

# The State of Transgender Health Care: Policy, Law, and Medical Frameworks

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I review the current status of transgender people's access to health care in the United States and analyze federal policies regarding health care services for transgender people and the limitations thereof. I suggest a preliminary outline to enhance health care services and recommend the formulation of explicit federal policies regarding the provision of health care services to transgender people in accordance with recently issued medical care guidelines, allocation of research funding, education of health care workers, and implementation of existing non-discrimination policies. Current policies denying medical coverage for sex reassignment surgery contradict standards of medical care and must be amended. (*Am J Public Health*. 2014;104:e31–e38. doi:10.2105/AJPH.2013.301789)

The term *transgender* is an adjective that has been widely adopted to describe people whose gender identity, gender expression, or behavior does not conform to what is socioculturally accepted as, and typically associated with, the legal and medical sex to which they were assigned at birth.<sup>1</sup> Gender nonconformity, or a desire to express gender in ways that differ from gender-cultural norms linked to sex assigned at birth, was until very recently considered a mental pathology by the psychiatric community.<sup>2</sup> Although recognition and classification of gender nonconformity appeared in Western medicine in the 1920s, gender identity disorder (GID) first appeared as a distinct diagnosis in the American Psychiatric Association's (APA's) third edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM)* in 1980<sup>2</sup> and remained a category until the newest edition of the *DSM* (the *DSM-5*).<sup>3</sup> Over the past few decades, after professional as well as public debates, the APA has moved toward differentiating gender nonconformity from mental illness. On December 1, 2012, the board of the APA approved changing the diagnosis of GID to that of gender dysphoria in the *DSM-5*,<sup>3</sup> a significant move toward depathologizing gender variance. Psychiatrists increasingly agree that being transgender is not an illness to be cured or overcome (nor, for that matter, a state that can be altered). However, those who suffer because

of the misalignment of their physical characteristics with their gender identity may benefit from treatment.<sup>4</sup>

Current estimates have suggested that 0.3% of US adults, or close to 1 million people, identify as transgender.<sup>5</sup> (Other estimates have varied widely from a high prevalence of 1:500 or more<sup>6</sup> to 1:11 900–1:45 000 for male-to-female individuals and 1:30 400–1:200 000 for female-to-male individuals.<sup>7–10</sup>) Demographic studies to date have been limited<sup>7</sup> because national surveys have not included questions recognizing gender identity. Furthermore, important methodological debates remain unresolved, including those about conflation of terms (e.g., differentiation among *gender*, *gender identity*, and *sex*) and appropriate ways to accurately describe the transgender population (e.g., according to self-identification, gender expression, gender identity, or wish for medical treatment).<sup>8</sup> One way of estimating the proportion of transgender people in the population is through data on medical care, specifically medical assistance in the process of adapting gender presentation to align with identity, a process known as transitioning. However, this approach does not identify transgender people who have not opted for or who have faced insurmountable obstacles in accessing such care. Even using the conservative estimate of 0.3%, the number of people living in the United States who identify

as transgender is nearly 1 million. Health care for this population has historically been, and continues to be, overlooked by governmental, health care, and academic establishments.

Transgender people have a unique set of mental and physical health needs. These needs are compounded by prejudices against transgender people within both the medical system and society at large. These prejudices create barriers to accessing timely, culturally competent, medically appropriate, and respectful care.<sup>9,11,12</sup> These societal and medical barriers are associated with increased risk of violence, suicide, and sexually transmitted infections.<sup>11</sup> Additionally, transgender people may have health needs related to gender transition, including hormonal therapy and surgery, that can create an undesired and unavoidable dependency on the medical system for basic identity expression. This combination of high medical needs and barriers to accessing appropriate care may give rise to a self-perpetuating cycle of risk exposure, stigmatization, prejudice, and eventually poor health outcomes.

