



June 8, 2011

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: Comments on Forthcoming Centers for Medicare & Medicaid Services (CMS) Guidance Regarding Medical Decision-Making, Advance Directives, and Improving Access to Quality Healthcare for Lesbian, Gay, Bisexual, and Transgender (LGBT) Patients

Dear Dr. Berwick,

On behalf of the undersigned organizations, the National Center for Lesbian Rights (NCLR) submits the following comments in anticipation of CMS' forthcoming guidelines on medical decision-making and advance directives for lesbian, gay, bisexual, and transgender (LGBT) patients. As we understand it, these new guidelines will assist hospitals (including critical access hospitals, or CAHs) in protecting LGBT patients and their families by requiring compliance with existing regulations instead of creating new ones. Accordingly, we realize there will likely not be a public comment period, so we appreciate this opportunity to provide our thoughts in advance of the issuing of the new guidelines.

We are grateful for the leadership that the Obama administration and the Department of Health and Human Services (HHS) in particular have shown on increasing access to quality healthcare for the LGBT community. We appreciate the work HHS has done to comply with President Obama's April 15, 2010 memo directing HHS to identify other areas to increase quality care for LGBT patients. The recently enacted hospital visitation regulations were a critical step in protecting LGBT patients and their loved ones from being placed in the unconscionable position of being kept away from one another in the midst of tragedy and serious illness. However, in order to give full effect to those regulations, it is imperative that CMS issue supplemental guidance surrounding medical decision-making issues that arise for LGBT patients. Hospital visitation rights and medical decision-making are inextricably linked, and in order to fully protect the rights, dignity, and wishes of LGBT patients, guidance prohibiting discrimination against LGBT families is necessary.

The tragic story of Janice Langbehn and Lisa Pond was not only about a hospital's refusal to afford a same-sex couple equal visitation rights, it was also about a hospital's refusal

to respect the validly executed advance directive of a lesbian patient.¹ As a result, a couple of twenty years was kept apart when one of the partners was critically ill and on the brink of death. Langbehn was denied the right to be fully informed in order to make decisions about Lisa's care and the ability to speak on behalf of Lisa with respect to the right to be consulted about the course of her partner's treatment, despite being the person clearly most knowledgeable about Pond's wishes. And Pond was denied the fundamental right of autonomy – to choose a surrogate medical decision-maker and have that choice respected by healthcare providers when it mattered most. This case underscores the critical need for federal guidance to protect every person's right to autonomy with respect to medical decision-making.

LGBT individuals, couples, and their friends and families still face this type of mistreatment and utter disregard for their wishes on a routine basis in hospitals across the country. The need to make urgent decisions about medical care arise when tragedy has struck and people are already at their most vulnerable. No one is ever prepared for the dreadful experience of being hospitalized and being unable to make medical decisions on their own behalf. For LGBT patients and families, this tragedy is compounded by unjust laws and policies that often prevent those closest to the patient from speaking on behalf of their hospitalized loved one.

This is an area that has traditionally been left to the states, and to be clear, our recommendations are entirely consistent with this area remaining primarily a matter of state law. The guidance we suggest would merely provide baseline nondiscrimination provisions below which hospitals could not dip as a condition of receiving federal funds.

The primary goal of federal guidance about medical decision-making must be determining and protecting the wishes of the patient. All other goals should be secondary to the overarching aim of ensuring that decisions made on behalf of the patient reflect what that patient would have wanted as accurately as possible. This means that all medical decision-making guidance must create a structure that chiefly aims at ascertaining and respecting the patient's wishes, and listening to those who are most knowledgeable about the patient's wishes, regardless of whether their relationship with the patient is based on a legally recognized relationship under state law. We offer the following suggestions to increase quality care for LGBT patients and to ensure that healthcare providers have access to the people who can best communicate the wishes of the patient in situations like this.

¹Complaint PP 34-35, *Langbehn v. Pub. Health Trust of Miami-Dade County*, No. 08-21813-CIV (S.D. Fla. June 25, 2008).

A. Increase Number of People Who Complete Advance Directives

Obviously, the easiest way to determine a patient's wishes is to have the patient communicate those wishes through a validly executed advance directive. However, like most Americans, many LGBT individuals do not have advance directives.

Due to significant barriers in access to healthcare, LGBT patients, particularly people of color and those from low to moderate socio-economic backgrounds, are often less likely to take advantage of preemptive measures to improving care, such as executing advance directives.² We urge CMS to partner with LGBT advocacy organizations to increase the number of LGBT people who complete advance directives and thereby eliminate the number of uncertainties that can arise in the context of medical decision-making. This will need to involve dedicated outreach efforts to educate the LGBT community about the importance of advance directives, and a campaign dedicated to increasing awareness and access to documents to complete them and keep them on file in case of emergencies.

