



February 14, 2009

Paul M. Schyve, M.D.
The Joint Commission
One Renaissance Blvd.
Oakbrook Terrace, IL 60181

Re: Support for Inclusion of Sexual Orientation and Gender Identity or Expression in New Joint Commission Standards on Culturally Competent and Patient-Centered Care

Dear Dr. Schyve:

Lambda Legal Defense and Education Fund, Inc. (“Lambda Legal”) and the Gay & Lesbian Medical Association (“GLMA”) respectfully submit these comments to express our support for including sexual orientation and gender identity or expression in the draft standards that the Joint Commission is considering for field review. Lambda Legal is the oldest and largest national legal organization committed to achieving full recognition of the civil rights of lesbian, gay, bisexual and transgender (“LGBT”) people and those living with HIV through impact litigation, education and public policy work. GLMA is the world’s largest and oldest association of LGBT health care professionals and works to ensure equality in health care for LGBT patients and health care providers. Lambda Legal and GLMA draw on their respective expertise to provide the Joint Commission with an analysis of research data, authoritative medical organizations’ ethical rules, and applicable law and regulations to assist the Joint Commission in its consideration of these important questions. We appreciate this opportunity to provide input on these matters, which are of enormous concern to the communities we represent. We take seriously the responsibility to preserve the confidentiality of the Joint Commission's standards-development process, and have not shared the language of the draft standards with any individuals or organizations outside of our close working group.

The Introduction, below, provides background information concerning the LGBT population and the persistently unmet need for health care that is culturally competent with respect to the specific characteristics of LGBT individuals and communities. Following is a discussion of the three standards now being considered that will have the greatest impact on the quality of care delivered to LGBT patients, including references to the scientific literature,

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consensus practice and policies of leading health institutions, as well as to applicable law and regulations.

INTRODUCTION

According to U.S. Census data, an estimated 8.8 million lesbian, gay and bisexual people now live in the United States.¹ Assuming no undercount, census figures indicate that about 3 percent of all adults in the United States are gay or lesbian, roughly two percent of women and four percent of men.² An additional two percent of the population identifies as bisexual, though nearly 13 percent of women and 6 percent of men have reported they are attracted to both men and women.³ This is a substantial portion of the population, comparable to the number of Americans who identify with at least one racial or ethnic minority group, such as Native Americans (1.5%), Asian Americans (4.2%), and African Americans (12.9%).⁴

LGBT people reside in every county in the United States⁵ and constitute a richly diverse community that includes members of every racial and ethnic, religious, mental and physical ability/disability, age and socioeconomic group.⁶ Census data offer among the best available evidence from which to estimate the size of the LGBT population in the United States.⁷ There are nearly 780,000 same-sex couples in the United States,⁸ which represents a 30% increase in the number of reported couples from 2000 to 2005.⁹ Nearly 20% of same-sex couples are raising children under the age of 18 and, as of 2005, approximately 270,300 children are living in households headed by same-sex couples.¹⁰

LGBT individuals and their families are not limited to a few major urban areas in which they can expect to encounter hospitals and health care professionals who understand their needs and who treat them sensitively and without bias. Moreover, as discussed below, bias and lack of knowledge about the unique health concerns of LGBT persons are to be found everywhere, including in major urban centers with large LGBT populations. In addition, LGBT persons live in many parts of the country in which there are few or no antidiscrimination protections, protections that can help LGBT patients feel safe revealing their sexual orientation and/or

¹ Gates, 2006.

² Gates, G.J. & Ost, J., 2004.

³ Miller, et al., 2007.

⁴ United States Census Bureau, March 12, 2001, available at <http://www.census.gov/Press-Release/www/2001/cb01cn61.html>.

⁵ Romero, et al., 2007.

⁶ Romero, et al., 2007.

⁷ Gates, G.J. & Ost, J., 2004.

⁸ Gates, 2007.

⁹ Gates, 2006 .

¹⁰ Romero, et al., 2007.

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gender identity or expression. As discussed further below, patients' willingness to be open about who they are is critical to providers' ability to recognize and meet their health needs. There accordingly is an urgent need for these Joint Commission standards, which play such an important role in ensuring that hospital care reflects evidence-based best practice and is of appropriately high quality to the greatest extent possible.

I. LGBT Populations Properly Are Included in Cultural Competence Initiatives.

Many health organizations considering issues of cultural competence recognize the importance of including LGBT populations among others that are the subject of these initiatives, which is in keeping with the US Department of Health and Human Services' having identified elimination of health disparities among LGBT individuals as a major goal in its statement of national health priorities for this decade, *Healthy People 2010*.¹¹ The Commission to End Health Care Disparities, for example, which involves more than 35 health professional societies and other health organizations, includes LGBT populations in its charter.¹² Kaiser Permanente similarly has been a long-time leader in the field. Its *Provider's Handbook on Culturally Competent Care: Lesbian, Gay, Bisexual and Transgendered Population*, published in 2000, has been a much-admired source of guidance. Likewise, the American Medical Association has encouraged the Liaison Committee on Medical Education and the Accreditation Council for Graduate Medical Education to include LGBT health issues in the cultural competency curriculum for medical education.¹³ The Joint Commission itself has recognized the propriety of including LGBT populations in this work by, among other things, appointing the undersigned executive director of the Gay and Lesbian Medical Association to serve on the Expert Panel advising in the creation of these draft standards.

