August 27, 2010

The Honorable Donald Berwick
Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
Room 445-G
Hubert H. Humphrey Building
200 Independence Avenue SW
Washington, DC 20201

RE: CMS–3228–P
Medicare and Medicaid Programs: Changes to the Hospital and Critical Access Hospital Conditions of Participation to Ensure Visitation Rights for All Patients

Dear Dr. Berwick,

The National Coalition for LGBT Health ("the Coalition") welcomes the opportunity to submit comments on the proposed rule regarding "Changes to the Hospital and Critical Access Hospital Conditions of Participation to Ensure Equal Visitation Rights for All Patients."[1] As the President recognized in his April 15, 2010 Memorandum on Hospital Visitation, while hospital visitation is an issue that affects many people in the United States, it is of particular concern to lesbian, gay, bisexual, and transgender (LGBT) individuals and their families.

As a nationwide network of more than 75 advocacy and service organizations dedicated to improving the health of LGBT people, the Coalition considers these regulations to be a key step in recognizing and addressing the disparities in rights and access that affect the wellbeing of LGBT people in healthcare settings. We thank the Centers for Medicare and Medicaid Services (CMS) for the opportunity to comment, and we look forward to working with you to protect the right of all hospitalized patients to have their wishes respected concerning who may visit them or make medical decisions on their behalf.

Specifically, these comments: A) review the impact of hospital visitation and informed decision-making on LGBT individuals and their families; B) provide an overview of the evidence supporting the positive effects of broader visitation policies; C) discuss the benefits of the proposed rule; and D) address specific issues raised in the proposed rule. We would like to thank our allied organizations in the New Beginning Initiative coalition for their assistance in developing these comments.

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[1] 75 Fed. Reg. 36,610 (June 28, 2010).

A. Impact of Discrimination in Visitation and Informed Decision-Making Policies on LGBT Individuals and Families

The families of LGBT people, like many other families, are diverse and vary in configuration. Currently, however, only a small number of these families are protected by law, and these protections are tenuous at best. Due to the lack of consistent relationship recognition for same-sex couples across jurisdictions in the United States, a couple that is legally married in one state may be considered legal strangers in another. This problem is compounded by the lack of protections for families that cannot or do not fit the narrow definition of family ties created by blood, marriage, or adoption. Like groups such as widowed elders, members of religious orders, and unmarried opposite-sex couples, many LGBT people forge families knit by bonds of affection and affinity rather than legal coupled status, particularly in states where their relationships are denied legal recognition. These families, which may include partners, extended family members, and close friends, are vital components of an individual's wellbeing, and their support is rarely more important than in the stressful environment of a hospital setting.

Unfortunately, many hospitals and other healthcare facilities do not currently have policies in place that fully protect the right of patients to designate visitors, nor do they equally respect all advance healthcare directives (AHDs) and other legal instruments involved in the informed decision-making process. Moreover, many LGBT people are unable to afford or are unaware that they will need AHDs, or they are caught off guard when an unexpected medical emergency arises.

Without clear guidance on hospital policy surrounding visitation and informed decision-making, hospital staff and administrators are left to navigate each situation arbitrarily, sometimes with devastating consequences. The well-known example of Janice Langbehn and her partner Lisa Pond is sadly not unique.[2] Despite an AHD designating Janice as Lisa's legal representative, a Florida hospital refused Janice and their children access to Lisa's bedside as she lay dying. Janice was told by hospital staff that she was in an "anti-gay" city and state and that she and the couple's children were prohibited from seeing Lisa because they were not "family."[3]

Numerous cases from across the country testify to the perilous position of LGBT people in healthcare settings. Tragedy can ensue as years of shared history and even valid legal documents are arbitrarily dismissed. In Maryland, hospital staff ignored the California domestic partnership and Power of Attorney testifying to the relationship between Bill Flanigan and his mortally ill partner, Robert Daniel, telling Flanigan that only "family" were allowed to visit patients.[4] In a Seattle case, hospital staff barred Charlene Strong from the bedside of her partner of ten years, Kate Fleming, claiming that she was not

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[2] Parker-Pope, T. (May 18, 2009). *Kept From a Dying Partner's Bedside.* The New York Times. Accessed at: http://www.nytimes.com/2009/05/19/health/19well.html.

