



GLMA
GAY & LESBIAN MEDICAL ASSOCIATION

NHeLP
NATIONAL HEALTH LAW PROGRAM

August 27, 2010

Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS-3228-P
P.O. Box 8010, Baltimore, MD 21244-1850

Re: Support for CMS-3228-P, “Changes to the Hospital and Critical Access Hospital Conditions of Participation To Ensure Visitation Rights for All Patients”

To the Centers for Medicare & Medicaid Services:

Lambda Legal Defense and Education Fund, Inc. (“Lambda Legal”), the Gay & Lesbian Medical Association (“GLMA”) and the National Health Law Program (“NHeLP”) respectfully submit these comments in support of the proposed regulations entitled, “Changes to the Hospital and Critical Access Hospital Conditions of Participation To Ensure Visitation Rights for All Patients” (the “Proposed Rules”),¹ but with recommendations for changes needed to protect patients and their families from discrimination effectively in times of medical crisis.

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. Lambda Legal’s work to ensure health care fairness for LGBT and HIV positive people has included pathbreaking court victories and policy work to eliminate discriminatory barriers to health care based on sexual orientation, gender identity or HIV status.² GLMA is the world’s largest and oldest association of LGBT health care professionals. Dedicated to ensuring equality in health care for LGBT patients and health care providers, GLMA is a national leader in public policy advocacy related to the full range of issues affecting LGBT health. Founded in 1969, NHeLP is a national public interest law firm working to improve access to quality care on behalf of limited-income people and others who experience health care disparities, by providing legal and policy analysis, advocacy, information and education. NHeLP is committed to ensuring cultural and linguistic access to health care, regardless of race, ethnicity, national origin, gender,

¹ The Proposed Rules were published at 75 FR 36610-36615 (June 28, 2010).

² For example, Lambda Legal and GLMA provided the Joint Commission with briefing about the social science, ethical rules and law supporting the Joint Commission’s decision to adopt standards protecting LGBT and other minority patients from discrimination. These comments are available at www.lambdalegal.org, *Health Care Fairness*, <http://www.lambdalegal.org/issues/health-care-fairness> (last visited on August 25, 2010).

sexual orientation, gender identity, or other personal traits.³ NHeLP has also conducted significant research into the medical consequences of health care refusals as they conflict with practice guidelines and accepted standards of care.⁴

Lambda Legal, GLMA and NHeLP draw upon their respective fields of expertise to provide the Centers for Medicare & Medicaid Services (“CMS”) with the following analysis of applicable law, health care professionals’ ethical rules, and social science research to demonstrate that ensuring non-discriminatory visitation rights for all families improves patient outcomes. We appreciate this opportunity to provide input on these matters, which are of enormous concern to the communities we represent.

I. INTRODUCTION AND SUMMARY OF KEY COMMENTS

Countless LGBT people in this country continue to endure hardships because health care provider prejudice, ignorance and apathy needlessly keep patients isolated from their families and other supportive loved ones in times of medical crisis. The LGBT community members that our organizations serve have reported being barred from a dying partner’s bedside, being denied the ability simply to be together to provide comfort in areas where different-sex couples freely offer each other support, choosing to skip necessary procedures because their partner was not allowed to stay with them overnight though different-sex spouses are, being turned away when offering important medical information about their partner or child, and otherwise being treated as a stranger or, at best, a “friend” although their relationship to the patient was, by all fair measures, unmistakably familial and supportive in nature.⁵

³ Over the years, NHeLP has established an expertise in the area of cultural and linguistic access for vulnerable populations and has published many resources, including reports and studies on related federal and state legal requirements, as well as promising practices, available at www.healthlaw.org. Most recently, NHeLP collaborated with the Joint Commission on its new monograph *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals*, available at: <http://www.jointcommission.org/PatientSafety/HLC> (last visited on August 25, 2010). This resource guide provides recommendations to ensure that hospitals effectively address unique patient needs and comply with new standards for patient-centered communication and existing Joint Commission requirements, including those addressing the needs of the LGBT community. *See id.* at pp. 16, 88.

⁴ Fogel, Susan B; Weitz, Tracy A., *Health Care Refusals: Undermining Quality Care for Women*, National Health Law Program (2010), available at http://www.healthlaw.org/images/stories/Health_Care_Refusals_Undermining_Quality_Care_for_Women.pdf (last visited on August 25, 2010).

⁵ Lambda Legal’s national health care survey, *When Health Care Isn’t Caring, Lambda Legal’s Survey on Discrimination Against LGBT People and People Living with HIV*, (Feb. 2010), <http://www.lambdalegal.org/publications/when-health-care-isnt-caring> (last visited on August 25, 2010), confirms and underscores the pervasive discrimination against LGBT people in healthcare settings, and that visitation discrimination is part of a larger dynamic that leads to

Recognizing the need to redress this urgent problem, Lambda Legal, GLMA and NHeLP have engaged in education, policy and other advocacy work to persuade health care providers and organizations that discriminatory practices with respect to the provision of culturally and linguistically competent health care, including hospital visitation and related issues, are harmful and unacceptable. But the need for additional legal and policy tools is all too plain. In 2002, Lambda Legal represented Bill Flanigan in litigation designed to hold a Maryland hospital accountable for its staff's refusal to heed his pleas to be by the side of his dying partner, Robert Daniel. Although Lambda Legal and GLMA together conducted an educational campaign that succeeded in improving somewhat the hospital's visitation policies, the court case did not succeed in winning damages despite the appallingly callous conduct of the hospital's staff.⁶ Five years later, Lambda Legal filed suit on behalf of Janice Langbehn and her children on whom had been inflicted cruel and needless suffering during an eight hour period while they were kept from Lisa Pond, Janice's life partner and the children's other mother, as Lisa slipped from semi-consciousness to brain death.⁷ Like Bill Flanigan, the Langbehn-Pond family similarly was thwarted in their efforts to see justice when a federal court ruled that no right to visitation exists under Florida law, adding insult to grave injury. GLMA and other local organizations succeeded in improving the policies of the Florida hospital where Lisa Pond was taken, in much the same way advocacy efforts resulted in improved policies at the Maryland hospital where Robert

systematically poorer health outcomes for LGBT people. This larger dynamic also includes disproportionate poverty among same-sex couples as compared to heterosexual couples (contrary to popular myth), and the underinsurance of partnered lesbians and gay men that flows from the federal government's ongoing discrimination against same-sex couples. See Albelda, Randy; Badgett, M.V. Lee; Schneebaum, Alyssa; Gates, Gary J., *Poverty in the Lesbian, Gay and Bisexual Community*, (March 2009), available at http://www.law.ucla.edu/williams_institute/pdf/LGBPovertyReport.pdf (last visited on August 25, 2010); and Ponce, Ninez A.; Cochran, Susan D.; Pizer, Jennifer C.; Mays, Vickie M., *The Effects Of Unequal Access To Health Insurance For Same-Sex Couples In California*, 29(8) *Health Affairs*, pp. 1539-1548 (2010), available at http://www.lambdalegal.org/news/pr/ca_20100624_study-proves-strong-link.html (last visited on August 25, 2010).

GLMA publications address the widespread discrimination faced by LGBT patients and their families by providing resources for health care providers. See, e.g., *Guidelines for Care of Lesbian, Gay, Bisexual, and Transgender Patients*, available at http://glma.org/_data/n_0001/resources/live/GLMA%20guidelines%202006%20FINAL.pdf (last visited on August 25, 2010).

⁶ See *Flanigan v. University Of Maryland Medical System*, Compl., par. 3 ("Daniel fell fatally ill and Defendant Hospital admitted him, having notice through Daniel's accompanying medical records—and Flanigan's statements to Defendant Hospital at the time—that Flanigan was Daniel's family and legal agent for health care decisions. But Defendant Hospital blocked any communication between Daniel and Flanigan as Daniel slipped into unconsciousness, alone and without comfort, support, and solace during his final hours. The two partners were unable to speak with each other before Daniel's death."), available at <http://data.lambdalegal.org/pdf/118.pdf> (last visited on August 25, 2010).

⁷ See *Langbehn v. Public Health Trust*, 661 F. Supp. 2d 1326, 1331-1334 (S.D. Fla. 2009).

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Daniel was taken, but the ongoing, pervasive discrimination in visitation against LGBT patients and their families underscores the urgent need for greater protections.

