

October 12, 2004

Paul M. Schyve, M.D.
Senior Vice President
Joint Commission on Accreditation of Healthcare Organizations
One Renaissance Boulevard
Oakbrook Terrace, IL 60181

Re: JCAHO Accreditation Standards for Notification of Institutional Ethical or Religious Restrictions on Delivery of Care

Dear Dr. Schyve:

As organizations committed to ensuring that health care consumers are appropriately informed about their treatment options, we are writing to request a modification of the current Joint Commission on Accreditation of Healthcare Organizations (JCAHO) standards for hospitals and other health care organizations. The proposed standard, as requested in the December 16, 2002 letter to you from the National Women's Law Center and others, requires that entities that have institutional ethical or religious restrictions concerning certain health care services provide explicit appropriate and timely written notice of those restrictions to patients and prospective patients.

The Need for the Proposed Modification

As noted in the 2002 letter, many religiously sponsored hospitals and health care organizations refuse to provide (or refuse to forgo, in the end-of-life context) certain health care on the ground that doing so violates their ethical or religious rules.¹ Often, nonsectarian hospitals that are affiliated with these religious entities are also governed by these religious restrictions.² Health care consumers are often unaware of these limitations, and therefore consent to be admitted to the hospital—or to be transferred to a hospital with restrictions—without knowledge of these service limitations. For example, in a nationwide survey of women 18 and older, 45 percent said that if they were admitted to a Catholic hospital, they believed they would be able to get medical services that may

¹ The U.S. Conference of Catholic Bishops' *Ethical and Religious Directives for Catholic Health Care Services* ("the Directives") govern the delivery of care at Catholic health care institutions and limit many different types of services; available at: <http://www.nccbuscc.org/bishops/directives.htm>. Although other religious entities also may limit care, the Directives are the most extensive.

² In 1998, for example, of the 36 Catholic/non-Catholic mergers and affiliations for which information was available (out of a total of 43 Catholic/non-Catholic transactions that year), almost half (17) resulted in all or some reproductive health services being discontinued; a similar percentage of transactions resulted in reduced services in transactions from 1990 to 1998. Liz Bucar, *Caution: Catholic Health Restrictions May be Hazardous to Your Health* (Washington, DC: Catholics for a Free Choice, 1999), 5.

go against Catholic teaching.³ Even women who thought services might be limited did not know how broad the restrictions were. While 62 percent identified abortion when asked to name services that are contrary to Catholic teaching, only 43 percent named birth control, and less than seven percent were able to identify any other restricted services, including emergency contraception, sterilization, or infertility treatment.⁴

This lack of information can be particularly problematic when patients enter a hospital for treatment of specific conditions and assume that related services would also be available if they so desired. For example, a pregnant woman who is contemplating a post-partum tubal ligation needs to know when she is planning her care that the local hospital where her obstetrician has privileges and that markets itself as offering comprehensive obstetrical and gynecological services does not offer tubal ligation because of religious restrictions. It is not adequate to provide this information at or after her admission to the hospital. Having the information in a timely way would enable the prospective mother to evaluate whether she still wants to deliver at that hospital even with the restriction, or whether she would like to go elsewhere.

Similarly, many Alzheimer's patients and their families want to know whether the hospital will honor legally permissible patient or family preferences to terminate artificially administered nutrition and hydration, or instead refuse and invoke institutional religious restrictions.

There is ample evidence that these restrictions in fact do limit care.⁵ The materials cited in the footnote contain a number of concrete examples of patients who suffered injuries resulting from the restrictions on care. They illustrate, together with the study

³ Belden, Russonello & Stewart, *Religion, Reproductive Health and Access to Services: A National Survey of Women* (Washington, DC: Belden, Russonello & Stewart, 2000), 1, 9, 14, 20 [hereinafter Belden, Russonello] (reporting results of survey conducted by in April 2000). See also ACLU Reproductive Freedom Project, *Religious Refusals and Reproductive Rights* (New York, NY: ACLU, 2002) at 20-21 (in 2001 focus group, 76 percent said they opposed "giving hospitals an exemption from the law allowing them to refuse to provide medical services they object to on religious grounds"). For more discussion on the scope of the issue of religious restrictions and notice, see Elena N. Cohen and Alison Sclater, *Truth or Consequences: Using Consumer Protection Laws to Expose Institutional Religious Restrictions on Reproductive and Other Health Care* (Washington, DC: National Women's Law Center, 2003), available at: <http://www.nwlc.org/pdf/TruthOrConsequences2003.pdf> [hereinafter *Truth or Consequences*].