[3] Lambda Legal. (2008). *Langbehn v. Jackson Memorial Hospital*. Accessed at http://www.lambdalegal.org/in-court/cases/langbehn-v-jackson-memorial.html

[4] *Gay Marriage*. (September 5, 2003). The CQ Researcher, Congressional Quarterly. Vol. 13, No. 30. Accessed at: http://www.princeton.edu/~ccameron/KoreaIIE/IIE337/CaseClass4.pdf

"immediate family." By the time another relative of Fleming's gave permission by phone for Charlene to visit, Kate had only hours left to live.[5] When a hospital cannot find what it considers an acceptable legal representative or next of kin, or when distant or estranged relatives refuse to acknowledge the validity of a same-sex couple's relationship, many patients and their partners must suffer alone, without the comfort of being able to be with each other. The proposed rule is a laudable and important step by CMS toward remedying this situation and ensuring that all patients in facilities covered by this rule can trust that their visitation rights and wishes will be treated according to an equal standard of respect, dignity, and compassion.

B. Evidence Supports Open Visitation Policies

A growing body of evidence indicates that open visitation policies confer significant positive benefit on patients and their families. Studies in a wide variety of healthcare settings, including the most high-intensity settings, such as emergency rooms (ERs) and intensive care units (ICUs), show that open visitation policies can have a positive effect on the treatment a patient receives and on patient prognosis and recovery. Chosen family members can serve as vital support structures by sharing necessary information about a patient's medications and medical history, facilitating communication between patients and providers, and working with nurses and physicians to ensure that the patient receives appropriate follow-up care after discharge.[6] [7] Open visitation policies also foster a better relationship between patients' family members and attending medical professionals, making malpractice lawsuits less likely.[8]

Open visitation policies can also influence recovery by helping relieve anxiety for both patients and families. Research indicates that a frequently cited need of ICU patients is a feeling of safety. The perception of safety has an obvious and demonstrated link with the presence of family and friends.[9] Allowing visitors to be present also promotes the wellbeing of those close to a patient by relieving anxiety and promoting open communication.[10] [11] Several studies have demonstrated that visitation by family and friends is linked to an increase in feelings of safety and reductions in physiological and emotional stress among patients.[12]

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[5] Fears, D. and Sun, L. (April 17, 2010). *Those who have been there praise Obama's mandate on gay visitation rights*. The Washington Post.
[6] Kleinpell, R. (2008). Visiting Hours in the Intensive Care Unit: More Evidence That Open Visitation is Beneficial. *Crit Care Med* 36(1): 334-335.
[7] Berwick, DM and M Kotagal. (2004). Restricted Visiting Hours in ICUs: Time to Change. *J Am Med Assn* 292: 736-737.
[8] Mason, DJ. (2003). Family Presence: Evidence versus Tradition. *Am J Critical Care* 12: 190-192.
[9] Hupcey, JE. (2000). Feeling Safe: The Psychosocial Needs of ICU Patients. *J Nursing Scholarship* 32(4): 361-367.
[10] Simon, Phillips, Badalamenti, Ohlert, and Krumberger. (1997). Current Practices Regarding Visitation Policies in Critical Care Units. *Am J Crit Care* 6: 210-217.
[11] Marfell, JA and JS Garcia. (1995). Contracted Visiting Hours in the Coronary Care Unit: A Patient-Centered Quality Improvement Project. *Nursing Clinics of North America*, 30(1): 87-96.
[12] Krapohl. (1995). Research Analysis: Visiting Hours in the Adult Intensive Care Unit: Using Research to Develop a System that Works. *Dim Crit Care Nursing* 14(5): 245.

Perhaps most importantly, providing for more open visitation promotes recovery and a better prognosis for the patients receiving treatment. This and other beneficial effects that the presence of loved ones has on patient recovery have been documented by over ten years of research.[13] [14]

Recognizing the beneficial impact of open visitation policies on patients and their families, a handful of states and localities have enacted laws mandating that every patient's choice of visitors be fully respected. As an important corollary, some of these laws seek to codify the extension of full faith and credit to all valid AHDs and other legal documents designating the patient's chosen representative, regardless of the state in which they were executed. For example, Delaware requires the following of all hospitals in regard to patient visitation and informed decision-making:

> (a) Each Hospital shall include in its visitation policy a provision allowing each competent adult patient to receive visits from any individual from whom a patient desires to receive visits, subject to restrictions contained in the visitation policy related to a patient's medical condition, the number of visitors simultaneously permitted in a patient's room, and the Hospital's visitation hours, as well as protective orders issued by a Court.
> (b) Each Hospital shall honor each adult patient's desires set forth in the adult patient's power of attorney documents, advance healthcare directives, and any similar documents..."[15]

Some healthcare facilities, such as many of those featured in the annual Healthcare Equality Index compiled by the Human Rights Campaign (HRC) and the Gay and Lesbian Medical Association (GLMA), are also independently beginning to enact visitation policies that are inclusive of all chosen family members.[16] The Joint Commission, a leading hospital accreditation organization, recommends the following language in policies dealing with diverse definitions of family: "Define *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

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[13] Mason. Supra note 3.