In many states there is limited legal recourse when LGBT patients and their families are mistreated by health professionals, and litigating such cases always is emotionally wrenching. As a result, few such cases have been brought and even fewer have succeeded—underscoring further the need for these Proposed Rules to provide meaningful protections. While advance directives sometimes help, private documents alone are not adequate protection, as demonstrated by the *Langbehn* and *Flanigan* cases—both of which involved couples with durable health care powers of attorney. Despite their having borne the burdens of keeping such legal papers at hand while traveling, their documents were ignored and Janice Langbehn and Bill Flanigan both remained unable to gain access to their loved one's side due to the antigay bias of hospital staff.

Given the obvious need for greater national uniformity and certainty for patients, and for health care providers and organizations,⁸ these Proposed Rules do promise improvement by clearly prohibiting discrimination, and by underscoring the seriousness of the need for change by wielding a powerful enforcement penalty.

To assist CMS with its evaluation of the Proposed Rules, Lambda Legal, GLMA and NHeLP offer the following research and analysis that confirm overwhelmingly what the Proposed Rules recognize—invidious bias has no place in the practice of medicine, and discriminatorily denying ill patients the company of their loved ones in times of medical crisis is cruel and inhumane. These comments contain the following sections:

- Section II, at pages 6 - 8, reviews state laws, rules of ethics and other regulatory standards that prohibit discrimination in health care settings, including with respect to

⁸ The lack of adequate national standards for hospital visitation promotes inconsistency with often devastating effect for LGBT patients and their families. For example, Bill Flanigan was able to remain with his beloved Daniel at Hartford Hospital throughout the night one day before his partner died. However, medical necessity required that Daniel be transferred to another hospital where the couple's familial relationship was ignored. Janice Langbehn was told that she could be by her dying partner's side by one doctor, only to then be ignored and blocked hour after hour by the trauma unit receptionist who held the keys.

Similarly, in one of the few cases to confirm a same-sex partner's right to challenge a discriminatory denial of patient visitation, Sharon Reed initially was told by her dying partner's physician that she could hold vigil overnight in the ICU to help ease the suffering of Jo Ann Ritchie, Sharon's life partner of 17 years. *Reed v. ANM Healthcare*, 147 Wash. App. 1044, 2008 WL 5157869, *1-*3 (Ct. App. 1 Div. 2008). But at shift change, the incoming nurse ejected Sharon from the room despite Jo Ann's obvious distress and the fact that Sharon held Jo Ann's medical power of attorney. *Id.* at *1-*2. By the time Sharon was permitted to rejoin her beloved, Jo Ann "was 'in an extremely drugged state.' Life-prolonging measures were no longer possible, and [she] died a few hours later."

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visitation policies, underscoring that the Proposed Rules' antidiscrimination provisions are well-supported in the prevailing guidelines for health care providers and organizations.

- Section III, at pages 8 - 15, provides the following responses to CMS's requests for comment on various issues in the preamble and the Proposed Rules:
 - documentation of the patient-visitor relationship rarely should be required, and any such requirements must not apply in a discriminatory manner to LGBT people;
 - the rules for hospice and nursing home facilities regarding visitation must include explicit nondiscrimination language to protect LGBT patients and their families effectively;
 - Proposed Rules 482.13(h) and 485.635(f) rightly require written notification of hospital policies setting medical or other reasonable limitations on visitation, but must include an appeal procedure for visitation denials;
 - the notice that patients should be given about their rights must include, at a minimum, information about a procedure for appealing visitation denials and the patient's right to designate a health care agent; and,
 - a review of the important changes needed to ensure that existing regulations adequately protect LGBT patients' rights to designate a representative and to have that agent's instructions be respected.
- Section IV, at pages 15 - 25, reviews the overwhelming consensus in the social science literature that liberalizing visitation improves patient health outcomes and provides indispensable education and support for the family members who will care for the patient after discharge.

In sum, these comments underscore that hospital personnel should manage limitations on number and duration of visits according to patients' medical and emotional needs, not presumptions about blood or legal relationships that may deprive patients of critically important support from a range of sustaining personal relationships.

Lambda Legal, GLMA and NHeLP very much appreciate this administration's recognition that an affirmative national approach to this problem urgently is needed. The Proposed Rules are an important start. Based on our respective areas of work to reduce discrimination in health care services, and to increase culturally competent care, we believe it is crucial that the proposed text be strengthened and clarified as further explained below. Otherwise, these rules will have diminished ability to require respect in the visitation context for the range of sustaining personal relationships on which patients depend. We respectfully submit these comments with hope that these rules will spur the change in understanding among health professionals necessary to safeguard LGBT patients and their loved ones.

American Psychiatric Association¹³ and World Medical Association.¹⁴

The Joint Commission—which accredits and certifies more than 17,000 health care organizations and programs in the United States, and whose approval is recognized by a majority of state governments as a condition of licensure and eligibility to receive Medicaid reimbursement—also has adopted standards prohibiting discrimination based on sexual orientation and gender identity or expression.¹⁵

B. Many States' Laws Reinforce The Consensus Reflected In The Research Literature And Ethical Rules That Discrimination Based On Sexual Orientation Is Harmful To Patient Care.

In a growing trend, more and more states are including sexual orientation in their laws prohibiting discrimination in public accommodations, including health care facilities and provision of health services, to reduce the harms caused by discrimination.¹⁶ Eliminating public accommodations discrimination is particularly compelling in the health care context, as the

¹³ 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, *The Principles of Medical Ethics, with Annotations Especially Applicable to Psychiatry*, (2009), <http://www.psych.org/MainMenu/PsychiatricPractice/Ethics/ResourcesStandards/PrinciplesofMedicalEthics.aspx> (last visited on August 25, 2010).

¹⁴ The World Medical Association (“WMA”) is an international association representing physicians. 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*, (2006), <http://www.wma.net/en/30publications/10policies/c8/index.html> (last visited on August 25, 2010).

¹⁵ The Joint Commission, *New & Revised Standards & EPs for Patient-Centered Communication*, (n.d.), http://www.jointcommission.org/NR/rdonlyres/26D4ABD6-3489-4101-B397-56C9EF7CC7FB/0/Post_PatientCenteredCareStandardsEPs_20100609.pdf (last visited on August 25, 2010).

¹⁶ 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.

California Supreme Court recently confirmed in its unanimous decision that health professionals may not discriminatorily withhold medically appropriate care from lesbian or gay patients regardless of the providers' personal or religious beliefs about treating those patients. *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").

III. THE PROPOSED RULES

A. Any Criteria Identifying Those Rare Cases In Which It May Be Appropriate To Require Documentation Of A Patient-Visitor Relationship Must Not Permit Discriminatory Selection Of LGBT People.

The Proposed Rules provide that "the requirement [to allow visitation] would need to be flexible enough in its application to permit the hospital or CAH to require written documentation of patient representation by legally valid advance directives, such as durable powers of attorney and health care proxies (as opposed to verbal designation of the representative by the patient), but only in rare cases. CMS "seek[s] comment on how best to identify these rare cases." Further, the Rules provide that "at a minimum, a hospital or CAH may not require documentation where the patient has the capacity to speak or otherwise communicate for himself or herself; where patient representation automatically follows from a legal relationship which is recognized under State Law (for example, a marriage, a civil union, a domestic partnership, or a parent-child relationship); or where requiring documentation would discriminate on an impermissible basis."

We believe such written documentation should be required, as with heterosexually married patients, only in the very rarest of cases—such as when more than one person claims to be a patient's spouse, partner or surrogate. In *all* other cases, verbal representation of a family relationship recognized under the law of any state should suffice—as it does currently for all incapacitated heterosexual patients whose husband, wife, parent or adult child seeks access to the hospital bedside. There is no legal barrier to inclusion of same-sex couples' marriages, civil unions and registered domestic partnerships among the indicia of a familial or other very close personal relationship that automatically should open otherwise potentially barred hospital doors in order to allow the patient to have the person or people to whom they are closest, and on whom they very likely depend emotionally, by their side in their time of need. These indicia of close personal relationships should guide hospital staff decision-making in the patient visitation context regardless of whether the state in which the hospital is located confers broad legal rights and responsibilities on persons for other purposes based on such relationships.

Accordingly, we recommend that the Proposed Rules be revised to ensure that among the usual situations that do *not* require written documentation are (1) those in which patient representation automatically follows from a legal relationship recognized under *the laws of any state* and (2) those in which a visitor identifies herself or himself as the patient's adult partner, parent, child, or as playing a significant role in the patient's life.