In addition to outreach to the community, we urge CMS to work with hospitals and CAHs to simplify the process by which patients can designate representatives. CMS should require facilities to inform patients of their right to designate a representative and provide forms for them to do so. For example, patients could choose a medical decision-maker on one of the forms they fill out when they visit a hospital, and that information can be kept on file with other patient information to which other providers have access. We additionally urge CMS to require facilities to provide patients with easy-to-use forms for designating a representative and to allow for verbal designation of a representative in emergency situations. Finally, CMS should require facilities to affirmatively notify patients that the right to designate a representative is not dependent upon a particular state's laws concerning the relationship between the patient and their designated representative.

While these steps can significantly increase the number of patients who have advance directives, additional guidance is also needed to ensure that advance directives of LGBT patients are respected by healthcare providers.

B. Ensure Respect for Validly Executed Advance Directives

Where a patient has an advance directive, it is imperative that healthcare providers are aware of it, and that it is followed. We encourage CMS to make every effort to ensure that all validly executed advance directives are available to and respected by all healthcare providers. In order to do this, CMS should issue guidance that prohibits the use of so-called "conscience

²See Laura F. Redman. *Out the Invisible Poor: Why Economic Justice and Access to Healthcare is an LGBT Issue*, Georgetown Journal on Poverty, Law & Policy, Vol. XVII, Summer 2010, No. 3, 453; HARRIS INTERACTIVE ET AL., FEWER THAN HALF OF ALL LESBIAN, GAY, BISEXUAL, AND TRANSGENDER ADULTS SURVEYED SAY THEY HAVE DISCLOSED THEIR SEXUAL ORIENTATION TO THEIR HEALTH CARE PROVIDER (2002), available at http://www.witeckcombs.com/news/releases/20021217_health.pdf.

clauses” to disregard any aspect of an advance directive based on sexual orientation or gender identity, and increase healthcare providers’ access to advance directives.

1. Clarification of Role of Refusal-to-Treat Clauses with Respect to Advance Directives

We encourage CMS to issue guidance clarifying that so-called “conscience clauses,” which enable designated medical providers in some states to refuse to provide certain treatments under specific circumstances, do not authorize healthcare providers to disregard advance directives. Specifically, we urge CMS to make it clear that while a healthcare provider may object to the performance of a specific medical service or treatment where permitted to do so by state law, healthcare providers may never rely on these clauses to refuse to respect the authority of an expressly named medical decision-maker in an advance directive.³ This distinction is crucial. The purpose of refusal-to-treat laws is to enable health care providers to refrain from participating in certain *treatments* contrary to their sincerely held religious, moral and ethical beliefs. Honoring the designation of an individual as a surrogate decision-maker is not a specific treatment or procedure, and permitting a provider to disregard such a designation would not be an appropriate or lawful use of these clauses. We urge CMS to clarify that designations of medical decision-makers fall outside the bounds of refusal to treat clause protection, and healthcare providers may not disregard such designations.

Every state permits individuals to name anyone of their choosing as a surrogate health care decision-maker. A surrogate need not be in a legally recognized relationship with the patient, nor is a surrogate required to be a family member. No state restricts who a patient may designate based on either the patient’s or the surrogate’s sexual orientation or gender identity. Accordingly, no state permits a provider or healthcare facility to decline to follow the directions of a patient, expressed in writing under established state mechanisms, with regard to a surrogate decision-maker because of the sexual orientation or gender identity of the patient, the proxy, or the visitor(s), or whether or not the patient and proxy and/or visitor are same-sex couples, domestic partners, civil union partners or spouses.

This well-established legal structure is based on respect for personal autonomy and a recognition that every person has the right to make his or her own medical decisions and to select

³No state statute is written broadly enough for a healthcare provider to object to the very existence of the advance directive. While most states have statutes permitting healthcare providers to refuse to perform certain services, they all have limitations. The vast majority of these statutes are narrow in focus and allow providers to object to only a small group of procedures. See Guttmacher Institute, *State Policies in Brief: Refusing to Provide Health Services* (May 1, 2011), available at http://www.guttmacher.org/statecenter/spibs/spib_RPHS.pdf; see also Matthew White, *Conscience Clauses for Pharmacists: The Struggle to Balance Conscience Rights with the Rights of Patients and Institutions*, 2005 Wis. L. Rev. 1611, 1631 (2005). Only a handful of states have enacted broader clauses, however, even the broad clauses are only broad with respect to the services that can form the basis for the objection and with respect to who may make a conscientious objection. There remains an understood requirement that the objection be made to a medical service, treatment, or procedure.