Transition-related medical care, otherwise referred to as gender-confirming therapy, is designed to assist an individual with the adjustment of primary and secondary sexual characteristics to align with gender identity.<sup>9,13</sup> Such therapy may include hormonal therapy, surgical therapy, or both depending on individual needs and wishes, as well as ability to access such services. Procedures for gender confirmation may include breast or chest surgery, hysterectomy, genital reconstruction, facial hair removal, and plastic reconstruction, as appropriate to the particular person.<sup>14</sup>

Denial of, or severely limited access to, medical care for transgender people, whether explicitly by refusal of coverage or implicitly by prejudice and lack of knowledge among health care workers, may have detrimental effects on both short- and longer term health

and well-being of transgender people. Moreover, the failure to comprehensively address the medical needs of transgender people stands in contradiction to the medical profession's prized values of equity and respect.<sup>15</sup> As such, I argue that a new approach is urgently needed: one that not only recognizes the unique health care needs of this group of people, but does so in an ethical, principled, and timely manner.

## TRENDS IN DATA COLLECTION

Over the past few decades, a growing body of research has been published regarding lesbian, gay, bisexual, and transgender (LGBT) health.<sup>16,17</sup> However, most of the literature and published data have involved sexual minorities (i.e., lesbians, gays, and bisexuals) or the LGBT community as a whole, leaving unaddressed specific needs, issues, and barriers faced by transgender and gender-nonconforming people. Although a growing body of literature has addressed the overall health and health indicators of transgender people,<sup>12,18,19</sup> the evidence-based work on gender-confirming treatment (medical and surgical transition care) is still limited. For example, few high-quality systematic studies have been conducted<sup>20</sup>; of those conducted, many are observational in nature.<sup>4,11,21</sup> (Because of the relative availability of funding for HIV/AIDS-related research and high HIV prevalence among transgender people,<sup>11</sup> much of the research to date regarding transgender health policy has focused on HIV/AIDS; see also Brennan et al.<sup>21</sup>) Further compounding the lack of rigorous research and data, the limited body of published work includes examples of research that may be construed as objectifying and may lead to misunderstanding or prejudice by readers (including authors' use of assigned rather than chosen gender pronouns<sup>22</sup>), which brings with it the risk of perpetuating or deepening misconceptions and unconscious prejudices among health care professionals.

In the past few years, several key public health bodies have recognized the lack of robust data on health indicators and on what constitutes medically appropriate care and the negative effect it has had on the quality of care provided to sexual and gender minorities; attempts to address these knowledge gaps have

resulted in recent reports on LGBT health, for example, by the Institute of Medicine<sup>17</sup> and Healthy People 2020.<sup>23</sup>

In a recently published response to the Institute of Medicine report on LGBT health, the National Institute of Health's LGBT Research Coordinating Committee found that most LGBT health research

is focused in the areas of Behavioral and Social Sciences, HIV (human immunodeficiency virus)/AIDS, Mental Health, and Substance Abuse. Relatively little research has been done in several key health areas for LGBT populations including the impact of smoking on health, depression, suicide, cancer, aging, obesity, and alcoholism.<sup>24(p8)</sup>

In this same report, the LGBT Research Coordinating Committee called for increased research on transgender-specific health needs, including those associated with transitioning and the safety and efficacy of surgical sex reassignment procedures, as well as mental health and routine clinical care.

On June 29, 2011, US Department of Health and Human Services Secretary Kathleen Sibelius announced that the department would begin collecting data in its population health surveys that would facilitate identification of health issues and reduction of health disparities among LGBT populations.<sup>25</sup> These data will be collected by integrating questions regarding sexual orientation and gender identity into the National Health Interview Survey and, as an initial step toward the creation of a governmental standard for LGBT health data collection, under Section 4302 (nondiscrimination) of the Patient Protection and Affordable Care Act (ACA).<sup>26</sup> Starting in January 2013, the National Health Interview Survey has included a sexual-orientation specific question. HHS is currently testing survey questions on gender identity with the express purpose of capturing data about transgender people.<sup>27</sup>

## MEDICAL NEEDS

Transgender people, particularly low-income transgender people and transgender people of color, have reported even higher rates of discrimination in accessing competent and comprehensive care than other sexual minorities.<sup>28</sup> In 2008, the National Center for Transgender Equality and the National Gay

and Lesbian Task Force partnered to conduct the first large-scale, national survey of transgender people, funded by the Network for LGBT Health Equity (formerly the Network for LGBT Tobacco Control). The study's overarching objective was to map out the needs of and the issues faced by transgender people.<sup>11</sup> The 70-question survey was developed by an interdisciplinary team of social and health science researchers, grassroots and national transgender rights advocates, expert lawyers, statisticians, and LGBT movement leaders. The survey was completed online or in paper form and returned by more than 7500 respondents recruited through community organizations and community e-mail distribution lists, with direct outreach through organizations serving hard-to-reach populations, such as rural, homeless, and low-income transgender and gender-nonconforming people. The responses of 6456 people were included in the analysis, with a geographical distribution representative of the US population.

