surgery as well. But not all transgender people can or will take those steps, and a transgender identity is not dependent upon medical procedures.

*GLAAD Media Reference Guide: Transgender Issues*, GLAAD, <http://www.glaad.org/reference/transgender> (last visited Dec. 14, 2015).

2. GLAAD defines “gender nonconforming” as

[a] term used to describe some people whose gender expression is different from conventional expectations of masculinity and femininity. Please note that not all gender non-conforming people identify as transgender; nor are all transgender people gender non-conforming. Many

access to preventive health care and routine services due to the gender marker<sup>3</sup> on file with their insurance provider. For example, men who have a uterus, ovaries, and/or breasts can be at risk for cancer in these organs.<sup>4</sup> Thus, a transgender man<sup>5</sup> who identifies and presents as male may need Papanicolaou (Pap) smears to screen for cervical cancer.<sup>6</sup> However, those who have a male gender marker on file are often denied coverage for Pap smears and other reproductive health-related preventive services even though they need this care.<sup>7</sup> Similarly, transgender women are often denied coverage for prostate exams despite their risk for prostate cancer.<sup>8</sup>

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people have gender expressions that are not entirely conventional—that fact alone does not make them transgender. Many transgender men and women have gender expressions that are conventionally masculine or feminine. Simply being transgender does not make someone gender non-conforming. The term is not a synonym for transgender or transsexual and should only be used if someone self-identifies as gender non-conforming.

*Id.*

3. A gender marker is an indicator of gender or gender identity. It is typically listed on identity documents and asked for on most forms.
  4. See *Key Transgender Health Concerns*, VANDERBILT UNIV. MED. CTR., <https://medschool.vanderbilt.edu/lgbti/key-transgender-health-concerns> (last visited Dec. 14, 2015).
  5. A transgender man is someone who was assigned a female sex at birth but identifies as male. *GLAAD Media Reference Guide: Transgender Issues*, GLAAD, <http://www.glaad.org/reference/transgender> (last visited Dec. 14, 2015). This is sometimes shortened to “trans man” or “FTM,” an abbreviation for female-to-male. *Id.* A transgender woman is someone who was assigned male at birth but identifies as female. *Id.* This can be shortened to “trans woman” or “MTF,” an abbreviation for male-to-female. *Id.* Some people prefer simply to be called *women* or *men*, without a modifier. *Id.*
  6. See *id.*
  7. These services are often still labeled as “women’s” health, a design that excludes those who may need the same services but do not identify as women. See, e.g., WOMENSHEALTH.GOV, U.S. DEP’T OF HEALTH & HUMAN SERVS., OFFICE ON WOMEN’S HEALTH, <http://www.womenshealth.gov/> (last visited Dec. 14, 2015) (discussing health topics “for women”); *Affordable Care Act Rules on Expanding Access to Preventive Services for Women*, U.S. DEP’T OF HEALTH & HUMAN SERVS., <http://www.hhs.gov/healthcare/facts/factsheets/2011/08/womensprevention08012011a.html> (last visited Jan. 10, 2016) [hereinafter *Affordable Care Act Rules*] (discussing rules on expanding access to preventive health care services “for women”). The U.S. Department of Health’s website notes that “well-woman visits”
    - include[] an annual well-woman preventive care visit for adult women to obtain the recommended preventive services, and additional visits if women and their health care providers determine they are necessary to deliver those services. These visits will help women and their health care providers determine what preventive services are appropriate, and set up a plan to help women get the care they need to be healthy.
- Affordable Care Act Rules*, *supra*; see also *Men’s Health: Men’s Topics A-Z*, CTRS. FOR DISEASE CONTROL & PREVENTION, <http://www.cdc.gov/men/az/index.htm> (last visited Dec. 14, 2015).
8. See Cécile A. Unger, *Care of the Transgender Patient: The Role of the Gynecologist*, 210 AM. J. OBSTETRICS & GYNECOLOGY 16, 21 (2014) (noting that “[s]ome plans deny coverage for gender-specific care based on a patient’s natal sex and only cover care that is consistent with the patient’s current gender”).

Robert Eads was a transgender man diagnosed with cervical and ovarian cancer in 1996.<sup>9</sup> Despite this diagnosis, more than twenty gynecologists refused to treat him over a ten-month period.<sup>10</sup> The providers stated that they and other patients were uncomfortable with his transgender status and feared that treating him would harm the reputation of their medical practices.<sup>11</sup> Eads eventually found a doctor who offered to treat him.<sup>12</sup> Because the cancer had gone untreated for so long, however, it had metastasized to other parts of his body and proved to be fatal.<sup>13</sup> This tragic outcome is an example of the potential effect of denying people gender incongruent health care.<sup>14</sup>

Gender incongruent health care is the medical treatment an individual's physiology requires that does not match traditional notions regarding the care their gender needs.<sup>15</sup> It encompasses many of the benefits deemed essential in the Patient Protection and Affordable Care Act, such as preventive screenings and primary care, mental and behavioral health coverage, general wellness services, and reproductive and sexual health services.<sup>16</sup>

Though recently acknowledged in medical journals, gender incongruent

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9. Mathura Ravishankar, *The Story About Robert Eads*, J. GLOBAL HEALTH, JGH ONLINE (Jan. 18, 2013), <http://archive.is/rOWbe>.
10. *Id.*
11. *Id.*
12. *Id.*
13. See Kari E. Hong, *Categorical Exclusions: Exploring Legal Responses to Health Care Discrimination Against Transsexuals*, 11 COLUM. J. GENDER & L. 88, 121 (2002); see also Letter from Lambda Legal Def. & Educ. Fund, to U.S. Dep't of Health & Human Servs., Re: Request for Info. Regarding Nondiscrimination in Certain Health Programs or Activities (Sept. 30, 2013), [http://www.lambdalegal.org/sites/default/files/ltr\\_hhs\\_20130930\\_discrimination-in-health-services.pdf](http://www.lambdalegal.org/sites/default/files/ltr_hhs_20130930_discrimination-in-health-services.pdf); see also Elvis Mitchell, "Southern Comfort": *Genders that Shift, but Friends Firm as Bedrock*, N.Y. TIMES (Feb. 21, 2001), <http://www.nytimes.com/2001/02/21/arts/21COMF.html>; see also Ravishankar, *supra* note 9.
14. Kate Walsham refers to "gender-incongruent care" and "gender-incongruent procedures" in her article *De-Gendering Health Insurance: A Case for a Federal Insurance Gender Nondiscrimination Act*, 24 HASTINGS WOMEN'S L.J. 197 (2013); see also Letter from Lambda Legal Def. & Educ. Fund, *supra* note 13 (referring to this care as "sex-specific medical care").
15. Walsham, *supra* note 14, at 198 n.4.
16. See *Essential Health Benefits*, HEALTHCARE.GOV, <https://www.healthcare.gov/glossary/essential-health-benefits/> (last visited Jan. 4, 2016). According to the website, essential health benefits that must be covered in certain plans include the following:
- ambulatory patient services; emergency services; hospitalization;
  - maternity and newborn care; mental health and substance use disorder services, including behavioral health treatment; prescription drugs;
  - rehabilitative and habilitative services and devices; laboratory services;
  - preventive and wellness services and chronic disease management; and
  - pediatric services, including oral and vision care.
- Id.*; see also Kellan Baker, *Connecting with Coverage: 4 Things LGBT People Need to Know About the Health Insurance Marketplaces*, CTR. FOR AM. PROGRESS (Sept. 12, 2013), <http://www.americanprogress.org/issues/lgbt/report/2013/09/12/74069/connecting-with-coverage-4-things-lgbt-people-need-to-know-about-the-health-insurance-marketplaces/>.

health care has been largely absent from legal discourse. The literature on access to transgender health care has focused overwhelmingly on the laws and policies regarding transition-related care, or care that is sought to assist individuals in their physical, mental, or surgical transition.<sup>17</sup> But transgender health care also includes culturally competent primary care.<sup>18</sup> Legal literature tends to combine transition-related and primary care, while in practice, different laws and policies govern each. Thus, this analysis explores access to gender incongruent health care, not just transition-related care.

Specifically, this Article brings legal attention to pervasive barriers to gender incongruent health care that remain despite recent advances in law and policy.<sup>19</sup> Part II of this Article provides background on the history of gender identity discrimination and outlines the prevalence and impact of primary care denials on patients, medical providers, and the public.

Part III reviews state and federal statutes (including the Patient Protection and Affordable Care Act), case law, Medicaid regulations, Veterans Administration directives, insurance coding procedures, and American Medical Association policies regarding access to preventive health care. Current law forbids providers from denying primary care on the basis of gender identity; medical agencies formally recognize the health disparities and consequences of denying comprehensive care; and insurance coding practices allow coders and providers to override automatic denials of coverage for gender incongruent care. Yet these laws and policies, which should provide a solid foundation for accessing care, have regulatory and enforcement gaps that must be closed to ensure holistic implementation of and access to competent and comprehensive primary care.

Part IV highlights some of the obstacles and barriers that transgender and gender nonconforming people encounter despite the laws and regulations that facially provide access to comprehensive primary care. Some individuals face outright denials of the health care coverage their bodies need, while others forgo health care altogether to avoid a hostile or unwelcoming medical environment.

Part V illustrates how individuals are responding to these barriers. Twenty transgender and gender nonconforming individuals from across the United States and Canada, representing a range of ages and gender identities, were interviewed for this study.<sup>20</sup> Interviewees explained their responses to the obstacles impeding access to primary care, including forgoing care due to discrimination and harassment, paying medical expenses out of pocket, or using a gender marker

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17. See, e.g., *Transition-Related Health Care*, LAMBDA LEGAL, [http://www.lambdalegal.org/publications/trt\\_transition-related-health-care](http://www.lambdalegal.org/publications/trt_transition-related-health-care) (last visited Dec. 14, 2015).

18. TRANSGENDER LAW CTR., *TRANSGENDER HEALTH BENEFITS: NEGOTIATING FOR INCLUSIVE COVERAGE* 4 (2014), <http://transgenderlawcenter.org/wp-content/uploads/2014/01/Health-Insurance-Exclusions-Guide-2-WEB.pdf>.

19. See *infra* Part II.B.

20. All names of interviewees have been changed to protect their privacy.

that is inconsistent with their identity. Their experiences illustrate the health care barriers this community faces and demonstrate the various responses individuals use to adapt to lack of care.

Finally, Part VI proposes actions that promote comprehensive and appropriate health care, such as cultural competency training for medical providers and staff, insurance coding system reform, coordinated care among providers, bolstered complaint mechanisms, and new intake procedures. A coordinated effort, led by transgender and gender nonconforming people in conjunction with legal, medical, and insurer/payer bodies, can ensure the implementation of best practices and lead to comprehensive and culturally competent health care. Ideally, this coordinated effort will help remove existing barriers and create laws, directives, and regulations that will compel health care providers, insurers and payers, legal and governmental bodies, and transgender and gender nonconforming patients to work together to overcome barriers and ensure access to comprehensive health care.

## II. UNDERSTANDING THE PROBLEM

Part II provides background on medical discrimination based on transgender or gender nonconforming status. It then describes the many populations that these health care barriers affect, including transgender and gender nonconforming individuals, medical professionals, and the public.

### A. Medical Discrimination Based on Gender Identity

The reach and scope of the denial of gender incongruent health care is rooted in the history of medical discrimination against LGBT individuals.<sup>21</sup> For example, until May 2013, medical and psychological communities officially labeled transgender and gender nonconforming individuals as suffering from “Gender Identity Disorder” (GID).<sup>22</sup> The American Psychiatric Association updated this diagnosis in the Fifth Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) to “Gender Dysphoria.”<sup>23</sup> While this change removed the word “disorder” from the diagnosis, the new entry still perpetuates the notion that a transgender or gender nonconforming individual is mentally ill. In response to the change, many activists urged that continuing to label expressions of gender variance as symptoms of mental disorder stigmatizes

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21. *Cf.* GAY HISTORIES AND CULTURES: AN ENCYCLOPEDIA 713–14 (George E. Haggerty ed., 2000) (discussing how the DSM-I listed “homosexuality” as a “sexual deviation” and a subtype of “sociopathic personality disturbance” and noting that the American Psychiatric Association did not change this entry until 1973).
  22. AM. PSYCHIATRIC ASS’N, GENDER DYSPHORIA (2013), <http://www.dsm5.org/Documents/Gender%20Dysphoria%20Fact%20Sheet.pdf>.
  23. The Diagnostic and Statistical Manual of Mental Disorders, § 302.85 (Am. Psychiatric Ass’n 5th ed.) (2013) [hereinafter DSM-V]; *see also* Mark Moran, *New Gender Dysphoria Criteria Replace GID*, AM. PSYCHIATRIC ASS’N (Apr. 3, 2013), <http://psychnews.psychiatryonline.org/doi/full/10.1176/appi.pn.2013.4a19>.

and harms transgender individuals.<sup>24</sup> Other advocates in the transgender community expressed concern that removing GID from the DSM completely would lead to denials of medical and surgical care for transgender adults, as medical coverage is often dependent on whether such care is necessary to treat an articulated “diagnosis.”<sup>25</sup>

Recent surveys reveal the continued existence of discrimination against transgender individuals by the medical community. A 2011 survey, which questioned more than 6,450 individuals who are transgender and/or gender nonconforming, reported that 28% of survey participants postponed medical care when sick or injured due to discrimination.<sup>26</sup> The data also showed that respondents visiting doctors’ offices, hospitals, and clinics felt unsafe: over one quarter of respondents reported verbal harassment in these spaces.<sup>27</sup> One quarter of respondents also reported delaying other necessary care because of disrespect and discrimination on the part of medical providers.<sup>28</sup>

## B. Affected Populations

The inaccessibility of gender incongruent health care affects several populations.<sup>29</sup> This section explores its impact on three groups in particular: transgender and gender nonconforming individuals, medical providers, and the

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24. See Jack Drescher, *Queer Diagnoses: Parallels and Contrasts in the History of Homosexuality, Gender Variance, and the Diagnostic and Statistical Manual*, 39 ARCH. SEXUAL BEHAV. 427, 428 (2010).

25. *Id.*

26. JAIME M. GRANT ET AL., INJUSTICE AT EVERY TURN: A REPORT OF THE NATIONAL TRANSGENDER DISCRIMINATION SURVEY 2, 72 (2011) [hereinafter INJUSTICE AT EVERY TURN]. The National Gay and Lesbian Task Force and the National Center for Transgender Equality gathered data for the report by conducting the National Transgender Discrimination Survey. *Id.* at 2. To update this data, the National Center for Transgender Equality has launched a follow-up survey, the 2015 U.S. Trans Survey (“USTS”), to “give researchers, policymakers, and advocates the ability to see the experiences of trans people over time, how things are changing, and what can be done to improve the lives of trans people.” *About: Purpose of the 2015 U.S. Trans Survey*, 2015 U.S. TRANS SURVEY, <http://www.ustranssurvey.org/study/> (last visited Dec. 14, 2015); *U.S. Trans Survey Frequently Asked Questions: Who is Conducting the USTS?*, 2015 U.S. TRANS SURVEY, <http://www.ustranssurvey.org/faq/> (last visited Dec. 14, 2015). To accomplish these goals, the USTS will be conducted every five years. *Id.* Further, “[t]he USTS will significantly improve measures in the survey to allow for comparing the lives of trans people to the U.S. population as a whole.” *About: Purpose of the 2015 U.S. Trans Survey, supra*. “This is crucial for demonstrating the disparities faced by trans people in the U.S.” and will allow advocates to better understand the needs of transgender people and how discrimination against them impacts other groups. *Id.*

27. INJUSTICE AT EVERY TURN, *supra* note 26, at 72, 74.

28. *Id.* at 76.

29. See generally *Lesbian, Gay, Bisexual and Transgender Health*, OFFICE OF DISEASE PREVENTION & HEALTH PROMOTION, <http://www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health> (last visited Dec. 14, 2015) [hereinafter *Lesbian, Gay, Bisexual and Transgender Health*] (discussing health disparities among different LGBT groups).

public.

### 1. Transgender and Gender Nonconforming Individuals

Barriers to gender incongruent health care affect transgender and gender nonconforming individuals in a number of ways. Limited insurance coverage, outright denials, or incompetent care lead to the underdiagnosis of breast, cervical, and prostate cancers, as well as increased disease progression.<sup>30</sup> While this Article focuses on transgender and gender nonconforming individuals generally, it is important to note that patients' experiences are not homogeneous. Together with violence, stigma, and minority stress, factors such as socioeconomic status, race, geographic location, education level, immigration status, employment, age, and ethnicity impact this population's mental and physical health.<sup>31</sup>

The barriers transgender and gender nonconforming individuals face when seeking primary and preventive care may lead to underdiagnosis and increased progression of cancer and other diseases.<sup>32</sup> Transgender men without bilateral mastectomies and transgender women taking estrogen are at risk for breast cancer.<sup>33</sup> A 2013 study reports that transgender men have 37% lower odds of being up to date with Pap smears compared to cisgender women.<sup>34</sup> For some transgender women, the prostate is not removed "because the operation is cumbersome and comes with possible complications, including urinary

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30. *Id.*; see also Parker Hurley, *Ovarian Cancer Risk and Incidence in Transgender Men*, NAT'L LGBT CANCER NETWORK, [http://www.cancer-network.org/media/pdf/Trans\\_men\\_and\\_ovarian\\_cancer.pdf](http://www.cancer-network.org/media/pdf/Trans_men_and_ovarian_cancer.pdf) (last visited Dec. 14, 2015).
  31. See generally THE HEALTH OF LESBIAN, GAY, BISEXUAL AND TRANSGENDER PEOPLE: BUILDING A FOUNDATION FOR BETTER UNDERSTANDING, INSTIT. OF MED. (US) COMM. ON LESBIAN, GAY, BISEXUAL, AND TRANSGENDER HEALTH ISSUES & RESEARCH GAPS AND OPPORTUNITIES 20–23 (2011), <http://www.ncbi.nlm.nih.gov/books/NBK64810/> [hereinafter IOM] (applying minority stress, social ecology, and intersectionality models to highlight how a combination of factors can impact health); see also MEREDITH D. TEMPLE-O'CONNOR & ELIZABETH WEHR, NAT'L INSTS. OF HEALTH, CONSIDERATION OF THE INSTITUTE OF MEDICINE (IOM) REPORT ON THE HEALTH OF LESBIAN, GAY, BISEXUAL, AND TRANSGENDER INDIVIDUALS 2, 10 (2013), [http://report.nih.gov/UploadDocs/LGBT%20Health%20Report\\_FINAL\\_2013-01-03-508%20compliant.pdf](http://report.nih.gov/UploadDocs/LGBT%20Health%20Report_FINAL_2013-01-03-508%20compliant.pdf). It is also important to note that some of these factors may afford some individuals privileges in navigating health care and insurance systems.
  32. See Lauren Dutton et al., *Gynecologic Care of the Female-to-Male Transgender Man*, 53 J. MIDWIFERY & WOMEN'S HEALTH 331, 332 (2008) (stating that "transgender men are not receiving appropriate primary care," which "puts them potentially at increased and unnecessary health risks").
  33. See Angela Robertson Bazzi et al., *Adherence to Mammography Screening Guidelines Among Transgender Persons and Sexual Minority Women*, 105 AM. J. PUB. HEALTH 2356, 2356 (2015) (citing Jordana Phillips et al., *Breast Imaging in the Transgender Patient*, 202 AM. J. ROENTGENOLOGY 1149 (2015)) (noting that the "finding that transgender patients had reduced odds of mammography adherence is of particular concern for transmen without bilateral mastectomy who remain at risk for breast cancer"); *id.* at 2356–57 (noting that experts recommend mammography for all women, including those taking estrogen).
  34. Sarah M. Peitzmeier et al., *Pap Test Use Is Lower Among Female-to-Male Patients Than Non-Transgender Women*, 47 AM. J PREVENTIVE MED. 808, 809 (2014).



incontinence.”<sup>35</sup> The presence of the prostate in transgender women can increase prostate cancer risk, and “[i]t is possible that prostate cancers developing in MTF individuals are more aggressive.”<sup>36</sup> Medical data thus show the risk that breast, cervical, and prostate cancers will progress when transgender and gender nonconforming individuals are not properly screened.