his or her own surrogate decision-maker.⁴ That right belongs inherently to the individual, not to the government. Therefore, honoring a designated medical decision-maker does not require the provider to approve of the relationship between the patient and the surrogate. Rather, it requires only that the provider respects the authority granted to the surrogate. As a result, no conscientious objection can be made because the provider's religious or moral beliefs are not implicated by a responsibility to simply recognize the authority of the designated decision-maker. We urge CMS to clarify this point to avoid any confusion about whether a refusal to treat clause may be invoked to disregard the advance directives of LGBT patients.

2. Creation of Nationwide Database of Advance Directives

In order to increase access to patients' advance directives regardless of where the patient is hospitalized, we recommend CMS create and operate a nationwide database for advance directives or work with the Office of the National Coordinator for Health Information Technology to make the sharing of these directives part of any improvement to the electronic medical record system. Of course this information must be shared in a way that cannot be used to discriminate and that includes appropriate restrictions on acquisition, retention, and use so as to protect the privacy of those whose data is being collected. This will provide patients with the security and peace of mind of knowing that no matter where they are hospitalized, the decisions they have made about their course of treatment and their designated surrogate will be respected. This issue is especially critical for LGBT patients and families whose rights vary significantly as they travel from one state to another. Without access to the advance directive of an LGBT patient, surrogacy decisions will be made based on a state's decision-making statute, which, as will be explained, frequently fail to recognize same-sex partners as the most appropriate surrogate decision-maker. The result is that LGBT patients are plagued by uncertainty concerning whether their wishes will be respected even when they do execute advance directives. The only way to remedy this is to make sure that advance directives are accessible to all healthcare providers regardless of where a person is hospitalized.

While this is a long-term project, there are efforts that can be made now to take advantage of existing infrastructure. There are currently eight states that have databases that house advance directives for patients within the states.⁵ We recommend that HHS work with these states to make the information on these databases available to all hospitals and CAHs regardless of whether the facility is the primary place where the patient receives care. We further urge HHS to work with other states to create these databases. This work would be invaluable in

⁴See *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 286-287 (U.S. 1990).

⁵ Arizona (https://www.azsos.gov/adv_dir/); California (<https://www.sos.ca.gov/ahcdr/>); Idaho (<http://www.sos.idaho.gov/general/hcdr.htm>); Montana (<https://doj.mt.gov/consumer/consumer/advancedirectives.asp>); North Carolina (<https://www.secretary.state.nc.us/ahcdr/>); Vermont (<http://healthvermont.gov/vadr/index.aspx>); Washington (<http://www.doh.wa.gov/livingwill/>); West Virginia (<http://www.wvendoflife.org/e-Directive-Registry>).

providing LGBT patients the assurance that executing an advance directive would allow them to exercise autonomy over their course of treatment and their surrogate decision-maker, even if they are hospitalized in a state that does not respect the rights of LGBT patients and their families. We further recommend that HHS find other ways to work with hospitals to ensure that this information follows a patient in the same way a patient's medical history does. Simply having this information on file for patients with all other essential health information would be a powerful tool to eliminate the guesswork in a vitally important area of patient care. Including information about a patient's designated medical decision-maker in the patient's Electronic Health Records and Health Information Exchange systems could facilitate making this information available to all healthcare providers who come into contact with the patient.

C. Ensure Designation of Most Appropriate Surrogate for Incapacitated Patients Without Advance Directives

Perhaps the most challenging scenario to address is where an incapacitated patient does not have an advance directive. In this situation, healthcare providers are placed in the unenviable position of attempting to guess who the patient would most trust making decisions about the course of treatment. Most states have attempted to resolve this issue by creating prioritized rankings of family members to which the duties of a surrogate would automatically flow. This list typically begins with a spouse or next of kin, and proceeds through some degree of kinship.