The landmark survey confirmed and expanded existing knowledge regarding areas of increased risk and specific difficulties that transgender people face in navigating the health care system.<sup>11</sup> It found that 19% of respondents reported having been denied health care by a provider because of their gender identity, and 28% reported verbal harassment in a medical setting. More than a quarter (28%) of respondents postponed care because of discrimination and disrespect, and a third (33%) postponed preventive care. Nineteen percent of respondents reported that they lacked insurance coverage (compared with 15% of the general population at that time<sup>29</sup>), and a lower proportion of insured people received employment-based insurance than in the general population, which is likely attributable to high rates of job loss resulting from bias (as reported in the survey).<sup>11</sup>

Looking at specific vulnerabilities, the survey reported that transgender people have a particularly high likelihood of being HIV-positive and using drugs, alcohol, or smoking as a mechanism to cope with discrimination compared with the general population. The lifetime suicide attempt rate was 41% of the respondent population (compared with 1.6% in the general population).<sup>11</sup> Each of these vulnerabilities was enhanced among racial

minorities and among those participating in sex work, drug use and sales, or both. The survey reported that 75% of transgender women (i.e., female-identified or male-to-female transgender people) and more than 90% of transgender men (i.e., male-identified or female-to-male transgender people) either had or wanted to have surgical treatment, and 85% of transgender people either had or hoped to have hormonal treatment.<sup>11</sup>

A modest but growing body of research has examined the efficiency of medical treatment. Gender-confirming surgery, often referred to as sex reassignment surgery (SRS),<sup>1</sup> has been shown to be beneficial in alleviating gender dysphoria (the distress associated with the difference between an individual's expressed or experienced gender and socially assigned gender).<sup>4,30,31</sup> A 1992 study reported that hormone therapy improves quality of life as assessed by the Short Form-36 (SF-36) Health Survey, a 36-question validated survey assessing measures of health and well-being.<sup>32</sup> Increasingly, the overall consensus among those providing medical care to transgender people is that

sex reassignment generally, and SRS specifically, is associated with a high degree of patient satisfaction, a low prevalence of regrets, significant relief of gender dysphoria, and aggregate psychosocial outcomes that are usually no worse and are often substantially better than before sex reassignment.<sup>33(pp423-424)</sup>

Medical professional associations are increasingly publicly supporting inclusion of health care for transgender people and opposing the commonly held but slowly changing notion that such care is frivolous, cosmetic, experimental, or unnecessary. Since the early 1980s, the World Professional Association for Transgender Health (WPATH, formerly known as the Harry Benjamin International Gender Dysphoria Association) has been publishing standards of care (SOC).<sup>9</sup> Both SRS and hormonal therapy are endorsed by the SOC as necessary care for gender dysphoria, being both effective and often life saving.<sup>9</sup> Other professional societies, including the American College of Obstetricians and Gynecologists,<sup>34</sup> the Endocrine Society,<sup>35</sup> the American Medical Association,<sup>36,37</sup> and the American Psychological Association,<sup>38</sup> have endorsed these recommendations. They have each published

statements encouraging care for transgender patients and urging public and private health insurance coverage for treatment of gender dysphoria.