Health care denials also impact patients’ mental health. Inadequate care can cause built-up levels of frustration in patients, often with no outlet, which can lead to depression, anxiety, or violence. As CM, a genderqueer individual in Los Angeles, stated, “the accumulation of all of this stress [from health care denials] makes me sometimes turn to alcohol or pot, and then seeing incompetent doctors and therapists to help with this anxiety usually triggers the stress and it becomes a cycle.”<sup>37</sup> In Toronto, EV, a transgender man, stated that going to the doctor or a mental health provider can be counterproductive.<sup>38</sup> EV elaborated that when providers make assumptions about gender identity and therefore sexual orientation, he leaves feeling worse.<sup>39</sup> The National Transgender Discrimination Survey reports that 26% of respondents currently use or have used alcohol and drugs specifically to cope with medical provider mistreatment due to respondents’ transgender or gender nonconforming status.<sup>40</sup>

Together, insurance denials and discrimination increase the risks transgender and gender nonconforming individuals face when excluded from primary health care. Understandably, these denials have a widespread impact not only on those individuals who have been denied health care, but also on their communities and networks. In addition to the emotional ramifications of seeing a loved one suffer, ignoring transgender and gender nonconforming populations is costly.<sup>41</sup> The costs are preventable: coverage and early treatment can defray

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35. Lauren E. Holz & Michael Goodman, *Epidemiology of Advanced Prostate Cancer: Overview of Known and Less Explored Disparities in Prostate Cancer Prognosis*, 39 CURRENT PROBL. CANCER 11, 14 (2015) (citing L. J. Gooren, E. J. Giltay, & M. C. Bunck, *Long-term Treatment of Transsexuals with Cross-Sex Hormones: Extensive Personal Experience*, 93 J. CLINICAL ENDOCRINOLOGY & METABOLISM 19 (2008)).

36. *Id.* (citing Rafal Turo et al., *Metastatic Prostate Cancer in Transsexual Diagnosed After Three Decades of Estrogen Therapy*, 7 CANADIAN UROLOGICAL ASS’N J. 7 (2013)).

37. Telephone Interview with CM (Sept. 14, 2014). The University of California, Berkeley, Gender Equity Resource Center defines “genderqueer” as

[a] person whose gender identity is neither man nor woman, is between or beyond genders, or is some combination of genders. This identity is usually related to or in reaction to the social construction of gender, gender stereotypes and the gender binary system. Some genderqueer people identify under the transgender umbrella while others do not.

*Definition of Terms*, GENDER EQUITY RES. CTR., [http://geneq.berkeley.edu/lgbt\\_resources\\_definition\\_of\\_terms](http://geneq.berkeley.edu/lgbt_resources_definition_of_terms) (last updated July 2013).

38. Telephone Interview with EV (Nov. 4, 2014).

39. *Id.*

40. INJUSTICE AT EVERY TURN, *supra* note 26, at 81.

41. *See Affordable Care Act Rules*, *supra* note 7 (noting that for all Americans, including transgender and/or gender nonconforming individuals, chronic diseases “are responsible for 7 of 10 deaths . . . each year and account for 75 percent of the nation’s health spending”).

medical bills for individuals and communities.<sup>42</sup> Preventive care and screenings will not only save lives by catching diseases such as cancer early, but they will also protect patients and their families from the exorbitant medical bills that often result from delays in care.<sup>43</sup> The barriers to accessing full primary and preventive care that transgender and gender nonconforming individuals face negatively affect not only those individuals directly denied access and their close support systems, but also medical providers.

## 2. Medical Providers

Denials of appropriate care also affect health care providers, often through doctor frustration and burnout. The Institute for Healthcare Improvement created a three-pronged approach as a model for providers. Known as the Triple Aim, it seeks to 1) improve the health of populations, 2) enhance the patient experience, and 3) reduce the per capita cost of health care.<sup>44</sup> However, to realize these goals, physicians are required to increase services despite having limited resources. As Thomas Bodenheimer notes, this can lead to burnout: “The wide gap between societal expectations and professional reality has set the stage for 46% of US physicians to experience symptoms of burnout.”<sup>45</sup> The main determinant of physician satisfaction is the ability to provide quality care, so when physicians are dissatisfied with their ability to provide care, that is an early warning sign of a health care system that has created barriers to high-quality practice.<sup>46</sup>

To close the gap between societal expectations and doctors’ capabilities, doctors Thomas Bodenheimer and Christine Sinsky advocate funneling more financial and personnel resources to primary care centers.<sup>47</sup> Achieving the desired level of patient-focused care will require a 59% increase in staffing alone.<sup>48</sup> These organizations advise that if primary care’s available resources continue to diverge from society’s expectations for primary care, “feelings of betrayal and the wearing down from daily stress voiced by primary care

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42. *See id.*

43. *See id.*

44. Donald M. Berwick et al., *The Triple Aim: Care, Health, and Cost*, 27 HEALTH AFFAIRS 759, 760 (2008), <http://content.healthaffairs.org/content/27/3/759.full>.

45. Thomas Bodenheimer & Christine Sinsky, *From Triple to Quadruple Aim: Care of the Patient Requires Care of the Provider*, 12 ANNALS FAM. MED. 573, 573–74 (2014), <http://www.annfammed.org/content/12/6/573.full> (citing Tait D. Shanafelt et al., *Burnout and Satisfaction with Work-life Balance Among US Physicians Relative to the General US Population*, 172 ARCHIVES INTERNAL MED. 1377 (2012)).

46. *Id.* at 574 (citing MARK W. FRIEDBERG ET AL., RAND CORP., FACTORS AFFECTING PHYSICIAN PROFESSIONAL SATISFACTION AND THEIR IMPLICATIONS FOR PATIENT CARE, HEALTH SYSTEMS AND HEALTH POLICY (2013), [http://www.rand.org/content/dam/rand/pubs/research\\_reports/RR400/RR439/RAND\\_RR439.pdf](http://www.rand.org/content/dam/rand/pubs/research_reports/RR400/RR439/RAND_RR439.pdf)).

47. *See id.* at 575 (citing M.S. Patel et al., *Estimating the Staffing Infrastructure for a Patient-Centered Medical Home*, 19 AM. J. MANAGED CARE 509 (2013)).

48. *Id.*

practitioners will grow.”<sup>49</sup> This will lead to “deep and long lasting” negative impacts on patient-centered care.<sup>50</sup> Bodenheimer and Sinsky describe health care as “a relationship between those who provide care and those who seek care . . . that can only thrive if it is symbiotic, benefiting both parties.”<sup>51</sup> Providing gender incongruent health care means providing culturally sensitive and appropriate care. Thus, doctors must learn about procedures that may be new to them, such as Pap smears for men on testosterone who might have dry and sensitive tissue. Learning how to care for patients appropriately may be the key to reducing provider burnout. Resources should therefore be allocated to training doctors on providing culturally and medically competent care.

### 3. The Public at Large

Lastly, primary health care denials affect the public. As noted above, lack of access to proper health care can lead to underdiagnosis of breast, cervical, and prostate cancers and increased disease transmission and progression.<sup>52</sup> Respondents to the National Transgender Discrimination Survey “reported over four times the national average of HIV infection, with rates higher among transgender people of color.”<sup>53</sup> In 2008, the Centers for Disease Control estimated the number of newly sexually transmitted infections (STIs) to be 20 million; total infections in the United States are now 110 million.<sup>54</sup> The treatment of STIs costs over \$16 billion.<sup>55</sup> While this data is not specific to the transgender population, it shows that increased rates in STIs create huge costs for the health care system and society as a whole. Given the higher rates of disease transmission and progression among transgender and gender nonconforming individuals, a failure to provide comprehensive care for these individuals will heighten the financial burden on the larger community.

In fact, the American Medical Association estimated that providing access to transition-related care is nearly cost saving.<sup>56</sup> In 2001, the city and county of San Francisco, California eliminated transgender access exclusions from its employee health plan.<sup>57</sup> Five years later, San Francisco dropped the employee surcharge that it had implemented to cover the expanded benefits after

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49. *Id.*

50. *Id.*

51. *Id.*

52. *Lesbian, Gay, Bisexual and Transgender Health*, *supra* note 29; *see also* Hurley, *supra* note 30.

53. INJUSTICE AT EVERY TURN, *supra* note 26, at 80.

54. *Sexually Transmitted Diseases (STDs)*, CTRS. FOR DISEASE CONTROL & PREVENTION, <http://www.cdc.gov/std/products/infographics.htm> (last updated Mar. 28, 2013).

55. *Id.*

56. *See* Daphna Stroumsa, *The State of Transgender Health Care: Policy, Law, and Medical Frameworks*, 104 AM. J. PUB. HEALTH e31, e33 (2014).

57. *Id.*

reimbursement costs turned out to be significantly lower than estimated.<sup>58</sup> Thus, health care costs did not rise because covered care increased. While this example relates specifically to transition-related care, it suggests that increasing access to gender incongruent health care would not necessarily lead to increased collective medical costs.

### III. APPLICABLE LAWS, POLICIES, REGULATIONS, AND DIRECTIVES

Part III outlines the current laws, policies, regulations, and directives on access to gender incongruent health care and identifies the gaps that allow barriers to persist. In response to overwhelming denials of health coverage, many federal and state legislatures and medical associations have developed laws and policies that aim to increase access to comprehensive care and to ameliorate broader harms. Examples of these attempts to reduce barriers to care are addressed in turn.

#### A. The Patient Protection and Affordable Care Act

The Patient Protection and Affordable Care Act (ACA) is federal legislation that expands public and private insurance coverage and provides federal subsidies to help individuals pay for health insurance.<sup>59</sup> The law advances prevention and wellness, reduces health disparities, and improves access to health care services.<sup>60</sup> ACA's Section 1557, a civil rights provision, protects against discrimination based on gender identity.<sup>61</sup> According to the Director of the Office for Civil Rights, "[t]his landmark civil rights provision makes it illegal to discriminate against people because of their race, color, national origin, *sex (this includes discrimination based on gender identity or the failure to conform to sex stereotypes)*, age, or disability in most health care settings (such as hospitals or clinics)."<sup>62</sup> Section 1557 also applies to the ACA's Health Insurance Marketplaces.<sup>63</sup> Under the Act, transgender and gender nonconforming individuals' plans should cover the care and services offered to others on the plan, such as mammograms, Pap smears, and prostate exams, regardless of gender identity.<sup>64</sup>

The Office for Civil Rights (OCR) has its own regulations to enforce

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58. *See id.*

59. *See generally* 42 U.S.C. §§ 18001–18122 (2010); 26 U.S.C. § 36B

60. *See Section 1557 of the Patient Protection and Affordable Care Act*, U.S. DEP'T OF HEALTH & HUMAN SERVS., <http://www.hhs.gov/ocr/civilrights/understanding/section1557/> (last visited Jan. 8, 2016).

61. *Id.*; Patient Protection and Affordable Care Act § 1557, 42 U.S.C. § 18116 (2010).

62. Leon Rodriguez, *Ending Discrimination in Health Care: New Tools from the Affordable Care Act*, BLOG.AIDS.GOV (Sept. 25, 2013), <http://blog.aids.gov/2013/09/ending-discrimination-in-health-care-new-tools-from-the-affordable-care-act.html>.

63. *Id.*

64. Baker, *supra* note 16.

Section 1557.<sup>65</sup> OCR prohibits insurers from employing “marketing practices or benefit designs that will have the effect of discouraging the enrollment of individuals with significant health needs in health insurance coverage.”<sup>66</sup> This regulation also specifically prohibits insurers from discriminating based on an individual’s sex or gender identity.<sup>67</sup> As the Department of Health and Human Services noted in a comment to the final rule, “[a] number of commenters recommended that we expand this section to prohibit discrimination based on sex, gender identity, sexual orientation, having a particular medical condition, and other factors.”<sup>68</sup> However, the agency explained that “[t]he regulation as written prohibits benefit discrimination on the grounds articulated by Congress in section 1302(b)(4) of the Affordable Care Act, as well as those in 45 CFR 156.200(e), which include race, color, national origin, disability, age, sex, gender identity and sexual orientation.”<sup>69</sup> OCR’s regulation thus specifically articulates that gender identity is a protected class in the context of health care access under the ACA.

## B. Centers for Medicare and Medicaid Services

The Centers for Medicare and Medicaid Services (CMS) is one of several agencies advancing law and policy on gender incongruent health care. CMS administers federal health benefits and monitors Qualified Health Plans (QHP) in the Federally-Facilitated Marketplace.<sup>70</sup> The QHPs cover all mandatory benefits of the Affordable Care Act.<sup>71</sup>

Because QHPs may not discriminate on the basis of gender identity, CMS recommends that all QHP materials contain a nondiscrimination clause that

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65. See Section 1557 of the Patient Protection and Affordable Care Act, *supra* note 60.

66. 45 C.F.R. § 147.104(e) (2013).

67. § 147.104(e).

68. Patient Protection and Affordable Care Act; Standards Related to Essential Health Benefits, Actuarial Value, and Accreditation, 78 Fed. Reg. 12,834, 12,846 (Feb. 25, 2013) (to be codified at 45 C.F.R. pts. 147, 155, 156), <http://www.gpo.gov/fdsys/pkg/FR-2013-02-25/pdf/2013-04084.pdf>.

69. *Id.*

70. See U.S. Dep’t of Health & Human Servs., 2015 Letter to Issuers in the Federally-Facilitated Marketplaces (Mar. 14, 2014), <http://www.cms.gov/CCIIO/Resources/Regulations-and-Guidance/Downloads/2015-final-issuer-letter-3-14-2014.pdf> [hereinafter U.S. Dep’t of Health & Human Servs., 2015 Letter to Issuers].

71. See 45 C.F.R. § 155.20 (defining Qualified Health Plans generally); see also *Qualified Health Plan*, HEALTHCARE.GOV, <https://www.healthcare.gov/glossary/qualified-health-plan/> (last visited Jan. 6, 2016) (defining a Qualified Health Plan as “an insurance plan that is certified by the Health Insurance Marketplace, provides essential health benefits, . . . and meets other requirements”); see also *Qualified Health Plan: What Is a Qualified Health Plan?*, OBAMACARE FACTS, <http://obamacarefacts.com/insurance-exchange/qualified-health-plan/> (last visited Jan. 6, 2016) (defining a Qualified Health Plan as “a health plan certified by the marketplace to meet new benefit and cost sharing standards” and stating that QHPs “count as minimum essential coverage”).

includes sex and gender identity.<sup>72</sup> If CMS receives a consumer complaint, it will send the complaint to the state department of insurance for investigation and then follow that investigation with necessary enforcement action against the issuer, agent, or broker.<sup>73</sup> CMS also strives to increase coverage by using a billing and coding system that reduces automated denials based on gender identity.<sup>74</sup>

### C. Veterans Health Administration

In 2013, the Veterans Health Administration (VHA) created a directive that established a policy for providing respectful delivery of health care to all transgender veterans enrolled in the Department of Veterans Affairs (VA) health care system, or who are otherwise eligible for VA care.<sup>75</sup> The directive mandates that “transgender patients and intersex individuals [be] provided all care included in VA’s medical benefits package.”<sup>76</sup> It states that doctors and staff are responsible for treating patients with respect, addressing and referring to transgender and gender nonconforming patients by their self-identified gender and name, and providing room assignments and access to restrooms based on self-identified genders, “irrespective of appearance and/or surgical history” and “in a manner that respects the privacy needs of transgender and non-transgender patients alike.”<sup>77</sup> Further, all computerized records must reflect the patient’s self-identified gender.<sup>78</sup> Through these policies, the VA’s directive supports comprehensive and respectful primary care for its enrolled transgender veterans.

Robust implementation of the VA policies may be the key to meeting the primary health care needs of transgender veterans. Two interviewees in Louisiana shared that their VA care was satisfactory in part because their

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72. See Patient Protection and Affordable Care Act; Standards Related to Essential Health Benefits, Actuarial Value, and Accreditation, 78 Fed. Reg. 12,834, 12,846.

73. See U.S. Dep’t of Health & Human Servs., 2015 Letter to Issuers, *supra* note 70, at 37. In a 2015 guidance letter, the Centers for Medicare and Medicaid Services stated:

As we noted in the 2014 Letter to Issuers, states generally regulate health plan marketing materials and other related documents under state law, and CMS does not intend to review QHP marketing materials for compliance with state standards as described at §156.225(a). In FFM states where there is no or minimal review of QHP marketing materials for compliance with §156.200(e) and §156.225(b), CMS may review QHP marketing materials for compliance with these standards. CMS will work with states to determine where additional monitoring and review of marketing activities may be needed.

*Id.*

74. For a more detailed discussion of CMS billing and coding, see *infra* Part IV.B.

75. VHA Directive 2013-003, *Providing Health Care for Transgender and Intersex Veterans*, DEP’T OF VETERANS AFFAIRS 1 (2013), [http://www.va.gov/vhapublications/ViewPublication.asp?pub\\_ID=2863](http://www.va.gov/vhapublications/ViewPublication.asp?pub_ID=2863) [hereinafter VHA Directive 2013-003]; see also 38 C.F.R. § 17.38(c) (2011).

76. VHA Directive 2013-003, *supra* note 75, at 2.

77. *Id.* at 3.

78. *Id.*

provider is both the Assistant Chief of Staff and a transgender woman herself, which “helps the whole climate.”<sup>79</sup> Having a strong advocate in a position of power has therefore contributed to the successful implementation of health care in this region. The interviewees’ experience suggests that the VA’s success is due to a combination of the VA policy and the specific provider; providing good care thus depends both on the policies in place and on the way individual providers implement those policies.

