August 27, 2010

Donald Berwick, M.D.
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 Administrator Berwick:

The undersigned organizations, representing millions of patients, consumers, and health care providers are submitting these comments in regard to, and in strong support of, Proposed Rule on 42 CFR Parts 482 and 485, "Changes to the Hospital and Critical Access Hospital Conditions of Participation to Ensure Equal Visitation Rights for All Patients."[1] The right of equal visitation will benefit anyone in the United States who has a family knit by bonds of affection and affinity rather than legal coupled status. As the President recognized in his April 15 memorandum, equal visitation rights will allow widows and widowers who do not have children; members of religious orders; lesbian, gay, bisexual and transgender (LGBT) people whose relationships may not be legally recognized; and others to have their chosen family members, friends, and loved ones by their sides and able to represent their wishes in their time of need. We appreciate the strong stance in support of visitation rights and nondiscrimination that the Centers for Medicare and Medicaid Services (CMS) have taken in the Proposed Rule. In addition, we would like to thank CMS for the opportunity to comment on this Proposed Rule, and we look forward to working with you on the implementation of the provisions it outlines for protecting the visitation rights of all patients.

Currently, many hospitals do not have policies in place that fully protect the rights of patients to designate visitors and that require all advance healthcare directives and other legal instruments involved in the informed decision-making process to be equally respected. As a result, groups such as widowed elders, members of religious orders, and unmarried different-sex couples who have chosen families of affinity and affection may be denied the right to have their loved ones by their sides when they are ill or incapacitated. Chosen families, which may include partners, extended family members, and close friends, provide vital information, support and care when a loved one is ill. Studies in a wide variety of healthcare settings, including emergency rooms and intensive care units, show that allowing chosen family members to be present with patients promotes recovery and a better prognosis.[2] Chosen family members may share necessary

[1] 75 Fed. Reg. 33610.
[2] *See, e.g.*, J. E. Hupcey. *Feeling Safe: The Psychosocial Needs of ICU Patients*, 32 J. NURSING SCHOLARSHIP 361 (2000); S.K. Simon, et al Current Practices Regarding Visitation Policies in Critical Care Units, *Am J Critical Care* 210 (1997).; Greta L. Krapohl, *Research Analysis: Visiting Hours in the Adult Intensive Care Unit: Using Research*

information on a patient's medications and medical history, facilitate communications between patients and providers, and work with nurses and physicians to ensure that the patient receives appropriate follow-up care after discharge.[3] Without clear guidance on the appropriate treatment of all patients and their chosen visitors and representatives, hospital staff and administrators are left to navigate each situation as they see fit, sometimes with disastrous consequences, such as when loved ones are denied the right to visit a dying patient. The Proposed Rule is a laudable and ethical step by CMS toward remedying this situation and ensuring that all patients in Medicare and Medicaid-participating facilities can trust that their rights and wishes will be treated according to an equal standard of respect, dignity, and compassion.

We have four specific recommendations to strengthen the Proposed Rule and ensure that all patients have the right to be visited by and have their wishes represented by their chosen family members, friends, and loved ones. We propose that CMS:

I. Emphasize that visitation restrictions are valid for clinical reasons only.

II. Add protected categories to those on the basis of which hospitals and Critical Access Hospitals (CAH) are prohibited from discriminating.

III. Clarify that written documentation of a relationship may only be required in the rarest of cases and can not be required on a discriminatory basis.

IV. Modify sections 482.12(h)(4) and 485.635(f)(4) so that they do not distinguish between "immediate family members" and other designated visitors.

I. Emphasize that visitation restrictions are valid for clinical reasons only.

Section 482.13 of the Proposed Rule states that "A hospital must have written polices and procedures regarding the visitation rights of patients, including those setting forth any clinically necessary or reasonable restriction or limitation that the hospital may need to place on such rights." The background of the Proposed Rule refers to policies that are "generally recognized by the Nation's hospitals and CAHs,"[4] but provides little other guidance as to what constitutes "clinically reasonable" restrictions. Although there are times when it may be appropriate for hospitals to have visitation policies subject to additional restrictions, such restrictions should only be permitted for clinical reasons. Hospitals should not be able to use "clinical reasons" as a broad, blanket exception to the Proposed Rule. Therefore, we recommend that the Proposed Rule include guidance for hospitals emphasizing the clinical nature of acceptable restrictions and clarifying that CMS does not permit hospitals participating in Medicare and Medicaid to enact restrictions on visitation that are not based on accepted clinical practice or legitimate concerns

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to Develop a System that Works, 14 DIMENSIONS OF CRITICAL CARE NURSING 245 (1995); J.A. Marfell & J.S. Garcia, *Contracted Visiting Hours in the Coronary Care Unit: a Patient-Centered Quality Improvement Project*, 30 NURSING CLINICS NORTH AMERICA, 87 (1995).