In terms of costs, the American Medical Association has estimated provision of health care to transgender people to be nearly cost saving (incremental cost-effectiveness estimate = \$500).<sup>37</sup> In 2001, San Francisco, California, became the first US city and county to remove transgender access exclusions from its employee health plan; in 2006, employee surcharges to cover these benefits were dropped because costs of reimbursement proved to be significantly lower than previously estimated.<sup>39</sup>

Beyond insurance coverage, access to care is limited by the dearth of physicians who focus on, or are comfortable with, providing care for transgender people. A stark example is the paucity of surgeons performing genital reconstructive surgery: As of 2012, only 6 identified surgeons in the United States performed genital reconstructive surgery (Eric Plemons, PhD, written communication, January 3, 2013), thus limiting options for people seeking this surgery.

Other issues that transgender people often encounter in their interaction with the health care system include lack of respect and acceptance of chosen gender by health care staff, privacy and safety,<sup>1</sup> cultural appropriateness and understanding, and adequate knowledge of some of their specific medical needs.<sup>11,12,40</sup> (For example, while breach of confidentiality is always a serious matter, it can have particularly far-reaching consequences for the safety of transgender people when it leads to involuntary "outing," or exposure of transgender identity.) Given the widespread lack of knowledge about transgender populations, and the absence of transgender health issues from most medical school curricula,<sup>41</sup> much remains to be done to shape a medical workforce that is well informed regarding the needs of this population and capable of providing appropriate care. Therefore, educating health practitioners about these issues is crucial. Of utmost importance is education of primary care providers, along with specialists in fields of particular relevance (including endocrinology, urology, obstetrics and gynecology, and plastic and reconstructive surgery, as well as emergency

medicine). However, because physicians from all specialties treat transgender people, the basics of transgender health care should be addressed in medical, physician assistant, and nursing schools on a national scale.

## US REGULATORY AND POLICY LANDSCAPE

Among issues of access to care that must be addressed nationally, that of insurance coverage and affordability of care has primary importance.

### Federal Agencies and Regulations

As the US population ages, an increasing proportion of the population, including the transgender population, will become dependent on Medicare for access to care. Although Medicare covers both routine care (through parts B and 1) and hormonal treatment (part D), SRS is not covered. The specific language used by the Center for Medicare and Medicaid Services in explaining this lack of coverage is telling:

Transsexual surgery, also known as sex reassignment surgery or intersex surgery, is the culmination of a series of procedures designed to change the anatomy of transsexuals to conform to their gender identity. Transsexuals are persons with an overwhelming desire to change anatomic sex because of their fixed conviction that they are members of the opposite sex. For the male-to-female, transsexual surgery entails castration, penectomy and vulva-vaginal construction. Surgery for the female-to-male transsexual consists of bilateral mastectomy, hysterectomy and salpingo-oophorectomy, which may be followed by phalloplasty and the insertion of testicular prostheses. Transsexual surgery for sex reassignment of transsexuals is controversial. Because of the lack of well controlled, long term studies of the safety and effectiveness of the surgical procedures and attendant therapies for transsexualism, the treatment is considered experimental. Moreover, there is a high rate of serious complications for these surgical procedures. For these reasons, transsexual surgery is not covered by Medicare.<sup>42(sect140.3)</sup>

Several issues arise from this language. First, SRS is neither controversial nor experimental; rather, it is a well-recognized therapy advocated for by leading medical associations. This claim cannot serve as a basis for denying coverage for necessary treatment. The terminology and definitions in this statement are inaccurate, outdated, and inconsistent with



current APA guidelines. The statement conflates intersexuality with being transgender and fails to acknowledge the wide range of possible gender expressions. Neither does it address the high rate of serious sequelae of failing to treat transgender people who have a need for gender-confirming surgery. Risk of complication is not sufficient grounds for rejecting treatment. As with any other procedure, one must evaluate the potential risk of complication in the context of the condition being treated and the risks of failure to treat.