Additionally, we recommend inclusion of the following or similar language: *In the foregoing situations in which no documentation is required, a hospital or CAH may not require documentation in a discriminatory manner. For example, a CAH or hospital may not require proof of relationship only with respect to patients with a same-sex spouse or registered domestic partner if proof is not similarly required concerning patients with a different-sex spouse.*

B. The Hospice Conditions Of Participation And Nursing Home Requirements Regarding Visitation Should Include Explicit Nondiscrimination Protections.

CMS notes that existing inpatient hospice conditions of participation in 42 C.F.R. 418.100(e) and nursing home resident rights provisions under 42 C.F.R. 483.10(j) address visitors, and seeks feedback regarding CMS's suggestion that explicit antidiscrimination protections may not be necessary in those sections. Lambda Legal, GLMA and NHeLP strongly urge CMS to include express prohibitions on discrimination based on race, color, national origin, language, immigration status, religion, sex, sexual orientation, gender identity, disability, or any other ground unrelated to a patient's medical needs¹⁷ in those sections and any others necessary to prohibit hospice facilities, nursing homes, and Medicare and Medicaid providers and suppliers from discriminating against LGBT patients' families. Please note that this list includes as prohibited grounds for discrimination language, immigration status and any other ground unrelated to a patient's medical needs, and we strongly recommend inclusion of those characteristics in the Proposed Rules, as well.¹⁸ Time and time again LGBT people have experienced discriminatory treatment in the absence of such protections because general rules often are not sufficient to shield them from mistreatment. As Janice Langbehn and Bill Flanigan discovered, prejudice and misunderstanding have led far too many individuals and institutions erroneously to conclude that LGBT people do not have families, and thus this minority population simply is excluded routinely from institutional rules and individual practices that reliably allow visitation for recognized, heterosexual family members. Moreover, no one benefits from *less* clarity about the law's requirements, and everyone benefits from *greater* clarity about providers' obligations under the law, as will be provided if these antidiscrimination provisions are made explicit. Health care providers deserve a clear statement of the law's requirements, and patients unquestionably rely upon such protections to make sure loved ones can be at their bedside in times of crisis.

¹⁷ See 42 C.F.R. § 124.603(a), which requires that health facilities receiving federal funds under the Hill-Burton Act (42 U.S.C. § 291 *et seq.*) make services available to persons residing in the health facility's service area without discrimination based on a number of enumerated characteristics, including "any other ground unrelated to the individual's need for the service."

¹⁸ While discrimination based on language and immigration status generally are understood to be included as national origin discrimination, we strongly encourage inclusion of these characteristics to more clearly communicate the existing duty not to discriminate on those grounds, since this obligation often is misunderstood by providers, and pervasive national origin discrimination continues to be a problem in health care settings.

C. Proposed Sections 482.13(h) And 485.635(f) Rightly Require Written Notification Of Hospital Policies Placing Medically Necessary Or Other Reasonable Restrictions On Visitation, And Should Establish An Appeal Procedure.

Lambda Legal, GLMA and NHeLP strongly support Section 482.13(h)'s and Section 485.635(f)'s requirements that hospitals maintain written policies that specify the medical or other reasonable restrictions that the facility may place on visitation. Medical crises can be tremendously stressful and chaotic, and clearly defined rules assist patients, visitors and health care staff alike. Because discrimination in health care settings remains pervasive, however, we are concerned that seemingly neutral restrictions can be applied against LGBT visitors in a discriminatory manner. Accordingly, we believe the Proposed Rules can and should do more to assist LGBT patients and visitors when they perceive that rules or policies have not been applied neutrally as to them. In particular, the non-discrimination provisions of the Proposed Rules could be much more effective if patients and/or visitors could quickly appeal a seemingly discriminatory visitation denial. Section 482.13(a)(2), which requires that hospitals establish a process for responding to patient grievances and appropriately inform patients about that process, provides a model for an appeals process that similarly should be extended to visitors of both hospitals and critical access hospitals.

D. Form Of Patient Notices.

The Proposed Rules seek comment on the style and form that "patient notices or disclosures would need to follow so that patients would be best informed" about their visitation rights. Such disclosures will be much more effective and meaningful if they include information about the following:

- (1) The grievance procedure that patients and visitors may follow to appeal a denial of visitation; and,
- (2) The patient's right to complete an advance directive or other designation of a health care agent to represent the patient and make decisions in the event of incapacity.

According to Title VI of the 1964 Civil Rights Act,¹⁹ and to ensure "meaningful access" for the hospitals' limited-English proficient ("LEP") patients, the patient notices and disclosures should be considered "vital documents" in order that the LEP patients would understand their visitation rights.²⁰ At a minimum, this would require the translation of the patient notices and disclosures into the frequently encountered languages of the LEP groups that the hospital serves

¹⁹ 42 U.S.C. § 2000d.

²⁰ Office for Civil Rights, U.S. Department of Health and Human Services, *Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition Against National Origin Discrimination Affecting Limited English Proficient Persons*, 68 Fed. Reg. 47311, 47318 (Aug. 8, 2003).

and/or will likely be affected, in accordance with guidance issued by the Office for Civil Rights, U.S. Department of Health and Human Services.²¹

E. Changes Are Needed To Ensure That Existing Regulations Protect LGBT Patients' Rights To Designate A Representative Who Will Be Respected.

CMS has requested comments about whether the existing rules in 42 C.F.R. § 482.13(b)(2) “effectively address[] any inappropriate barriers to a patient’s ability to designate a representative, and consistently ensure[] the right to designate a representative for all patients in all Medicare- and Medicaid-participating hospitals.” Some important changes are needed for 42 C.F.R. § 482.13(b)(2) adequately to ensure that gay people may designate a decision-maker, have that designation respected, and receive meaningful representation by their designee.

Section 482.13 does not—but should—expressly provide access to the patient. Section 482.13, while allowing patients to designate a representative to make health care decisions, does not expressly provide representatives a right of access to the patient to assess his or her condition, which is critical to ensure that health care decisions are informed.²² As the tragic facts and disappointing decision in *Langbehn v. Public Health Trust* show, this concern is not hypothetical. Such denials of access not only are cruel and inhumane, but compromise patient health when a representative cannot monitor the patient’s condition closely, and receive key medical information timely, in order to direct the patient’s care in an informed manner. Accordingly, the Proposed Rules should state expressly not only that patients have a right to designate a representative to speak on their behalf, but also that the representative must have visitation privileges unless medically contraindicated, and must not be denied access for lack of a formal familial status recognized by the law of any particular state or federal law.

Patients must be able to designate a representative regardless of whether the state in which they are hospitalized recognizes a formal legal relationship between them. Section 482.13(b)(2) contains an unnecessary limitation that creates a particular vulnerability for same-sex couples. Section 482.13(b)(2) provides that a representative, “as allowed under State law,” has the right to make decisions about the patient’s care. This confusing clause may be misunderstood as limiting the designation of a representative to persons with a relationship to the patient that is recognized in a particular way under state law, and could lead health care providers mistakenly to conclude that a lack of formal state recognition for a couple’s

²¹ *Id.* at 47318-19. The guidance provides additional requirements for the hospital and other federally-funded facilities, such as the development of a language access plan, including the provision of interpreters and translated materials, a needs assessment, staff training, notice of the availability of language assistance services, and monitoring and updating of the language access plan.

²² 42 C.F.R. § 482.13(b)(2) (“The patient or his or her representative (as allowed under State law) has the right to make informed decisions regarding his or her care. The patient’s rights include being informed of his or her health status, being involved in care planning and treatment, and being able to request or refuse treatment.”)

relationship precludes the designation of a same-sex partner as a health care agent. While such an interpretation would be incorrect, we know that individuals and institutions routinely, wrongfully invoke a lack of formal recognition of same-sex relationships under state family law to deny lesbian and gay partners rights to which they plainly are entitled under other laws. Moreover, because state laws vary in their respect for advance health care directives, this “state law” caveat does not create a reliable set of rules for patients and their representatives, promoting confusion and potentially subordinating patients’ wishes to the whims of others. The review of the social science research data in Section IV below documents the important benefits of visitation for patient health, underscoring that unfounded and arbitrary restrictions based on confusion about state law should not be permitted.