We believe that the Joint Commission and other organizations considering practice guidelines relating to cultural competence and patient-centered care should include "sexual orientation" and "gender identity or expression" as much as possible because these characteristics – like religion, race, ethnicity and language spoken – correlate to health disparities (see below), and also because gaps in understanding between LGBT patients and the health care providers who care for them have such potential to impair communications related to the provision of care.

¹¹ US Department of Health and Human Services. (2000). *Healthy People 2010: Understanding and Improving Health*, 2nd ed., US Government Printing Office.

¹² More information is available at <http://www.ama-assn.org/ama/no-index/legislation-advocacy/12812.shtml>.

¹³ See American Medical Association Policy H-295.878 Eliminating Health Disparities - Promoting Awareness and Education of Lesbian, Gay, Bisexual, and Transgender (LGBT) Health Issues in Medical Education, available at <http://www.ama-assn.org/ama/pub/about-ama/our-people/member-groups-sections/glb-advocacy-committee/ama-policy-regarding-sexual-orientation.shtml>.

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II. Culturally Competent Care for LGBT People Requires Openness About Patients' Sexual Orientation and Gender Identity or Expression.

Knowing a patient's sexual orientation and/or gender identity can be vital to quality of care. For example, sexually active gay and bisexual men should be vaccinated for hepatitis A and B,¹⁴ and should be screened for anal cancer.¹⁵ Cervical and prostate cancer screenings can remain important for female-to-male and male-to-female transgender patients, respectively.¹⁶ And because recent studies indicate that sexual minority women smoke at almost twice the rate of heterosexual women (29.8% versus 17.0%),¹⁷ awareness that a patient is a lesbian can prompt the provider to be sure to inquire whether the patient smokes and, if so, whether she is receptive to assistance regarding cessation. Moreover, relationship status obviously is important in understanding a patient's support network, in counseling patients with regard to smoking cessation (because of the importance of second-hand smoke in controlling a patient's smoking triggers), domestic violence, and for other reasons.

Kaiser Permanente provides a relevant example in that it instructs its professional staff to develop cultural competence in order to be able to care for LGBT patients in a respectful, nondiscriminatory manner that meets their medical needs as required by professional standards of care.¹⁸ Kaiser's approach is consistent with the American Medical Association's recognition of the importance of openness in regard to sexual orientation and gender identity or expression. For example, AMA ethical rule H-160.991, "Health Care Needs of the Homosexual Population," states: "unrecognized homosexuality by the physician or the patient's reluctance to report his or her sexual orientation and behavior can lead to failure to screen, diagnose, or treat important medical problems."¹⁹ The rule adds that the AMA "believes that the physician's nonjudgmental recognition of sexual orientation and behavior enhances the ability to render optimal patient care in health as well as in illness."²⁰

¹⁴ Makadon, et al., 2008.

¹⁵ Although anal cancer is uncommon in the general population, it has been suggested that its incidence is approximately 80 times higher in gay and bisexual men. *Id.* at 177, citing Knight, D, Health care screening for men who have sex with men, *American Family Physician*, 2004; 69:2149-56.

¹⁶ Makadon, et al., 2008.

¹⁷ Makadon, et al., at 168, citing Tang, H., Greenwood, G.L., Cowling, D.W., et al, Cigarette smoking among lesbians, gays, and bisexuals: how serious a problem? *Cancer Causes and Control*, 2004; 15:797-803 and Burgard, SA, Cochran, SD, and Mays VM, Alcohol and tobacco use patterns among heterosexually and homosexually experienced California Women, *Drug and Alcohol Dependence*, 2005; 77:61-70.

¹⁸ See Kaiser Permanente National Diversity Council, *A Provider's Handbook on Culturally Competent Care: Lesbian, Gay, Bisexual and Transgendered Population* (2000).

¹⁹ See <http://www.ama-assn.org/ama/pub/about-ama/our-people/member-groups-sections/glb-adv-committee/ama-policy-regarding-sexual-orientation.shtml>.

²⁰ See <http://www.ama-assn.org/ama/pub/about-ama/our-people/member-groups-sections/glb-adv-committee/ama-policy-regarding-sexual-orientation.shtml>.