In June 2011, in an effort to standardize care for transgender veterans, the Veterans Health Administration in the US Department of Veterans Affairs (VA) published directives regarding provision of care to transgender (and intersex) veterans (Patrick Paschall, JD, policy counsel, National Gay and Lesbian Task Force, oral communication, January 8, 2013). The directives state that

medically necessary care is provided to enrolled or otherwise eligible intersex and transgender Veterans including hormonal therapy, mental health care, preoperative evaluation, and medically necessary post-operative and long-term care following sex reassignment surgery.<sup>43(p2)</sup>

This policy clarifies the obligation of VA medical providers to extend comprehensive care to transgender veterans. The directives, however, deny coverage of SRS on the basis of a VA regulation excluding gender alterations from the medical benefits package,<sup>44</sup> despite the recognition of such alterations as part of care. Furthermore, these directives also contradict VA policy to provide “care and treatment to Veterans that is compatible with generally accepted standards of medical practice.”<sup>34,35,37,43(p2)</sup> However, an increasing commitment to LGBT inclusion in the VA, particularly through the recently founded Office for Diversity and Inclusion, has led to significant progress in health care delivery for transgender people. In June 2011, the Veterans Health Administration added protections based on gender identity to Equal Employment Opportunity Commission protections for employees,<sup>45</sup> and it is currently providing training for health care providers in services for transgender veterans.<sup>46</sup>

High rates of unemployment in the transgender population are also a major barrier to

maintaining health and appropriate health care.<sup>2</sup> Accordingly, employment of transgender people in the health care workforce is recommended because it offers an important avenue to address some of the challenges and barriers this population faces in the health care system. Although the burden of educating medical professionals should not rest on transgender people, increasing participation of transgender people in the health care workforce can facilitate and catalyze education and increase the understanding of issues faced by transgender people. This, in turn, has the potential to create safer and welcoming spaces for transgender people who seek medical care. Regarding employment more generally, in April 2012 the Equal Employment Opportunity Commission ruled that the Civil Rights Act’s prohibition against sex employment discrimination (title VII) applies to transgender people. See *Macy v Holder*.<sup>47</sup>

In July 2012, in response to a letter from LGBT organizations, the US Department of Health and Human Services issued a statement clarifying that the ban on sex discrimination in section 1557 (nondiscrimination) of the ACA includes discrimination on the basis of gender identity.<sup>48</sup> This federal policy statement, the 1st of its kind, has wide implications, including for Medicare and Medicaid. This statement, along with the Equal Employment Opportunity Commission ruling, should not only increase access of transgender people to appropriate health care but also help alleviate concerns about discrimination and promote active participation in the health care system.

Some additional protections for transgender people are expected with implementation of the ACA. Standards for qualified health providers (QHPs) participating in the exchange programs ban discrimination in any of their activities, including on the basis of sexual orientation or gender identity:

Non-discrimination. A QHP issuer must not, with respect to its QHP, discriminate on the basis of race, color, national origin, disability, age, sex, gender identity or sexual orientation.<sup>49(p916)</sup>

Additionally, coverage denial based on being transgender as a preexisting condition will be banned under the ACA starting in 2014. To what extent and how promptly these protections will be implemented, and whether

they will lead to higher rates of coverage for mental health services, cross-sex hormone therapy, or gender affirmation surgery, remains to be seen. These advances do not, however, provide an explicit and directed protection of transgender people within the health care system, nor do they address coverage of specific treatments that transgender people may need.

The Ending LGBT Health Disparities Act, a federal bill introduced in 2009, proposed the addition of a sexual orientation and gender identity nondiscrimination clause to all Medicaid, Medicare, and Children’s Health Insurance programs, with *gender identity* meaning

the gender-related identity, appearance, or mannerisms, or other gender-related characteristics of an individual, with or without regard to the individual’s designated sex at birth.<sup>50</sup>

The bill included federal grants to improve access and health promotion to gender and sexual minorities, in part through dedicated LGBT health centers, research related to gender and sexual minorities’ health disparities, and a requirement that sexual orientation and gender identity be included in federally funded health surveys. It also aimed to amend the Public Health Services Act by setting national standards for cultural competency of health care service to include sexual and gender minority cultural competency. Also important, the bill included a prohibition against discrimination on the basis of sexual orientation or gender identity under the health benefits program for federal employees and in the provision of health care and other benefits for members of the armed forces and veterans. This bill, though it did not directly relate to treatment coverage, would not only have increased access to care for all those directly affected by it, but may also have helped create a positive and inclusive climate for transgender people as full members of the population whose health is of concern. The bill was not passed, however, and so developments in enabling access to care for transgender people remain dependent on incremental advances within the current legal frameworks.