[14] See, e.g., Sims, JM. (2006). A Look at Critical Care Visitation: the Case for Flexible Visitation. *Dim Crit Care Nursing,* 25(4): 175-80; Schulte, DA, Burrell, LO, Gueldner, SH, Bramlett, MH, Fuszard, B, Stone, SK, & Dudley, WN. (1993). Pilot Study of the Relationship Between Heart Rate and Ectopy and Unrestricted versus Restricted Visiting Hours in the Coronary Care Unit. *Am J Crit Care*, 2(2): 134-136; Hendrickson, SL, (1987). Intracranial Pressure Changes and Family Presence. *J Neuro Nursing,* 19(1): 14-7; Simpson, T, Shaver, J. (1990). Cardiovascular Responses to Family Visits in Coronary Care Unit Patients. *Heart Lung*, 19(4): 344-51; Eichhorn, DJ, Meyers, TA, Guzzetta, CE, Clark, AP, Klein, JD, Taliaferro, E, & Calvin, AO. (2001). Family Presence During Invasive Procedures and Resuscitation: Hearing the Voice of the Patient. *Am J Nursing*, 101(5): 48-55; Hanson, C and D Strawser. (1992). Family Presence During Cardiopulmonary Resuscitation: Foote Hospital Emergency Department's Nine-Year Perspective. *J Emergency Nursing,* 18(2): 104-6; and Robinson, SM, Mackenzie-Ross, S, Campbell, Hewson GL, Egleston, CV, & Prevost, AT. (1998). Psychological Effect of Witnessed Resuscitation on Bereaved Relatives. *Lancet,* 352(9128): 614-7.

[15] Del. Code Ann. tit. 16 §1020

[16] Human Rights Campaign. (2010). *Healthcare Equality Index*. Washington, DC: Human Rights Campaign.

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."[17]

These actions by individual states and healthcare facilities are important steps toward a common standard of rights and respect for all hospitalized individuals and their families. However, such assurances are limited to only a very small handful of states, localities, and healthcare facilities. As a result, the vast majority of the U.S. population cannot benefit from these policies. In most states, as well as in the eyes of the federal government, same-sex couples and their children are still not granted important protections under the law, meaning that rights and protections that exist in one state or in a particular healthcare facility are likely to be absent in neighboring jurisdictions. LGBT families and individuals can lose their rights simply by taking a vacation or moving for a new job. It is unconscionable that in the U.S. today, patient protections—particularly in an area of such stress and vulnerability as healthcare settings—should be arbitrary and inadequate for some individuals simply on the basis of geography. As both the Presidential Memorandum and the proposed rule recognize, the time has come for the federal government to fix this uneven patchwork of inadequate protections. The proposed rule will provide a vital backstop of support for those states and facilities that are making efforts to treat all patients and their family members equally, and it will also provide a minimum standard of protection for LGBT people who are not fortunate enough to live in one of the few states that recognize their rights on an equal basis with those of their colleagues and neighbors.

C. Benefits of the Proposed Rule

As CMS notes in the proposed rule, the benefits of the rule will "amply justify its relatively small costs." The positive impacts of the rule include significant, non-quantifiable benefits such as distributive impacts, equity, respect for patient autonomy, and the emotional benefits of open visitation policies described above, all of which are important aspects of the overall quality of patient experience in healthcare settings. Moreover, it is possible that hospital staff who treat patient visitors in a nondiscriminatory manner will be more inclined to provide the highest quality of care to every patient, regardless of factors such as sexual orientation or gender identity.