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Research has found that many LGBT patients want their health providers to be aware of their sexual orientation and gender identity. In one study, 89% of lesbians reported that they would have “come out” to their providers if they had been given the opportunity, and 94% felt that it was important to do so in order to ensure more appropriate care, understanding, honesty, and inclusion of their partner.²¹ Similarly, 85% of respondents in a survey of 500 men and women over age 25 expressed a desire to talk with their health providers about sexual issues, but 68% were reluctant to raise the topic themselves, and 71% worried that their concerns would be dismissed.²²

III. LGBT People Commonly Experience Discrimination in Health Care Settings.

*When Jamie Beiler went to the doctor’s office in Kissimmee Florida, the last thing she expected to receive was a packet of anti-gay propaganda referring to homosexuality as “sinful” and “impure” and advising lesbians and gay men to change their sexual orientation. ... [The doctor’s] office manager ... informed Beiler that their office routinely disseminates the anti-gay materials to patients.*²³

*In 1995, Tyra Hunter was injured in an automobile accident. When first-responding EMT personnel discovered she had male genitalia, they stopped treating her and stood back, making derogatory comments. She died later that night.*²⁴

*“I’ve gotten used to Blacks and Jews, but I can’t get used to the homos.”
– A Vermont medical faculty member to a student.*²⁵

Numerous public health studies have documented that bias against LGBT individuals pervades the health care system.²⁶ A study by Kaiser Permanente confirmed that these

²¹ Makadon, et al., 2008, citing Geddes, VA (1994). Lesbian expectations and experiences with family doctors, *Cam. Fam. Physician*, 40:908-20.

²² Makadon, et al., at 6, citing Marwick, Cl., Survey says patients expect little physician help on sex, *Journal of the American Medical Association* 1999; 281:2173-4.

²³ Mautner Project, Lesbian Files Complaint Against Doctor for Prescribing Anti-Gay “Treatment,” available at <http://mautnerproject.org/home/766.cfm>, see also http://www.washblade.com/thelatest/thelatest.cfm?blog_id=5040.

²⁴ GLMA, 2001.

²⁵ Schatz and O’Hanlan, 1994.

²⁶ Meyer, 2001; Council on Scientific Affairs, American Medical Assoc., 1996; Laura Dean *et al.*, 2000; Xavier, Honnold & Bradford, 2007. LGBT people have a long history of understandable mistrust of medical systems, from years of being pathologized within these systems. Homosexuality was considered a mental illness by the majority of medical practitioners in the past (from about 1900 to 1970), and was a diagnostic category of mental illness in the Diagnostic and Statistical Manual (DSM) until 1973. Julie A. Greenberg, *Symposium:*

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problems exist even in places with larger numbers of LGBT people, like California. Kaiser summarized its findings as follows:

Extensive research on attitudes toward homosexuals among health care providers shows a disturbing picture. Studies have shown that the attitudes of health care providers reflect those of the general population. Most health related training ignores or does not adequately incorporate LGBT issues in the curricula....

LGBT patients have reasonable fears of discrimination when they seek health care services. These fears have been supported by research that demonstrates a lack of understanding and sensitivity by health care providers toward lesbians and gay men that often results in the delivery of substandard care.

(Kaiser Permanente National Diversity Council, 2000.)²⁷

IV. LGBT People Experience Significant Health Disparities Correlated at Least in Part to Discrimination and Culturally Inadequate Care.

[A] 35-year-old male patient presented with headaches to neurologist William S. Gilmer, MD, at his private practice at Park Plaza Hospital in Houston, Texas. When Gilmer asked him who his primary care physician was, the patient said that he didn't have one. "In fact," he told Gilmer, "I haven't been to the doctor in 15 years." His last visit to the doctor, which he described to Gilmer, may explain why. When the patient was 22, a breakup with a lover ended in the lover's suicide, and the patient found himself nearly incapacitated by grief. So he sought help from his long-time primary care doctor, hoping to find relief from his uncontrollable crying, inability to concentrate, and overall depression. His doctor's advice? "Son, you need to get down on your knees and pray to be saved from this problem. That's what I can do to help

Therapeutic Jurisprudence: Defining Male and Female: Intersexuality and the Collision Between Law and Biology, 41 ARIZ. L. REV. 265, n. 160. Gender identity disorder was added in the next edition of the DSM (1980) and the medicalization of transgender identity remains a controversial issue (Hale, 2007). Medical attempts to change sexual orientation through lobotomies, electric shock treatments, hormone treatments, and lengthy psychiatric institution stays have been denounced by some medical societies, but yet "reparative therapies" are still offered by a number of psychiatric practitioners, many of whom are affiliated with particular religious groups. See, for example, Drescher & Zucker, 2006; Erzen, 2006; Hodges, 2007; National Association for Research and Therapy for Homosexuality, www.narth.com.

²⁷ Based on its own findings, Kaiser's Handbook instructed the professional staff to develop cultural competence in order to be able to care for LGBT patients in a respectful, nondiscriminatory manner that meets their medical needs as required by professional standards of care.

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you.” The “problem” the doctor was referring to wasn’t the patient’s grief – it was his sexual orientation.²⁸

Discrimination against LGBT individuals has been shown to have serious health consequences. Researchers at Stanford University and the University of California at Los Angeles, for example, have documented the correlation between increased incidence of late-treated cancer and other ailments and widespread bias by medical practitioners against lesbians.²⁹ These experts have concluded that this correlation most likely is due to the fact that “lesbian and bisexual women appear less likely to undergo routine screening procedures” because of “negative experiences with health care practitioners.”³⁰ A 1990 study similarly revealed that, due to negative experiences with providers, almost 50% of lesbians rarely or never sought care despite adequate access to health care.³¹ Numerous other studies looking at both women and men have found that many LGBT patients avoid care because they feel unsafe or fear discrimination. For example, one study reported that only 37% of LGBT patients directly disclosed their sexual orientation to their provider, primarily because of lack of opportunity and fear that inadequate health care would result.³² The United States Health Resources Services Administration report *Healthy People 2010: Companion Document for Lesbian, Gay Bisexual, and Transgender (LGBT) Health* likewise confirmed that bias against LGBT patients pervades the medical profession, and has important, preventable health consequences.³³ The consequences of LGBT people’s experiences with discriminatory health care providers obviously are serious.