### Court Decisions and Treatment Coverage

Given prisoners’ restriction of liberties, it is perhaps not surprising that some of the most serious limitations on transgender people’s

access to health care have been in the US prison system. In most states, either incarcerated transgender people are housed according to their external genitals or no specific policy exists regarding their treatment and housing.<sup>51,52</sup> More surprising, perhaps, is that these abuses coexist alongside some of the most important advancements in protection of these rights. In several instances, federal courts have upheld the rights of transgender prisoners to receive both hormonal and surgical treatment. These decisions were based on the WPATH standards of care and on expert opinions that transition care (both hormonal and surgical) is medically necessary. The courts reasoned that the denial of transition care amounts to cruel and unusual punishment, a violation of the Eighth Amendment.

A landmark case is *Fields v Smith*.<sup>53</sup> In 2005, Wisconsin passed the Inmate Sex-Change Prevention Act, prohibiting funding of transition therapy (both hormonal and surgical) for transgender prisoners.<sup>54</sup> Several transgender women whose care was abruptly cut off filed against this law, claiming unconstitutionality on the basis of both the Eighth Amendment (cruel and unusual punishment) and the Equal Protection Clause. A federal district court found that the law constituted deliberate indifference to the plaintiffs' medical needs in violation of the Eighth Amendment and violated the plaintiffs' right to equal protection. The Seventh Circuit court affirmed the district court's order.

In *Adams v Federal Bureau of Prisons*<sup>55</sup> in 2010, a federal district court judge denied a motion to dismiss the complaint of Vanessa Adams, who was denied hormonal treatment. Though Adams was by that time receiving care, the Federal Bureau of Prisons had not changed its policy of refusing hormone therapy for transgender people. The case resulted in a reversal of policy that denied inmates initiation of treatment of GID. In *Kosilek v Spencer*<sup>52</sup> in 2012, the District of Massachusetts Court ruled in favor of Michelle Kosilek, requiring the Massachusetts Department of Corrections to provide SRS for Kosilek. The court based its ruling on doctors' expert opinions stating that in severe cases SRS is medically necessary; in this case, Justice Wolf, citing the WPATH Standards of Care, upheld previous rulings that GID is a severe medical condition requiring

treatment. Justice Wolf also underscored that treatment cannot be denied on the basis of cost, because prisoners routinely receive care that is perceived as expensive. As Levi<sup>56</sup> pointed out, more than asserting the right or need for treatment of GID or limits to treatment within the prison system, the Kosilek ruling relates to what she called *transgender exceptionalism*, or the fear of controversy as a guiding principle for decisions made by government officials. In *O'Donnabhain v Commissioner* in 2010, the US Tax Court ruled in a manner similar to the rulings regarding prisoners' right to transition care.<sup>57</sup> The court found that SRS and hormonal therapy are tax deductible under the Internal Revenue Code because they constitute necessary medical treatment.

Given these affirmations by the judicial system of the medical necessity for transition care, I argue that the federal Medicaid program should require participating states to cover gender-confirming treatment.<sup>58</sup> Although according to the statute governing the Medicaid programs (Title XIX of the Social Security Act, 42 USC § 1396), states "may place appropriate limits on a service based on such criteria as medical necessity,"<sup>59(p273)</sup> they may also not arbitrarily deny benefits solely on the basis of "diagnosis, type of illness, or condition."<sup>59(p273)</sup> In fact, as early as 1980, the US Court of Appeals (Eighth Circuit) found that denial of coverage for SRS is an

arbitrary denial of benefits based solely on the diagnosis, type of illness, or condition where physician and hospital care are mandatory services and such surgery is "the only successful treatment known to medical science."<sup>60</sup>

A previously used measure for the reasonableness of the legislature's standards has been general acceptability by the professional medical community as an "effective and proven treatment."<sup>61</sup> Thus, although coverage of treatment must ultimately depend on particular need, as prescribed by the treating physician, it seems clear that as a category of treatment, gender-confirming care should be covered by individual states' Medicaid programs, as by other publicly funded programs.

