

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,

We are writing 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” (“Rule”).

We would like to start by thanking the Centers for Medicare and Medicaid Services (“CMS”) for their thoughtful work to date. We are confident that the final rules will go a very long way in overcoming the long-standing injustices lesbian, gay, bisexual, and transgender (LGBT) people have faced in hospital visitation.

Our colleagues at the National Coalition for LGBT Health, national LGBT legal groups, and other health-specific organizations have submitted comprehensive comments and recommendations. We support those views and wish to highlight areas we believe are most important.

### **The Rule is Sorely Needed**

President Obama’s April 15 memorandum acknowledged that hospital visitation is of particular concern to LGBT people and their families. This reality cannot be over-stated and that is precisely why the Rule is so important. The stories of heartbreaking and insulting treatment around hospital visitation are unbelievably common among LGBT people:

- Individuals being unable to visit their partners of 20 or 30 years because they are not viewed as “family;”
- Hospital staff arbitrarily dismissing legal documentation proving a couple’s relationship because it is issued by another state; and
- LGBT people consistently being forced to “prove” their connection to a patient, while no questions are asked when a heterosexual person simply identifies him or herself as a spouse, sibling, parent or other family member.

Sometimes, these tragedies get public attention, such as the incident in Florida involving Janice Langbehn and her partner Lisa Pond. But the vast majority of these injustices go unnoticed or unreported because of the lack of recourse for victims.

There are several reasons for this disparate treatment of LGBT patients and their families. One reason is the small number of states that extend legal relationship recognition to same-sex couples, whether through

marriage, domestic partner registries, or civil unions. A second reason is the inconsistent way same-sex marriages, domestic partnerships, and civil unions are recognized by other jurisdictions. A same-sex couple can be lawfully married in Iowa, for example, but lose that legal status when they cross into any adjoining state. Still another reason is the ways by which so many LGBT people create and sustain family which, due to a history of familial estrangement and legal discrimination, is through bonds of affection and affinity rather than blood or formal “legal” status.

The overarching problem to date has been the lack of uniform guidance for hospitals and other health care facilities protecting the right of patients to designate visitors and ensure that advance health care directives (“AHDs”) and other similar legal documents are respected. As a result, hospitals and their staffs deal with these situations in vastly different ways that are often profoundly harmful to LGBT people.

These reasons highlight why the Rule is so important, so praiseworthy, and so long-overdue.

The final rules need to include and/or address the following:

### **Protected categories in patient visitation**

The Rule instructs all Medicare- and Medicaid-participating hospitals not to “restrict, limit, or otherwise deny visitation privileges on the basis of race, color, national origin, religion, sex, sexual orientation, gender identity, or disability.” Given the issues around who is considered “family,” the problems around interstate recognition of same-sex marriages, civil unions, and domestic partnership, and to safeguard visitation rights for other groups that are vulnerable to discrimination we recommend adding marital status, family composition, and primary language to the list of protected categories, wherever those categories appear in the new rules.

### **Inclusive language in patient visitation policies**

The Rule directs hospitals 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 objective behind this provision, the term “immediate family member” is actually confusing and can be seen as disparaging to existing LGBT families. A better way would be to use the same list of protected categories mentioned above and have the rule: “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.”

### **Informing patients of their rights**

The 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 make sure this happens, we wholeheartedly endorse the recommendations of the National Coalition on LGBT Health (“Coalition”), including requiring hospitals to give each patient a single sheet explaining their visitation rights at intake with language such as: “[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 information for contacting a dedicated staff member concerning visitation issues, including complaint and appeal procedures. This information must be made available to each patient and their visitors in their preferred language.

### **Protecting the Right of LGBT Patients to Designate a Representative**

Centers for Medicare & Medicaid Services requested comments about whether the existing rules “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.” Three important changes are needed to ensure that LGBT people may designate a decision-maker, have that designation respected, and receive meaningful representation by that individual.

1. The rules need hospitals to provide patients with easy-to-use forms for designating a representative and to provide for verbal designation of a representative in emergency situations. The current rules contain no guidance on designating a representative and impose no obligation on facilities to ensure patients’ rights to designate a representative. Like most Americans, many LGBT individuals do not have health care proxies or representative designations. Moreover, many hospitals do not inform patients of their right to designate a representative or provide forms for them to do so. This situation can be remedied for LGBT people and others by amending the rules to provide that (a) patients have the right to designate a representative and hospitals have the obligation to provide patients with designation forms; and (b) in emergency situations, patients have the right to verbally designate a representative. The right to designate a representative should be included on the sheet spelling out a patient’s visitation rights, as discussed above.

2. 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. As discussed above, many legal LGBT relationships are not recognized once they cross state lines. The current rule states, “The patient or his or her representative (as allowed under State law) has the right to make informed decisions regarding his or her care.” Because the clause “as allowed under State law” could be read as limiting the designation of a representative to persons with a relationship to the patient that is specifically recognized under that state’s law, it should be removed.