#### D. State Law

There is a complicated interplay between federal and state laws dealing with gender identity documentation and access to health care. Whereas federal law guarantees access to health care, state laws may impede and impact these rights.<sup>80</sup> Inconsistencies between state and federal records complicate this issue because some identity documents are state-issued, like licenses and birth certificates, while others are federally issued, like Social Security cards and passports. In most states, if a person is enrolled in a federal health insurance program like Medicaid, Social Security data will populate their insurance record.<sup>81</sup> However, the gender marker listed in the individual’s Social Security records may conflict with their current gender identity and the gender listed on state-issued identification documents, leading to automatic refusals of health coverage.<sup>82</sup> The Social Security Administration allows individuals to update personal information but requires certain types of identity evidence.<sup>83</sup> The permissible evidence includes

full-validity, 10-year U.S. passport with the new sex; State-issued amended BC [birth certificate] with the new sex; court order directing legal recognition of change of sex; or medical certification of appropriate clinical treatment for gender transition

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79. Telephone Interview with CL (Oct. 9, 2014); Telephone Interview with DL (Oct. 9, 2014).
80. Anti-miscegenation law, for example, demonstrates the historical tension between federal and state laws in the United States. *See, e.g., Loving v. Virginia*, 388 U.S. 1, 12 (1967) (“Under our Constitution, the freedom to marry or not marry, a person of another race resides with the individual and cannot be infringed by the State.”).
81. *Medicaid Information*, U.S. SOC. SEC. ADMIN., <https://www.socialsecurity.gov/disabilityresearch/wi/medicaid.htm> (last visited Jan. 4, 2016) (noting that the majority of states determine Medicaid eligibility based on Social Security eligibility).
82. *Know Your Rights: Social Security*, NAT’L CTR. FOR TRANSGENDER EQUAL., <http://www.transequality.org/know-your-rights/social-security> (last visited Jan. 10, 2016) (“[If] a person is enrolled in Medicare, or the Medicaid and Supplemental Security Income (SSI) programs, their insurance record will be based on Social Security data. In that case, they may experience automatic refusals for coverage of services that appear inconsistent with a gender marker in Social Security records.”).
83. U.S. SOC. SEC. ADMIN., PROGRAM OPERATIONS MANUAL SYSTEM (POMS), RM 10212.200: CHANGING NUMIDENT DATA FOR REASONS OTHER THAN NAME CHANGE (2013), <https://secure.ssa.gov/poms.nsf/lnx/0110212200>.

in the form of an original signed statement from a licensed physician (i.e., a Doctor of Medicine (M.D.) or Doctor of Osteopathy (D.O.)).<sup>84</sup>

This requirement can be difficult, if not unachievable, for many transgender and gender nonconforming individuals.

The story of AP, a transgender woman living in Texas, illustrates how difficult it can be for a transgender or gender nonconforming individual to navigate conflicting state and federal laws.<sup>85</sup> AP was born in Mississippi and assigned a male gender marker upon birth, which remains listed on her Mississippi birth certificate.<sup>86</sup> When she moved to Louisiana, she was able to change her gender marker on her Louisiana license to female to reflect her true gender after she got a letter from her doctor stating that she had met the conditions necessary to “complete her transition.”<sup>87</sup> When AP moved to Texas, she wanted to get a Texas driver’s license, but Texas policy requires that a form of primary identification (birth certificate or passport) corroborate an individual’s gender before that gender can be listed on a license.<sup>88</sup> To change her Mississippi birth certificate, she needed to have gender reassignment surgery.<sup>89</sup> Even then, the “change” would be a mere annotation in the margin, not a newly issued birth certificate.<sup>90</sup> Consequently, AP chose to change the gender on her passport and use it as her primary identification to acquire a Texas license with an accurate gender marker.<sup>91</sup> In detailing the challenges of navigating these systems and incongruent laws, AP also explained that each process requires understanding, time, and money—resources not everyone has.<sup>92</sup> AP described the whole process as a “legal conundrum.”<sup>93</sup>

Most states do not explicitly prohibit health insurance discrimination based on gender identity, even though sex discrimination provisions and public accommodations laws should, by definition, prohibit exclusion of gender incongruent care.<sup>94</sup> It is also still not clear how federal sex discrimination

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84. *Id.*

85. See Telephone Interview with AP (Nov. 18, 2014).

86. *Id.*

87. This requirement is broad so as to allow “completion” to be determined by the patient and doctor without requiring surgery. See Matt Flegenheimer, *Easing the Law for New Yorkers Shifting Gender*, N.Y. TIMES, Oct. 8, 2014, at A1 (stating that “[i]n 2010, the United States Department of State removed the surgical requirement for updating passports” and noting that other jurisdictions and federal agencies have since adopted similar policies).

88. Telephone Interview with AP, *supra* note 85.

89. *Id.*

90. *Id.*

91. *Id.*

92. *Id.*

93. *Id.*

94. See NAT’L CTR. FOR LESBIAN RIGHTS, STATE BY STATE GUIDE TO LAWS THAT PROHIBIT DISCRIMINATION AGAINST TRANSGENDER PEOPLE (2010), <http://www.lgbtagingcenter.org/resources/pdfs/StateLawsThatProhibitDiscriminationAgainstTransPeople.pdf>; see also *Healthcare Laws and Policies: Private Insurance*, MOVEMENT



provisions will be interpreted with respect to gender incongruent care in states with no explicit protections. Insurance laws can be explicitly protective but general in scope,<sup>95</sup> thus, directives or bulletins might be needed to address specific forms of anti-transgender discrimination in health insurance.

California, Oregon, and Washington are helpful examples of states that have passed explicit protections through coverage directives. California's Insurance Gender Nondiscrimination Act (IGNA), passed in 2005, prohibits insurance companies and health care plans from discriminating on the basis of gender.<sup>96</sup> The California Code of Regulations now states that an admitted insurer shall not "discriminate on the basis of an insured's or prospective insured's actual or perceived gender identity, or on the basis that the insured or prospective insured is a transgender person."<sup>97</sup>

The California legislature has also passed a law, AB 496, to promote cultural and linguistic competency in the medical field. The state law requires "training programs to be formulated in collaboration with LGBT and intersex medical societies, among others, and specifies the accreditation standards as well as the competency standards for those developing the trainings."<sup>98</sup> AB 496 broadens the definition of "cultural and linguistic competency" to include understandings of how culture, ethnicity, sexual orientation, gender identity, and gender expression affect diagnosis, treatment, and clinical care.<sup>99</sup> IGNA therefore protects transgender and gender nonconforming individuals' right to access gender incongruent care in California while AB 496 aims to ensure that the care is provided in a culturally competent manner.

Washington has also committed to ensuring complete health coverage for transgender individuals. In a letter to health insurance carriers in Washington state, the Office of the Insurance Commissioner states that it will "review filings

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ADVANCEMENT PROJECT, [http://www.lgbtmap.org/equality-maps/healthcare\\_laws\\_and\\_policies](http://www.lgbtmap.org/equality-maps/healthcare_laws_and_policies) (last visited Jan. 2, 2016); *What You Need to Know About the Affordable Care Act: New Year Edition*, ADVANCING TRANSGENDER EQUALITY: THE BLOG OF THE NAT'L CTR. FOR TRANSGENDER EQUAL., <http://transgenderequality.wordpress.com/2014/01/09/what-you-need-to-know-about-the-affordable-care-act-new-year-edition/> (last visited Jan. 2, 2016).

95. HHS proposed a rule to implement new protections against sex discrimination. *HHS Takes Next Step in Advancing Health Equity Through the Affordable Care Act*, U.S. DEPT. OF HEALTH & HUMAN SERVS. (Sept. 3, 2015), <http://www.hhs.gov/about/news/2015/09/03/hhs-takes-next-step-advancing-health-equity-through-affordable-care-act.html> (acknowledging that the current wording is too vague and requires clarification that "[t]he proposed rule establishes that the prohibition on sex discrimination includes discrimination based on gender identity").
96. AB 1586, 2005 Cal. Legis. Serv. Ch. 421 (West).
97. CAL. CODE REGS. Tit. 10 § 2561.2 (2012); *see also* CAL. INS. CODE § 10140(h) (2011), ("Sex" as used in this section shall have the same meaning as 'gender.' 'Gender' means sex, and includes a person's gender identity and gender expression. 'Gender expression' means a person's gender-related appearance and behavior whether or not stereotypically associated with the person's assigned sex at birth.")
98. A.B. 496, 2013-14 Reg. Sess. (Cal. 2014) (codified at CAL. BUS. & PROF. CODE § 2190.1).
99. CAL. BUS. & PROF. CODE § 2190.1(c)(1)(D) (2014).

and coverage for prohibited exclusions and for whether medically necessary services for transgender individuals are covered to the same extent that those services are covered for non-transgender individuals enrolled in the same plan.”<sup>100</sup> The letter makes clear that Washington state law provides transgender policyholders the same benefits as individuals seeking medically necessary care.<sup>101</sup>

In 2012, Oregon’s insurance regulator wrote a similar bulletin to Oregon insurers that offered a guideline for compliance with the Oregon Equality Act. One of the principles states that “an insurer may not discriminate on the basis of an insured’s or prospective insured’s actual or perceived gender identity, or on the basis that the insured or prospective insured is a transgender person.”<sup>102</sup> It explains that a violation of the Act, and thus discrimination, would occur if an insurer required a payment that was based on an insured’s actual or perceived gender identity.<sup>103</sup> For example, denying a transgender man coverage for a Pap smear because of his identification as a man would constitute illegal discrimination. On the other hand, if Pap smears were categorically denied to all insured, regardless of gender, gender identity, or sex, then denying a transgender man coverage would not constitute a violation of the Oregon Equality Act. Thus, like California and Washington, Oregon has enacted laws to protect transgender and gender nonconforming individuals from insurance discrimination based on gender identity.

### E. The American Medical Association

The American Medical Association (AMA), a professional regulatory body, likewise promotes access to health care for transgender patients. Its Advisory Committee on LGBT issues has outlined several policies meant to ensure that transgender and gender nonconforming individuals get the care they need. For example, one of the AMA policies on LGBT issues states that the AMA opposes the denial of health insurance on the basis of sexual orientation or gender identity.<sup>104</sup> Another AMA policy states:

A physician may decline to undertake the care of a patient whose

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100. State of Wash., Office of Ins. Comm’r, Letter to Health Insurance Carriers in Washington State 2 (June 25, 2014), <http://www.insurance.wa.gov/about-oic/newsroom/news/2014/documents/gender-identity-discrimination-letter.pdf>.

101. *Id.*

102. OR. DEP’T OF CONSUMER & BUS. SERVS., OR. INS. DIV. BULLETIN INS 2012-1, APPLICATION OF SENATE BILL 2 (2007 LEGISLATIVE SESSION) TO GENDER IDENTITY ISSUES IN THE TRANSACTION AND REGULATION OF INSURANCE IN OREGON 2 (Dec. 19, 2012), <http://www.oregon.gov/DCBS/insurance/legal/bulletins/Documents/bulletin2012-01.pdf>.

103. *Id.*

104. *See AMA Policies on LGBT Issues: H-180.980 Sexual Orientation and/or Gender Identity as Health Insurance Criteria*, AM. MED. ASS’N, <http://www.ama-assn.org/ama/pub/about-ama/our-people/member-groups-sections/glb-t-advisory-committee/ama-policy-regarding-sexual-orientation.page?> (last visited Jan. 3, 2016).

medical condition is not within the physician's current competence. However, physicians who offer their services to the public may not decline to accept patients because of race, color, religion, national origin, sexual orientation, gender identity or any other basis that would constitute invidious discrimination.<sup>105</sup>

Thus, if a doctor's competency includes performing Pap smears, that doctor may not refuse to perform a Pap smear on a patient because that patient is male.<sup>106</sup> In another policy, the AMA "supports a national health survey that incorporates a representative sample of the U.S. population of all ages (including adolescents) and includes questions on sexual orientation, gender identity, and sexual behavior."<sup>107</sup> The importance of including gender identity information on national health surveys is discussed further below.

These laws, policies, directives, and regulations offer both specific and general protection of gender identity and claim to ensure access to health care regardless of gender. Still, profound barriers remain that continue to result in denials of coverage and access to gender incongruent health care for many transgender and gender nonconforming individuals.

#### **IV. Persisting Barriers Despite Updated Laws**

Part IV relies on interviews conducted for this study to describe the barriers that transgender and gender nonconforming individuals face when seeking competent health care. Some patients face outright denials of coverage for care appropriate for their bodies, while others face hostile or unwelcoming environments at doctors' offices that discourage them from seeking care. Part A expands on these provider-side barriers, such as harassment, hostility, and misunderstanding. Part B discusses the hurdles on the insurer/payer side, including insurance coding, billing, intake procedures, and forms. The failure of current law and policy to eliminate barriers to gender incongruent health care suggests that law alone does not resolve this issue. Instead, a holistic approach is recommended, one that relies on patient- and advocate-led efforts alongside insurer/payer reform and medical provider training.

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105. *AMA Policies on LGBT Issues: E-9.12 Patient-Physician Relationship: Respect for Law and Human Rights*, AM. MED. ASS'N, <http://www.ama-assn.org/ama/pub/about-ama/our-people/member-groups-sections/glb-adv-advocacy-committee/ama-policy-regarding-sexual-orientation.page?> (last visited Jan. 3, 2016).

106. This, however, is complicated by the fact that performing Pap smears on some men may require additional knowledge about vaginal atrophy.

107. *AMA Policies on LGBT Issues: H-440.885 National Health Survey*, AM. MED. ASS'N, <http://www.ama-assn.org/ama/pub/about-ama/our-people/member-groups-sections/glb-adv-advocacy-committee/ama-policy-regarding-sexual-orientation.page?> (last visited Jan. 3, 2016).

## A. Health Care Providers and Staff

Outright denials are only one type of barrier to patient care. This section offers background on the harassment that transgender and gender nonconforming patients often face in medical settings, be it in the waiting room or in the doctor's office. It then analyzes how patients' humiliation due to hostile or ignorant providers serves as a barrier to accessing care. Lastly, it discusses how the lack of provider understanding and cultural competency can also prevent patients from receiving effective health care.

### 1. Harassment

Harassment leads to denials of care whether or not it is intentional. In a recent survey of 337 transgender U.S. veterans, participants reported that their health care facility denied name changes in the system and that non-medically trained personnel, nurses, and doctors treated them with disrespect.<sup>108</sup> This sort of harassment damages patients' perceived relationship with their health care provider and may cause those in need of care to forgo necessary medical attention, rather than withstand embarrassment and frustration.

RO, a transgender man in Louisiana, stated that when he asked the staff at his doctor's office to allow him to check into his appointment using his preferred name, the doctor responded, "You expect us to change all of our policies to accommodate your needs? Why should we change what we are doing for one person? I don't want to deal with this."<sup>109</sup> RO felt isolated and demeaned when the doctor told him that "trans people are entitled" when they ask to be referred to by their preferred name and pronoun.<sup>110</sup> AP, a transgender woman in Texas, shared that when doctors do not use her correct pronoun, it is "demeaning, hurtful, and traumatic," and "it hurts no matter the doctor's intent."<sup>111</sup>

In addition to widespread administrative confusion and misunderstanding, many transgender and gender nonconforming individuals face animus and deliberate negativity due to their gender identity or expression. JA shared an example of harassment at a hospital in Oakland, California.<sup>112</sup> While in the hospital bed he began to menstruate and asked for a tampon.<sup>113</sup> A nurse said, "Oh, so you're a man, but now you want a tampon!?"<sup>114</sup> JA felt ashamed and

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108. J. Craig Phillips & Carol A. ("Pat") Patsdaughter, *Transitioning into Competent Health and HIV Care for Transgender Persons*, 20 J. ASS'N. NURSES IN AIDS CARE 335, 336 (2009), <http://www.sciencedirect.com/science/article/pii/S1055329009001058> (citing Monica Helms, *Transgender U.S. Veterans Ages 56-Plus Report Difficulties with VA Healthcare*, OUTWORD 1-3 (Fall 2008-Winter 2009)).

109. Telephone Interview with RO (Dec. 7, 2014).

110. *Id.*

111. Telephone Interview with AP, *supra* note 85.

112. Telephone Interview with JA (Sept. 14, 2014).

113. *Id.*

114. *Id.*

degraded.<sup>115</sup> The nurse offered him only a pad, but he could not use it because he was wearing boxers instead of underwear.<sup>116</sup> Consequently, he felt alone and that he could not trust the nurses to provide what he needed.<sup>117</sup>

Patients who *do* seek care sometimes choose not to disclose their identity to providers because they fear losing care or being unable to find a new culturally competent provider. Patients may hesitate to talk with their doctors about identity if they believe the provider will discriminate against them, stop providing care, treat them differently, bill them, or code their procedures to preclude coverage. In Louisiana, MS, a genderqueer individual who identifies “as in-between but on the male side,”<sup>118</sup> stated that he loves his doctor and has been seeing her for years; however, he has refrained from asking her what she would do regarding coding and providing care if he changed his gender marker with the office or insurance provider to male, because he wants to avoid any stigma.<sup>119</sup> The Institute of Medicine describes this situation as a proximal stress process.<sup>120</sup> This process includes “*perceived stigma* (which relates to the expectation that one will be rejected and discriminated against and leads to a state of continuous vigilance that can require considerable energy to maintain; it is also referred to as *felt stigma*), and *concealment of one’s sexual orientation or transgender identity*.”<sup>121</sup> The proximal stress process can have numerous damaging effects on an individual’s emotional and physical well-being. In addition to harassment, humiliation and insufficient medical care are two of the most significant processes creating proximal stress in the health care context.

## 2. Humiliation

Another provider-side barrier is humiliation. Humiliation occurs when staff members harass patients, when patients must refute their own identity to get health care, and when patients must violate their own privacy rights. These situations create a unique barrier to accessing health care.

Humiliation often starts in the waiting room. DL, a transgender woman in Louisiana shared, “I went to the doctor’s office and I was all dressed up in heels. While I was in the waiting room they called ‘Daniel.’”<sup>122</sup> It was embarrassing and degrading for the receptionist to call DL an inaccurate former name.<sup>123</sup> It disclosed sensitive personal information to other patients and created

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115. *Id.*

116. *Id.*

117. *Id.*

118. Telephone Interviews with MS (Sept. 10, 2014 & Oct. 6, 2014). MS identifies as “in-between” and uses male pronouns because in-between pronouns are “too hard.” *Id.*

119. *Id.*

120. See IOM, *supra* note 31, at 20.

121. See *id.*

122. Telephone Interview with DL, *supra* note 79.

123. *Id.*

opportunities for further humiliation by outing her to everyone in the room.<sup>124</sup> The experience created an unpleasant atmosphere throughout the waiting room, with uncomfortable stares from other patients and the receptionist's shame when she realized the impact she had on DL.<sup>125</sup> Describing the experience in her interview, DL exclaimed that "it was horrible for everyone!"<sup>126</sup>

When CM, a patient who identifies as genderqueer, went to a CVS Minute Clinic to be examined for a urinary tract infection, the nurse looked at them and said the clinic did not treat or test men for UTIs.<sup>127</sup> Thus, in one brief moment, the nurse assumed, incorrectly, CM's gender identity, gender, and sex and denied CM health care based on that assumption. To correct this assumption in a way the nurse would understand, CM felt forced to use gender incongruent descriptors, even though they would never use that terminology to describe themselves.<sup>128</sup> It felt degrading to tell the nurse "I am female, not male" when CM does not identify as either; the statement conflicted with their sense of self and undermined their dignity.<sup>129</sup> CM expressed discomfort with the responsibility of describing genderqueer identity to receive basic treatment: "I don't want to have to make every moment a teachable moment, but I also don't want to have to have this continue for the next person. It's a burden at least once a day, every day!"<sup>130</sup> Nevertheless, CM and other transgender and gender nonconforming patients are often forced to choose between undermining their own identity and receiving inaccurate or insufficient health care.