Many states currently have laws that explicitly deny Medicaid coverage of gender-confirming therapies, either specifically (e.g., Iowa,<sup>62</sup> Massachusetts<sup>63</sup>) or because it is included in the category of cosmetic and experimental

surgery (e.g., Missouri<sup>64</sup> and Illinois<sup>65</sup>).<sup>58</sup> Legal challenges to the legislation have been successful in those states that did not have a statute or regulation explicitly excluding transition treatment from being covered; existing treatment exclusions have consistently been upheld.<sup>58</sup> After such challenges, Iowa and Minnesota added provisions excluding SRS from Medicaid coverage; currently, only California covers SRS under Medi-Cal.<sup>58</sup> However, True<sup>58</sup> suggested that the *O'Donnabhain* ruling may affect Medicaid coverage of SRS because upheld exclusions were based on the premise of lack of medical necessity for SRS. As medical opinion confirms that SRS is necessary, effective, nonexperimental, and without a comparable substitute; this opinion becomes even more widely echoed in the medical literature and court decisions; and the WPATH standards of care gain recognition as the professionally accepted guidelines for treatment of gender dysphoria, the provisions and statutes excluding coverage of gender-confirming surgery are likely to become increasingly harder to defend. I would contend that the argument for such provisions to be found invalid by the courts under the Federal Medicaid Act will be increasingly strong because they appear to be based on invalid rationales, put unreasonable restrictions on medically necessary treatment, and discriminate on the basis of diagnosis, which is in violation of the Federal Medicaid Act. Successful challenges to the legality of Medicaid coverage denial may also affect denial under Medicare and in the VA.

## DIAGNOSES AND THEIR EFFECT ON CARE

In the United States, the medical establishment follows the APA definition as set out in the *DSM* for diagnosis and care of transgender people. In the fourth edition, text revision, of the *DSM* (*DSM-IV-TR*), diagnostic criteria for GID included strong and persistent cross-gender identification, persistent discomfort with the current sex, or sense of inappropriateness in the gender role of that sex.<sup>66</sup> More importantly, the discomfort must cause clinically significant distress or impairment in social, occupational, or other important areas of functioning. In the *DSM-5*, GID has been replaced with the term *gender dysphoria*.<sup>3</sup>

The new classification emphasizes gender incongruence rather than cross-gender identification in an effort to reflect the individual's felt sense of incongruence with natal gender, as opposed to pathologizing gender-atypical behavior. (Despite the APA's stated intention, the new criteria seem to retain diagnosis based on gender nonconformity and fail to differentiate between distress caused by societal prejudice and that caused by a mental disorder.) Additionally, gender dysphoria is now separated from the chapters on sexual dysfunctions and paraphilias. In contrast to the dichotomized *DSM-IV-TR* GID diagnosis, the type and severity of gender dysphoria can be inferred from the number and type of indicators and from the severity measures.

At the outset, I must state that the inclusion of gender identity and transgender-related matters in the *DSM* reflects an inherent problem. Although diagnostic coding is necessary to facilitate access to medical and surgical transition care, the pathologizing and stigmatizing suggested by its designation as a mental disorder is not. Such designation gives rise to an inherent contradiction in terms: what is presented as a mental condition has recognized medical and surgical treatment:

Gender Dysphoria is a unique condition in that it is a diagnosis made by mental health care providers, although a large proportion of the treatment is endocrinological and surgical.<sup>3(p14)</sup>

These treatments are aimed not at affecting or changing mental state but rather at addressing the physical components that lead to the dysphoria. Such logic makes GID or gender dysphoria a unique case of surgically treatable mental illness, which is an oxymoron.

When the category of gender dysphoria was proposed, several LGBT and transgender organizations, including Lambda Legal, urged the APA to prioritize coverage of transitional treatment of transgender people as a medical necessity for a recognized condition over demedicalizing and depathologizing transgender people.<sup>67</sup> The current changes reflect an effort to strike a balance between stigmatization and the need to maintain access to care.<sup>68</sup>

Future deliberations as to how to enable coverage of transgender-related care without designating a mental condition might consider an approach similar to that taken toward

pregnancy and preventive care. Pregnancy is a condition that is recognized clinically and coded under the World Health Organization's *International Classification of Diseases*.<sup>69</sup> It is treated, billed, and covered accordingly (with various policy options related to coverage of what is medically deemed necessary) without being pathologized. Similarly, preventive care is offered and routinely covered and is often considered necessary, independent of any diagnosis. So, too, I would suggest, can need for SRS be covered for transgender people without necessitating a *DSM* diagnosis.