The unnecessary “as allowed under State law” clause in Section 482.13(b)(2) not only is irrelevant to patient health, but also is out of step with legal protections for patients’ rights to designate a representative of their choice. The right to direct one’s health care by designating any competent adult as one’s surrogate or agent is a right of constitutional dimension.²³ As one state supreme court aptly noted, “[p]atients do not lose their right to make decisions affecting their lives simply by entering a health care facility. Despite conceded good intentions, a health care provider’s function is to provide medical treatment in accordance with the *patient’s* wishes and best interests.” *Matter of Dubreuil*, 629 So.2d 819, 822 (Fla. 1993) (emphasis added). This right extends to all relevant decisions concerning one’s health.²⁴ In the context of an advance directive, the agent stands in the shoes of the patient, holding the full extent of the patient’s right to direct medical treatment in keeping with the patient’s wishes.²⁵

Section 482.13’s reference to Section 489.102 raises a question whether medical providers could refuse to honor advance healthcare directives, and could undercut Section 482.13’s protections for all patients, including LGBT patients. CMS asks whether Section 482.13 effectively addresses “inappropriate barriers” to the ability to designate a representative, and “consistently ensures the right to designate a representative.” Section 489.102, referenced by Section 482.13, specifies very limited instances in which services or procedures specified in advance health care directives may be refused. Though Section 489.102’s terms are narrow, they undercut protections for patients and respect for their autonomy generally and, if misunderstood, could leave LGBT patients vulnerable. To be clear, Section 489.102(c)(2) is limited to refusals to provide services or procedures called for in an advance health care directive, as described in 489.102(a)(1)(ii)(C), which refers specifically to “the range of *medical conditions or procedures* affected by the conscience objection” (emphasis added), and cannot reasonably be understood to allow a health care provider to refuse to honor those portions of an advance directive that designate a same-sex partner as a health care decision-maker. Yet our experience tells us that laws routinely are misunderstood and misapplied, and that risk is particularly acute for LGBT patients who continue to face pervasive bias in health care settings. While Section 489.102

²³ See, e.g., *Cruzan by Cruzan v. Director, Missouri Dept. of Health*, 497 U.S. 261 (1990).

²⁴ See, e.g., *Harrell v. St. Mary’s Hosp., Inc.*, 678 So.2d 455, 456-457 (Fla. Dist. Ct. App. 1996).

²⁵ See, e.g., *Treated With Respect: Enforcing Patient Autonomy By Defending Advance Directives*, 6 Marq. Elders Advisors 217 (2005) (citing *Cruzan*).

should, as a broader issue, be modified to make clear that health professionals are duty-bound to render competent care based on medically relevant criteria, and not on personal beliefs about groups of patients, *at a minimum* Section 482.13 must make clear that hospitals and providers may never deny a designated same-sex partner any of the full range of patient-representative rights, or refuse to carry out that representative's instructions, simply because the representative is a same-sex partner and/or is an LGBT person. This important clarification is not only the clearly proper reading of the regulations, but is consonant with existing law. *See North Coast Women's Care Medical Group, Inc. v. Superior Court*, 44 Cal. 4th 1145, 1158-1159 (2008) (recognizing that while health care providers may decline to provide certain *procedures*—in very limited instances and when doing so is consistent with the standard of care—they cannot lawfully or ethically discriminate against certain groups of *people* on invidious grounds such as sexual orientation or gender identity).²⁶

F. The Regulations Must Address One Of LGBT Patients' Greatest Vulnerabilities—The Question Of Who May Visit When An Incapacitated Patient Has Not Designated A Decision-Making Agent.

The Proposed Rules are silent regarding the circumstance in which LGBT patients and their families are perhaps most vulnerable—when a patient is incapacitated and has not previously designated in writing a health care agent or representative. LGBT patients far too often experience discriminatory visitation denials even when they *have* designated an agent in writing, and patients who have not done so—a common circumstance²⁷—are even more

²⁶ Though concerns about the limited refusals of care potentially allowed by Section 489.102 may be beyond the scope of this rulemaking process, refusal clauses significantly undercut public health as a general matter because they may allow religiously or other personally motivated refusals of care that are inconsistent with the governing standards of care. Lambda Legal, the National Coalition for LGBT Health and NHeLP have addressed this problem in detail in their comments supporting the proposed rescission of the so-called “conscience” regulations promulgated during the final hours of the Bush administration, and now codified at 45 C.F.R. Part 88. The comments submitted by Lambda Legal and the National Coalition for LGBT Health are available at www.lambdalegal.org/in-court/legal-docs/ltr_hhs_20090406_refusal-rule-comment-re-lgbt-hiv-impacts.html (last visited on August 25, 2010), and NHeLP's comments are available at http://www.healthlaw.org/images/stories/NHeLP_Comments_to_Rescind_HHS_Refusal_Regulations.pdf (last visited on August 25, 2010). It is of significant concern to the undersigned organizations that 45 C.F.R. pt. 88 has not yet been rescinded.

²⁷ A Pew Research Center survey in 2006 found that only 29 percent of people had a living will; in 2007, a Harris Interactive study put the proportion with advance directives at two in five. Even among “severely or terminally ill patients,” the majority had no advance directives in their medical records, researchers for the federal Agency for Healthcare Research and Quality reported a few years ago. *See* Span, Paula, *Why do We Avoid Advance Directives?*, N.Y. Times, April 20, 2009, <http://newoldage.blogs.nytimes.com/2009/04/20/why-do-we-avoid-advance-directives> (last visited on August 25, 2010). These statistics are silent as to the number of people who designate a surrogate, a number that is undoubtedly much smaller.

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vulnerable. Many patients do not complete such written designations because they are unaware of the right to do so, or lack information about the process for formalizing that designation. CMS misses a critical opportunity to protect LGBT patients in some of their greatest moments of need by remaining silent on visitation rights for such patients and their loved ones.

Lambda Legal, GLMA and NHeLP believe that CMS should issue regulatory guidance that provides clear rules about visitation for incapacitated patients who have not designated a health care agent in writing. Such rules should be broad and inclusive because the literature (surveyed in Section IV, below) demonstrates beyond doubt that liberal visitation generally promotes patient health and recovery. Liberal rules also are appropriate because hospitals plainly may restrict visitation on clinical or other reasonable grounds, which provides sufficient protections for patient health whenever visitation is medically contraindicated. For these reasons, we urge CMS to adopt regulations for incapacitated patients without a designated agent that incorporate at least the following two key principles.

First, visitation should be allowed for any person who plays a significant role in the patient's life. This standard is recommended by the Joint Commission, the preeminent accreditor of health care organizations across the nation, which urges organizations to “incorporate the concepts of effective communication, cultural competence, and patient- and family-centered care” into existing policies by:

Defin[ing] *family* to explicitly include any individual that plays a significant role in the patient's life such as spouses, domestic partners, significant others (of both different-sex and same-sex), and other individuals not legally related to the patient. Use this expanded definition in all hospital policies, including those addressing visitation, access to chosen support person, identification of surrogate decision-makers and advance directives.²⁸

The Healthcare Equality Index (“HEI”), a joint collaboration of the Human Rights Campaign and GLMA that surveys health care organizations’ policies regarding LGBT patients and their families (as well as LGBT employees), echoes this recommendation, and makes an important addition regarding parents. The HEI calls for health care organizations to include in their definitions of “family”:

a minor patient's parents, regardless of the gender of either parent. Solely for purposes of visitation policy, the concept of parenthood is to be liberally construed without limitation as encompassing legal parents, foster parents, same-

²⁸ The Joint Commission, *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals*, p. 34 (2010), <http://www.jointcommission.org/NR/rdonlyres/87C00B33-FCD0-4D37-A4EB-21791FB3969C/0/ARoadmapforHospitalsfinalversion727.pdf> (last visited on August 25, 2010).

sex parent[s], step-parents, those serving in loco parentis, and other persons operating in caretaker roles.²⁹

This standard's inclusion of individuals operating in a caretaking role for children is particularly important for LGBT parents, many of whom live in jurisdictions that limit their ability to establish a legally enforceable parent-child relationship, but who are no less a loving, caregiving parent to their children.

Second, *the Proposed Rules should make expressly clear that a person with whom the patient is in an adult domestic relationship formally recognized under the laws of any state or municipal government should be permitted to visit.* When a same-sex couple has entered into an adult domestic relationship status in any state or locality, they have taken an important step to confirm their close family relationship. Entering such a relationship status can and should be understood for visitation purposes as a designation by each individual of the other as an immediate family member, and visitation for the partner should be no more restrictive than any other immediate family member. As described above, documentation must not be required from such a partner when documentation is not similarly required from couples who represent themselves as immediate family by saying they are heterosexually married.