3. A patient’s representatives must have access to the patient and be able to determine who else may visit the patient. The current rules do not—but should—expressly provide access to the patient. A representative needs to have access to a patient to make informed and ongoing healthcare decisions on the patient’s behalf. In addition, as the representative is given the authority to make healthcare decisions on the patient’s behalf, the final Rule should make it clear that this authority includes decisions about who should be allowed to visit the patient. We recommend that the Rule provide that a representative (a) must have visitation privileges unless medically contraindicated, (b) has the authority to decide which other persons have visitation privileges, and (c) may not 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.

### **“Rare Cases” Requiring Written Documentation for Visitation**

The Rule states that “the requirement [to provide visitation] would need to be flexible enough in its application to permit the hospital or CAH<sup>1</sup> to require written documentation of patient representation by

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<sup>1</sup> Critical Access Hospital

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.” The Centers for Medicare & Medicaid Services asked for comments on how best to identify these rare cases. The Rule also 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.”

We agree that 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. We support the Coalition’s recommended additions to the Rule, including (a) that it is permissible for a hospital to 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; and (b) that hospitals should follow the inclusive standard of family recommended by accreditation bodies, i.e., that “‘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.”

### **Restrictions on visitation**

The Rule says, “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.” It gives 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.” Additional guidance is needed here because there is no agreed-to set of standards in this area and no consensus on what restrictions are inappropriate or unnecessary. In spite of evidence showing how beneficial visitation is to patients, many hospitals use their own logistical issues – not clinical ones – to deny or restrict visitation. Therefore, we recommend that the rules provide that hospitals may not restrict visitation for reasons that are not based on accepted clinical practice or legitimate concerns about patient health or safety.

### **Application of Rules to Critical Access Hospitals and Other Health Care Facilities**

We wholeheartedly support CMS in proposing that the new rules apply to Critical Access Hospitals. These facilities often serve the most vulnerable types of patients in areas where there are few other options. There is no reason why they should not be required to treat patients and their visitors with the same measure of respect and dignity as all other Medicare- and Medicaid-participating hospitals.

The Centers for Medicare & Medicaid Services also asked for comments on visitation requirements for other Medicare and Medicaid providers, such as hospices and nursing homes. We strongly recommend that these facilities be covered by the same rules as hospitals and CAHs. The need for and the benefits that flow from visitation are just as important – and sometimes even more so – for patients in hospices and nursing homes than for those in hospitals. The standards and rules for all facilities should be consistent.

### **Technical Assistance in Compliance**

The President’s April 15 memorandum requested that CMS “issue new guidelines . . . and provide 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.” We recommend that CMS identify (and create, where necessary) best practices for training staff and administrators on cultural competency, including LGBT cultural competency, and the benefits of open visitation policies. While the LGBT community is not the only group that will benefit from the Rule, the current patchwork of state laws and public attitudes about LGBT people make it particularly important that CMS weigh in with clear and consistent cultural competency standards for LGBT patients and their visitors.

## **Conclusion**

In conclusion, we again thank you and CMS for the careful thought that went into the Rule and the areas where comments were specifically requested. We are confident the final rule will be a significant step forward in improving the way all patients, their visitors, and their families – especially LGBT patients, their visitors, and their families - are treated by Medicare- and Medicaid-participating facilities. We thank you again for the opportunity to comment on this Rule.

Sincerely,

Affirmations: Metro Detroit's Community Center for LGBT People and Their Allies  
American Academy of Physician Assistants (AAPA)  
American Civil Liberties Union (ACLU)  
Basic Rights Oregon  
California LGBT Health and Human Services Network  
CenterLink: The Community of LGBT Centers  
Center on Halsted, Chicago, IL  
Empire State Pride Agenda  
Equality California  
Equality Hawaii Foundation  
Equality Long Island  
EqualityMaine  
Equality North Carolina  
Equality Ohio  
Equal Rights Washington  
Fair Wisconsin  
Fairness West Virginia  
Florida Together Federation  
Garden State Equality  
Gay & Lesbian Community Center of Baltimore  
Gay & Lesbian Community Center of Southern Nevada  
Gil Gerald & Associates  
Kentucky Fairness Alliance  
L.A. Gay & Lesbian Center  
LGBT Resource Center, University of California San Francisco  
Long Island Gay and Lesbian Youth (LIGALY)  
Long Island GLBT Community Center (The Center)  
Long Island GLBT Services Network  
Massachusetts Transgender Coalition  
Mautner Project: The National Lesbian Health Organization  
MEGA Family Project  
Mental Health America of Northern California  
Metropolitan Community Church of New York (MCCNY) Charities  
Milwaukee LGBT Community Center

National Black Justice Coalition  
National Center for Lesbian Rights (NCLR)  
National Coalition of Anti-Violence Programs  
National Gay and Lesbian Chamber of Commerce (NGLCC)  
National Youth Advocacy Coalition (NYAC)  
New Mexico GLBTQ Centers  
New York Association for Gender Rights Advocacy (NYAGRA)  
One Iowa  
Parents, Families and Friends of Lesbians and Gays (PFLAG) National  
PROMO (Missouri)  
Resource Center Dallas  
Sage Upstate  
Services and Advocacy for GLBT Elders- Long Island (SAGE-LI)  
Tennessee Equality Project  
Tennessee Transgender Political Coalition  
Transgender Education Network of Texas  
TransOhio  
The Equality Network (Oklahoma)  
The Trevor Project  
Vermont Freedom to Marry Task Force