## RECOMMENDATIONS

Given the widespread acknowledgment of the health care needs of transgender people, action must be taken to ensure timely access to appropriate care. Such action includes, first and foremost, a requirement that all governmentally funded programs, including the VA, Medicaid and Medicare, Children's Health Insurance Program, and Indian Health Services, include coverage of transition care and a requirement to ensure safe, appropriate, and sensitive care in federally funded health centers.

Private insurance may ultimately follow adoption of full coverage by federally funded programs, but until it does, federal guidelines protecting transgender people from discrimination by private insurance companies is warranted, including a ban on the practice of denying medical care coverage by linking the care to transition (which is not covered under most policies). To what extent the inclusion of gender identity in the ACA nondiscrimination clause will lessen this type of denial remains to be seen. Continued monitoring is necessary. More importantly, because a relatively high proportion of transgender people are uninsured, the expansion of Medicaid after implementation of the ACA significantly increases transgender people's access to medical care (beyond transition care and SRS).

As work to enhance access to medical care progresses, the need for appropriate care will also increase. Models of care for marginalized minority populations with particular health needs can be based on existing general health care systems or implemented through specialized clinics and health care centers. Spurred

by the AIDS epidemic and its toll on the gay community, dedicated LGBT health centers have been active in the United States since the 1980s. Although only a handful of centers are, at present, dedicated explicitly and exclusively to transgender patients, LGBT community health centers have provided care and often been active participants in and drivers of knowledge accumulation and dissemination regarding transgender health and treatment. These centers include the Fenway Center in Boston, Massachusetts; the Callen Lorde Community Health Clinic in New York City; and the Lyon-Martin Health Services in San Francisco. Achieving widespread access to acceptable, competent, appropriate, and affordable care, while promoting centers of clinical and research excellence in transgender health care, will require a combination of creating and strengthening dedicated centers as well as addressing transgender people's health needs within the general health system.

Bias against transgender people takes an enormous toll on their health through direct harm, lack of appropriate care, and a hostile environment and through transgender people's avoidance of the medical system as a result of discrimination and lack of respect. The medical establishment has a duty, and an ability, to protect transgender patients from such harms. Transgender-sensitive care must be incorporated into medical, nursing, and paramedical curricula, as has been done with other cultural competencies. Clear guidelines for all federally funded health centers, in line with the WPATH standards of care, need to be drafted and adopted by leading medical societies, including guidelines related to appropriate language, adoption of gender-neutral bathrooms, health records respectful of names and gender pronouns, and other safe environment measures.

Federal grants should be offered for programs teaching postgraduate-level care of transgender patients, including SRS. The ACA has taken a first positive step in that direction by providing funding for LGBT cultural competency trainings, which have already been implemented in big-city health departments, with training underway for staff of the National Health Service Corps.

Such measures are not only essential for the creation of an equitable health system, but will



also likely result in improved health outcomes for the transgender population as barriers to access are removed and knowledge is enhanced. Incorporation of questions regarding gender identity into health surveys will also enable monitoring of progress and effects of these measures.

National surveys and health-related data sets must start to gather information about populations of transgender people by including questions pertaining to gender identity and sexual orientation. Several approaches are possible (including self-identification and identification of gender expression), and although none are perfect and all raise potential issues related to disclosure and the tension between identity and behavior, inclusion of such questions is a necessary step toward building a foundation of knowledge regarding the health and needs of transgender people. Though the National Transgender Discrimination Survey is an immense step forward in gathering data on health needs as transgender people perceive them, a need remains for data collection on outcomes, both through incorporating gender-identity identifiers into existing national surveys and through directed research. Last, it is essential that those who are caring for transgender patients collect and publish their data, in order to improve care for transgender people. It goes without saying that all such research must be conducted with sensitivity and respect toward participants. ■

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Human participant protection was not required because this study involved no participants.

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