⁴ Belden, Russonello, *supra* note 3, at 1, 9, 14, 20.

⁵ *Truth or Consequences*, *supra* note 3, especially 5-12 (nn. 12, 13), 32-35; Elena N. Cohen and Jill C. Morrison, *Hospital Mergers and the Threat to Women's Reproductive Health Services: Using Charitable Assets Laws to Fight Back* (Washington, DC: National Women's Law Center, 2001), 23-37, available at: <http://www.nwlc.org/pdf/mergerca.pdf>; Judith C. Appelbaum and Jill C. Morrison, "Hospital Mergers and the Threat to Women's Reproductive Health Services: Applying the Antitrust Laws," 26 *N.Y.U. Rev. L. & Soc. Change* (2000-2001), 33-36, available at: <http://www.nwlc.org/pdf/nyuarticle.pdf>; Patricia Miller and Celina Chelala, *Catholic HMOs and Reproductive Health Care* (Washington, DC: Catholics for a Free Choice), 16-17; Patricia Miller, *Merger Trends 2001: Reproductive Health Care in Catholic Settings* (Washington, DC: Catholics for a Free Choice, 2001), 10; Leora Eisenstadt, "Separation of Church and Hospital: Strategies to Protect Pro-choice Physicians in Religiously Affiliated Hospitals," 15 *Yale J. Law and Feminism* 135 (2003); Leslie Laurence, "The Hidden Threat That Puts Every Woman at Risk" *Redbook* (July 2000), 112; Catherine Weiss and others, *Religious Refusals and Reproductive Rights* (New York, NY: ACLU Reproductive Freedom Project, 2002), 14-18; *Brownfield v. Daniel Freeman Marina Hosp.*, 256 Cal. Rptr. 240, 244-45 (Ct. App. 1989); *In re Requena*, 517 A.2d 886, 890-91 (N.J. Super. Ct. Ch. Div.), *aff'd*, 517 A.2d 869 (N.J. Super. Ct. App. Div. 1986).

documenting the substantial nationwide scope of the problem of lack of information about hospital policies restricting care, how important it is that JCAHO require that hospitals provide notice of such policies.

Specific Language Modification⁶

To address these and other similar concerns, we urge you to adopt the following proposed standard that will facilitate patients' informed consent and protect their health:

Health care organizations must maintain written policies and provide prominent and timely notice to patients (and prospective patients) before admission and before transfer if possible (otherwise, at admission and transfer) concerning any institutional religious or ethical restrictions to providing (or, in the end-of-life context, forgoing) health care services. Such written policies and patient notices must include a clear and precise statement of the medical conditions and procedures/treatment affected by the restriction, as well as the scope of the restriction. At a minimum, such policies and notices must be prominently posted in the facility and be included prominently in patient, family, and staff education and marketing material.

Application of the Proposed Standard

When health care consumers have a reasonable expectation that a particular service will be available at a facility, notice of exclusion of that service is important for informed patient decision-making. Indeed, many religiously affiliated health care organizations have emphasized the importance of the development of procedures to facilitate open and honest communication with the public they serve.⁷

The standard we propose would, in a straightforward way, simply require that entities with institutional ethical or religious health care restrictions communicate those restrictions to health care consumers in a clear and timely way. Our proposal is designed to be practical and is limited in several respects. It concerns *institutional* religious or moral objections, not *individual* health care professionals' objections concerning certain care. The new standard does *not* require that a hospital that has such institutional ethical or religious restrictions provide or forgo the services at issue, only that it provides appropriate notice to those potentially affected by the restriction. Moreover, institutional

⁶ The language is modeled after 42 CFR § 489.102 (CMS requirements for providers concerning advance directives). This proposed standard is substantially similar to the standard proposed in the 2002 letter to you.