The benefits of the proposed rule for patients, family members, friends, and hospitals are likely to grow under the Affordable Care Act (ACA), with its focus on patient-centered care, the role of patient caregivers, and the quality of healthcare services delivery. For example:

- Section 3026 of the ACA establishes a community-based care transitions program to improve transitions between care settings (e.g., hospital-to-nursing home; hospital-to-home) for high-risk Medicare beneficiaries. Many of the potential care

[17] The Joint Commission. (2010). *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals.* Oakbrook Terrace, IL: The Joint Commission.

transition interventions suggested in the ACA include, where appropriate, the patient's caregiver in the care transition services.

- Section 3021 of the ACA establishes the Center for Medicare and Medicaid Innovation (CMI) to identify and test innovative payment and service delivery models that can reduce Medicare spending while preserving or enhancing quality. Among the factors the ACA suggests for possible testing is "whether the model places the applicable individual, including family members and other informal caregivers of the applicable individual, at the center of the care team of the applicable individual."

- Section 3506 of the ACA creates a shared decision-making program "to facilitate collaborative processes between patients, caregivers or authorized representatives and clinicians that engages the patient, caregiver or authorized representative in decision-making, provides patients, caregivers or authorized representatives with information about trade-offs among treatment options, and facilitates the incorporation of patient preferences and values into the medical plan."

In total, CMS estimates the total first-year cost of implementing the rule to be $0.9 million for all facilities. This cost, when spread across the more than 6,000 Medicare- and Medicaid-participating hospitals and critical access hospitals (CAHs) affected by the rule, is indeed far exceeded by the benefits of the rule, such as the psychological and physical benefits it provides to patients and their families and the benefits that participating facilities stand to gain in areas such as quality of service delivery and patient satisfaction.

D. Specific Issues Raised in the Proposed Rule

The Coalition applauds CMS for its response to the President's charge regarding patient visitation and informed decision-making. In this section, our comments respond to the following issues:

1. Establishment and scope of protected categories in patient visitation
2. Inclusive language in patient visitation policies
3. Clinically necessary and reasonable restrictions on visitation
4. Designation of patient representative
5. Hospital written policies
6. Informing patients
7. Application to critical access hospitals (CAHs)
8. Application to hospices, nursing homes, and other providers
9. Technical assistance in implementation

Noting that the Presidential Memorandum treats visitation and informed decision-making separately, our comments offer recommendations for ensuring that LGBT individuals and families are fully protected from discrimination in *both* visitation and informed decision-making.

1. Establishment and scope of protected categories in patient visitation

The proposed rule instructs all Medicare- and Medicaid-participating hospitals to "(n)ot restrict, limit, or otherwise deny visitation privileges on the basis of race, color, national origin, religion, sex, sexual orientation, gender identity, or disability." The explicit inclusion of sexual orientation and gender identity in the Medicare and Medicaid conditions of participation (CoPs) is a critical step in ensuring equal visitation rights of LGBT people who are hospitalized. In addition, the rule would require that the policy be uniformly implemented in all hospitals covered by the proposed rule.

We applaud CMS for this language but respectfully request that CMS expand the list of protected categories. To fully safeguard visitation rights for the LGBT community as well as for other groups, such as people with low English proficiency, that are vulnerable to discrimination in healthcare settings, we recommend adding several protected categories to those listed in the proposed rule. As amended, §482.13(h)(3) and §485.635(f)(3) would read as follows: "… Not restrict, limit, or otherwise deny visitation privileges on the basis of race, color, national origin, religion, sex, sexual orientation, gender identity, ~~or~~ disability, marital status, family composition, or primary language."

2. Inclusive language in patient visitation policies

The proposed rule directs hospitals and CAHs to "(e)nsure that all visitors designated by the patient (or representative, where appropriate) enjoy visitation privileges that are no more restrictive than those that immediate family members would enjoy." While we appreciate the effort to make this policy as inclusive as possible, we are concerned that the "immediate family member" language unintentionally creates a hierarchy of family relationships in which some family members, such as domestic partners, same-sex spouses, or same-sex parents of minor children, may not be considered "immediate." Such family members may therefore be at risk of being treated unfairly by some hospital staff or administrators, despite the proposed rule's intent to the contrary.

To guide hospital staff and administrators regarding the appropriate treatment of all patients and their visitors, we recommend that this language be changed to emphasize a single, uniform standard of visitation rights that should apply throughout all Medicare- and Medicaid-participating hospitals and CAHs. As amended, §482.13(h)(4) and §485.635(f)(4) would read as follows: "… Ensure that all visitors designated by the patient (or representative, where appropriate) enjoy full and equal visitation privileges regardless of race, color, national origin, religion, sex, sexual orientation, gender identity, disability, marital status, family composition, or primary language." ~~that are no more restrictive than those that immediate family members would enjoy~~.