IV. THE EMPIRICAL LITERATURE DEMONSTRATES THAT GREATER VISITATION ACCESS FOR FAMILIES, INCLUDING SAME-SEX COUPLES AND THEIR CHILDREN, IMPROVES PATIENT OUTCOMES.

*It is clear that both the family and the patient have the need to be together at such a threatening time as end of life. The family is not the visitor at this time—the staff are.*³⁰

A. Increased Visitation Rights Are A Strong Health Care Trend, Supported Both By Professional Health Care Association Guidance And The Empirical Literature.

As researchers have studied and quantified the beneficial effects of patient visitation, and health care practices have evolved in kind, a consensus has emerged in favor of liberalized visitation policies that are more patient- and family-centered. Several prominent health care associations have endorsed increased visitation by publicly urging health care organizations to adapt their policies accordingly. In 2001, the Institute of Medicine “strongly recommended that health care delivery systems become patient-centered rather than clinician- or disease-centered,” which includes a focus on the “physical comfort and emotional support of patients and family

²⁹ Human Rights Campaign, *LGBT-Inclusive Definitions of Family*, (n.d.), <http://www.hrc.org/issues/11333.htm> (last visited on August 25, 2010)

³⁰ Kirchhoff, Karin T.; Faas, April I., *Family Support at End of Life*, 18(4) American Association of Critical-Care Nurses, Advanced Critical Care, pp. 426-435, at p. 432 (Oct.-Dec. 2007).

members.”^{31, 32} A task force of the American College of Critical Care Medicine has recommended open visitation in the adult intensive care setting on a case-by-case basis, and that families be encouraged to provide as much care as the patient’s condition allows.³³ The Institute for Healthcare Improvement has published on its website “Don Berwick’s Challenge: Eliminate Restrictions on Visiting Hours in the Intensive Care Unit,” advocating that “some hospitals execute a two-month trial of entirely open visiting in a Critical Care Unit,” based on conclusions that it is rational, humane and evidence-based to eliminate restrictions in critical care units.³⁴ The Institute for Patient- and Family-Centered Care recommends that health care staff facilitate information sharing with and participation by family members, with such relationships defined in a flexible and inclusive manner.³⁵

Professional health care organizations also recognize that providing same-sex couples, and LGBT parents, equal visitation rights is good medicine:

- American Medical Association, Policy H-215.965: “Resolved that our American Medical Association encourage all hospitals to add to their rules and regulations, and to their Patient’s Bill of Rights, language permitting same-sex couples and their dependent children the same hospital visitation privileges offered to married [heterosexual] couples.”³⁶

³¹ Davidson, Judy E.; Powers, Karen; Hedayat, Kamyar M.; Tieszen, Mark; Kon, Alexander A.; Shepard, Eric; Spuhler, Vicki; Todres, I. David; Levy, Mitchell; Barr, Juliana; Ghandi, Raj; Hirsch, Gregory; Armstrong, Deborah, *Clinical Practice Guidelines for Support of the Family in the Patient-Centered Intensive Care Unit: American College of Critical Care Medicine Task Force 2004–2005* (hereinafter as “*Clinical Practice Guidelines*”), 35(2) *Critical Care Medicine*, pp. 605-622, at p. 605 (2007).

³² Griffin, Terry, *Family-centered Care in the NICU* (hereinafter as “*Care in the NICU*”), 20(1) *Journal of Perinatal & Neonatal Nursing*, pp. 98-102 (Jan.-Mar. 2006). (“Family-centered care (FCC) is an approach to the planning, delivery, and evaluation of healthcare that is based upon a partnership between healthcare professionals and families of patients. There are 4 basic concepts of FCC: dignity and respect, information sharing, family participation in care, and family collaboration.”).

³³ *Clinical Practice Guidelines*, *supra* note 27, pp. 613, 609.

³⁴ Berwick, Don, *Don Berwick's Challenge: Eliminate Restrictions on Visiting Hours in the Intensive Care Unit*, (n.d.), <http://www.ihl.org/IHI/Topics/CriticalCare/IntensiveCare/ImprovementStories/DonBerwicksChallengeEliminateRestrictionsonVisitingHoursintheIntensiveCareUnit.htm> (last visited on August 25, 2010).

³⁵ *Institute for Patient- and Family-Centered Care Frequently Asked Questions*, (n.d.), <http://www.ipfcc.org/faq.html> (last visited on August 25, 2010).

³⁶ *Hospital Visitation Privileges for GLBT Patients*, (n.d.), <https://ssl3.ama-assn.org/apps/ecom/PolicyFinderForm.pl?site=www.ama-assn.org&uri=/ama1/pub/upload/mm/PolicyFinder/policyfiles/HnE/H-215.965.HTM> (last visited on August 25, 2010).

- Emergency Nurses Association, position statement on “Family Presence at the Bedside During Invasive Procedures and Cardiopulmonary Resuscitation” (2005): Advocating that, “Emergency departments support the option of family presence during invasive procedures and cardiopulmonary resuscitation.”³⁷
- American Society of PeriAnesthesia Nurses, “A Position Statement on Visitation In Phase I Level of Care” (2007): “A growing body of evidence supports both patients’ and families’ need for increased visitation in the Intensive Care Units. In addition, evidence directly related to the Postanesthesia Care Unit Setting reveals that visitation in Phase I level of care benefits both patients and families.”³⁸
- American Academy of Pediatrics’ Institute for Family-Centered Care, Policy Statement on “Family-Centered Care and the Pediatrician’s Role” (2003): Including among “Core Principles of Family-Centered Care” that pediatricians must respect each child and his or her family and honor a range of different types of diversity.³⁹
- The American Hospital Association (“AHA”) partnered with the Institute for Family-Centered Care (“IFCC”) to produce a toolkit with strategies for change that was distributed to the C.E.O. of every hospital across the country. The resource guide produced as part of this effort recommends, *inter alia*, that hospitals “not label family members as ‘visitors’ and ... not limit the hours they may spend at the patient’s bedside.”⁴⁰

These professional policies and guidelines are well-supported by the empirical literature.^{41, 42} A survey of over 300 studies by the American College of Critical Care Medicine

³⁷ *Emergency Nurses Association Position Statement - Family Presence at the Bedside During Invasive Procedures and Cardiopulmonary Resuscitation*, (2005), http://www.ena.org/SiteCollectionDocuments/Position%20Statements/Family_Presence_-_ENA_PS.pdf (last visited on August 25, 2010).

³⁸ *Position Statement 11 – American Society of PeriAnesthesia Nurses - A Position Statement on Visitation in Phase I Level of Car*, (Oct. 2007), https://www.aspan.org/Portals/6/docs/ClinicalPractice/PositionStatement/11-Visitation_Ph_I.pdf (last visited on August 25, 2010).

³⁹ Eichner, Jerrold M.; Johnson, Beverley H, *American Academy of Pediatrics, Institute for Family-Centered Care Policy Statement, Family-Centered Care and the Pediatrician’s Role*, 112(3) *Pediatrics*, (Sept. 2003).

⁴⁰ *Strategies for Leadership: Advancing the Practice of Patient- and Family-Centered Care*, (Sept. 2004), <http://www.aha.org/aha/content/2005/pdf/resourceguide.pdf> (last visited on August 25, 2010).

⁴¹ Sullivan, Ellen E, *Family Visitation in PACU*, 16(1) *Journal of PeriAnesthesia Nursing*, pp. 29-30, (Feb. 2001) (summarizing several studies demonstrating benefits of liberalized visitation for patients and families).

⁴² Bonifacio, Nerrisa C.; Boschma, Geertje, *Family Visitation in the PACU, 1984-2006* (hereinafter as “*Family Visitation in the PACU, 1984-2006*”), 23(2) *Journal of PeriAnesthesia Nursing*, pp. 94-101, (Apr. 2008) (surveying research and noting trend of greater support for

Task Force found that “the preponderance of the literature supports greater flexibility in ICU visitation policies.”⁴³ This literature is discussed in more detail below, including the strong trend, aptly described by one practitioner: “Flexible visitation and family-centered care is here to stay.”⁴⁴

B. Visitation Helps Improve Patient Health.

Many patients identify access to and support from visitors as an important part of their recovery process.⁴⁵ A number of studies demonstrate that the “respectful treatment of, and caring for, family and friends by health care providers is paramount to the level of support experienced by the patients themselves,”⁴⁶ because visitation facilitates comfort and reassurance from loved ones.⁴⁷ In fact, visitation by supportive family and friends “can increase patients’ will to live, give them security, and ease their emotions.”⁴⁸ Patients also “are less likely to worry about their family members when they can see them often.”⁴⁹ These are all conclusions that GLMA’s health care professional membership can affirm based on their daily experiences with patients.