In addition, there is mounting evidence of the negative impacts of living with minority stress caused by discrimination in society generally, including higher rates of depression,

²⁸ American Medical Student Association 51st Annual Convention, 2001.

²⁹ See, e.g., O’Hanlan, 1995; O’Hanlan, 1996 (“In a survey of nearly one thousand southern California physicians, one third of physicians in primary care specialties were found to have significantly homophobic attitudes.”); Cochran, et al., 2001.

³⁰ Cochran, et al., 2001. See also Eliason & Schope, 2001 (survey of 88 lesbian, gay and bisexual people in the Midwest found that only 37% directly told their health care provider of their sexuality; 15% indirectly revealed their sexuality, such as mentioning a partner; and 38% avoided questions about sexuality. Strategies that were often or always used to protect themselves during a health care visit included: closely monitoring the health care provider’s behavior for clues of acceptance (55%), controlling information until sure that the health care provider can be trusted (54%), and scanning the environment for clues of inclusivity (37%)).

³¹ Makadon, et al., at 420, citing Zeidenstein, L., Gynecological and childbearing needs of lesbians, *J. Nurse Midwifery*, 1990; 35:10-8.

³² *Id.*, citing Eliason and Schope, Does “Don’t ask, don’t tell” apply to health care? Lesbian, gay, and bisexual people’s disclosure to health care providers, *Journal of the Gay and Lesbian Medical Association*, 2001; 5:125-34. See generally, Council on Scientific Affairs, 2006; Dean, et al., 2000; and Meyer, 2001.

³³ GLMA, 2001.

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anxiety disorders, suicide attempts, and substance abuse, to name a few.³⁴ Individuals with multiple minority status – such LGBT people who also are a member of a minority racial, ethnic or religious group – may face multiple sources of discriminatory treatment. The related stress can lead to greater risk behaviors, such as smoking and drinking, which can exacerbate individual health problems and disparities on a community-wide basis.³⁵

Following are specific draft standards with additional supporting evidence for each one.

PROPOSED STANDARDS AND DISCUSSION

I. Draft Standard LD.04.03.01. The hospital provides services that meet patient needs.

EP A The needs of the population(s) served are determined by obtaining available community-level data such as:

- Language(s) spoken
- Race/ethnicity
- Religion(s)
- Socioeconomic status
- Education level
- Sexual orientation
- Gender identity or expression

Discussion

As discussed above, a growing body of respected studies has established that members of the LGBT community experience significant health disparities, some of which are correlated to discriminatory treatment of LGBT people within the health care system. Community-level data about LGBT health disparities are available to an ever-increasing degree, and demonstrate an important parallel to the decades of data now available about health disparities related to race, ethnicity, language, and other variables. Similar to the demonstrated link between discriminatory treatment within health care of racial and ethnic minorities and health disparities³⁶ – based in part on care providers' failure properly to diagnose and treat racial and

³⁴ Cochran & Mays, 2007; Cochran, Keenan, Schober, & Mays, 2000; Drabble & Trocki, 2005; Gilman, Cochran, Mays, et al., 2001; Hughes, Wilsnack, Szalacha, et al., 2006; Kipke, Weiss, Ramirez, et al, 2007; Mays & Cochran, 2003.

³⁵ Mays, V.M., Yancey, A.K., Cochran, S.D., Weber, M., & Fielding, J.E. (2002).

³⁶ Committee on Understanding and Eliminating Racial & Ethnic Disparities in Health Care, Institute of Medicine, 2003.

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ethnic minority patients, and patients' avoidance of such discrimination by foregoing preventive and other medical treatment – LGBT patients also often defer medical care to avoid discriminatory treatment, and frequently are fearful about revealing medically relevant information related to their sexual orientation or gender identity. Health care providers accordingly should consult community-level data for the same reasons such data play an invaluable role in providing culturally competent care for other minority groups: providers must be able to understand the various health disparities LGBT people face so they can provide appropriate and sensitive care, including properly screening and diagnosing patients.³⁷

II. Draft Standard RC.02.01.01. The medical record contains information that reflects the patient's care, treatment, and services.