Similarly, JA, a transgender man, said that every time he visits his medical office, he writes his preferred name on the sign-in sheet and tells the staff.<sup>131</sup> Still, he often hears, "Well, in the computer it says X."<sup>132</sup> These conversations invariably occur in the public waiting room, in front of the receptionist, the other medical staff, and the other patients.<sup>133</sup> As with CM, JA is then forced to publicly describe himself in gender inaccurate terminology to correct the mistaken identity.<sup>134</sup>

This waiting room scenario is common to many of the transgender and gender nonconforming patients interviewed. This type of situation requires patients to disclose personal medical and anatomical information and strips away the anonymity guaranteed to others through the Health Insurance Portability and

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124. *Id.*

125. *Id.*

126. *Id.*

127. Telephone Interview with CM, *supra* note 37. The CVS policy that does not cover UTI tests for men creates another problem altogether, but that is outside of the scope of this analysis.

128. *Id.*

129. *Id.*

130. *Id.*

131. Telephone Interview with JA, *supra* note 112.

132. *Id.*

133. *Id.*

134. *Id.*

Accountability Act (HIPAA),<sup>135</sup> as well as state laws that also protect the privacy of medical information.<sup>136</sup> When these waiting room situations arise, transgender and gender nonconforming patients are put in the position of violating their own HIPAA protections by revealing personal medical information to a whole waiting room of individuals.<sup>137</sup> DL, CM, and JA’s experiences illustrate how transgender and gender nonconforming individuals must confront humiliating circumstances before they even access health care. Humiliation occurs when staff members harass patients, when patients must refute their own identities to get health care, and when patients are forced to violate their own privacy rights. These situations create a unique barrier to health care access.

### 3. Misunderstanding

Feeling misunderstood or ignored can serve as a barrier to accessing gender incongruent health care because it leads to poor quality of care. Misunderstanding manifests in two ways: first, when providers misunderstand transgender and gender nonconforming identity and culture; and second, when providers misunderstand specialized medical needs for this population. As in the earlier CVS example, many patients say they are forced to educate providers to get the care they need.<sup>138</sup> This lack of understanding of the “health beliefs, practices, and cultural and linguistic needs of diverse patients” limits the efficacy of the care patients receive.<sup>139</sup>

Many transgender and gender nonconforming people feel forced to educate their health providers on gender identity and expression—and many wish they did not have this responsibility. Just as CM at the CVS clinic did not want to make every health care transaction a teachable moment, RO stated, “I don’t want

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135. For information on HIPAA, see generally *Health Information Privacy*, U.S. DEP’T OF HEALTH & HUMAN SERVS., <http://www.hhs.gov/ocr/privacy/> (last visited Jan. 3, 2016).

136. For example, California enacted the Confidentiality of Medical Information Act, which defines “medical information” as “any individually identifiable information, in electronic or physical form, in possession of or derived from a provider of health care, health care service plan, pharmaceutical company, or contractor regarding a patient’s medical history, mental or physical condition, or treatment.” CAL. CIV. CODE § 56.05(j) (2013). In general, this information cannot be released or disclosed without the consent of the patient. *See* CAL. CIV. CODE § 56.10(a) (2000); *see also* P. JON WHITE ET AL., *PRIVACY AND SECURITY SOLUTIONS FOR INTEROPERABLE HEALTH INFORMATION EXCHANGE: REPORT ON STATE MEDICAL RECORD ACCESS LAWS 3-1* (Aug. 2009) (noting that states have a statutory or regulatory provision that allows individuals to access their medical records). While some states have more attenuated provisions, with few detailed standards, others have frameworks that are as detailed as the HIPAA Privacy Rule, with explicit right of access, processes for denial of access, and the right to amend information. *Id.* The provisions vary from state to state, but where there is no state law, the HIPAA Privacy Rules apply. *Id.*

137. A full analysis would include examining the analogous privacy issues regarding electronic HIV databases.

138. *See, e.g.*, Telephone Interview with CM, *supra* note 37.

139. *Clear Communication: Cultural Respect*, NAT’L INSTS. OF HEALTH, U.S. DEP’T OF HEALTH & HUMAN SERVS., <http://www.nih.gov/clearcommunication/culturalcompetency.htm> (last reviewed Oct. 29, 2015).

to be a social worker when I walk in here. I don't want to have to educate my doctor."<sup>140</sup> But he did it anyway; RO provided his doctor with the World Professional Association of Transgender Health (WPATH) Standards of Care so his doctor could educate himself.<sup>141</sup> The WPATH Standards of Care compile scientific and expert data and provide guidance for health providers to treat transgender and gender nonconforming individuals with appropriate care in order "to maximize their overall health, psychological well-being, and self-fulfillment."<sup>142</sup>

Others interviewees observed a similar lack of education on the part of health professions. CM said, "I need access to competent doctors who know about my specific issues."<sup>143</sup> EH, a genderqueer person in San Francisco, stated that they like to engage in community education, but they do not want to have to educate unknowledgeable doctors.<sup>144</sup> These interviewees are not alone. According to the results of the National Transgender Discrimination Survey, fifty percent of the 6,450 transgender and gender nonconforming participants reported having to teach their medical providers about transgender care.<sup>145</sup> Often, the only way to get competent care is to educate doctors, but this poses an unfair burden on patients who want respect and appropriate medical care without the additional work of self-advocacy.

Many individuals do not seek care because medical services and labels are dysphoric and trauma-inducing. For example, a transgender man might not identify with having a vagina, so the process of getting a Pap smear is both physically and emotionally painful.<sup>146</sup> JA confirmed that for most transgender men he knows, getting a Pap smear is traumatic.<sup>147</sup> Many of his FTM friends thus avoid exams, even though they need them and want to be healthy.<sup>148</sup> He suggested that "there needs to be a way for transgender men to have support when getting Pap smears, [to] show, institutionally, that transgender people matter."<sup>149</sup> The consequences of not getting regular Pap smears include undetected cancers or other health complications.<sup>150</sup> A lack of compassionate

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140. Telephone Interview with RO, *supra* note 109.

141. *Id.*

142. ELI COLEMAN ET AL., THE WORLD PROF'L ASS'N FOR TRANSGENDER HEALTH, STANDARDS OF CARE FOR THE HEALTH OF TRANSEXUAL, TRANSGENDER, AND GENDER NONCONFORMING PEOPLE 1 (Version 7, 2012) [hereinafter WPATH SOC].

143. Telephone Interview with CM, *supra* note 37.

144. Telephone Interview with EH (Oct. 20, 2014).

145. INJUSTICE AT EVERY TURN, *supra* note 26, at 72.

146. WPATH SOC, *supra* note 142, at 66.

147. Telephone Interview with JA, *supra* note 112.

148. *Id.*

149. *Id.*

150. See *Cancer Information*, JOHNS HOPKINS EDUC. & RESEARCH CTR. FOR OCCUPATIONAL SAFETY & HEALTH, [http://www.jhsph.edu/research/affiliated-programs/korean-american-cancer-project-in-maryland/cancer\\_information.html](http://www.jhsph.edu/research/affiliated-programs/korean-american-cancer-project-in-maryland/cancer_information.html) (last visited Jan. 5, 2016) ("If all women had pelvic exams and Pap tests regularly, most precancerous conditions would be detected and treated before cancer develops.").



and competent care incentivizes the risky behavior of forgoing regular care.

Many transgender and gender nonconforming patients must also educate their health care providers about specialized medical concerns. Transgender and gender nonconforming patients have a variety of unique medical needs. For example, a transgender woman may need both prostate and breast cancer screenings. Similarly, doctors must know how to perform medical examinations on individuals who have received gender-affirming surgery.<sup>151</sup> Data show an increased risk of breast cancer in postmenopausal women exposed to the hormones estrogen and progestin.<sup>152</sup> As a result, doctors recommend patients who undergo surgical removal of one or both testicles stop taking certain hormones soon after surgery, or get screened earlier for breast cancer.<sup>153</sup> If patients themselves do not know these medical details, they cannot inform their doctors. This may increase their risk of developing a disease. Transgender and gender nonconforming patients therefore require treatment from medical professionals well versed in their unique medical needs.

Another example of medical incompetency occurs when providers fail to address or acknowledge gender identity when they present medical information to patients. Sometimes lab results are compared to those of a specific sex to decide if a result is abnormal. For example, one woman stated that her doctor compared her bone density scan results to “males of her age” rather than females.<sup>154</sup> Bone density results are analyzed along *T*- and *Z*-scores, which compare an individual’s result to what is “normally expected in a healthy young adult of [one’s] sex.”<sup>155</sup> The National Osteoporosis Society (NOS) states that “sex hormones are important in regulating the growth of the skeleton and maintaining the strength of the bone” and that estrogen and testosterone have measurable effects on bone.<sup>156</sup> The NOS has not expanded on whether the process should be adapted to compare results to people who have the same hormone levels, rather than sex or gender identity. Though best practices on this issue remain unclear, it seems appropriate for a doctor to, at the very least, acknowledge the incongruence when presenting the data.<sup>157</sup>

This lack of understanding also affects when services are offered or denied to patients based on their actual or perceived gender. The WPATH Standards of Care state that offering gender incongruent services to transgender and gender

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151. Unger, *supra* note 8, at 22.

152. *Id.*

153. *Id.*

154. Telephone Interview with SMJ (Oct. 9, 2014).

155. *Tests and Procedures: Bone Density Test*, MAYO CLINIC, <http://www.mayoclinic.org/tests-procedures/bone-density-test/basics/results/prc-20020254> (last visited Dec. 15, 2014).

156. NAT’L OSTEOPOROSIS SOC’Y, TRANSSEXUAL PEOPLE AND OSTEOPOROSIS, <http://www.nos.org.uk/document.doc?id=1369> (last updated Oct. 2014).

157. A similar comparison occurs when doctors compare brain scan results to a male or female brain, even though the patient identifies as genderqueer. A full analysis of this issue is outside the scope of this Article.

nonconforming patients can be gender-affirming, as when medical professionals offer mammograms to MTF patients.<sup>158</sup> Patients may feel equally excluded when denied these services. CL, a transgender woman in Louisiana, was offended when her medical office did not offer her a mammogram or inform her about what the office referred to as “women’s” health services.<sup>159</sup> CL’s gender marker is female, but she was not provided with “women’s” routine care, causing her to feel excluded and leaving her with the sense that her gender identity was not being taken seriously.

Together, a better understanding of gender identity and expression, language, and cultural and medical competency can improve health care providers’ ability to offer a higher quality of care and reduce barriers to gender incongruent health care.

## **B. Insurers/Payers**

Common practices and procedures on the insurer/payer side also affect access to gender incongruent health care. Some formidable hurdles include insurance coding, billing, intake procedures, and forms. The United States currently has a multiple payer system, in which the private insurance industry (collecting premiums and payments from individuals and businesses) and the government (collecting taxes from individuals and businesses) both provide funds for health care.<sup>160</sup> To determine what health care services and procedures will be covered under either of these reimbursement models, most payers depend on medical billing and coding, the system that organizes diagnoses and procedures into categories with corresponding coverage. Defining the scope of primary care and coverage can lead to additional barriers for transgender and gender nonconforming patients, as a procedure’s categorization determines whether it will be covered by the patient’s insurance policy. Categorizing a procedure as primary care can mean full coverage, whereas categorizing the same procedure as transition-related can lead to a denial. Insurers can also force patients to self-designate using incorrect gender markers: when individuals complete forms that require choosing a gender, many are forced to pick a label that does not accurately represent their gender identity or expression.

### **1. Lack of Financial Coverage Due to Insurance Coding Practices**

Whether a patient receives insurance coverage often depends on a combination of two insurance codes: 1) the diagnosis code, which includes the explanation or reason for medical care, and 2) the procedure code, which lists the procedure performed on the patient.<sup>161</sup> The doctor’s office sends both of these

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158. WPATH SOC, *supra* note 142, at 66.

159. Telephone Interview with CL, *supra* note 79.

160. *See* KAO-PING CHUA, AM. MED. STUDENT ASS’N, SINGLE PAYER 101, <http://www.amsa.org/wp-content/uploads/2015/03/SinglePayer101.pdf> (last updated 2008).

161. CTRS. FOR MEDICARE & MEDICAID SERVS., U.S. DEP’T. OF HEALTH & HUMAN SERVS.,

codes, along with the bill, to the insurance provider. The insurer’s computer system then determines whether the two codes match to detect fraudulent or incorrect coding.<sup>162</sup> Red flags may arise when this data gets cross-referenced against patient-identifying data.<sup>163</sup> For example, if the gender on file for a patient is male, the diagnosis and procedure codes may be listed in the computer as diagnoses or procedures only appropriate for or available to women.<sup>164</sup> This computerized mismatch may result in an automated denial, or the mismatch may be manually overridden by an insurance agent.<sup>165</sup>

The insurance coding system presents at least three key problems for transgender and gender nonconforming patients. First, it leaves too much discretion to insurance overrides to catch mistakes. Second, it gives physicians too much discretion over how they code types of care. And finally, it can put an unnecessary burden on administrators and physicians. Bestowing such discretion on the insurance override makes the system dependent on the override’s ability to catch each mistake and fix it. According to JR, a transgender man in Oakland, the overrides “need clear guidance, training and education regarding competence. We’re engaging with a deeply dysfunctional system.”<sup>166</sup> Because they have so much discretion, overrides must understand the situations where a billing or procedure code seems incongruent with a patient’s identity information.

In the Medicare context, the Centers for Medicare and Medicaid Services mandate that the coder responsible for administering and processing Medicare claims<sup>167</sup> override any denials based on rejections for “gender/procedure conflict,” since these denials are considered “inappropriate.”<sup>168</sup> To do this, the

ICD-9-CM, ICD-10-CM, ICD-10-PCS, CPT, AND HCPCS CODE SETS 2, 3 (May 2015), <http://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/ICD9-10CM-ICD10PCS-CPT-HCPCS-Code-Sets-Educational-Tool-ICN900943.pdf>. A special thank you to Anand Kalra, Program Administrator at the Transgender Law Center, for explaining the coding system in the context of gender incongruent health care.

162. *Id.*; Telephone Interview with Anand Kalra (Oct. 28, 2014).

163. *Id.*

164. CTRS. FOR MEDICARE & MEDICAID SERVS., U.S. DEP’T OF HEALTH & HUMAN SERVS., PUB. NO. 100–04, MEDICARE CLAIMS PROCESSING: INSTRUCTIONS REGARDING PROCESSING CLAIMS REJECTING FOR GENDER/PROCEDURE CONFLICT 1, 3 (2009), <https://www.cms.gov/Regulations-and-Guidance/Guidance/Transmittals/downloads/R1877CP.pdf> [hereinafter MEDICARE CLAIMS PROCESSING].

165. *Id.* at 3–4.

166. Telephone Interview with JR (Oct. 13, 2014).

167. *See generally Medicare Administrative Contractors*, CTRS. FOR MEDICARE & MEDICAID SERVS., <http://www.cms.gov/Medicare/Medicare-Contracting/Medicare-Administrative-Contractors/MedicareAdministrativeContractors.html> (last updated Dec. 16, 2015, 4:00 PM) (discussing the role of Medicare Administrative Contractors in the processing of medical claims). Note that the term “coder” here can refer to anyone who may be coding Medicare claims, including Medicare Administrative Contractors and medical practitioners, among others.

168. MEDICARE CLAIMS PROCESSING, *supra* note 164, at 3–4.

person coding specific outpatient claims (known as Part A claims) should list condition code 45 (“Ambiguous Gender Category”) with the procedure code to prevent any automated denials.<sup>169</sup> For other claims (Part B claims), CMS requires coders to use a certain modifier (called a KX modifier) while coding to flag potential gender identity issues and allow the claim to process without automatic denial.<sup>170</sup> This complex, patchwork system serves to eliminate automated denials based on gender incongruence, but it relies on a coder’s discretion to include the modifier.<sup>171</sup>

A second problem with relying on insurance coding for coverage is the huge amount of discretion physicians exercise in the initial coding of medical diagnoses and procedures. When doctors have the discretion to decide whether a health issue is transition-related, coding a procedure as such can lead to an inadvertent exclusion of coverage for necessary procedures, as a patient’s policy may not cover transition-related care. Sometimes there is overlap between gender incongruent care and transition-related care. One interviewee gave the example where a transgender individual’s heart condition would not be covered if their doctor determined it was transition-related—a possibility because transgender individuals are often at a higher risk for heart disease from hormone use, smoking, and obesity.<sup>172</sup> The care for their heart condition could be considered preventive/routine *or* transition-related; however, because their doctor would have the discretion to code the procedure, the doctor would have the power to determine their insurance coverage.<sup>173</sup> Even a well-meaning doctor may inaccurately assume that a necessary procedure is transition-related and therefore outside of coverage.

A third problem with the insurance coding system is that an accumulation of payer claim denials can lead physicians to burn out from administrative burden. When coding leads to mistaken automated denials, doctors must spend time and energy re-coding procedures and diagnoses. As noted by the American Medical Association, “[d]enials, while not always unavoidable and whether the fault of the provider or the payer, still contribute heavily to the overall administrative cost through waste and redundancy.”<sup>174</sup> In this way, gaps in the system and discretionary factors create increased burdens not only for patients (who may be forced to pay out of pocket for services that should be covered), but also for health care and insurance professionals who must navigate a complex and leaky system. The current insurance coding system gives providers and

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169. *Id.*

170. *Id.*

171. *Id.*

172. Telephone Interview with JR, *supra* note 166; *see also Key Transgender Health Concerns*, *supra* note 4.

173. *Id.*

174. *Administrative Burden Index Score 6: Administrative Burden Associated with Claim Denials*, AM. MED. ASS’N, 5, <http://www.medicaldataexpress.com/WorkArea/DownloadAsset.aspx?id=6384> (last visited Jan. 8, 2015).

overrides too much discretion over the coding and billing processes. This can result in denials of covered care as well as physician and insurer burnout from trying to remedy those denials.

## 2. Limited Coverage Through Employer Insurance Plans

Another insurer-side barrier arises when transgender and gender nonconforming patients rely on insurance coverage through their employers, but the employer's policy does not cover appropriate preventive care.<sup>175</sup> In its 2016 Corporate Equality Index (CEI), the Human Rights Campaign looked at 851 employers from all major industry sectors and U.S. geographic regions to rank which companies provided "transgender-inclusive health care coverage."<sup>176</sup> For the purposes of the study, such coverage was defined as "equal health insurance benefits for transgender individuals without exclusion for medically necessary care," and coverage without any blanket exclusions based on gender identity (e.g., excluding transgender men from access to Pap smears based on their male gender marker).<sup>177</sup> While 87% of CEI-rated employers include "gender identity" in their nondiscrimination policies, only 60% of those businesses offer transgender-inclusive health care benefits.<sup>178</sup> This means that even among *insured* transgender and gender nonconforming individuals, patients may not be receiving coverage for the health care their bodies require.

## 3. Gendered Fields in Intake Forms

Administrative practices in insurance coverage create another barrier for many transgender and gender nonconforming individuals. Intake and registration forms often assign patients a gender, and errors in those forms and processes frequently result in humiliation or denial of care for transgender and gender nonconforming patients. Just as the construct of race can be reproduced and proliferated in prisons through intake forms and software fields, so too can gender be constructed in patient intake forms during the medical administrative process.