3. Clinically necessary or reasonable restrictions on visitation

The preamble to the proposed rule makes reference to certain circumstances in which hospitals may limit or otherwise restrict patient visitation rights. According to the proposed rule, "a patient visitation rights requirement...would need to accommodate

medically appropriate visitation policies generally recognized by the Nation's hospitals and CAHs, i.e., those that set forth any clinically necessary or reasonable restrictions or limitations on visitors." The text goes on to provide examples such as "when the patient is undergoing care interventions, when there may be infection control issues, or when visitation may interfere with the care of other patients." We are concerned that CMS does not provide any further guidance on what constitutes "clinically necessary or reasonable" restrictions. The background of the proposed rule refers to policies that are "generally recognized by the Nation's hospitals and CAHs," but there is no one set of restrictions that are universally applicable and, more importantly, no nationwide consensus on what restrictions are inappropriate and unnecessary.

However, studies demonstrating the positive effects of open visitation, such as those cited above, reveal that even in high-intensity settings such as coronary care units (CCUs), ERs, and ICUs, the chief "reasonable" restriction on patient visitation that is most often asserted is for purposes of infection control.[18] We are concerned that in some cases what may be cited as "reasonable" restrictions, such as those around ongoing care interventions, may actually be more logistical concerns that have the potential to be broadly interpreted by overworked staff in a manner that runs counter to the intention of the proposed rule. To ensure that restrictions on visitation access are appropriately formulated and fairly enforced, the proposed rule should include additional guidance for hospitals regarding the truly clinical nature of acceptable restrictions and clarifying that CMS does not permit hospitals participating in Medicare or Medicaid to enact restrictions on visitation that are not based on accepted clinical practice or legitimate concerns about patient health or safety, or that are rooted in discriminatory attitudes toward LGBT people or their families. As part of this guidance, CMS should strike the example of "when the patient is undergoing care interventions" from the preamble to the proposed rule.

4. Designation of patient representative

The proposed rule states that "the requirement [to provide 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 healthcare proxies (as opposed to verbal designation of the representative by the patient), *but only in rare cases*" (emphasis added). CMS "seek[s] comment on how best to identify these rare cases." Further, the proposed rule provides 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."

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[18] See, e.g., Lee, MD, Friedenberg, AS, Mukpo, DH, Conray, K, Palmisciano, A, Levy, MM. (2007). Visiting hours policies in New England intensive care units: Strategies for improvement. *Crit Care Med* 35(2):497-501.

We believe such written documentation should be required, as with married opposite-sex 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 confirmation of a family relationship recognized under the law of any state should suffice, as it does currently for incapacitated heterosexual patients whose husband, wife, parent, or adult child seeks access to their bedside. Moreover, though many same-sex couples live in states where they do not have access to the benefits and protections of official relationship recognition, their families are no less deserving of recognition and their needs in hospital settings are no less pressing than those of their heterosexual counterparts. Furthermore, the requirement of written documentation is likely to have a disparate impact on lower income or non-English-proficient LGBT individuals and families, who may not be aware of or be able to afford legal documentation of their relationship. There is no legal barrier to the inclusion of the marriages, civil unions, and registered domestic partnerships of same-sex couples among the indicators of a familial or other close personal relationship for purposes of hospital visitation and informed decision-making.[19] These indicators of close personal relationships should guide hospital staff for these purposes regardless of whether the state in which the hospital is located confers legal rights and responsibilities on the basis of such relationships to same-sex couples for other purposes.

Accordingly, we recommend that the preamble to the proposed rule be revised to read as follows: "We believe 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 recognized under the law of any 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. The requirement of avoiding discrimination on an impermissible basis means, for example, that a hospital or CAH may require proof of relationship status from patients with a same-sex spouse or registered domestic partner *only* if proof is similarly required from patients with an opposite-sex spouse. Moreover, CMS recognizes that many same-sex couples live in states where they enjoy no legal protections and that some may not be able to afford or may be unaware of the need for AHDs or other legal instruments. Therefore, when making determinations of representation for a patient unable to verbally designate his or her representative, hospitals and CAHs should adhere as closely as possible to the inclusive standard of family recommended by accreditation bodies like The Joint Commission. This definition of family "explicitly [includes] 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." The Joint Commission recommends that hospitals "(u)se this expanded