⁷ See Michael Place, "The Sunshine Covenant: Part of Hospitals' Mission is to Share Information with Patients, Public," *Mod. Healthcare*, Apr. 7, 2003, at 24 ("The Catholic Health Association has a continuing commitment to promoting transparency and community accountability.... As we serve, we engage with people in their most vulnerable moments and they rely on us to put their interests first. The relationship is, in essence, a covenant based on trust that requires honesty, openness and reciprocity by both parties.... Every participant in the healthcare system should be accountable to their communities, but accountability depends on the availability of accurate information presented fairly and intelligently.... We as leaders in the [health care system] encourage the development of responsible and reliable programs and methods for demonstrating accountability to the communities we serve so that we can strengthen the bonds of trust that are essential to the well-being of our nation's healthcare system").

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ethical and religious positions are not likely to be affected by financial, legal liability, or other external factors, and therefore are not likely to be subject to constant modification. Finally, the requested standard could be incorporated into currently existing policies and notices, including but not limited to those addressing marketing material, written notice to patients at and before (when possible) admission and transfer, education of staff, and patient and family education. The minimal institutional burden of providing notice is clearly outweighed by the major benefit consumers receive by being informed about significant restrictions to care of which they are likely not otherwise to be aware.

The Relationship between the Proposed Modification and JCAHO's Mission

As noted in the 2002 letter, JCAHO historically has been a leader in the area of patient protection, especially as it relates to institutions' ethical responsibilities and the patients' right to receive information that facilitates their decision-making. For example, JCAHO led the industry in adopting standards concerning do-not-resuscitate and palliative care policies. The proposed general recommendation is consistent with the intent behind several already existing JCAHO requirements.⁸ In addition to implementing the above proposed standard, JCAHO should also expand the "Speak Up" and "Quality Check"⁹ initiatives to include information about key restrictions on care.

The National Women's Law Center and the undersigned organizations welcome the opportunity to work with JCAHO to provide any assistance toward implementing these recommendations. We look forward to hearing from you.

Sincerely,



Elena N. Cohen
National Women's Law Center



Judy Waxman
National Women's Law Center

Abortion Access Project
American Academy of Neurology
American Association of University Women
American Civil Liberties Union
American Medical Student Association
American Medical Women's Association
American Public Health Association

⁸ The language could appear in standards specifically addressing patient rights and organizational ethics (e.g., 2004 *Hospital Accreditation Standards* RI.1.10, RI.1.20, RI.1.30, RI.2.10, RI.2.20, RI.2.30, RI.2.40, RI.2.70, RI.2.80, RI.2.90, RI.2.100, RI.2.180, PC.1.10, PC.4.10, LD.3.30, LD.3.60, LD 3.90, LD.3.120, HR.2.10, MS.2.20, MS.420). We understand that even though JCAHO is constantly revising the format of its standards, the commitment to quality health care will remain paramount.

⁹<http://www.jcaho.org/accredited+organizations/speak+up/facts+about+the+speaking+up+program.htm>;
<http://www.jcaho.org/quality+check/guides/hos.htm>.

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Americans for Better Care of the Dying
Americans United for Separation of Church and State
Association of Academic Health Centers
Association of Reproductive Health Professionals (ARHP)
Black Women's Health Imperative
Catholics for a Free Choice
Center for Medical Consumers
Center for Medicare Advocacy
Center for Reproductive Rights
Center for Women Policy Studies
Citizen Action of New York
Citizen Advocacy Center
Community Catalyst
Compassion in Dying Federation
Connecticut Coalition for Choice
Hadassah, the Women's Zionist Organization of America
Health and Medicine Policy Research Group
Institute for Reproductive Health Access
Interfaith Impact of New York State
Ipas
Mautner Project, the National Lesbian Health Organization
The MergerWatch Project
NAACP
NARAL Pro-Choice America
National Coalition for LGBT Health
National Consumers League
National Health Law Program (NHeLP)
National Latina Health Organization
National Partnership for Women & Families
National Women's Health Network
National Women's Law Center
Native American Women's Health Education Resource Center
New York State Coalition Against Sexual Assault
Northwest Women's Law Center
OWL, the voice of midlife and older women
The Parkinson's Disease Foundation, Inc.
Physicians for Reproductive Choice & Health (PRCH)
Planned Parenthood Federation of America
Religious Coalition for Reproductive Choice
Reproductive Health Technologies Project
Save Our Services on Long Island (SOS-LI)
Sexuality Information and Education Council of the United States (SIECUS)
Society for Women's Health Research
Women's Health & Family Planning Associates of Texas