Gendering intake forms can lead to exclusions of care. CM, a genderqueer person in Los Angeles shared that they hate having to answer gendered questions on medical or insurance forms, specifically regarding periods, Pap smears, and

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175. See NAT'L CTR. FOR TRANSGENDER EQUAL., HEALTH CARE RIGHTS AND TRANSGENDER PEOPLE, [http://www.transequality.org/Resources/HealthCareRight\\_UpdatedAug2012\\_FINAL.pdf](http://www.transequality.org/Resources/HealthCareRight_UpdatedAug2012_FINAL.pdf) (last updated Mar. 2014).

176. HUMAN RIGHTS CAMPAIGN, CORPORATE EQUALITY INDEX 2015: RATING AMERICAN WORKPLACES ON LESBIAN, GAY, BISEXUAL AND TRANSGENDER EQUALITY 22 (2015) [hereinafter HRC CEI 2015].

177. *Id.*

178. *Id.* at 24.

pregnancies.<sup>179</sup> They stated that intake forms should leave questions open so that patients can answer if applicable, instead of gendering the line of questioning (if M, see \_\_\_\_, if F, see \_\_\_\_).<sup>180</sup> CM's experience demonstrates how questions about gender that lead to questions about care are detrimental to patient care: when the line of questioning is tied to an initial question about gender, many relevant follow-up questions and services are left invisible and ignored. Intake forms also pose a problem in how they construct gender and force participants to identify in incorrect ways.

With regard to race classification in prisons, Philip Goodman explains that “[a]dministrators create the forms (paperwork) that drive, mold, and constrain the entire categorization process: they create the institutional framework within which categorization unfolds.”<sup>181</sup> Similarly, the experiences of transgender and gender nonconforming patients demonstrate how “institutional categories necessarily alter individuals’ own [gender] labels and self-identification in an effort to feed the regulatory machinery to which we are all subject.”<sup>182</sup> Many people interviewed for this article stated that they retain inaccurate gender markers specifically so they can access health care that matches their bodies.<sup>183</sup>

In prisons, systems construct race rigidly. Along the wall of a dormitory housing unit in a California prison, a researcher found small boxes labeled “Black Barber,” “White Barber,” and “Hispanic Barber,” where prisoners could place a haircut request inside the box for the race with which they identified.<sup>184</sup> The researcher continued:

[T]hese boxes symbolize the extent to which officers and inmates perform an understanding of “race” as fixed and immutable. After all, there were only three boxes: those who consider themselves “Other” or “Asian” or “Native American” (and so forth) presumably choose the box with which they most closely affiliate. In addition, important for our analytical purposes, there is no room for liminality here—one chooses a box, and only one box.<sup>185</sup>

Like in the haircut example, most transgender and gender nonconforming patients must pick a single, immutable “box” at the doctor’s office that categorizes them as “male” or “female.” If one identifies their gender as both, neither, fluid, or something else, they are forced to forgo that identity to pick one of the options that are available. Liminal options, such as gender nonconforming or genderqueer, are rarely offered. Thus, intake forms and administrative

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179. Telephone Interview with CM, *supra* note 37.

180. *Id.*

181. Philip Goodman, *It’s Just Black, White, or Hispanic: An Observational Study of Racializing Moves in California’s Segregated Prison Reception Centers*, 42 LAW & SOC’Y REV. 735, 737 (2008).

182. *Id.* at 742.

183. *See, e.g.*, Telephone Interview with JA, *supra* note 112.

184. Goodman, *supra* note 181, at 746.

185. *Id.*

processes assign gender in ways that often do not match individuals' identities much in the same manner that race is assigned to people in prisons.

While many federal and state laws and policies facially provide access to gender incongruent health care, transgender and gender nonconforming individuals still face tremendous barriers to competent medical care as a result of harassment, humiliation, lack of provider understanding, and insurance coding and administrative practices. These individuals respond in a variety of ways.

## V. HOW INDIVIDUALS RESPOND TO BARRIERS

Transgender and gender nonconforming individuals have varied responses to health care barriers. Four common response strategies include 1) paying out of pocket for care; 2) using an inaccurate gender pronoun; 3) forgoing care; and 4) creating an individualized system with their provider and/or payer. These responses include both problems and solutions. For example, those who would have to pay out of pocket to fund care but cannot afford to do so end up not receiving care. Similarly, while self-advocating to create an individualized system can feel empowering, it can also be a burden. Structural changes are necessary to ensure that those without the tools or desire to self-advocate are also guaranteed access to care.

### A. Paying Out of Pocket

When faced with insurance coverage denials, many patients pay expenses out of pocket to receive the medical care they need. VV, an undocumented transgender woman, has only emergency medical coverage.<sup>186</sup> To protect her health, she gets free vaccinations from the fire department, and when sick, she either pays out of pocket to see a doctor or self-diagnoses and prescribes.<sup>187</sup>

Though VV adapts to her health care limitations, her solutions are not a guaranteed fix.<sup>188</sup> VV purchases hormones through friends instead of through a doctor's prescription, so she does not know if her self-prescribed doses are best for her body.<sup>189</sup> Her undocumented status has compounding effects.<sup>190</sup> Ideally, she would have insurance under the ACA that would cover all care, including hormones, so that she could access them safely; however, she cannot apply for ACA coverage until she is granted asylum.<sup>191</sup> Alternatively, VV hopes that once she is able to get a work permit, her employer will provide insurance.<sup>192</sup>

OH, a transgender man in Orange County, California, explained that to

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186. Interview with VV, in Phoenix, Ariz. (Sept. 10, 2014).

187. *Id.*

188. *Id.*

189. *Id.*

190. *Id.*

191. *Id.*

192. *Id.*

receive competent medical care, he attended his local Planned Parenthood “Transgender and Genderqueer Night” but had to pay out of pocket to obtain care.<sup>193</sup> OH also goes to a medical clinic in San Diego that serves low-income transgender patients, but it does not accept insurance.<sup>194</sup> As a result, he has to pay out of pocket to receive care there as well.<sup>195</sup> He has searched for competent, covered providers but has not found anybody accepting new patients.<sup>196</sup> EI, a transgender man in Los Angeles, California, stated that the gender marker with his insurance provider is male, which precludes coverage for Pap smears.<sup>197</sup> To obtain the preventive care he needs, EI pays out of pocket to receive Pap smears.<sup>198</sup> Paying out of pocket for preventive care is not financially feasible for many people in need of medical attention; thus, it is not a sustainable or equitable response to health care denials.

### B. Using a Gender Inconsistent with One’s Identity

Individuals also respond to barriers by selecting genders on intake forms that do not match their identities in order to avoid automated denials. HealthCare.gov lists all of the services that Marketplace Health Plans must provide; however, it labels some of the services as only “for women.”<sup>199</sup> Labeling these services “for women” excludes people who do not identify as women, but who are in need of preventive care and access to critical services. Thus, to gain access to routine medical care or preventive screening exams, many transgender people keep gender markers that do not match their identity.

RD, a transgender man in Denver, Colorado, kept his gender marker as female with his insurance company to maintain access to Pap smears and other exams.<sup>200</sup> When RD legally changed his name, the Human Resources specialist at his place of employment changed his gender marker to male, thinking the female listing must have been a mistake.<sup>201</sup> RD then tried to change his gender marker back to female, but the insurer required the HR representative to make the change with the insurance company.<sup>202</sup> RD explained that while this was a hassle, it ended up being fine, since he was “out” as transgender at work.<sup>203</sup> He stated that had he not been out, this could have been “really horrible.”<sup>204</sup> He has

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193. Interview with OH, in Irvine, Cal. (Sept. 16, 2014).

194. *Id.*

195. *Id.*

196. *Id.*

197. Telephone Interview with EI (Sept. 2, 2014).

198. *Id.*

199. See, e.g., *Preventive Health Services for Women*, HEALTHCARE.GOV, <https://www.healthcare.gov/what-are-my-preventive-care-benefits/women> (last visited Jan. 4, 2016).

200. Telephone Interview with RD (Oct. 7, 2014).

201. *Id.*

202. *Id.*

203. *Id.*

204. *Id.*



since thought about changing his gender marker with his insurance provider, but there are problems either way: if he changes his gender marker to male, his testosterone will be covered, but his Pap smears will not.<sup>205</sup> Having to weigh access to needed medical services against living authentically is not a fair—or legal—burden.

MS, a genderqueer interviewee in Louisiana, does not identify as male or female, but as “in-between and on the male side.”<sup>206</sup> MS uses male pronouns because “in-between pronouns,” or gender neutral pronouns such as “ze” and “they,” are difficult for people to understand, and he prefers not to deal with the extra hassle.<sup>207</sup> MS changed his name legally in 2014 with his health insurance provider and on his voter identification and license.<sup>208</sup> He did not change his name on his passport or on his birth certificate.<sup>209</sup> While he wants to change the gender marker on his identity documentation, he faces two issues: first, the gender marker he identifies with—gender neutral—is not yet an option; second, he is afraid that he would no longer have access to Pap smears.<sup>210</sup>

Fear of legal consequences can likewise lead a person to use a gender marker inconsistent with their identity. RO, a transgender man in Louisiana, stated that he keeps his gender marker with his insurance provider as female because he is afraid that marking his identity as male would be considered fraud.<sup>211</sup> Some insurance plans charge expensive premiums or monthly fees for different genders, and the fear of being accused of cheating this system drives many not to use their affirmed gender.<sup>212</sup> GC, another transgender man in Louisiana, stated that his doctor’s intake form “only offers male or female and sometimes I don’t check either. I don’t want to check male in case I get in trouble with insurance, and I’m not female, so I don’t check any.”<sup>213</sup> Interviewees MS and CM shared that they do not know the implications of having different genders listed on different forms and with different agencies.<sup>214</sup> They fear the unknown consequences of using one institution’s identity

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205. *Id.*

206. Telephone Interview with MS, *supra* note 118. MS described himself as “in-between genders” but uses male pronouns instead of gender-neutral pronouns, such as “they” or “ze.”  
*Id.*

207. *Id.*

208. *Id.*

209. *Id.*

210. *Id.*

211. Telephone Interview with RO, *supra* note 109.

212. Automobile insurance and life insurance also assess coverage and premiums based on gender. Interviewees discussed their concern that having different gender markers on different forms, or markers that are not verifiable with primary sources of identification (such as birth certificates or passports), might make them liable for fraud.

213. Telephone Interview with GC (Oct. 9, 2014).

214. *See, e.g.*, Telephone Interview with CM, *supra* note 37 (asking, “What will the legal implications be for using different genders on different forms, like for background checks?”); Telephone Interviews with MS, *supra* note 118.

document—such as a state driver’s license—in one realm, and a document from a different institution—such as a federally issued passport—in another.<sup>215</sup> This only adds to the difficulty, discussed above, of having to prove one’s identity using various pieces of supplemental documentation that list different names and/or genders. The fear and confusion stemming from these disjointed systems sometimes propels individuals to use genders other than their own and to mask their true identities.

### C. Forgoing Care

Some transgender or gender nonconforming individuals decide—or are forced—to forgo care due to discomfort or inability to pay out of pocket for medical expenses.<sup>216</sup> RO has never received a Pap smear because he has not found a provider that he trusts.<sup>217</sup> He has had hurtful encounters with health care providers and says he “is not in a place where [he] could handle it. It’s hard to come back from bad experiences.”<sup>218</sup> When one provider told him that “trans people are entitled” when they ask to be referred to using their preferred name and pronoun, he again had to look for a new doctor.<sup>219</sup> He fears “the experience of going in and having to explain all of his background. Talking about all the things that have happened over [his] lifetime and boiling it down for a stranger, or a new doctor, [would be] hard.”<sup>220</sup> He does not even want to see a gynecologist because he is afraid of what the doctor would ask him.<sup>221</sup> RO stated that he is “sensitive to people’s reactions and that it would be too upsetting and triggering for [him].”<sup>222</sup> He shared that “providers shouldn’t make their ignorance the patient’s problem. Patients should never feel judged.”<sup>223</sup>

OH, from Orange County, California, stated that his last Pap smear was probably about three years ago, before he transitioned, even though he thinks he falls into the category of needing one every year.<sup>224</sup> He shared that he probably could find a doctor who would perform the exam but has been putting it off for a couple of years because of the discomfort and energy involved.<sup>225</sup> OH explained how gender dysphoria made these types of exams very emotionally and physically difficult for him.<sup>226</sup> Further, it requires “so much effort to navigate

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215. *Id.*

216. For a detailed discussion of this topic, see Jennifer Wong, *Recasting Transgender-Inclusive Healthcare Coverage: A Comparative Institutional Approach to Transgender Healthcare Rights*, 31 LAW & INEQ. 471, 488 (2012).

217. Telephone Interview with RO, *supra* note 109.

218. *Id.*

219. *Id.*

220. *Id.*

221. *Id.*

222. *Id.*

223. *Id.*

224. Interview with OH, *supra* note 193.

225. *Id.*

226. *Id.*

these systems [to find a covered and competent provider] that there's a disincentive to keep trying."<sup>227</sup> He stated that the gender dysphoria already deters him, so the additional barriers justify not going: "It would depend on whether it was an emergency. If it was a situation where I wanted a particular outcome, such as pregnancy, I would go. Otherwise, for day-to-day care, it's just not worth it."<sup>228</sup>

GC, a transgender man in Louisiana, shared that he does not know the last time he had a Pap smear.<sup>229</sup> He heard about "a gynecologist who is really trans friendly, who schedules appointments for trans folks at the beginning of the day, so they don't have to wait in the waiting room with others."<sup>230</sup> He tends not to go, however, since he does not know which doctors his insurance provider covers.<sup>231</sup> He said that in his experience, the recommended doctors often are not covered.<sup>232</sup>

JA stated that he avoids health care altogether because his medical visits have been awkward and uncomfortable.<sup>233</sup> The last time he saw a gynecologist, she and the staff continued to use his legal name and misgender him, even after he told them his preference.<sup>234</sup> "They would say 'Miss' and use my birth name—eventually I just accepted that they would treat me as a girl there."<sup>235</sup> He has not yet found a primary care provider who respects him.<sup>236</sup> Providers often use inaccurate pronouns and ignore him when he corrects them.<sup>237</sup>

AP, a transgender woman in Texas, shared that when she was living in Louisiana, she began to self-administer unlawfully obtained hormones because she was not "out" to her doctor.<sup>238</sup> She stated that she had high blood pressure, but when it came time to renew her blood pressure medication, she was afraid to go to her doctor and tell him about her unprescribed hormones.<sup>239</sup> Hormone therapy falls under transition-related care, but her fear of outing herself to her doctor led her to forgo access to her blood pressure medication and thereby deny

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227. *Id.*

228. *Id.*

229. Telephone Interview with GC, *supra* note 213.

230. *Id.*

231. *Id.*

232. *Id.*

233. Telephone Interview with JA, *supra* note 112.

234. *Id.*

235. *Id.*

236. *Id.*

237. *Id.*

238. Telephone Interview with AP, *supra* note 85; *see also* Michael Silverman, *Symposium Presentation: Issues in Access to Healthcare by Transgender Individuals*, 30 WOMEN'S RIGHTS L. REP. 347, 349 (2009) ("What we see happening, unfortunately, is a gray or black market in things like hormones. We have stories of our clients buying hormone treatments on the street. Often it works out fine because our clients learn from their friends what dosage to take."). Silverman is now the Executive Director of the Transgender Legal Defense and Education Fund.

239. Telephone Interview with AP, *supra* note 85.

herself needed primary care.<sup>240</sup> She had to forgo care not because of a denial, but because of obstacles she placed in front of herself out of fear.<sup>241</sup> This patient experienced a type of minority stress referred to as internalized or felt stigma,<sup>242</sup> which ultimately served as a barrier to accessing needed care.

As these examples illustrate, when confronted with the many humiliations, complexities, and dysfunctions in the health care system, many transgender and gender nonconforming individuals forgo care.

#### D. Creating an Individualized System

Some patients successfully access appropriate care. This access may work in a piecemeal manner, in which a patient interacts with a sympathetic or culturally competent receptionist or doctor who allows access. Alternatively, a patient may self-advocate for referrals to competent providers.

In the first scenario, where patients visit culturally competent providers, the staff may be willing to create an individualized system that enables the patient to declare a preferred name and gender that the providers will use. Staff could insert a description of the scenario into a “Notes” field in their computer system. Alternatively, when a doctor is billing the insurance company, the doctor might code various procedures in ways that ensure coverage. While these are not systemic fixes, they enable patients and providers to work out a system that ensures the individual patient is respected and can access covered care.

In the second scenario, a patient may work to get access to an outside provider. In San Francisco, EH, a genderqueer student, stated that their university’s health insurance program did not offer medical providers who were culturally competent.<sup>243</sup> The university’s on-call provider “was weirded out and wouldn’t touch me.”<sup>244</sup> EH petitioned the university for a referral to a competent queer health clinic in San Francisco that their student insurance would cover.<sup>245</sup> The petition required several steps, including a primary consultation with a university provider, who judged the patient’s concerns and needs as compared to what the university plan offered.<sup>246</sup> EH had to research and find an outside provider who was both competent and accepting new patients.<sup>247</sup> Only then would the university provider make a referral to the student’s preferred provider.<sup>248</sup> EH explained that “while I eventually was able to see [the competent outside provider], this process took a lot of time and resources and should have

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240. *Id.*

241. *Id.*

242. See IOM, *supra* note 31, at 21 (explaining that minority stress processes are “both external (enacted stigma) and internal (felt stigma, self-stigma)”).

243. Telephone Interview with EH, *supra* note 144.

244. *Id.*

245. *Id.*

246. *Id.*

247. *Id.*

248. *Id.*

been embedded in a policy so that other students don't have to face the same hurdles to receiving appropriate care."<sup>249</sup>

As EH articulated, relying on an individualized path is not a structural fix. The system remains dependent on knowledgeable, proactive providers and staff to ensure access; it also requires patients to self-advocate in a health care setting, which can be very difficult. Self-advocacy depends on patients knowing their legal rights (so they know when they have a claim) and how to fight to obtain the access they are guaranteed under the law. They must have the time and energy to make claims and create networks. They may need to write letters and make speeches—each requiring verbal skills and literacy. They may have to out themselves to friends and family and the public at large. During this process, patients may face minority stress responsibility, which refers to the conflict between feeling a responsibility toward the rest of one's community and wanting to get coverage for oneself as quickly as possible.<sup>250</sup> In short, self-advocacy makes every doctor's trip a political event; it is an unreasonable burden with which to task every transgender person.

## **VI. PROPOSALS TO ENSURE COMPREHENSIVE & APPROPRIATE ACCESS**

As interviewee LJ stated, “[w]e need the insurance and political systems to give us the same rights, access, services, and concern as given to any other human being. We need the world to decide that it's ethical to help and protect us.”<sup>251</sup>

The current laws and policies that address gender incongruent care are insufficient on their own. To ensure their implementation and enforcement, we need a coordinated effort by patients, providers, insurers and payers, and governmental bodies. Despite positive advancements in law and policy, too many barriers remain for transgender and gender nonconforming individuals, and these barriers produce too many grave public health and economic effects. Laws regarding access do not necessarily need to be reformed, but an intersectional approach must be taken to put these policies into practice and ensure access to primary care for all. The following sections highlight sector-specific reforms and encourage transgender and gender nonconforming patients, experts, and advocates to lead them.