Visitation can have other concrete benefits for the patient’s health as well. Visiting family members and friends can provide “additional information that can be helpful in patient

family visitation, reflecting “a shift from the traditional and paternalistic way of thinking and practice towards a holistic and compassionate approach to caring for the patient”).

⁴³ *Clinical Practice Guidelines*, *supra* note 27, p. 605.

⁴⁴ Miracle, Vickie A., *Critical Care Visitation*, 24(1) *Dimensions of Critical Care Nursing*, pp. 48-49, at p. 48 (reviewing the literature related to patient visitation and noting a trend in favor of increased visitation).

⁴⁵ Roland, Patricia; Russell, Janet; Richards, Kathy Culpepper; Sullivan, Sheila Cox, *Visitation in Critical Care: Processes and Outcomes of a Performance Improvement Initiative* (hereinafter as “*Visitation in Critical Care*”), 15(2) *Journal of Nursing Care Quality*, pp. 18-26, at p. 21 (2001). (65% of patients surveyed indicated that more open visitation was desirable, 90% identified visitors as very important, and 85% wanted family members to perform personal care for them).

⁴⁶ Price, Sheri; Noseworthy, Jennifer; Thornton, Juliet, *Women’s Experience with Social Presence During Childbirth* (hereinafter as “*Women’s Experience*”), 32(3) *The American Journal of Maternal/Child Nursing*, pp. 184-191, p. 185, 190 (May-Jun. 2007) (collecting sources).

⁴⁷ Sims, J.A.; Miracle, Vickie A., *A Look at Critical Care Visitation: The Case for Flexible Visitation* (hereinafter as “*A Look at Critical Care Visitation*”), 25(4) *Dimensions of Critical Care Nursing*, pp. 175-80, at p. 176 (Jul.-Aug. 2006) (“Recognizing the needs of family members and taking measures to meet them can lead to improved patient care outcomes.”).

⁴⁸ Giuliano, Karen K.; Giuliano, Anthony J.; Bloniasz, Elaine; Quirk, Pamela A.; Wood, Jan, *Families First, Liberal Visitation Policies May Be in Patients’ Best Interest* (hereinafter as “*Families First*”), 31(5) *Nursing Management*, pp. 46, 48, 50, at p. 46 (2000).

⁴⁹ *A Look at Critical Care Visitation*, *supra* note 43, p. 177.

care management,”⁵⁰ and “may actually assist in the provision of care by facilitating communication and providing feedback.”⁵¹ Having loved ones visit also provides an “opportunity [for family and friends] to identify needs that can be referred to other team members,” such as social workers, chaplains or clinical nurse specialists, which facilitates better patient care.⁵²

Studies have examined a variety of patient health indicators in connection with increased visitation, and the literature includes, as a few representative examples, the following findings:

- Visits longer than 15 minutes lead to decreases in blood pressure, intracranial pressure, and heart rate;^{53, 54, 55}
- Visitation can reduce patient anxiety, which can help surgical patients, in whom elevated levels of anxiety have been associated with higher levels of pain;^{56, 57}
- Visitors can reduce patient anxiety “during the critical time of recovery from anesthesia”;⁵⁸
- Visitation can reduce a patient’s heart rate;⁵⁹
- “[U]nrestricted visitation promotes stress reduction and a sense of calm, thus promoting patient rest”;⁶⁰

⁵⁰ Kleinpell, Ruth M, *Visiting Hours in the Intensive Care Unit: More Evidence that Open Visitation Is Beneficial* (hereinafter as “*More Evidence that Open Visitation Is Beneficial*”), Critical Care Medicine, pp. 334-335, at p. 335 (2008).

⁵¹ *Family Support at End of Life*, *supra* note 26, p. 432.

⁵² Cullen, Laura; Titler, Marita; Drahozal, Ronda, *Family and Pet Visitation in the Critical Care Unit* (hereinafter as “*Family and Pet Visitation*”), 23(5) Critical Care Nurse, pp. 62-67, p. 63 (Oct. 2003) (collecting authorities).

⁵³ *Visitation in Critical Care*, *supra* note 41, p. 19 (collecting research references).

⁵⁴ *Clinical Practice Guidelines*, *supra* note 27, p. 612 (“Descriptive studies of the physiologic effects of visiting on mental status, intracranial pressure, heart rate, and ectopy [] demonstrated no physiologic rationale for restricting visiting.”).

⁵⁵ *Family and Pet Visitation*, *supra* note 48, p. 62.

⁵⁶ DeLeskey, Kathleen, *Family Visitation in the PACU: The Current State of Practice in the United States* (hereinafter as “*Family Visitation*”), 24(2) Journal of PeriAnesthesia Nursing, pp 81-85, at p. 82 (Apr. 2009).

⁵⁷ *Family Visitation in the PACU, 1984-2006*, *supra* note 15, p. 96 (recounting study demonstrating that “surgical patients who received family visitation in the immediate postoperative period had significantly decreased patient anxiety scores compared with patients who did not receive family visitation”).

⁵⁸ *Family Visitation*, *supra* note 52, p. 82 (summarizing research).

⁵⁹ *Id.*, p. 82 (describing study showing that “patients in a coronary care unit had significantly lower heart rates after family visitation”).

⁶⁰ *Visitation in Critical Care*, *supra* note 41, p. 19 (collecting research references).

- Greater visitation can decrease a patient's sensory deprivation;⁶¹
- Caregiver support for women during labor and birth “has tangible benefits such as decreased operative delivery rates [and] less need for pain medication”,⁶² and,
- “It has been well documented that human presence and support during labor improve birth experiences and overall outcomes for the mother and the baby ... Several research studies have shown that in some cultures, physical and emotional support provided by female caregivers to laboring women resulted in better birth outcomes, such as more spontaneous vaginal deliveries, less intrapartum analgesia, less oxytocin, fewer amniotomies, fewer vacuum extractions, and fewer caesarean births.”⁶³

C. Increased Visitation Helps Children And Parents Alike In Coping With A Loved One's Illness.

“Restrictions placed on child visitation in most adult critical care units aren't based on evidence.”⁶⁴ Research on children permitted to visit in critical care settings indicates that those children experience fewer negative behavioral and emotional changes when allowed to visit, and “problems rarely occur[.]”^{65, 66} One study, for example, demonstrated that children's fears about parental death decrease when they are permitted to visit a parent in the intensive care unit.⁶⁷ Visitation with an ill family member can allay these concerns because often a “child's imagination creates more distressing images than the accurate information shared during a visit.”⁶⁸

Allowing parents access to their ill children also helps relieve family stress, both for the parents as caretakers and for the recovering child. The literature indicates that “[f]actors associated with the highest stress for parents of neonatal and pediatric patients include disruption

⁶¹ Quinio, Philippe; Savry, Christophe; Deghelt, Arnaud; Guilloux, Matthieu; Catineau, Jean; de Tinténiac, Anne, *A Multicenter Survey of Visiting Policies in French Intensive Care Units* (hereinafter as “*A Multicenter Survey of Visiting Policies*”), 28 *Intensive Care Medicine*, pp. 1389–1394, at p. 1391 (2002).

⁶² Tillett, Jackie, *Are Open Visitation Policies Beneficial for Women?*, *Journal of Perinatal and Neonatal Nursing*, pp. 193-194, at p. 193 (Jul.-Sep. 2006) (also noting that, “[m]others who received continuous support during labor also were more satisfied with their birth experiences than those mothers who did not have a continuous support person present at the bedside.”).

⁶³ *Women's Experience*, *supra* note 42, p. 185.

⁶⁴ *Families First*, *supra* note 44, p. 48.

⁶⁵ *Visitation in Critical Care*, *supra* note 41, p. 19.

⁶⁶ *A Multicenter Survey of Visiting Policies*, *supra* note 57, p. 1392 (citing a pilot study showing that children permitted to visit a critically ill family member “demonstrated less negative behavior and emotional changes than children who [were] not”).