[19] Five states (MA, IA, CT, VT, and NH) and the District of Columbia have extended equal rights in marriage to same-sex couples, and nine others provide some form of relationship recognition for same-sex couples, such as domestic partnerships and civil unions. Accessed at: http://www.hrc.org/documents/Relationship_Recognition_Laws_Map.pdf

definition in all hospital policies, including those addressing visitation, access to chosen support person, identification of surrogate decision-makers and advance directives."[20]

In the preamble to the proposed rule, CMS requests comments regarding 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) to adequately ensure that people in same-sex relationships may designate a decision-maker, have that designation respected, and receive meaningful representation by their designee. Section 482.13(b)(2) currently contains an unnecessary limitation that creates a particular vulnerability for same-sex couples by providing that only a representative "as allowed under State law" has the right to make decisions about the patient's care. This clause may wrongly be interpreted to limit the role of representative to persons with a legal relationship to the patient that is specifically recognized under state law. In other words, the current Section 482.13(b)(2) could lead healthcare providers to mistakenly conclude that a lack of formal state recognition for a couple's relationship precludes the designation of a same-sex partner as a healthcare agent. While such an interpretation is incorrect, the Coalition regularly hears from the LGBT people that we represent that hospital staff and administrators routinely invoke a lack of formal relationship recognition under individual state law to discriminate against same-sex couples. Moreover, because state laws vary greatly in their respect for AHDs generally, this "state law" caveat creates an unreliable and unpredictable set of rules for patients and their representatives, inviting confusion and potentially subordinating patient autonomy to the whims of others.

This clause in Section 482.13(b)(2) clearly runs counter to patient autonomy and the individual's right to designate a representative of his or her choice. The right to direct one's healthcare by designating any competent adult as one's healthcare agent is a right of constitutional dimension.[21] 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 concededly good intentions, a health care provider's function is to provide medical treatment in accordance with the *patient's* wishes and best interests" (emphasis added).[22] This right extends to all relevant decisions concerning one's health.[23] In the context of an AHD, the agent stands in the shoes of the patient and holds the full extent of the patient's right to direct the patient's care in keeping with the patient's healthcare wishes.[24]

Moreover, Section 482.13 of the CoPs does not—but should—expressly provide access to the patient. While the CoPs currently allow patients to designate a representative to

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[20] The Joint Commission. (2010). *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals.* Oakbrook Terrace, IL: The Joint Commission.
[21] See, e.g., *Cruzan by Cruzan v. Director, Missouri Dept. of Health*, 497 U.S. 261 (1990).
[22] *Matter of Dubreuil*, 629 So.2d 819, 822 (Fla. 1993).
[23] See, e.g., *Harrell v. St. Mary's Hosp., Inc.*, 678 So.2d 455, 456-457 (Fla. Dist. Ct. App. 1996).
[24] See, e.g., 6 MARQ Elders Adv 217, TREATED WITH RESPECT: ENFORCING PATIENT AUTONOMY BY DEFENDING ADVANCE DIRECTIVES, (Spring 2005) (citing *Cruzan*).

make healthcare decisions, they do not expressly provide representatives the right to access the patient to assess his or her condition, which is critical to ensuring that healthcare decisions are informed.[25] As the tragic facts and disappointing decision in *Langbehn v. Public Health Trust* show, this concern is not hypothetical: refusals to allow a legally designated patient representative access to a patient's bedside has occurred before and will occur again in the absence of clear guidance from regulatory authorities like CMS. Such denials of access compromise patient health, since they mean the representative cannot monitor the patient's condition on an ongoing basis and receive the accurate and complete information about diagnosis and treatment necessary to direct the patient's care in an informed manner.

Overall, Section 482.13(b)(2) must ensure the following: (1) that each patient has the right to designate a representative to speak on his or her behalf, (2) that the representative must have visitation privileges unless medically contraindicated, and (3) that no patient representative may be denied access for lack of a formal familial status recognized by the law of the state in which the hospital is located or by federal law.