### **A. Providers**

This section discusses ways providers can ensure greater access to gender incongruent health care. Specifically, it details the need for cultural competency

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249. *Id.*

250. *See* IOM, *supra* note 31, at 10.

251. Telephone Interview with LJ (Oct. 9, 2014).

trainings for providers and staff, coordinated care among providers, intake reform, and implementation of an electronic medical database.

### 1. Providing Cultural Competency Training

One interviewee described the importance of attending a culturally competent health clinic as follows: “The queer health clinic where I go is pretty close to ideal. They are culturally aware and are sensitive. This is my third year going there. I don’t know what I would do without them. *It would be horrible without them.*”<sup>252</sup>

Even when access to primary care is covered and legally available, perceived disrespect and lack of understanding still act as barriers to care.<sup>253</sup> Medical providers should understand the vulnerabilities specific to transgender and gender nonconforming patients and learn culturally competent techniques, such as using accurate and affirming language to describe their patients’ bodies. Medical providers must also be *medically* competent, or versed in unique transgender health needs, so they can provide appropriate care for their patients’ bodies.

#### a. Cultural Competency

Cultural competency training should inform medical providers of the history of discrimination and violence against transgender and gender nonconforming people in the United States as a way to better equip providers to screen patients for harm and provide appropriate care. JA, a transgender man in Los Angeles, explained that “trans people deal with disproportionate violence, so it is important for doctors to recognize that because we’re in a violent society, a lot of trans patients are survivors of violence.”<sup>254</sup> According to the National Coalition of Anti-Violence Programs, transgender survivors were twice as likely as non-transgender individuals to face threats or intimidation within violent relationships and almost twice as likely to experience harassment.<sup>255</sup> Doctors need to know this type of information so they can provide sensitive exams, screen for domestic violence or intimate partner violence, and build trust with patients so patients feel safe disclosing their experience of different forms of violence.

Cultural competency trainings also introduce providers to appropriate and

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252. Telephone Interview with MT (Oct. 12, 2014) (emphasis added).

253. See generally IOM, *supra* note 31; see also A.B. 496, 2013–14 Reg. Sess. (Cal. 2014) (codified at CAL. BUS. & PROF. CODE § 2190.1); THE JOINT COMM’N, ADVANCING EFFECTIVE COMMUNICATION, CULTURAL COMPETENCE, AND PATIENT- AND FAMILY-CENTERED CARE FOR THE LESBIAN, GAY, BISEXUAL, AND TRANSGENDER (LGBT) COMMUNITY: A FIELD GUIDE (2011).

254. Telephone Interview with JA, *supra* note 112.

255. NAT’L COAL. OF ANTI-VIOLENCE PROGRAMS (NCAVP), LESBIAN, GAY, BISEXUAL, TRANSGENDER, QUEER, AND HIV-AFFECTED INTIMATE PARTNER VIOLENCE IN 2012, at 32 (2013).

affirming language, which can improve quality of care.<sup>256</sup> Positive treatment practices include using gender-neutral language to describe body parts and actions and following the patient's lead by using the language with which the patient feels comfortable. An interviewee noted that it is

[i]mportant for doctors to know that many trans people have different ways to refer to their different body parts, and then being open to whatever people say is their language. When asking about menstruation, ask, "When is the last time you bled?" not "when was your last period?" Use non-gendered ways to refer to body parts. For example, say "chest exam" not "breast exam." Doctors should acknowledge that for many transgender patients there may be challenges to receiving care for genders that they don't identify as.<sup>257</sup>

At transgender health clinics in San Francisco and Los Angeles, doctors referred to one patient's enlarged clitoris as his phallus, which felt affirming.<sup>258</sup>

In an article titled *About Purportedly Gendered Body Parts*, transgender legal activist Dean Spade described the need to use language that does not gender body parts:

We can use "people who menstruate" or "people who are pregnant" or "people who produce sperm" or other terms like these rather than using "male," "female" or "pregnant women" as a proxy for these statuses. In this way we get rid of the assumptions that all people who identify as a particular gender have the same kind of body or do the same things with their bodies, as well as the mistaken belief that if your body has/does that thing it is a particular gender. Examples: "This exercise is not recommended for people who are menstruating." "People who are trying to become pregnant should not take this medication." "People who produce sperm should be warned that this procedure could [a]ffect their fertility." . . . Our bodies have varying parts, but it is socialization that assigns our body parts gendered meaning.<sup>259</sup>

As Spade suggests, using non-gendered language in the medical context can reduce trauma associated with receiving health care. In addition to language about body parts, appropriate language about roles and relationships can also be affirming for transgender individuals. For example, in a survey documenting the experiences of transgender men who birthed children after transitioning, participants "used words such as 'dad,' 'carrier,' and 'gestational parent' to

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256. Another proposal regarding language is to de-gender "women's" and "men's" health so that those seeking gender incongruent care can access any procedures their bodies need.

257. Telephone Interview with JA, *supra* note 112.

258. Telephone Interview with EI, *supra* note 197.

259. Dean Spade, *About Purportedly Gendered Body Parts*, DEAN SPADE (Feb. 3, 2011), <http://www.deanspade.net/wp-content/uploads/2011/02/Purportedly-Gendered-Body-Parts.pdf>.

affirm their male gender identity and describe their parenting role.”<sup>260</sup> Using language that affirms the patient’s gender identity is important to developing a trusting relationship between patient and provider.

### b. Medical Competency

When medical providers understand the nuanced effects of hormones on the body, they are better able to provide effective primary care. In its Standards of Care, WPATH explains that taking testosterone can lead to “atrophic changes of the vaginal lining,” which can cause a burning sensation.<sup>261</sup> It explains how an

examination can be both physically and emotionally painful, but lack of treatment can seriously aggravate the situation. Gynecologists treating the genital complaints of FTM patients should be aware of the sensitivity that patients with a male gender identity and masculine gender expression might have around having genitals typically associated with the female sex.<sup>262</sup>

Culturally competent doctors should know that transgender men taking testosterone might need to use estrogen cream starting two weeks prior to a Pap smear due to vaginal atrophy and dryness, which causes the tissue to become more sensitive and less lubricated.<sup>263</sup> Similarly, providers must understand protocols that are specific to prostate cancer screenings for transgender women. For example, the Endocrine Society recommends performing transvaginal palpitation in addition to the standard annual rectal examination.<sup>264</sup> Doctors must be well-informed about these physical and emotional sensitivities, both to provide competent care and to ensure the patient is as comfortable as possible.<sup>265</sup>

In a study of Canadian physicians regarding the problems physicians face

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260. Alexis D. Light et al., *Transgender Men Who Experienced Pregnancy After Female-to-Male Gender Transitioning*, 124 *OBSTETRICS & GYNECOLOGY* 1, 4 (2014).

261. WPATH SOC, *supra* note 142, at 66–67.

262. *Id.*

263. Telephone Interview with CM, *supra* note 37; *see also Diseases and Conditions: Vaginal Atrophy*, MAYO CLINIC, <http://www.mayoclinic.org/diseases-conditions/vaginal-atrophy/basics/definition/con-20025768> (last visited Jan. 4, 2016).

264. Holz & Goodman, *supra* note 35, at 15 (citing Walter Bockting et al., *Care of Transsexual Persons*, 364 *NEW ENG. J. MED.* 2559 (2011)).

265. *See* R. NICK GORTON, JAMIE BUTH & DEAN SPADE, *MEDICAL THERAPY AND HEALTH MAINTENANCE FOR TRANSGENDER MEN: A GUIDE FOR HEALTH CARE PROVIDERS*, 41, 72–73, (2005), [http://www.nickgorton.org/Medical%20Therapy%20and%20HM%20for%20Transgender%20Men\\_2005.pdf](http://www.nickgorton.org/Medical%20Therapy%20and%20HM%20for%20Transgender%20Men_2005.pdf); *see also* Memorandum from the Ctr. for Clinical Standards & Quality/Survey & Certification Group, Ctrs. for Medicare & Medicaid Servs., U.S. Dep’t of Health & Human Servs., to State Survey Agency Directors (Aug. 22, 2014) (promoting a learning tool to educate care providers about the needs and rights of older LGBT adults through training modules).



when caring for transgender patients, researchers found that “the disciplinary division of responsibility within medicine” complicates care since “few practitioners identify trans healthcare as an interest area.”<sup>266</sup> This means few providers train to become “specialists” in transgender or gender nonconforming care, and as a result, they feel ill-equipped to provide the appropriate care for their patients. The study ultimately suggests that some ways to overcome this and other barriers are to provide practitioners with information about clinical guidelines, include transgender health issues in medical education, and bolster “trans-focused and trans-friendly primary care models.”<sup>267</sup> In this way, all providers can be equipped with the tools to provide competent care to their patients.

### c. Training Logistics

Existing funds can underwrite such training. For example, Federally Qualified Health Centers, including community health centers and public housing centers, serve as “safety net” providers “to enhance the provision of primary care services in underserved urban and rural communities.”<sup>268</sup> They have a two percent technical assistance requirement, meaning they can use allocated funds to develop and provide training on transgender issues.<sup>269</sup> Similarly, the Human Rights Campaign offers providers free online webinars on transgender sensitivity. The webinars offer a variety of topics, including an introduction to LGBTQ identities; discrimination (as experienced in health care and society); how to strengthen clinician-client communication; “differences between gender creative and transgender identities among children and adolescents as well as the unique health concerns among transgender youth, along with hormonal and surgical treatment options for transgender youth clients”; and “items that should be assessed or examined during follow-up visits with transgender adults and strategies for providing inclusive care.”<sup>270</sup> These types of trainings equip providers with the tools to address the specific health needs of transgender and gender nonconforming individuals in a culturally sensitive way. When providers use sensitive and affirming language and understand the primary health concerns affected by hormone therapy, they are

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266. John W. Snelgrove et al., “Completely Out-at-Sea” with “Two-Gender Medicine”: A Qualitative Analysis of Physician-Side Barriers to Providing Healthcare for Transgender Patients, 12 BIOMEDCENTRAL HEALTH SERVS. RES. 1 (2012), <http://www.biomedcentral.com/1472-6963/12/110>.

267. *Id.*

268. CTRS. FOR MEDICARE & MEDICAID SERVS., U.S. DEP’T OF HEALTH & HUMAN SERVS., FEDERALLY QUALIFIED HEALTH CENTER: RURAL HEALTH FACT SHEET SERIES 1 (2013) <https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/downloads/fqhcfactsheet.pdf>.

269. INJUSTICE AT EVERY TURN, *supra* note 26, at 2.

270. *Healthcare Equality Index: HEI Training on the CAL*, HUMAN RIGHTS CAMPAIGN, <http://www.hrc.org/hei-training-on-the-cal#.VdovlKbJVek> (last visited Jan. 4, 2016).

better able to provide respectful care and remedy the discrimination many face in health care settings.

Cultural competency should also be taught to soon-to-be providers so they may offer competent care as soon as they enter the field. The American Medical Student Association suggests students learn certain guidelines for their approach to primary care for transgender patients:

One important rule is to remember that medical care should focus on the body parts a person has, whether those are congruent with the gender identity or not. For example, an affirmed male may still have a cervix, in which case he should be followed with PAP smears. An affirmed female most likely still has a prostate, in which case she should be screened for prostate cancer at the appropriate age.<sup>271</sup>

Guidelines like these are a crucial component of medical training that will ensure doctors provide appropriate primary care to transgender and gender nonconforming patients.

Medical providers should also be educated regarding their rights and responsibilities so they know what services they can or must offer under the law. As SMJ, a transgender woman in Louisiana, put it, “many trans folks need letters from doctors, but the doctors are hesitant or scared to write the letters because they don’t know about the rules. They need to be trained on their rights, responsibilities, and liabilities.”<sup>272</sup> SMJ explained that if left untrained, the doctors would rely on their fear and ignorance to guide their practice and what services they are willing to provide, which in turn dictates what health services their patients receive.<sup>273</sup> As MS noted, “[e]ven doctors have their personal fears and biases, which sometimes get translated onto their patients.”<sup>274</sup>

In their interview, SMJ referred to doctor letters that confirm a patient has “completed transition” and that are sometimes used to secure updated identity documents.<sup>275</sup> Providing these letters is the responsibility of physicians who provide primary and transition-related care. However, the hesitance many doctors demonstrate toward writing them illustrates that all providers of health care to transgender and gender nonconforming individuals must know the laws that protect them and their patients. Regarding the doctors who treat transgender or gender nonconforming patients, DL stated, “We’re nervous, but the doctors are nervous too!”<sup>276</sup> Through the Louisiana Trans Advocates, SMJ helped develop a training for doctors and providers so they know to ask the “right”

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271. *Transgender Health: Primary Care*, AM. MED. STUDENT ASS’N, <http://www.amsa.org/AMSA/Homepage/About/Committees/GenderandSexuality/TransgenderHealthCare.aspx> (last visited Jan. 4, 2016).

272. Telephone Interview with SMJ, *supra* note 154.

273. *Id.*

274. Telephone Interview with MS, *supra* note 118.

275. Telephone Interview with SMJ, *supra* note 154; *see also* Flegenheimer, *supra* note 87.

276. Telephone Interview with DL, *supra* note 79.

questions.<sup>277</sup> The training, “Trans 101 for Medical Professionals,” was used in six cities across Louisiana; she hopes it will expand beyond Louisiana’s borders so that others are trained around the country.<sup>278</sup> SMJ remarked that this information needs to spread so that providers understand who their patients are: “[w]e need to put a normal face on this.”<sup>279</sup> Having transgender and gender nonconforming activists give trainings allows individuals to provide information about their own communities and help answer questions providers may have about a population they know little about.

In Oakland, California, the Kaiser Multi-Specialty Transitions Department provides information on its website about local culturally competent providers.<sup>280</sup> A patient stated that if a recommended doctor is not accepting new patients, the Clinic still allows a transgender or gender nonconforming patient to obtain access to that provider.<sup>281</sup> He explained that Kaiser allows this discretion because “they understand that *it’s a specific-need population and that cultural competency is crucial*.”<sup>282</sup> Kaiser’s process underscores the importance of cultural competency in providing medical services to transgender and gender nonconforming patients.

Cultural competency training is necessary to ensure patients get adequate medical care. As described above, emotional pain can discourage transgender patients from accessing preventive health care just as much as physical pain. This pain can be multiplied when the provider lacks sensitivity and cultural competency. When medical providers are competent and respectful, patients are more likely to seek care.

## 2. Promoting Holistic “Coordinated Care” Among Providers

It is important to have a primary care doctor who helps coordinate all areas of health care because of the effects that overlapping medical services can have on each other. While this is important for all patients, it is especially important for transgender and gender nonconforming patients due to the particular challenges of health care experiences for these individuals. For example, a coordinating doctor would know that an increase in testosterone, and the vaginal atrophy it can cause, might affect how a transgender patient receives a Pap smear.<sup>283</sup> Additionally, RO shared that when he asked his dermatologist how a new acne medication would interact with his hormones, the dermatologist said

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277. Telephone Interview with SMJ, *supra* note 154.

278. *Id.* Between fifty and sixty people attended each training. *Id.*

279. *Id.*

280. See *Transgender Care: Delivering Culturally Competent Care to Our Transgender Members*, KAISER PERMANENTE, <https://thrive.kaiserpermanente.org/care-near-you/northern-california/eastbay/departments/transgender-care/> (last visited Jan. 4, 2016).

281. Telephone Interview with JR, *supra* note 166.

282. *Id.* (emphasis added).

283. Unger, *supra* note 8.

she did not know, which made him nervous.<sup>284</sup> He would have liked to discuss the new medication with a coordinating doctor who could have answered this question.<sup>285</sup>

For many transgender and gender nonconforming patients, their endocrinologist serves as their de facto primary care provider and health care coordinator because they understand the effects of hormones on their patients' primary care needs.<sup>286</sup> Moreover, when an endocrinologist recognizes that their patient is not getting proper care elsewhere, they often step into the role of primary care doctor out of necessity, playing an important role in the delivery of preventive care.<sup>287</sup> While this can serve as a temporary fix for many patients who are unable to see primary care providers, this is not a solution for the medical profession's failure to train primary care physicians to provide competent and inclusive care.<sup>288</sup> According to the WPATH Standards of Care, if a primary care provider cannot deliver all medical services, it is essential to have ongoing communication among the various providers to ensure appropriate overall care.<sup>289</sup> HM, a transgender man in San Francisco, stated:

The ideal health care experience would be modeled around the HMO system, where there is a primary care provider who is the coordinator of care, since the personalized relationships are really important. The primary provider would be the central point-person who would coordinate all other care. It would be holistic, since that provider would know the patient's history, background, lifestyle, and would coordinate it all together. It would be respectful and culturally competent, they would talk to you and know about you, not just based on form questions. Patients would have an ongoing relationship with a provider.<sup>290</sup>

HM describes a system where care is provided centrally and coordinated among providers to ensure patients receive effective care.

The Affordable Care Act created the Community Health Center Fund to promote coordinated primary and preventive care in a "medical home," which aims to reduce health disparities for underserved populations.<sup>291</sup> It highlights a team-based approach to care that includes a wide variety of practitioners, such as

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284. Telephone Interview with RO, *supra* note 109.

285. *Id.*

286. *See, e.g.*, Telephone Interview with EI, *supra* note 197. EI stated that he used his endocrinologist as a "general" provider. *Id.* He noted that his endocrinologist offered to perform his Pap smears, knowing that EI did not want to have to go to a separate "women's health clinic." *Id.* *See also* Telephone Interview with AM (Dec. 12, 2014) (stating that her endocrinologist in New Orleans served as her primary care provider).

287. Telephone Interview with RO, *supra* note 109.

288. *Id.*

289. WPATH SOC, *supra* note 142, at 65.

290. Telephone Interview with HM (Oct. 7, 2014).

291. HEALTH RES. & SERVS. ADMIN., U.S. DEP'T OF HEALTH & HUMAN SERVS., FACT SHEET 2 (2014), <http://bphc.hrsa.gov/about/healthcenterfactsheet.pdf>.

physicians, nurses, assistants, dental providers, midwives, behavioral health care providers, social workers, and health educators.<sup>292</sup> This model of integrated care would ensure that patients receive information and care appropriate for their bodies and identities. For HM, the team of doctors would know all of the medications and hormones he is taking and could advise against certain combinations by explaining their effects. Team-based care is essential for transgender and gender nonconforming patients to close gaps in the care provided by different specialists.

Given the long history of discussing queer identity through a mental health lens, holistic gender incongruent care requires *both* physical and mental health care. Mental health care services should be a key part of all primary care services. In 2013 and 2014, the Health Resources and Services Administration (HRSA) awarded millions of dollars in ACA funding to open new or renovate existing health centers, to expand services, and to hire new mental health professionals promoting integrated models of primary care.<sup>293</sup> The World Health Organization, for example, advocates integrating mental health services into primary care to improve health outcomes, bolster social integration, and reduce stigma.<sup>294</sup> The ACA's Health Insurance Marketplace already includes depression screenings in preventive health coverage.<sup>295</sup> While the WHO and ACA proposals support integrating mental health into primary care for all patients, these recommendations could prove especially helpful to transgender and gender nonconforming individuals who must often seek mental health counseling before gender affirming surgery.<sup>296</sup> Because of this requirement, including mental health services in primary care is a particularly important step in promoting holistic and coordinated care for transgender and gender nonconforming patients.