⁶⁷ *Clinical Practice Guidelines*, *supra* note 27, p. 608.

⁶⁸ *Family and Pet Visitation*, *supra* note 48, p. 64.

of normal interactions with the child,⁶⁹ as would occur if a parent were barred from seeing his or her child.⁷⁰ Parents denied access to their children also can feel “frustrated, angry and undervalued.”⁷¹ Allowing parents to visit their children significantly benefits the family by encouraging information sharing between staff and family, recognizing family members as key decision-makers and “acknowledg[ing] the important role parents play in the recovery of their child.”⁷² Parental access to their children thus significantly decreases parental anxiety.⁷³

Parental visitation also can be beneficial to the health of an ill child.⁷⁴ One study found that “anxiety exhibited by children was because of separation from the parents; parents described feelings of relief when they saw their child; children’s stress behaviors of crying, anger, and fear were alleviated with parental presence in the [post-anesthesia care unit]; and a child’s negative experience during hospitalization correlated directly with future behavioral problems.”^{75, 76} Parental presence in the hospital room also can enhance parents’ ability to care for and help children recover from illness.⁷⁷

⁶⁹ *Clinical Practice Guidelines*, *supra* note 27, p. 608.

⁷⁰ *Care in the NICU*, *supra* note 28, p. 99 (“It is well documented that alteration in parent role is a stressor for NICU parents . . . If mothers are denied opportunities to mother their infants, they may feel confused, tense, and anxious and may struggle to know and connect with the baby.”).

⁷¹ Griffin, Terry, *Facing Challenges To Family-Centered Care I: Conflicts Over Visitation* (hereinafter as “*Family-Centered Care I*”), 29(2) *Pediatric Nursing*, pp. 135-137, at p. 136 (Mar.-Apr. 2003).

⁷² *Family-Centered Care I*, *supra* note 67, p. 136 (also noting that “policies that recognize and respect a family’s right to define itself and that respect family individuality will recognize the value of giving parents or guardians, not hospital staff, the opportunity to decide whose presence would be most beneficial to the child or family”).

⁷³ Powers, Karen S.; Rubenstein, Jeffrey S., *Family Presence During Invasive Procedures in the Pediatric Intensive Care Unit: A Prospective Study* (hereinafter as “*Family Presence During Invasive Procedures*”), 153 *Archives of Pediatrics & Adolescent Medicine*, pp. 955-958, at p. 955 (1999) (in a pilot study, parental presence during an invasive pediatric procedure significantly reduced parental anxiety related to that procedure).

⁷⁴ *Id.*, p. 955 (in a pilot study, 94% of nurses found parental presence during an invasive pediatric procedure to be helpful to the child).

⁷⁵ *Family Visitation in the PACU, 1984-2006*, *supra* note 38, p. 97 (summarizing research findings), see also p. 98 (in another study, “[d]ata revealed that the children exhibited a dramatic decrease in crying, restlessness, and were more comfortable during the parental visit.”).

⁷⁶ Kamerling, Susan N.; Lawler, Linda Cunningham; Lynch, Marie; Schwartz, Alan Jay, *Family-Centered Care in the Pediatric Post Anesthesia Care Unit: Changing Practice to Promote Parental Visitation* (hereinafter as “*Family-Centered Care in the PACU*”), 23(1) *Journal of PeriAnesthesia Nursing*, pp. 5-16, at p. 6 (Feb. 2008).

⁷⁷ *Care in the NICU*, *supra* note 28, p. 99 (visiting parents can be “taught nonmedicinal skills that can help decrease a baby’s discomfort and pain, such as pacifiers, administration of sucrose, positioning, and swaddling, so they can provide comfort measures during procedures”).

D. Inclusive Visitation Supports Family Members And Enhances Their Ability To Nurture The Patient.

A loved one's health crisis can be enormously stressful for family members,⁷⁸ and discriminatory denials of access to the patient needlessly compound that stress while depriving the patient of valuable nurturance.⁷⁹ Visitation rules that support the emotional needs of family members help improve patient outcomes by facilitating appropriate access, and reducing the anxiety that may hamper family members' ability to nurture the patient.^{80, 81, 82} In fact, "[s]tudies have shown that family members feel more relaxed and less anxious when they are able to visit at a time good for them and the patient," which is important when family members are juggling busy schedules and traveling for visits.^{83, 84} Accordingly, "[f]amily members report less exhaustion with an open visiting policy."⁸⁵ Increased visitation also facilitates greater information-sharing with the family and any other close emotional supporters, and in some instances helps them begin the work of grieving.⁸⁶

Increased access also can provide family members and other supporters with a greater sense of agency in emergency situations, because "[t]he opportunity to help care for [a] loved one decreases ... feelings [of helplessness]."^{87, 88} Additional benefits can flow from family and

⁷⁸ Kirchoff, Karin T.; Song, Mi-Kyung; Kehl, Karen, *Caring for the Family of the Critically Ill Patient* (hereinafter "*Caring for the Family*"), 20 *Critical Care Clinics*, pp. 453-466, at pp. 459-460 (2004) (summarizing research that demonstrates high percentages of family members experience depression and/or anxiety when a loved one is critically ill).

⁷⁹ Lee, Melissa D.; Friedenberg, Allison S.; Mukpo, David H.; Conray, Kayla; Palmisciano, Amy; Levy, Mitchell M., *Visiting Hours Policies in New England Intensive Care Units: Strategies for Improvement* (hereinafter as "*Visiting Hours Policies*"), 35(2) *Critical Care Medicine*, pp. 497-501, at p. 499 (2007) ("Restricting families' access to their loved one through limited visiting hours heightens this sense of helplessness by hindering families' ability to interact with their loved one.").

⁸⁰ *A Look at Critical Care Visitation*, *supra* note 43, p. 176.

⁸¹ *Caring for the Family*, *supra* note 74, p. 460 (noting that involving families in the care of the patient helps decrease family anxiety).

⁸² *Visiting Hours Policies*, *supra* 75, p. 499 ("Alternatively, liberalizing visiting hours allows families to have some control over access to their loved one and provides the opportunity to be part of the caretaker team.").

⁸³ *A look at Critical Care Visitation*, *supra* note 43, pp. 177-178.

⁸⁴ Abbott, Katherine H.; Sago, Joni G.; Breen, Catherine M.; Abernethy, Amy P.; Tulskey, James A., *Families Looking Back: One Year after Discussion of Withdrawal or Withholding of Life-Sustaining Support*, 29 *Critical Care Medicine*, pp. 197-201, at p. 199 (2001) (in a study of 48 family members with a relative in the intensive care unit, many "found comfort in being able to visit their loved one with little inconvenience" under an open visitation policy).

⁸⁵ *A Look at Critical Care Visitation*, *supra* note 43, p. 178.

⁸⁶ *Family Support at End of Life*, *supra* note 26, p.431.

⁸⁷ *Visitation in Critical Care*, *supra* note 41, p. 19.

friends' presence even during resuscitation of a patient, because it allows those providing support "to feel connected with their loved one and to understand that everything possible was done," and to "resolve otherwise lingering doubts or regrets."⁸⁹ Many of these dynamics are only reinforced in today's health services environment. "Our current healthcare era, marked by consumerism, shorter stays in the intensive care unit and the hospital, and nursing shortages" makes family-centered care more of an imperative, as "family members are taking on an ever-increasing role as direct caregivers."⁹⁰ Increased visitation helps caretakers adjust by giving health care providers more opportunities "to reinforce teaching concepts to patients and families."⁹¹

E. Greater Flexibility In Visitation Can Help Improve Staff Satisfaction.

Family visitation is beneficial for health care staff, as well as patients and their families.⁹² Allowing family members greater visitation can help increase "nurses' job satisfaction by providing positive feedback from family members and by decreasing the stress caused by family and patient dissatisfaction."⁹³ In fact, as one author has noted, "[m]ore frequent interactions between family and staff may also be one of the most rewarding components of providing care for the critically ill patient."⁹⁴ During the implementation of a program that increased parental visitation at the Children's Hospital of Philadelphia, one researcher examined the bases for staff concerns about patient safety, and concluded that "these patient safety concerns have not been reported in the literature nor realized in the practice of our unit."^{95, 96}

F. Visitors Need Not Impede The Provision Of Health Care To Patients.

The presence of family members generally does not interfere with patient care, and instead "can help facilitate communication between the patient and medical and nursing staffs." Visitors also can facilitate better quality care by providing "meaningful feedback about the patient's condition."⁹⁷ One study found that the calming influence on a patient of family

⁸⁸ *Clinical Practice Guidelines*, *supra* note 27, p. 609 ("the authors agree by consensus that liberal inclusion into care for those who desire it should be allowed").