- EP 1 The medical record contains the following demographic information:
- The patient's name, address, date of birth, and the name of any legally authorized representative
 - The patient's sex
 - The legal status of any patient receiving behavioral health care services
 - The patient and family's communication needs, including preferred language
 - The patient's race/ethnicity
 - The patient's religion/spirituality
 - The patient's education level
 - The patient's sexual orientation
 - The patient's gender identity or expression

Discussion

Lambda Legal and GLMA recommend the adoption of this standard with the following note – that the standards require forms and systems to *allow* sexual orientation and gender identity information to be captured in a routine manner without *requiring* the collection of this information if a patient is reluctant to disclose it or to have this information entered into the medical record. It is critically important to provide medical professionals a standardized means for capturing this information as part of a standard medical history conducted in a manner designed to make the patient comfortable, so that the patient can receive culturally competent care. The inclusion of these fields within the medical record will prompt clinicians to “ask the question” when appropriate and, just as important, will permit the hospital to query those data

³⁷ See AMA ethical rule “H-160.991 Health Care Needs of the Homosexual Population,” available at <http://www.ama-assn.org/ama/pub/about-ama/our-people/member-groups-sections/glb-advocacy-committee/ama-policy-regarding-sexual-orientation.shtml> (“unrecognized homosexuality by the physician or the patient's reluctance to report his or her sexual orientation and behavior can lead to failure to screen, diagnose, or treat important medical problems”).

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in order to assess health outcomes by patients according to sexual orientation and gender identity or expression. This is especially important because, unfortunately, despite the need for health providers to be proactive in raising the subject, only a minority (11%-37% according to one study) of primary care clinicians obtain a sexual history routinely in encounters with new adult patients.³⁸

Indeed, allowing physicians to capture this information in a standardized way can be an important part of delivering reliably competent care. As discussed above, studies suggest that LGBT populations are disproportionately at risk for various health conditions, and facilitating physicians' identification and notation of patients' sexual orientation and gender identity allows physicians more effectively to screen and diagnose potentially serious health issues and risk behaviors. For example, when a physician is alerted by the medical record that a male patient is gay or bisexual, the physician will know that an anal cancer screening may be appropriate, notwithstanding that anal cancer is uncommon in the general population.³⁹ Similarly, because studies indicate that lesbian and bisexual women smoke at almost twice the rate (29.8%) of heterosexual women (17.0%),⁴⁰ both the patient and physician may benefit when a physician is alerted to the lesbian or bisexual female patient's sexual orientation and recognizes the potential need to screen timely for smoking and offer smoking cessation resources.

The inclusion of these fields within the medical record obviously does not completely address the issue. Medical professionals will still need to practice in a sensitive and culturally competent way, creating an environment in which patients are confident that they will not be made to feel uncomfortable – at best – or face discrimination – at worst – if they disclose this information.⁴¹ We do believe that in the current legal and regulatory climate, it is important that the disclosure and recording of this information remain voluntary, because many LGBT patients remain vulnerable to discrimination and lack legal recourse in the majority of jurisdictions that do not offer statewide protection against sexual orientation or gender identity discrimination in public accommodations. Allowing for the capture of such information, without requiring it, promotes the paramount goal of delivery of appropriate patient care.

³⁸ Makadon, et al., 2008, citing Diamant, AL, Wold, C, Spritzer K, et al, Health behaviors, health status, and access to and use of health care, *Arch Fam Med*, 2009; 9:1043-51.

³⁹ *Id.*, citing Knight, D., 2004, discussing research indicating that anal cancer's incidence is approximately 80 times higher in homosexual and bisexual men than the general population.

⁴⁰ *Id.*, citing Tang, H. et al., 2004 and Burgard, S.A., 2005.

⁴¹ See, e.g., AMA Policy H-160.991, "Health Care Needs of the Homosexual Population," providing that the AMA "believes that the physician's nonjudgmental recognition of sexual orientation and behavior enhances the ability to render optimal patient care in health as well as in illness," available at <http://www.ama-assn.org/ama/pub/about-ama/our-people/member-groups-sections/glb-t-advisory-committee/ama-policy-regarding-sexual-orientation.shtml>.

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III. Draft Standard RI.01.01.01. The hospital respects patient rights.

EP C The hospital respects the patient’s right to receive care, treatment, and services in a manner free from discrimination based on age, race, ethnicity, religion, culture, physical or mental disability, socioeconomic status, insurance status, sex, sexual orientation, and gender identity or expression.

Discussion

Draft Standard RI.01.01.01 is well-supported by a policy consensus in the ethical and legal standards for health care professionals, which include non-discrimination rules as a critical component of providing the appropriate standard of care.

1. *The Ethical Standards by which Physicians and Other Health Care Providers Govern Themselves Prohibit Discrimination Based on Sexual Orientation and Gender Identity or Expression.*

Every major American medical association has promulgated ethical rules that prohibit discrimination against LGBT people in the practice of medicine, recognizing that such discrimination is harmful to patient health. A few representative organizations include the American Medical Association (“AMA”),⁴² California Medical Association,⁴³ American