### 3. Revising Intake Forms and Language

There are two main approaches to the question of how to revise intake forms with respect to sex, gender, and gender identity. The first approach seeks to abolish questions about gender on insurance and medical forms and replace them with questions about what services are needed or sought. A full analysis of this proposal would research whether a gender marker actually helps providers determine appropriate treatment; it would also explore the benefits and risks of

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292. *Id.* at 2–3.

293. *Id.* at 3.

294. WORLD HEALTH ORG., INTEGRATING MENTAL HEALTH SERVICES INTO PRIMARY HEALTH CARE (2007), [http://www.who.int/mental\\_health/policy/services/3\\_MHintoPHC\\_Infosheet.pdf](http://www.who.int/mental_health/policy/services/3_MHintoPHC_Infosheet.pdf).

295. See *Preventive Care Benefits for Adults*, HEALTHCARE.GOV, <https://www.healthcare.gov/preventive-care-benefits/> (last visited Jan. 4, 2016).

296. See, e.g., *Gender Reassignment Surgery*, AETNA (Oct. 2015), [http://www.aetna.com/cpb/medical/data/600\\_699/0615.html](http://www.aetna.com/cpb/medical/data/600_699/0615.html) (outlining requirements for coverage of gender affirming treatment and/or surgery, and noting that “[a]ll patients considering treatment need counseling and medical monitoring”).

having a gender marker designation on almost every form.<sup>297</sup> The other approach is to keep questions about gender but to use nuanced wording to capture new data and eventually provide better access to care and services. This Article will now explore the second approach in more detail.

Keeping gendered questions on intake forms provides an opportunity to capture more comprehensive population data on gender identity in the United States. The authors of the National Transgender Discrimination Survey reported that their findings confirm the need to create nuanced gender categories when collecting data on transgender and gender nonconforming individuals.<sup>298</sup> The survey provided study participants with multiple options for identifying and describing their gender identity, including “A) Male/man; B) Female/woman; C) Part time as one gender, part time as another; [and] D) A gender not listed here, please specify \_\_\_\_.”<sup>299</sup> The survey indicated that those without a listed gender identity (those who selected option (D)) were more likely than others to be HIV positive, to not know their status, to have attempted suicide at some point in their lives, and to avoid care when sick or injured due to fear of discrimination.<sup>300</sup> Allowing participants to write their own answers for gender identity resulted in “both unique demographic patterns as well as distinct experiences of discrimination,” which “would have been rendered invisible using cruder or more simplistic instruments.”<sup>301</sup>

When forms do ask for gender, not only should they allow the patient to self-identify their gender, but they should also give the patient an opportunity to describe the care being sought. CM suggested that gendered intake forms, which ask specific questions based on a listed gender, should instead allow patients to mark health concerns that are applicable to their bodies, even if those concerns are seemingly gender incongruent.<sup>302</sup> As noted above, when the line of questioning is tied to an initial question about gender, many relevant follow-up questions and services are left invisible and ignored. Including nuanced questions about gender and care would allow medical providers to capture helpful data that could be used to provide better care and inform policy.

#### 4. Capturing Demographic Information Using an Electronic Medical Database

Understanding the makeup of the transgender and gender nonconforming

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297. Regarding insurance actuarial tables, it would be necessary to know whether discrete gendered categories are actually needed and whether having a gender marker actually reduces or prevents incidents of security and fraud.

298. Jack Harrison et al., *A Gender Not Listed Here: Genderqueers, Gender Rebels, and OtherWise in the National Transgender Discrimination Survey*, 2 *LGBTQ POL’Y J.* 13, 14 (2011–2012).

299. *Id.*

300. *Id.* at 22.

301. *Id.* at 14.

302. Telephone Interview with CM, *supra* note 37.

population and what legal and medical issues are prevalent can help inform policy that promotes equity and accessibility. According to current figures, 700,000 transgender individuals live in the United States.<sup>303</sup> Several factors contribute to the unavailability of a perfect population estimate, including reluctance to self-identify as transgender, disagreement about definitions, and variable wording of survey questions.<sup>304</sup> A nationwide census would be crucial to identifying a more accurate figure.<sup>305</sup> In 2011, U.S. Department of Health and Human Services Secretary Kathleen Sebelius announced that the department would collect data in population health surveys to identify health issues and disparities among LGBT populations.<sup>306</sup> The department explained that it would start by integrating questions about sexual orientation and gender identity into the National Health Interview Survey.<sup>307</sup> The National Center for Transgender Equality proposes that transgender population data be captured in *all* population-wide government public health surveys.<sup>308</sup>

Capturing accurate and consistent data regarding gender identity is “essential for improving transgender health at the individual and community levels.”<sup>309</sup> This data would positively impact “three important domains: epidemiology (facilitating policy, research, and quality improvement efforts); medical (improving usefulness of health record data to providers and decision support systems); and patient-centered practice (improving patient experiences through the use of preferred names and pronouns).”<sup>310</sup> Collecting nuanced data is also crucial because individuals and communities use varying language to describe their own identities.

For offices already using electronic medical records, computer systems

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303. Gary J. Gates, *How Many People are Lesbian, Gay, Bisexual and Transgender?*, THE WILLIAMS INST. (Apr. 2011), <http://williamsinstitute.law.ucla.edu/wp-content/uploads/Gates-How-Many-People-LGBT-Apr-2011.pdf>.
304. Mona Chalabi, *Why We Don't Know the Size of the Transgender Population*, FIVETHIRTYEIGHT (July 29, 2014), <http://fivethirtyeight.com/features/why-we-dont-know-the-size-of-the-transgender-population/>.
305. *See Improving Data Collection for the LGBT Community*, U.S. DEP'T OF HEALTH & HUMAN SERVS., OFFICE OF MINORITY HEALTH, <http://minorityhealth.hhs.gov/omh/browse.aspx?lvl=3&lvlid=57> (last visited Jan. 4, 2016) (“[C]oncern continues as missing data tend to be concentrated in certain population sub-groups.”).
306. Stroumsa, *supra* note 56.
307. *Id.*
308. NAT'L CTR. FOR TRANSGENDER EQUAL., A BLUEPRINT FOR EQUALITY: A FEDERAL AGENDA FOR TRANSGENDER PEOPLE (2012), [http://www.transequality.org/sites/default/files/docs/resources/NCTE\\_Blueprint\\_for\\_Equality2012\\_FINAL.pdf](http://www.transequality.org/sites/default/files/docs/resources/NCTE_Blueprint_for_Equality2012_FINAL.pdf) (arguing that federally sponsored surveys should count transgender people: “[w]e need data about the lives of transgender people that is comprehensive, systematic, and collected regularly on a large scale.”).
309. Madeline B. Deutsch et al., *Collection of Gender Identity Data Using Electronic Medical Records: Survey of Current End-User Practices*, 25 J. ASS'N NURSES IN AIDS CARE 657, 662 (2014).
310. *Id.*

could easily prevent the kind of harassment that stems from using incorrect names and pronouns in the waiting room. Health care organizations should have a system that enables patients to provide their preferred name and gender pronouns in registration and intake documents so staff can see and consistently use the patients' preferred language.<sup>311</sup> Respecting patients' identities in this way could help reduce both intentional and unintentional harassment.

When electronic medical records do not identify transgender patients, the invisibility of those patients leads to fewer funding allocations, lower research efforts, and impaired quality improvement.<sup>312</sup> While WPATH has outlined best practice recommendations regarding data collection, end-user implementation and use patterns remain unknown.<sup>313</sup> Data is collected inconsistently and is often stored in many different locations within the electronic record across various platforms and institutions, creating additional challenges for providers and their staff.<sup>314</sup>

To resolve these inconsistencies, providers should implement the "two-step" approach to identify gender identity status.<sup>315</sup> This method involves first querying gender identity and then birth sex.<sup>316</sup> As noted by Madeline B. Deutsch et al., "[t]ransgender persons can be identified as those whose gender identity and birth sex are discordant."<sup>317</sup> With the two-step approach, it will be apparent if birth sex and gender differ, so the participant does not have to specifically identify as transgender.<sup>318</sup> It is important to note that there are race and class patterns of "choosing" versus not choosing the label "transgender." The Institute

311. See NAT'L LGBT HEALTH EDUC. CTR., AFFIRMATIVE CARE FOR TRANSGENDER AND GENDER NON-CONFORMING PEOPLE: BEST PRACTICES FOR FRONT-LINE HEALTH CARE STAFF 7 (2013), [http://www.lgbthealtheducation.org/wp-content/uploads/13-017\\_TransBestPracticesforFrontlineStaff\\_v6\\_02-19-13\\_FINAL.pdf](http://www.lgbthealtheducation.org/wp-content/uploads/13-017_TransBestPracticesforFrontlineStaff_v6_02-19-13_FINAL.pdf).

312. Deutsch, *supra* note 309, at 657.

313. *Id.* at 658.

314. *Id.*; see also Robert Tagalicod, *Health IT and Quality: Eliminating Health Disparities*, CMS.GOV (Sept. 20, 2013), [http://www.cms.gov/eHealth/ListServ\\_EliminatingHealthDisparities.html](http://www.cms.gov/eHealth/ListServ_EliminatingHealthDisparities.html). The Centers for Medicare and Medicaid Services state on the CMS.gov website:

CMS is working with its health care stakeholders to establish structured data definitions and the terms used in those definitions related to reporting health data for the LGBT communities. Our goal is to create better health for all Americans, at a lower cost, without endangering patients or negatively affecting the quality of care.

*Id.*

315. See GENIUSS GROUP, BEST PRACTICES FOR ASKING QUESTIONS TO IDENTIFY TRANSGENDER AND OTHER GENDER MINORITY RESPONDENTS ON POPULATION-BASED SURVEYS 9–11, 16, 19 (Jody L. Herman ed., 2014), <http://williamsinstitute.law.ucla.edu/wp-content/uploads/geniuss-report-sep-2014.pdf>; Deutsch, *supra* note 309.

316. *Id.*; see also Sean Cahill et al., *Do Ask, Do Tell: High Levels of Acceptability by Patients of Routine Collection of Sexual Orientation and Gender Identity Data in Four Diverse American Community Health Centers*, PLOS ONE 1 (Sept. 2014) <http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0107104#pone.0107104-Grant1> (describing the two-step approach).

317. Deutsch, *supra* note 309, at 658.

318. Chalabi, *supra* note 304 (citing Gary Gates, THE WILLIAMS INSTITUTE).



of Medicine states that an individual’s racial and ethnic communities are a strong component in shaping self-identification, the coming out process, available support and resources, and affirmation of gender-variant expression.<sup>319</sup> All of these factors ultimately influence health outcomes and add to the difficulty of capturing accurate data on gender identity.<sup>320</sup>

The need for capturing demographic information should be balanced with the need for privacy. Data collected in one domain should not disclose a patient’s gender identity in another, or patients will risk being outed when they seek medical care. While electronic medical records systems rely on documenting the details of a patient’s medical history, it would be inappropriate for this documentation to “broadly disclose transgender status to registration clerks, phlebotomists, or other staff in the health care system.”<sup>321</sup> Only the providers who need this information to provide competent medical services to the patient should have access to private patient information.

## B. Insurers/Payers

Comprehensive and appropriate access to gender incongruent health care requires a beneficial and well-maintained relationship between insurers/payers and billers. Insurers have the unique opportunity to modify or enact coding practices that capture relevant data and promote transgender-inclusive policy goals. Insurers also have the unique ability to mandate quality of care before providing reimbursement.

Medical insurance billers and coders navigate codes, claims, forms, common errors, and medical billing software.<sup>322</sup> Site information technology directors must know how to input data and code accurately to respect individuals seeking care and to ensure that the correct services are provided and covered appropriately.<sup>323</sup> This creates a path in the coding system to ensure payers are billed for medical services that match their patients’ needs, which is especially relevant to transgender and gender nonconforming patients.

As discussed above, new software systems should include form input fields that would capture relevant and appropriate information to prevent denials. In this case, the electronic data could facilitate efficiency and accuracy. The use of automation, such as “electronic eligibility verification,” can prevent many denials by “maximiz[ing] communication between physicians and payers.”<sup>324</sup>

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319. IOM, *supra* note 31.

320. *Id.*

321. Deutsch, *supra* note 309, at 660.

322. See *Medical Billing Training*, MEDICALBILLINGCAREER.ORG, <http://www.medicalbillingcareer.org/medical-billing-training.php> (last visited Jan. 4, 2016).

323. See *Medical Billing Coding*, MEDICALBILLINGCAREER.ORG, <http://www.medicalbillingcareer.org/medical-billing-coding/> (last visited Jan. 4, 2016).

324. *Administrative Burden Index Score 6: Administrative Burden Associated with Claim Denials*, *supra* note 174.

Verifying eligibility electronically allows the provider to receive quicker responses from insurers or payers regarding a patient's insurance coverage. The AMA supports this model because it can "reduce claims rejections and avoid the collection and billing costs stemming from insurance verification errors."<sup>325</sup> Reducing or removing the coding barrier would alleviate not only burdens on the patient, but also burdens on both the payer and the provider.

Researchers have suggested new ways to ask identity questions and use electronic medical records to better capture and store gender identity data. A 2013 study found that gender identity data are not stored consistently in the same demographics fields in electronic medical records.<sup>326</sup> Among various providers, preferred pronouns might be listed in "a dedicated preferred pronoun field, other demographics field, or within an alert or reminder system, the social history, or another unlisted location."<sup>327</sup> Further, patients' preferred names were only visible to all users in 47% of responses, and preferred pronouns in 27% of responses.<sup>328</sup> The authors of the study highlight a great need for system standardization, with training for providers so records are read and used consistently.<sup>329</sup> This insurer-driven education and guidance should help medical providers code correctly and consistently to ensure that transgender and gender nonconforming individuals have access to gender incongruent health care.

In addition to ensuring coverage for needed health care, it is crucial for insurance providers and payers to work toward improving quality of care for all transgender and gender nonconforming patients. One way of standardizing quality of care is through the use of measures codes, which contain information about the quality of care physicians are reporting.<sup>330</sup> The various, complex decisions that affect quality of health care do not fit easily into a checklist,<sup>331</sup> so "[c]urrent measurement systems define quality based on the results of structure, process, and outcomes measures."<sup>332</sup> Measures codes could help ensure physicians meet a minimum standard quality of care through payer review boards assessments. For example, individual practitioners or groups of practitioners must report data on health care quality to the Centers for Medicare and Medicaid Services or face negative payment adjustments.<sup>333</sup> This reporting

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325. See *Electronic Eligibility Verification Toolkit*, AM. MED. ASS'N, <http://www.ama-assn.org/ama/pub/advocacy/topics/administrative-simplification-initiatives/electronic-transactions-toolkit/eligibility-checking.page> (last visited Jan. 4, 2016).

326. Deutsch, *supra* note 309, at 659.

327. *Id.*

328. *Id.*

329. *Id.*

330. See *Measures Codes*, CMS.GOV, <http://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/PQRS/MeasuresCodes.html> (last visited Jan. 4, 2016).

331. See Thomas James III, *Is It Time to Change Directions of Quality Measures?*, 29 AM. J. MED. QUALITY 555, 555 (2014).

332. *Id.* at 556.

333. See *Physician Quality Reporting System: How to Get Started*, CMS.GOV, [https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/PQRS/How\\_To\\_Get\\_Started.html](https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/PQRS/How_To_Get_Started.html) (last visited Jan. 4, 2016).

requirement could be expanded to include aspects of gender incongruent care.

Reimbursement models can also fail to reward high-quality care when they focus on volume-based care rather than value-based care.<sup>334</sup> One proposal is to implement a “performance assessment-based payment model, which ties reimbursement to a physician or other health care professional’s ability to meet specified performance measures.”<sup>335</sup> This approach would provide an incentive for medical providers to become more attentive and competent in their treatment of transgender and gender nonconforming patients.

A recent proposal suggests that instead of relying on these self-defining determinations of quality, a more holistic process should be used to incorporate care that 1) promotes well-being, 2) is consistent with the values of the patient, 3) improves the health of the population, and 4) is rendered while keeping in mind limited personal and societal resources.<sup>336</sup> This model would combine the various factors that affect an individual or community, focusing on the intersecting effects of the “medical care system, the employer and educational system, community resources, and the family/social support systems.”<sup>337</sup> Understanding the effects of access to housing, employment, and correct identity documents on an individual’s health care can help the provider assess a patient’s underlying needs and provide referrals to organizations that can alleviate the social or legal causes of a health issue.

For example, an individual may experience housing discrimination and shelter exclusion based on her gender identity, which forces her to live on the street. Her chronic homelessness might lead to mental, physical, and emotional health challenges. Understanding the ways in which the medical, social, legal, and community systems interact is crucial to developing appropriate and comprehensive guidelines for competent care; a holistic approach to addressing health issues would also give rise to a more effective model for providing care to transgender and gender nonconforming patients.

### C. Governmental and Legal Bodies

Because of their ability to create and enforce laws to protect patients, governmental and legal bodies are also crucial to ensuring that transgender and gender nonconforming individuals have access to appropriate health care. This section proposes that continual use of incorrect pronouns and names should constitute harassment in the medical provider/patient context. It then explores the implementation of laws and policies through patient self-advocacy and the

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334. See AM. COLL. OF PHYSICIANS, THE ROLE OF PERFORMANCE ASSESSMENT IN A REFORMED HEALTH CARE SYSTEM 1 (2012), [http://www.acponline.org/advocacy/current\\_policy\\_papers/assets/performance\\_assessment.pdf](http://www.acponline.org/advocacy/current_policy_papers/assets/performance_assessment.pdf).

335. *Id.*

336. James III, *supra* note 331, at 556.

337. *Id.*

promulgation of regulations pertaining to gender incongruent health care.

### 1. Deeming Continual Incorrect Pronoun and Name Usage Harassment

The administrative complaint process can shape how laws are enforced. Recently, the Equal Employment Opportunity Commission (EEOC) and the U.S. Office of Special Counsel (OSC) each found that continual use of incorrect gender pronouns and names constitutes discriminatory sex-based harassment under Title VII.<sup>338</sup> In a complaint against the Department of Veterans Affairs, the EEOC found that the failure to revise agency records to reflect a transgender employee's correct name and gender pronouns constituted sex-based harassment, violating Title VII.<sup>339</sup> When the employee asked the supervisor to update his name, the supervisor reacted with hostility, refused to make the change, threatened to terminate all access to the database, and improperly accessed the employee's background investigation, "which contained personal information that [the employer] had no legitimate reason to know."<sup>340</sup> Because the hostile behavior continued for over a year, the EEOC found it "impacted [the employee's] ability to successfully meet the workload demands of his job without having to answer frequent personal questions about his gender identity."<sup>341</sup> The EEOC determined that the cumulative effect of the employer's treatment constituted illegal sex-based harassment.