[3] Donald Berwick & Meera Kotagal, *Restricted Visiting Hours in ICUs: Time to Change*, 292 J. AM. MED. ASSOCIATION, 736 (2004); R. Kleinpell, *Visiting Hours in the Intensive Care Unit: More Evidence That Open Visitation is Beneficial*, 36 CRITICAL CARE MEDICINE 334 (2008).

[4] 75 Fed. Reg. 36611.

about patient health and safety. When hospitals do restrict visitation, such restrictions should be for documentable reasons related to the specific health needs of the patient.

II. Add protected categories to those on the basis of which hospitals and CAHs are prohibited from discriminating.

Sections 482.12(h)(3) and § 485.635(f)(3) of the Proposed Rule instructs all Medicare-and Medicaid-participating hospitals to "(n)ot restrict, limit, or otherwise deny visitation privileges on the bases of race, color, national origin, religion, sex, sexual orientation, gender identity, or disability." As cited in the Presidential Memorandum, numerous groups of individuals and their chosen families, including widowed and childless elders and different-sex unmarried partners, are affected by discrimination in patient visitation. As discussed above, patients and their families benefit when hospitals and CAHs have open visitation policies. To safeguard the visitation rights for other groups that are vulnerable to discrimination in health care setting, we recommend adding several other protected categories to those on the basis of which hospitals and CAHs are prohibited from discriminating, including: marital status, family composition, age, language and immigration status. In addition, we recommend that the Proposed Rule make explicit that institutional or individual conscience cannot be used to deny a visitor access to the patient.

III. Clarify that written documentation of a relationship may only be required in the rarest of cases and can not be required on a discriminatory basis.

CMS seeks comment on how best to identify the rare cases in which a hospital or CAH may require written documentation of patient representation by legally valid advance directives, as opposed to verbal designation of the representative by the patient. The background to the Proposed Rule further states:

> [A]t 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.[5]

We believe such written documentation should be required 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. To clarify this, we recommend that the Proposed Rules be revised to ensure that among the usual situations that do not require written documentation are 1) situations in which patient representation automatically follows from a legal relationship which is recognized under the laws of any state; 2) situations in which a visitor claims to be a partner, parent or child; and 3) situations in which the relationship has been previously documented, such as in the case where the patient has already listed the visitor as "next of kin" or the patient is insured through the visitor's insurance. Further, we recommend inclusion of the following or similar language:

[5] 75 Fed. Reg. 36611.

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 hospital or CAH may not require proof of relationship status only with respect to patients with a same-sex spouse or registered domestic partner if proof is not similarly required with respect to patients with a different-sex spouse.

IV. Modify § 482.12(h)(4) and § 4 85.635(f)(4) so that they do not distinguish between "immediate family members" and other designated visitors.

Sections 482.12(h)(4) and § 485.635(f)(4) require 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 this is consistent with the language used by states that have established inclusive hospital visitation policies, we are concerned that the "immediate family member" language unintentionally creates a hierarchy of family relationship status in which chosen family members of affinity and affection are not considered to be "immediate family." 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. Therefore, we recommend that this language be changed to emphasize the single, uniform standard of visitation rights that shall apply throughout all Medicare- and Medicaid-participating hospitals and CAHs. As amended, § 482.12(h)(4) and § 485.635(f)(4) would read as follows:

> Ensure that all visitors designated by the patient (or representative, where appropriate) enjoy <u>full and equal</u> visitation privileges <u>according to the standards set out in the proceeding paragraph</u> ~~that are no more restrictive than those that immediate family members would enjoy~~.

V. Conclusion

We look forward to working with you on the implementation of the provisions outlined in this Proposed Rule to ensure that everyone has the right be visited by and have their wishes represented by their chosen family members, friends, and loved ones. Thank you for your consideration.

Sincerely,

AARP
American Academy of Family Physicians
American College of Obstetricians and Gynecologists
American Federation of State, County and Municipal Employees (AFSCME)
American Federation of Teachers
American Medical Women's Association
American Nurses Association
Asian & Pacific Islander American Health Forum
BluewaveNJ

Campaign for Community Change
Center for American Progress
Community Action Partnership
Families USA
Health Care for America Now
Interfaith Worker Justice – New Mexico
International Union, United Auto Workers
Leadership Conference on Civil and Human Rights
MergerWatch Project
National Asian Pacific American Womens' Forum (NAPAWF)
National Council of Jewish Women
National Education Association
National Latina Health Network
National Latina Institute for Reproductive Health
National Partnership for Women and Families
National Physicians Alliance
National Women's Health Network
National Women's Law Center
Planned Parenthood Federation of America
Public Justice Center
Raising Women's Voices for the Health Care We Need
Service Employees International Union (SEIU)
Southwest Women's Law Center
The Arc of the United States
The Episcopal Church
United Cerebral Palsy
United Church of Christ, Justice and Witness Ministries
USAction
Western North Carolina Conference Methodist Federation for Social Action
Women's Institute for a Secure Retirement (WISER)