⁴² The AMA, the leading national organization for medical professionals, has promulgated 28 policies proscribing sexual orientation and gender identity or expression discrimination, and recognizing the importance of culturally competent care based on sexual orientation. Those policies include “B-1.50 Discrimination,” “B-6.524 Council on Ethical and Judicial Affairs,” “D-65.995 Health Disparities among Gay, Lesbian, Bisexual and Transgender Families,” “D-65.996 Nondiscriminatory Policy for the Health Care Needs of the Homosexual Population,” “D-160.979 Health Care Disparities in Same-Sex Partner Households,” “D-295.995 Adoption of Sexual Orientation Nondiscrimination and Gender Identity in LCME Accreditation,” “D-515.997 School Violence,” “E-9.03 Civil Rights and Professional Responsibility,” “E-9.12 Patient-Physician Relationship: Respect for Law and Human Rights,” “E-10.05 Potential Patients,” “G-630.130 Discrimination,” “H-60.940 Partner Co-Adoption,” “H-65.976 Nondiscriminatory Policy for the Health Care Needs of the Homosexual Population,” “H-65.979 Sexual Orientation as an Exclusionary Criterion for Youth Organization,” “H-65.983 Nondiscrimination Policy,” “H-65.990 Civil Rights Restoration,” “H-65.992 Continued Support of Human Rights and Freedom,” “H-160.991 Health Care Needs of the Homosexual Population,” “H-180.980 Sexual Orientation and/or Gender Identity as Health Insurance Criteria,” “H-185.950 Removing Financial Barriers to Care for Transgender Patients,” “H-185.958 Equity in Health Care for Domestic Partnerships,” “H-215.965 Hospital Visitation Privileges for GLBT Patients,” “H-225.961 Medical Staff Development Plans,” “H-270.997 Legal Restrictions on Sexual Behavior Between Consenting Adults,” “H-295.878 Eliminating Health Disparities - Promoting Awareness and Education of Lesbian, Gay, Bisexual, and Transgender (LGBT) Health Issues in Medical Education,” “H-295.955 Teacher-Learner Relationship in Medical Education,” “H-295.969 Nondiscrimination Toward Medical School and Residency Applicants,” and “H-440.885 National Health Survey,” available at <http://www.ama-assn.org/ama/pub/about-ama/our-people/member-groups-sections/glb-advocacy-committee/ama-policy-regarding-sexual-orientation.shtml>.

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Academy of Family Physicians,⁴⁴ American College of Obstetricians and Gynecologists,⁴⁵ and the American Psychiatric Association.⁴⁶ The World Medical Association has done so as well.⁴⁷

2. *The Laws Of Numerous States Reinforce the Consensus Reflected in the Research Literature and Ethical Rules that Discrimination is Harmful to Patient Care.*

In a growing trend, more and more states are including sexual orientation and gender identity in their laws prohibiting discrimination in public accommodations, including medical facilities, to reduce the harms caused by discrimination.⁴⁸ Many states have long acknowledged that the anti-discrimination protections serve state interests of the highest

⁴³ The California Medical Association (“CMA”) has more than 35,000 members in all specialties in California. CMA, *Mission and History*, available at <http://www.cmanet.org/publicdoc.cfm?docid=10&parentid=1>. CMA publishes a “California Physician’s Legal Handbook,” which states that physicians “may not refuse to care for patients based on race, gender, sexual orientation or any other criteria that would constitute invidious discrimination. (CMA, 2002).

⁴⁴ The American Academy of Family Physicians (“AAFP”), which represents more than 94,000 family physicians, family medicine residents, and medical students, has issued a policy on discrimination providing that the AAFP, “opposes all discrimination in any form, including but not limited to, that on the basis of actual or perceived race, color, religion, gender, sexual orientation, gender identity, ethnic affiliation, health, age, disability, economic status, body habit[us] or national origin.” AAFP, *Discrimination, Patient*, available at <http://www.aafp.org/online/en/home/policy/policies/d/discrimination.html>.

⁴⁵ The American College of Obstetricians and Gynecologists (“ACOG”) has over 52,000 members and is a leading group of professionals providing medical care to women. ACOG, http://www.acog.org/from_home/acoginfo.cfm. ACOG describes as part of its reform agenda the need to “eliminate disparities in coverage, treatment, and outcomes due to differences in culture, race, ethnicity, socioeconomic status, and sexual orientation.” (ACOG, 2008)

⁴⁶ The American Psychiatric Association (“APA”) is a medical specialty society with over 38,000 members. The ethical code promulgated by the APA includes a section providing that, “A psychiatrist should not be a party to any type of policy that excludes, segregates, or demeans the dignity of any patient because of ethnic origin, race, sex, creed, age, socioeconomic status, or sexual orientation.” (APA, 2009)

⁴⁷ The World Medical Association (“WMA”) is an international association representing physicians. WMA, *International Code of Medical Ethics*, <http://www.wma.net/e/about/index.htm>. The WMA promulgates an International Code of Medical Ethics which provides that a doctor should not permit “considerations of age, disease or disability, creed, ethnic origin, gender, nationality, political affiliation, race, sexual orientation, social standing or any other factor to intervene between my duty and my patient.” WMA, *International Code of Medical Ethics*, www.wma.net/e/policy/c8.htm.