In another complaint filed with the OSC, ongoing bathroom restrictions and incorrect name and pronoun usage were "sufficiently frequent, pervasive, and humiliating to constitute" discrimination against a transgender female employee ("Jane Doe").<sup>342</sup> OSC acknowledged that

while certain employees may object to allowing a transgender individual to use the restroom consistent with his or her gender identity, coworker (or even supervisor) anxiety or confusion alone cannot justify discriminatory working conditions. Indeed, allowing the preferences or prejudices of coworkers to dictate the working conditions of another employee reinforces the very stereotypes and biases that Title VII is intended to overcome.<sup>343</sup>

Title VII states that it is unlawful to "discriminate against any individual with

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338. *Complainant v. Dep't of Veterans Affairs*, EEOC Appeal No. 0120133123, 2014 WL 1653484 (Apr. 16, 2014); U.S. OFFICE OF SPECIAL COUNSEL, OSC FILE NO. MA-11-3846, REPORT OF PROHIBITED PERSONNEL PRACTICE 1 (Aug. 28, 2014), [https://osc.gov/Resources/2014-08-28\\_Lusardi\\_PPP\\_Report.pdf](https://osc.gov/Resources/2014-08-28_Lusardi_PPP_Report.pdf); *see also*, *Jameson v. U.S. Postal Serv.*, EEOC Appeal No. 0120130992, 2013 WL 2368729, at \*2 (May 21, 2013) ("[I]ntentional misuse of the employee's new name and pronoun may cause harm to the employee, and may constitute sex based discrimination and/or harassment.").

339. *Complainant v. Dep't of Veterans Affairs*, 2014 WL 1653484, at \*2.

340. *Id.*

341. *Id.*

342. U.S. OFFICE OF SPECIAL COUNSEL, OSC FILE NO. MA-11-3846, *supra* note 338, at 6.

343. *Id.* at 8.

respect to his compensation, terms, conditions, or privileges of employment.”<sup>344</sup> To determine whether Jane Doe’s employer had violated Title VII, the OSC assessed the claim based on the “frequency of the discriminatory conduct; its severity; whether it [was] physically threatening or humiliating; and whether it unreasonably interfere[d] with an employee’s performance.”<sup>345</sup> Doe’s employer intentionally limited Doe’s ability to use the female restroom “until she underwent a final medical procedure” and inappropriately and invasively monitored the status of that procedure.<sup>346</sup> Her supervisor repeatedly used her birth name and male pronouns, and her manager regulated the content of her conversations with coworkers.<sup>347</sup> The OSC found that this treatment significantly restricted her working conditions and constituted sex-based harassment.<sup>348</sup>

The OSC also found that the employer-employee relationship and its hierarchy of authority played a role in the dynamic, as “the harassment stemmed from an abuse of the supervisor-subordinate relationship by Agency officials with the authority to take, recommend, and approve the actions at issue.”<sup>349</sup> Doe’s supervisor had the power to “approve and enforce” a transition plan, which outlined the bathrooms available to Doe and the types of conversations she could have with other employees.<sup>350</sup> These measures illustrated the imbalance of power between Doe and her supervisor, which made her especially vulnerable to harassment. The medical provider-patient relationship displays a hierarchy of authority similar to that inherent in the employer-employee relationship.

If misgendering a transgender or gender nonconforming individual or referring to them by an incorrect name can constitute Title VII discriminatory harassment in the workplace, then the same conduct should constitute harassment in the health care context. Similar to the employment context, there is an imbalance of power between health care providers and patients, as nurses and doctors act as gatekeepers to accessing health care in settings that can be traumatic and triggering for patients. As in employment cases, a court considering a case arising out of a medical visit should examine the frequency and severity of the name and gender misuse, whether the actions in question were humiliating, and whether they unreasonably interfered with the patient’s care. This might involve an examination of the number of times the doctor, nurse, or receptionist used incorrect names and pronouns after being informed of the patient’s preference. Humiliation and unreasonable interference could be

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344. 42 U.S.C. § 2000e-2(a) (2012).

345. U.S. OFFICE OF SPECIAL COUNSEL, OSC FILE NO. MA-11-3846, *supra* note 338, at 6 (citing *Harris v. Forklift Sys. Inc.*, 510 U.S. 17, 23 (1993)).

346. *Id.* at 7.

347. *Id.* at 6–7.

348. *Id.*

349. *Id.*

350. *Id.* at 7.

based on the tone of the inappropriate statements, the doctor's response after being corrected by the patient, whether the misuse "outed" the patient to strangers, whether the doctor refused to treat the patient, and the manner in which the doctor conducted the examination. Like employees, patients should be able to recover damages in a discriminatory harassment claim when their doctors, nurses, and staff continually refer to them using an incorrect name or pronoun.

## 2. Offering Potential Causes of Action

Intentional misgendering and misnaming, or the denial of services, access, or facilities in a doctor's office or waiting room could also give rise to various state-defined causes of action, such as invasion of privacy, public accommodations discrimination, or intentional infliction of emotional distress. Professionals in the medical field should be held responsible for intentionally harming patients and denying access in this way.

### a. Invasion of Privacy and Intrusion Upon Seclusion

When medical staff invade the privacy of a patient, the patient may have a claim for intrusion upon seclusion. In most states, an intrusion upon seclusion claim has four elements: the plaintiff must prove (1) there was an unauthorized intrusion or prying into his seclusion; (2) the intrusion was highly offensive or objectionable to a reasonable person; (3) the matter intruded upon was private; and (4) the intrusion caused anguish and suffering.<sup>351</sup> For example, an appellate court in Illinois held that the plaintiff suffered an invasion of privacy when the defendant used plaintiff's name without permission to order and charge plaintiff for items the plaintiff did not order.<sup>352</sup>

In the context of privacy in a medical setting, RD, the transgender man in Denver, might have a claim for intrusion upon seclusion against the human resources officer who changed his gender marker without permission.<sup>353</sup> The human resources officer read through RD's insurance file and saw his name listed alongside his gender assigned at birth.<sup>354</sup> The officer then decided the gender marker must be incorrect and changed it to male, which led to an insurance coverage denial for an upcoming Pap smear.<sup>355</sup> These actions constitute an unauthorized intrusion under the first prong of test.<sup>356</sup>

A reasonable person would also find the intrusion highly offensive, since it was not the duty of the human resources officer to make decisions about

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351. RESTATEMENT (SECOND) OF TORTS § 652(B) (AM. LAW INST. 1977); *Melvin v. Burling*, 490 N.E.2d 1011, 1013–14 (Ill. App. Ct. 1986).

352. *Melvin*, 490 N.E.2d at 1014.

353. See Telephone Interview with RD, *supra* note 200.

354. *Id.*

355. *Id.*

356. *Id.*

another’s gender identity or gender marker, or to change that individual’s personal information without permission. Further, an individual’s medical forms and gender identity are highly private matters, and the intrusion caused RD to suffer both financially and emotionally—from being denied coverage for necessary medical care and from knowing that other employees were looking at his files and making decisions about his gender. A court should therefore find that RD satisfied the four elements of an invasion of privacy claim.

### **b. Public Accommodation Discrimination**

While federal nondiscrimination laws do not cover gender identity, seventeen states and the District of Columbia prohibit discrimination based on gender identity in public accommodations.<sup>357</sup> In California, the Unruh Civil Rights Act provides that all persons “are entitled to the full and equal accommodations, advantages, facilities, privileges, or services in all business establishments of every kind.”<sup>358</sup> There are four elements for a California public accommodations discrimination claim based on gender identity:

- (1) [the defendant] denied/aided or incited a denial of/discriminated or made a distinction that denied full and equal accommodations/advantages/facilities/privileges/services [to the plaintiff];
- (2) a substantial motivation for [the defendant’s] conduct was its perception of [the plaintiff’s gender identity];
- (3) [the plaintiff] was harmed; and
- (4) [the defendant’s] conduct was a substantial factor in causing [the plaintiff’s] harm.<sup>359</sup>

In the medical context, a patient who was denied admission to see a doctor or undergo an exam, or otherwise barred from accessing facilities or services based on gender identity, would need to prove each of these elements to state a valid public accommodations discrimination claim. RO, the transgender man whose doctor raised his voice in disgust and stated that he did not want to deal with RO’s needs and should not have to change his entire system to accommodate one person, might have a valid public accommodations discrimination claim.<sup>360</sup> First, when the doctor yelled at RO and stated he would

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357. *Know Your Rights: Public Accommodations*, NAT’L CTR. FOR TRANSGENDER EQUAL., <http://transequality.org/know-your-rights/public-accommodations> (last visited Jan. 4, 2016).

358. *See* Unruh Civil Rights Act, CAL. CIV. CODE § 51(b) (2012); *see also* *Fact Sheet: General Information About the Unruh Civil Rights Act*, CAL. DEP’T OF FAIR EMP’T & HOUSING, FACT SHEET: GENERAL INFORMATION ABOUT THE UNRUH CIVIL RIGHTS ACT (2015), <http://www.dfeh.ca.gov/res/docs/publications/dfeh-250.pdf>. (last visited Jan. 10, 2016) (including hospitals on an incomplete list of businesses covered under the law).

359. Judicial Council of California Civil Jury Instructions (2003), CACI No. 3060.

360. Telephone Interview with RO, *supra* note 109. This patient lives in Louisiana, which does not have gender identity protective legislation. However, his scenario could also apply to a person in a state with nondiscrimination protections.

not treat him because he did not want to deal with his gender identity, he made a distinction that denied full and equal services to RO.<sup>361</sup> Second, the doctor stated that he did not want to work with RO specifically because of his gender identity, as the doctor did not want to “change all of [his] policies to fit [RO’s] need.”<sup>362</sup> Third, RO was harmed both emotionally and physically because he did not receive the medical attention that he needed. Fourth, the doctor’s conduct was a primary cause of RO’s harm.<sup>363</sup> Thus, RO likely has a valid case for public accommodations discrimination in California and states with similar laws.

### c. Intentional Infliction of Emotional Distress

A patient may also have a claim for intentional infliction of emotional distress (“IIED”). A successful IIED claim must meet the following four elements: (1) the defendant must act intentionally or recklessly; (2) the defendant’s conduct must be extreme and outrageous; and (3) the conduct must be the cause (4) of severe emotional distress.<sup>364</sup>

JA, the transgender man in Oakland who was denied tampons at the hospital, might use these factors to make a claim for intentional infliction of emotional distress.<sup>365</sup> First, the nurse acted intentionally when she refused to give him a tampon.<sup>366</sup> Second, the nurse stated that the denial was due to JA’s identity as a man and that men could not have tampons, even though she knew he was menstruating.<sup>367</sup> After deliberation, the nurse only provided a pad, knowing JA’s boxers could not accommodate a pad.<sup>368</sup> A court should find this action extreme and outrageous because it falls outside the range of permissible human behavior. In *Brandon v. County of Richardson*, the Supreme Court of Nebraska held that a transgender rape victim suffered intentional infliction of emotional distress by law enforcement officers when they used “crude and dehumanizing language” while interviewing the victim.<sup>369</sup> The court stated, “[C]onduct which might otherwise be considered merely rude or abusive may be deemed outrageous when the defendant knows that the plaintiff is particularly susceptible to emotional distress,”<sup>370</sup> or when the defendant has abused a position of power.<sup>371</sup> In JA’s case, the nurse understood JA was under emotional stress from being in the hospital and having to defend his gender identity and

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361. *See id.*

362. *See id.*

363. *See id.*

364. RESTATEMENT (THIRD) OF TORTS § 46 (AM. LAW INST. 2010).

365. *See* Telephone Interview with JA, *supra* note 112.

366. *See id.*

367. *See id.*

368. *See id.*

369. *Brandon v. Cnty. of Richardson*, 624 N.W.2d 604, 622 (2001).

370. *Id.* at 621.

371. *Id.*



health needs.<sup>372</sup> The nurse also held a position of power over JA, since she wielded decision-making authority over his access to needed medical supplies and services.<sup>373</sup>

Third, the nurse's decision to deny JA the tampon due to his gender identity was a substantial factor in causing his distress.<sup>374</sup> Finally, having to go without a tampon caused JA severe distress, as he was forced to undergo a physically uncomfortable and emotionally humiliating experience.<sup>375</sup> Under the four factors, JA likely has a valid claim for intentional infliction of emotional distress.

### 3. Ensuring Implementation of Laws and Regulations

The Department of Health and Human Services (HHS) Office for Civil Rights (OCR) is responsible for enforcing section 1557 of the Affordable Care Act.<sup>376</sup> Although they are anticipated, regulations for section 1557 have yet to be promulgated.<sup>377</sup> In September 2015, HHS published a notice of proposed rulemaking for regulations to enforce section 1557.<sup>378</sup>

Whether the enforcement mechanisms available to potential plaintiffs under section 1557 include a private right of action is an open question, but HHS interprets the section as allowing for private claims.<sup>379</sup> And though the Supreme Court is more hesitant to imply causes of action than in the past, at least two district courts have found that section 1557 contains a private right of action.<sup>380</sup>

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372. See Telephone Interview with JA, *supra* note 112.

373. See *id.*

374. See *id.*

375. See *id.*

376. See Request for Information Regarding Nondiscrimination in Certain Health Programs or Activities, 78 Fed. Reg. 46,558 (proposed Aug. 1, 2013) (to be codified at 45 C.F.R. Subtitle A), <http://www.gpo.gov/fdsys/pkg/FR-2013-08-01/html/2013-18707.htm>.

377. *Id.* at 46,559.

378. See Nondiscrimination in Health Programs and Activities, 80 Fed. Reg. 54,171 (proposed Sept. 8, 2015) (to be codified at 45 C.F.R. pt. 92), <https://www.federalregister.gov/articles/2015/09/08/2015-22043/nondiscrimination-in-health-programs-and-activities>.

379. *Nondiscrimination in Health Programs and Activities Proposed Rule*, U.S. DEP'T OF HEALTH & HUMAN SERVS., OFFICE FOR CIVIL RIGHTS (OCR), <http://www.hhs.gov/civil-rights/for-individuals/section-1557/nondiscrimination-health-programs-and-activities-proposed-rule/index.html> (last visited Jan. 11, 2016) ("In line with existing federal civil rights laws, the proposed rule provides for a private right of action, giving individuals the ability to file a lawsuit under Section 1557.").

380. See *Se. Pennsylvania Transp. Auth. v. Gilead Scis., Inc.*, 102 F. Supp. 3d 688, 698 (E.D. Pa. 2015) (because Section 1557 "cross-references . . . four federal civil rights statutes" that include a private right of action and a private remedy, the court found "that Congress intended to create a private right of action for alleged violations of Section 1557"); see *Rumble v. Fairview Health Servs.*, No. 14-CV-2037 SRN/FLN, 2015 WL 1197415, at \*7 (D. Minn. Mar. 16, 2015) ("Section 1557 provides Plaintiff with a private right of action to sue Defendants."). *But see Alexander v. Sandoval*, 532 U.S. 275, 286-87 (2001) ("[P]rivate rights of action to enforce federal law must be created by Congress. The judicial task is to interpret the statute Congress has passed to determine whether it displays an intent to create

While HHS has yet to promulgate implementing regulations for section 1557, OCR has enforced the provision in a number of administrative claims involving sex discrimination based on gender identity.<sup>381</sup> In New York, a transgender individual filed a complaint alleging gender identity discrimination in a hospital's patient room assignments.<sup>382</sup> The hospital entered a formal, voluntary agreement with OCR to ensure appropriate and equitable treatment and care by revising its admission and room placement policies and updating its staff training to include gender identity cultural competency.<sup>383</sup>

In Colorado, a transgender woman filed a complaint with OCR after she was denied coverage for a mammogram through the Colorado Women's Wellness Connection Program.<sup>384</sup> The Wellness Program receives funding from the Centers for Disease Control and Prevention (CDC) to provide coverage for mammograms and gynecological screenings for low-income and underinsured women.<sup>385</sup> In response to the woman's claim, the CDC issued guidance to clarify that its grants cover mammograms for transgender women who have taken or are taking hormones.<sup>386</sup> OCR subsequently confirmed that the Wellness Program had adopted its guidance and offered coverage to transgender women seeking mammograms.<sup>387</sup> These examples illustrate OCR's commitment to enforcing section 1557 as it pertains to gender incongruent health care.

Meanwhile, state regulators should provide specialized employee trainings to make access to comprehensive care more structured and sustainable. Such training should focus on "transgender-sensitive care," which must be incorporated into curriculum used to train medical professionals on providing appropriate and affirming care.<sup>388</sup>

Governmental bodies offer a variety of possibilities for improving access to gender incongruent health care. Courts can read section 1557 as providing a private right of action to patients who experience health care denials; courts can further hold that providers engage in unlawful harassment when they deliberately and continually use incorrect pronouns and names to refer to transgender and gender nonconforming patients. Agencies can implement laws and policies through the promulgation of regulations and support transgender and gender nonconforming individuals who are currently self-advocating. These bodies have

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not just a private right but also a private remedy . . . Without [statutory intent], a cause of action does not exist and courts may not create one, no matter how desirable that might be as a policy matter, or how compatible with the statute.") (internal citations omitted).

381. See *OCR Enforcement Under Section 1557 of the Affordable Care Act Sex Discrimination Cases*, U.S. DEP'T OF HEALTH & HUMAN SERVS., <http://www.hhs.gov/civil-rights/for-individuals/section-1557/ocr-enforcement-section-1557-aca-sex-discrimination/> (last visited Jan. 4, 2016).

382. *Id.*

383. *Id.*

384. *Id.*

385. *Id.*

386. *Id.*

387. *Id.*

388. Stroumsa, *supra* note 56, at e36.

a great deal of power to enforce existing laws and policies and improve access to gender incongruent health care.

## VII. CONCLUSION

Transgender and gender nonconforming individuals encounter significant barriers to accessing comprehensive health care that leave many without the services they need. Without comprehensive health care, this population suffers from disproportionately high rates of untreated cancers, sexually transmitted infections, and depression. These consequences of inadequate care affect not only individual patients who are denied health coverage, but also their friends, families, sexual partners, and the general public. Leading medical agencies propose a model of care that matches the patient's anatomy, regardless of identity; however, many providers continue to deny patients access to gender incongruent care out of fear, animus, or ignorance and misunderstanding. Similarly, insurance policies promote coding and billing practices that reduce erroneous denials; however, provider, biller, and overrider discretion often lead to lack of coverage. Federal and state laws and policies have changed recently to allow for greater access to gender incongruent health care, yet many transgender and gender nonconforming individuals still encounter harassment and humiliation when seeking treatment. These individuals are often in situations where they are forced to educate their providers on care appropriate for their bodies. Thus, in addition to the burdens of coverage denials, patients are effectively refused competent medical care.

Instead of enacting new laws to ameliorate these barriers and ensure access, a more structural overhaul of the current legal and medical system is necessary. This would include offering cultural competency trainings for providers and staff, promoting coordinated care among providers, reforming intake forms, capturing demographic information, clarifying private rights of action, and implementing regulations that outline a patient's available enforcement mechanisms. Ideally, a coordinated effort between health care providers, insurers and payers, legal and governmental bodies, and transgender and gender nonconforming patients is needed to remove the barriers that many individuals face when seeking gender incongruent health care. Such an effort would enable individuals to access covered care appropriate for their anatomy, which would reduce stigma, fear, and medical costs while improving public health.