Accordingly, the proposed rule should amend Section 482.13(b)(2) to read as follows: "The patient or his or her representative ~~(as allowed under State law)~~ has the right to make informed decisions regarding his or her care. A representative may be any individual that plays a significant role in the patient's life, such as a spouse, a domestic partner, a significant other (of both different-sex and same-sex), and other individuals not legally related to the patient. Legal recognition of a relationship under State or Federal law is not a prerequisite for designation of an individual as a patient's representative. The patient's rights and those of his or her representative include being informed of his or her health status, being involved in care planning and treatment, ~~and~~ being able to request or receive treatment, and, for patient representatives, the right to visitation privileges unless medically contraindicated."

5. Hospital written policies

As discussed above, the proposed rule requires that hospitals have written policies and procedures regarding the visitation of patients, including any clinically necessary or reasonable restriction or limitation that the hospital may need to place on such rights and the reasons for the clinical restriction or limitation. Hospitals would also be required to inform each patient, or their representative where appropriate, of the patient's visitation rights, including any clinical restriction or limitation on those rights, when the patient is informed of their other rights defined in the CoPs.

To ensure that all patients and their visitors fully understand their rights as defined in the CoPs, and to ensure that hospital staff and administrators consistently receive appropriate guidance on the implementation of nondiscrimination policies governing patient

[25] 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.")

visitation, CMS should require that the nondiscrimination language in the CoPs be included in each individual hospital's written policy. To comply, hospitals would be required to add the following language to their written policies: "[HOSPITAL NAME] does not restrict, limit, or otherwise deny visitation privileges on the basis of race, color, national origin, religion, sex, sexual orientation, gender identity, disability, marital status, family composition, or primary language." This policy should be translated into any language in which the hospital regularly provides information to patients and their families.

6. Informing patients

The proposed rule requires that each patient be informed of his or her right, subject to his or her continued consent, to receive the visitors whom he or she designates, whether a spouse, a domestic partner (including a same-sex domestic partner), another family member, or a friend.

To best ensure that patients are fully informed of these rights under the Patient Bill of Rights contained in the CoPs for hospitals participating in Medicare or Medicaid, CMS should require that each patient receive a single sheet on patient visitation rights at intake, as assumed in the cost analysis of the proposed rule. This requirement is in keeping with the note in the analysis of the proposed rule that most hospitals already have such requirements in place regarding patient notification of their rights under hospital policies, and that the additional burden of including notice of visitation rights and nondiscrimination policies will be "minimal." The sheet should include, in a readable size and typeface, the following language: "[HOSPITAL NAME] does not restrict, limit, or otherwise deny visitation privileges on the basis of race, color, national origin, religion, sex, sexual orientation, gender identity, disability, marital status, family composition, or primary language. You have the right to receive the visitors whom you (or your chosen representative, where appropriate) designate, including, but not limited to, a spouse, a domestic partner, another family member, or a friend. You have the right to withdraw visitation privileges at any time and for any reason." The sheet should also include, in plain language and in a readable size and typeface, information for a dedicated hospital staff member, administrator, or department whom the patient may contact by telephone, E-mail, mail, or in person with questions or concerns regarding patient visitation, including information about the hospital's complaint procedures. This information must be made available to each patient and their visitors in their preferred language.[26]

7. Application to critical access hospitals (CAHs)

The proposed rule is particularly important for CAHs, who often serve vulnerable patient populations in areas where patients have few options for pursuing medical care at other facilities when their wishes are not respected by hospital staff or administrators. We applaud the step by CMS to amend the CoPs for CAHs to explicitly include patient rights.

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[26] The Joint Commission. (2010).*Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals.* Oakbrook Terrace, IL: The Joint Commission.

To ensure that patients and their visitors at CAHs are treated with the same measure of respect and dignity as at other Medicare- and Medicaid-participating hospitals, we recommend that all of the requirements discussed above, including establishment and scope of protected categories in patient visitation, inclusive language in patient visitation policies, clinically necessary and reasonable restrictions on visitation, informed decision-making, "rare cases" exceptions in designation of patient representative, CAH written policies, and informing patients, be mandatory for CAHs as well.