⁴⁸ See, e.g., California, CAL. CIV. CODE § 51 *et seq.*; Colorado, COLO. REV. STAT. § 24-34-601; Connecticut, CONN. GEN. STAT. § 46a-63 *et seq.*; Hawaii, HAW. REV. STAT. § 489-1; Illinois, 775 ILL. COMP. STAT. 5/1-102; Iowa, IOWA CODE § 216.7; Maine, ME. REV. STAT. ANN. tit. 5, § 4551 *et seq.*; Maryland, MD. CODE ANN. art. 49B, § 5; Massachusetts, MASS. GEN. LAWS ch. 272, § 98; Minnesota, MINN. STAT. ANN. § 363A.11; New Hampshire, N.H. REV. STAT. ANN. § 354-A:16; New Jersey, N.J. STAT. ANN. § 10:5-4; New Mexico, N.M. STAT. § 28-1-7; New York, N.Y. EXEC. § 296(2)(a); Oregon, OR. REV. STAT. § 659A.403; Rhode Island, R.I. GEN. LAWS § 11-24-2.1 *et seq.*; Vermont, VT. STAT. ANN. tit. 9, § 4502; Washington, WASH. REV. CODE § 49.60.215; Washington, D.C., D.C. CODE § 2-1402.31; Wisconsin, WIS. STAT. § 106.52.

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order.⁴⁹ These interests are particularly compelling in the health care context, as the California Supreme Court recently confirmed in its unanimous decision that health professionals may not withhold medically appropriate care from lesbian or gay patients regardless of the care providers' personal or religious beliefs about treating those patients.⁵⁰

3. *Despite Increasing State Protections, Existing Law and Regulations Do Not Ensure Equal Treatment of LGBT Patients.*

As illustrated by footnote 48 above, fewer than half of all states currently have anti-discrimination laws protecting LGBT people, and no federal law protects LGBT people from discrimination in public accommodations. While we believe that existing anti-discrimination laws should be interpreted to provide robust protections in their respective jurisdictions, they are not adequate to protect the LGBT community from health care discrimination throughout the country. In addition, the *North Coast* case illustrates that even in states with strong laws forbidding discrimination against these patients, such as California, discrimination remains a problem and LGBT patients remain vulnerable to medical providers' confusion about their legal and ethical obligations to those in their care.

Because discrimination remains such a problem in the health care field despite important advocacy by many respected medical organizations, the Joint Commission's leadership on this issue at this time is vital to help prevent real-world experiences like the following:

"I have had male doctors avoid contact. I have had a female doctor say she was fine with it and then try to coerce me into saying sexual identity is purely a choice. My worst experience, the doctor lectured me on the Bible and changed her diagnosis (gay male, age 28)"⁵¹

"Dr. X...had a problem and he asked [my partner] to wait outside. I said you know what? I'm not talking to you without her here. He said, well, we can only talk to a spouse or you know, a family member. I said, well she's both. She's my wife and she's my family. She's my next of kin. I said you know, my mind is not clear and I'm not hearing half of the things that are being said. I want her present ... So he called her in. But when we were talking ... he would address me only."⁵²

⁴⁹ See, e.g., *Tenino Aerie v. Grand Aerie*, 148 Wn.2d 224, 246 (2002) (the purpose of Washington's anti-discrimination law "is a policy of the highest order.").

⁵⁰ *North Coast Women's Care Medical Group, Inc. v. Superior Court*, 44 Cal.4th 1145, 1158 (2008) (describing "California's compelling interest in ensuring full and equal access to medical treatment irrespective of sexual orientation").

⁵¹ Eliason & Schope, 2001, p. 130.

⁵² Boehmer & Case, 2004, p. 1887.

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Regardless of how long it will take for the legal system to achieve comprehensive anti-discrimination protections, the Joint Commission has an essential role to play now in ensuring appropriate patient care for LGBT patients. The Joint Commission accordingly should adopt a version of draft Standard RI.01.01.01 that includes sexual orientation and gender identity or expression.

IV. Draft Standard RI.01.02.01. The hospital respects the patient’s right to participate in decisions about his or her care, treatment, and services.

EP A To the extent possible, the hospital accommodates the patient's right to have in-person access to a family member or designated friend or advocate 24 hours a day, 7 days a week.

Discussion

The Joint Commission’s current definition of “family” recognizes that providing access to a patient’s chosen family is a critical component of quality care. A patient’s family plays a vital part in continued care and recuperation. While this is true for LGBT families and non-LGBT families alike, recognition for same-sex couples’ committed life-long relationships and caregiving roles is particularly important because LGBT people so often encounter hostility and denials of access to each other during medical emergencies.⁵³ Family caregivers are the “bedrock upon which this country’s healthcare system depends,” and the Joint Commission would help facilitate the caregiving responsibilities that couples assume by adopting the proposed change above.⁵⁴ This change is all the more important because the varying forms of family protection available to couples in different states can create confusion among health care providers and sometimes lead to improper denials of access to committed same-sex partners.⁵⁵

⁵³ See, e.g., *Flanigan v. University of Maryland Hospital System*, Circuit Court for Baltimore City, Maryland (2002) (hospital ignored durable power of attorney and registered domestic partnership to deny Bill Flanigan access to his life partner until after his partner had permanently lost consciousness, irretrievably denying the couple the opportunity to say goodbye, or Flanigan to communicate his partner’s wishes for foregoing life-prolonging treatment), information posted at <http://www.lambdalegal.org/our-work/in-court/cases/flanigan-v-university-of-maryland.html>.