⁸⁹ *Family and Pet Visitation*, *supra* note 48, p. 67.

⁹⁰ Henneman, Elizabeth A.; Cardin, Suzette, *Family-Centered Critical Care: A Practical Approach to Making It Happen* (hereinafter as "*Family-Centered Critical Care*"), 22(6) Critical Care Nurse, pp. 12-19, at p. 12 (Dec. 2002).

⁹¹ *More Evidence that Open Visitation Is Beneficial*, *supra* note 46, p. 334.

⁹² *Family-Centered Care in the PACU*, *supra* note 72, p. 6 ("children cried significantly less, were less restless, and were more comfortable during a parental visit.").

⁹³ *Visitation in Critical Care*, *supra* note 41, p. 19.

⁹⁴ *Family and Pet Visitation*, *supra* note 48, p. 64.

⁹⁵ *Family-Centered Care in the PACU*, *supra* note 72, p. 9.

⁹⁶ Kobberdahl, Tara Jo; Porter, Elizabeth L., *Innovative Solutions, Family-Centered Care Visitation Guidelines*, 28(4) Dimensions of Critical Care Nursing, pp. 169-170 (Jul.-Aug. 2009).

⁹⁷ *A Look at Critical Care Visitation*, *supra* note 43, p. 177.

presence “concurrently assist[ed] staff in the assessment and management of pain.”⁹⁸ Another observed that “support and comfort provided to the child by a parent may assist with orientation of a child emerging from anesthesia and decrease the need for medical and/or pharmacological restraints.”⁹⁹

G. The Greater Patient And Family Satisfaction Promoted By Increased Visitation Helps Reduce Formal Complaints Against Health Care Organizations And Providers.

An open visitation policy can significantly “improve[] family satisfaction with the critical care experience.”¹⁰⁰ One study of a Veterans Affairs hospital’s restrictive visitation policy noted that the restrictions caused some family members to become angry, including where family members had to travel longer distances to the health care facility, “leading to increased complaints and decreased satisfaction with care.”¹⁰¹ Other studies have found that wishing for more time with a terminally ill loved one, and not being with the loved one when he or she died, is associated with greater dissatisfaction with the care provided.¹⁰²

The corollary is true as well. Family presence, even during invasive procedures, “allows the development of a strong bond between patients’ family members and healthcare staff, making lawsuits unlikely,” including because family members then can see that everything has been done to help a loved one.^{103, 104} Other literature—looking generally at greater family access to and participation in treatment options—demonstrates increased satisfaction as access and participation are liberalized.¹⁰⁵

⁹⁸ *Family-Centered Care in the PACU*, *supra* note 72, p. 6.

⁹⁹ *Family-Centered Care in the PACU*, *supra* note 72, p. 6.

¹⁰⁰ *Family and Pet Visitation*, *supra* note 48, p. 62.

¹⁰¹ *Visitation in Critical Care*, *supra* note 41, p. 20.

¹⁰² Kjerulf, Maria; Regehr, Cheryl; Popova, Svelana R.; Baker, Andrew J., *Family perceptions of end-of-life care in an urban ICU*, 16(3) Canadian Association of Critical Care Nurses, pp. 22-25, at p. 24 (2005).

¹⁰³ Mason, Diana J., *Family Presence: Evidence Versus Tradition*, *Guest Editorial*, 12(3) American Journal of Critical Care, pp. 190-192, at p. 190 (2003).

¹⁰⁴ *Family-Centered Critical Care*, *supra* note 86, p. 13 (“Interventions such as having family members present during procedures and resuscitations help to reassure family members that everything possible is being done for the patient.”).

¹⁰⁵ McDonagh, Jonathan R.; Elliott, Tricia B.; Engelberg, Ruth A.; Treece, Patsy D.; Shannon, Sarah E.; Rubinfeld, Gordon D.; Patrick, Donald L.; Curtis, J. Randall, *Family Satisfaction with Family Conferences about End-of-Life Care in the Intensive Care Unit: Increased Proportion of Family Speech Is Associated with Increased Satisfaction*, 329(7) Critical Care Medicine, pp. 1484-1488, p. 1486 (2004) (a study of family conferences to discuss withdrawal of life-sustaining support in Seattle-area hospitals showed that allowing families proportionately more speech during the conference led families to perceive lower rates of conflict with the medical provider).

Additionally, clear rules help promote consistency of treatment for visiting family members, which also increases patient and family satisfaction with providers and health care organizations. When family members “see inconsistency in a visiting policy, they may start to question the existence of other inconsistencies, such as how treatments are carried out and how individual nurses manage patients’ problems (e.g., pain).”¹⁰⁶ Clear rules about visitation help promote consistent enforcement, which reduces friction among staff and confusion among families.^{107, 108, 109, 110, 111}

H. Broad And Inclusive Definitions Of Family Are Necessary For Health Care Organizations To Respond To Our Society’s Family Diversity.

Rigid and narrow definitions of family do not comport with “today’s varied family constellations,”¹¹² because increasing family heterogeneity means that the “nuclear family is no longer an inclusive description of every patients’ family.”¹¹³ The Institute for Patient- and Family-Centered Care, which defines family as “two or more persons who are related in any way—biologically, legally, or emotionally,” recognizes that the best practice is to allow “[p]atients and families [to] define their families.”¹¹⁴ The principle is important for many minority communities because “[t]oday’s society is multicultural and the definition of family varies by person.”¹¹⁵ Lambda Legal, GLMA and NHeLP strongly encourage incorporation of this approach explicitly into the Proposed Rules.

¹⁰⁶ *Family-Centered Critical Care*, *supra* note 86, p. 16.

¹⁰⁷ *Visitation in Critical Care*, *supra* note 41, p. 20 (“Inconsistent enforcement of this visitation policy created friction between nurses as well as confusion among families with regard to actual visiting hours.”).

¹⁰⁸ Levy, Mitchell M., *A View from the Other Side*, 35(2) *Critical Care Medicine*, pp. 603-604, at p. 604 (2007) (“the inconsistent enforcement of visitation policies all led to a sense within my family of us vs. them and that we had done something wrong”).

¹⁰⁹ *Family-Centered Care I*, *supra* note 67, p. 136 (“Inconsistencies in the interpretation of the visitation policy can lead to conflict between nursing staff and families”).

¹¹⁰ *Family-Centered Critical Care*, *supra* note 86, p. 16 (“Inconsistency wreaks havoc with families who are struggling to maintain some control over an otherwise uncontrollable situation. ... Inconsistencies are also detrimental to staff members and set up a ‘good nurse–bad nurse’ phenomenon that is difficult to resolve.”).

¹¹¹ *Visiting Hours Policies*, *supra* note 75, p. 500 (“In practice, however, restricted visiting hours policies have been associated with inconsistent enforcement, thereby confusing visitors and causing strife among the nursing staff. Consequently, restricted visiting hours policies are not a solution and have actually been shown to increase nursing stress.”).

¹¹² *Family-Centered Care I*, *supra* note 67, p. 136.

¹¹³ *Family and Pet Visitation*, *supra* note 48, p. 62.

¹¹⁴ *Supra* note 31.

¹¹⁵ *Family Support at End of Life*, *supra* note 26, p. 432.

V. CONCLUSION

Lambda Legal, the Gay & Lesbian Medical Association and the National Health Law Program strongly support CMS's efforts to ensure that LGBT patients, their families and their other close, sustaining relationships of choice are appropriately respected in times of medical crisis, consistently with health care ethics rules, anti-discrimination laws and other regulatory standards, and as warranted by the vast body of empirical literature. Indeed, the overwhelming consensus among these sources demonstrates that respecting patients' diverse families and sustaining relationships by allowing liberal visitation at the patient's bedside is good medicine. We respectfully request that CMS consider the issues addressed in these comments and our proposed changes for increasing the Proposed Rules' effectiveness in service of their ultimate objective—to improve public health and reduce health disparities by eliminating this cruel form of discrimination against LGBT patients and their loved ones.

Respectfully submitted,

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