8. Application to hospices, nursing homes, and other providers

In the proposed rule, CMS solicits comments on hospices, nursing homes, and other Medicare and Medicaid providers and patient visitation requirements. In response, we strongly urge the agency to extend the patient visitation and representation rights established in the proposed rule to all hospices and nursing homes. The preamble to the proposed rule notes that visitation policies for hospices and nursing homes are already very broad. However, for the reasons cited above in the section "Establishment and scope of protected categories in patient visitation," explicit mention of the groups protected by nondiscrimination policies is an invaluable component of ensuring that nondiscrimination is regularly practiced and enforced by staff and administrators at all facilities. Moreover, the proposed amendment to Section 482.13(b)(2), with its treatment of patient representatives, is an issue that applies to hospices and nursing homes as well as hospital settings. Including language about nondiscrimination in patient visitation and representation in the CoPs for hospices and nursing homes is therefore an important part of ensuring that patients, their family members, and their representatives are treated with appropriate respect and compassion in all healthcare facilities participating in Medicare or Medicaid.

We also suggest that CMS extend these rights to ambulatory surgical centers (ASCs). Ambulatory surgical centers furnish outpatient surgical procedures to patients who do not require an overnight stay following the procedure. According to the Medicare Payment Advisory Commission, in 2008, ASCs served 3.3 million Medicare beneficiaries. Medicare covers about 3,400 surgical procedures under the ASC payment system.[27] As such, we believe that the ASC conditions of coverage should be amended to require patient visitation policies in these facilities that are the same as the patient visitation policies for hospitals established in the proposed rule.

We therefore urge CMS to require the establishment of written ASC visitation policies and patient notification documents, consistent with our recommendations for the hospital written policies and notification documents.

9. Technical assistance in implementation

The Presidential Memorandum also requests that CMS "issue new guidelines, pursuant to your authority under 42 U.S.C. 1395cc and other relevant provisions of law, and provide

[27] Medicare Payment Advisory Commission. (March 2010). Report to Congress.

technical assistance on how hospitals participating in Medicare or Medicaid can best comply with the regulations and take any additional appropriate measures to fully enforce the regulations."[28] We recommend that this technical assistance take the form of creating or identifying existing best practices for training staff and administrators in all Medicare- and Medicaid-participating facilities affected by the proposed rule, including hospitals, CAHs, hospices, nursing homes, and other providers, on cultural competency and the benefits of open visitation policies. The cultural competency component is particularly important for the LGBT community: as in the case of Janice Langbehn and Lisa Pond, it is often staff and providers unfamiliar with or unsympathetic to the needs of LGBT people and families who unfairly discriminate in patient visitation or representation. While the LGBT community is not the only group that will benefit from the proposed rule, the current patchwork of state laws and public attitudes about LGBT people mean that clear and consistent guidance from CMS on appropriate standards of cultural competency as applied to LGBT patients is critical to upholding both the spirit and the letter of the proposed rule.[29] Training on LGBT cultural competency could be easily combined with training on other aspects of the diverse patient populations that Medicare- and Medicaid-participating hospitals serve, such as racial and ethnic minorities and patients with limited English proficiency.

Conclusion

In sum, we believe that the proposed rule is a significant step forward in ensuring that all patients, their visitors, family members, friends, and their representatives are treated fairly and in a manner that promotes positive experiences and health outcomes. The concerns of LGBT individuals and families in healthcare settings are often much broader than visitation and representation: other significant and pernicious problems include the outright denial of treatment to LGBT people on the basis of personal bias or discomfort on the part of providers.[30] Though much-needed change on these fronts remains to come, we recognize that the support from CMS for fairness and equality in patient visitation and representation demonstrated by this proposed rule is part of a broader movement towards fairness and equality in the treatment of all patients in healthcare settings, regardless of factors such as sexual orientation, gender identity, or other factors that lie at the root of disparities for different groups of people in healthcare access, quality of care, and treatment outcomes.

We thank you again for the opportunity to comment on this proposed rule, and we look forward to working with CMS on its implementation. Please do not hesitate to contact me with any questions or concerns. I can be reached at hinniss@lgbthealth.net or (202) 558-6828.

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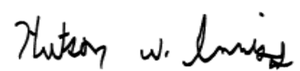
[28] http://www.whitehouse.gov/the-press-office/presidential-memorandum-hospital-visitation

[29] See, e.g., Gay and Lesbian Medical Association. (2006). Guidelines for Care of Lesbian, Gay, Bisexual, and Transgender Patients. Available from: http://www.glma.org/_data/n_0001/resources/live/GLMA%20guidelines%202006%20FINAL.pdf

[30] See, e.g., University of San Francisco Medical Center. (April 23, 2010). "USCF Community Celebrates Expansion of Visitation Rights." Available from http://today.ucsf.edu/stories/ucsf-community-celebrates-expansion-of-visitation-rights/

Sincerely,



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