⁵⁴ National Family Caregivers Association, *What Does Family Caregiving Mean?* Available at <http://www.strengthforcaring.com/manual/about-you-am-i-a-caregiver/what-does-family-caregiving-mean>.

⁵⁵ See Human Rights Campaign, *Relationship Recognition in the U.S.* (Nov. 13, 2008) (map illustrating state-wide relationship recognition statuses available to same-sex couples in different states); *Langbehn v. Jackson Memorial Hospital*, Case No. 08-21813-CIV-JORDAN/McALILEY (as Janice Langbehn and Lisa Pond were about to depart from Miami on a family cruise with their three children, Pond suddenly collapsed; hospital told Langbehn she was in an antigay city and state, and she was denied access to Pond for nearly 8 hours), information posted at <http://www.lambdalegal.org/our-work/in-court/cases/langbehn-v-jackson-memorial.html>.

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Although many leading health care organizations – such as the University of California at San Francisco, Kaiser Permanente and others – have decades of experience in tailoring care to LGBT populations, we recognize that these draft standards may appear novel and perhaps unnecessary to some who are less familiar with these populations. We also acknowledge that the evidence base relating to LGBT health is newer and less massive than that relating to racial and ethnic minorities and others who were the earliest subjects of health disparities reduction efforts. But the data establishing the excess burden of morbidity and mortality that LGBT people suffer and the need for cultural competence with respect to LGBT populations already is not just sufficient, it is compelling. Moreover, ignorance and stigma (and sometimes political goals unrelated to health care) too often have been to blame for the unwarranted exclusion of LGBT populations from publicly funded research programs and national practice standards. It is imperative that such counterproductive influences be recognized and resisted when they arise.

Our call to restructure medical records to permit the notation of sexual orientation and gender identity information may meet the objection that some clinicians are reluctant to ask questions that some patients might find intrusive or otherwise inappropriate. We all know that conversations about sexual matters can be awkward for both health professionals and patients. But as with all aspects of behavior, not just sexuality, good practice requires health professionals to develop the skills to elicit important information sensitively, in order to provide appropriate care. Provider ignorance or discomfort concerning minority sexual orientations and gender identities is not an appropriate justification for prescribing a different standard of care. Neither lack of familiarity nor discomfort is an appropriate ground for avoiding questions health professionals should ask or for omitting information that should be included in medical records. Rather, where it has been established that certain personal information often is relevant to understand a patient's health status and needs, that information should be sought routinely, though of course sensitively, in the clinical encounter. And where there is reason to believe that inappropriate disclosure of the information could harm the patient, confidentiality should be maintained responsibly and professionally, as with other private patient information.

The importance to the public health of moving past discomfort and stigma in health matters is well established. For example, open and frank communication between providers and their young patients is universally prescribed to help avoid sexually transmitted infections and unwanted pregnancies.⁵⁹ Another example, which played out in the political sphere, is of interest here. Twenty years ago, when the United States Senate was debating the Americans With Disabilities Act, the National Restaurant Association sought to exclude from its protections people with HIV or perceived to have HIV. The mechanism of transmission of HIV

⁵⁹ See, e.g., Sawsan, A.S., Gantt, A., & Rosenthal, M.S., Pregnancy Prevention in Adolescents, *American Family Physician*, 2004 Oct 15; 70(8):1457-8, available at <http://www.aafp.org/afp/20041015/1517.html>.



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was less well understood then, and the Association was worried that its members would suffer because customers would not patronize restaurants if they feared they could catch AIDS from gay waiters.

The Senate acted wisely then, refusing to exclude people with HIV from the protections of the ADA because there was strong – although not perfect – public health evidence that HIV could not be spread through casual contact. Our lawmakers took that stand, refusing to excise from the bill’s protections a particular category of persons with disabilities, knowing it meant that some restaurants probably would lose business if they hired waiters whom customers believed to be gay and feared would have HIV. The Senate made its decision based on the best public health data available at the time and because it placed a high value on nondiscrimination, accepting that some customer discomfort and potential negative impacts on restaurants likely would be the price, at least for a time. Predictably, the discomfort largely faded as the public learned more and became more comfortable with the epidemiological data relating to HIV transmission. Here too, the discomfort that some may feel about conversations between patients and their providers about sexual orientation and gender identity will diminish as awareness grows that human variance as to these traits is relatively common and that there are seriously problematic health ramifications of avoiding inquiry into these important aspects of patients’ identities and lives.

The Joint Commission now faces the decision whether or not to open public discussion on proposed standards based on a still-developing but already authoritative scientific evidence base that reveals pervasive discrimination, stigma, and health care disparities affecting LGBT populations. Although the action we are proposing might generate debate, it would be debate that must take place for the sake of the health of the American people.

Respectfully submitted,

**LAMBDA LEGAL DEFENSE
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