These rankings pose significant problems for LGBT patients and their families. First, most do not specify that a person need not have a biological or legal relationship in order to fall within each category, which disadvantages LGBT families who often do not have legally recognized or biological relationships with their family members. Second, while most states recognize that a spouse is likely the person to be most knowledgeable about a patient's wishes in the event of a medical emergency; most states do not allow a same-sex partner to be considered the default decision-maker, despite their having the same relationship with the patient as a legally recognized spouse. Finally, LGBT patients often do not have strong, close relationships to biological or legal family members. Seventeen states and the District of Columbia authorize a close friend to be named as a surrogate, but almost always at or near the end of the priority list, following a list of biological or legally recognized relationships.⁶ By elevating those relationships over family of choice relationships and declining to include broad definitions of family, these rankings pose a significant risk of granting decision-making authority to people who may or may not have sufficient knowledge of the patient's personal values and wishes for

⁶Alaska Stat. §13.52.030 (West 2007); Ariz. Rev. Stat. Ann. §36-3231 (West 2007); Colo. Rev. Stat. Ann. §15-18.5-103 (West 2007); 16 Del. Code §2507 (West 2007); D.C. Code §21-2210 (2007); Fla. Stat Ann. §765.401 (West 2007); Haw.Rev. Stat. §§327E-2 & E-5 (2007); 755 Ill Comp. Stat. §40/25 (West 2007); 18-A Me. Rev. Stat. Ann. §5-805(West 2007); Md. Health-Gen. Code Ann., §5-605 (West 2007); Miss. Code Ann. §§41-41-211; N.M. Stat. Ann. 1978 §24-7A-5 (West 2007); N.Y. Pub.Health Law §2965 (McKinney 2007) [Limited to DNR orders]; N.D. Cent.Code §23-12-13 (2007); Tenn. Code Ann §68-11-1806 (West 2007); W.Va. Code Ann. §16-30-8 (West 2007); Wis. Stat. Ann. §50.06 (West 2007) [Limited to certain facility admissions]; Wyo. Stat. Ann. §35-22-406 (2007).

medical care. In fact, some LGBT patients may feel so alienated from their biological family that they would not even fall on a list of potential surrogate decision-makers. In order to ensure that the wishes of LGBT patients are respected, guidance is necessary to ensure that various state law rankings are interpreted in the least discriminatory way possible to protect the rights of all patients. Specifically, we urge CMS to issue guidance ensuring that biological and legal relationships will not be favored over other relationships for the purposes of naming a medical decision-maker where there is no advance directive.

First, CMS should adopt a model policy for determining who should be a surrogate decision-maker and encourage states to adopt it. This policy should emphasize that ascertaining the wishes of the patient should be the primary concern and, accordingly, the person selected as the surrogate decision-maker should be the person most likely to be knowledgeable about the patient's wishes. Instead of relying on an arbitrary ranking of family members, the model policy should focus on determining who the patient was most likely to have wanted the act as a surrogate. This determination should be based on proof of a close, personal relationship such as proof of shared residence, a shared social or personal life, and a relationship that exhibits a particularly high level of closeness and care. The policy should encourage providers to rely on potential surrogates to identify themselves, and require proof of their relationship only where there is a conflict between one or more people claiming to be the patient's surrogate. In those situations, providers should be allowed to weigh indicia of a close relationship that proves the potential surrogate is in regular contact with the patient and has a special relationship with the patient that can reasonably be interpreted as embodying a family of choice that gives the individual specific familiarity with the patient's values and wishes. This policy should make clear that a relationship should not be afforded any extra consideration simply because it is based on a biological connection or is legally recognized as opposed to constituting a family of the patient's choice.

While a model policy will provide a useful option for states, it is critical that CMS also provide a baseline of protection for patients in all states. Thus, in addition to adopting a model policy, CMS should issue nondiscrimination guidance for medical decision-making as a condition for hospitals and CAHs participating in Medicare and Medicaid programs. In order to ensure that all patients have medical decisions made on their behalf by those people who are most equipped to do so, CMS must issue guidance prohibiting hospitals and CAHs from favoring biological or legally recognized relationships at the expense of other relationships.

Any guidance issued by CMS would need to specify that biological and legal recognition of a relationship cannot be a requirement to become a surrogate decision-maker. Some states have already enacted statutes that prohibit some of this discrimination. Maine and New Mexico, for example, both allow individuals who have relationships that share characteristics similar to that of a spouse to serve as a decision maker without requiring a domestic partnership, civil

union or marriage.⁷ They also both allow for an adult “who has exhibited special concern for the patient,” to be the surrogate decision-maker if no family members are available.⁸ Thus, decision-making authority would flow to close friends and family of choice, but only where no biological or legally recognized family members were available. While those structures provide a great deal of protection for LGBT patients, additional protections would be necessary to ensure that LGBT parents, who often do not have biological or legally recognized relationships to their children, are able to make medical decisions on behalf of their minor children; and, accordingly, that adult children of LGBT parents are able to make medical decisions on behalf of their parents.

In order to ensure that all decision-making on patients’ behalf is made by the person with the most knowledge of the patient’s wishes, and to increase accessibility for LGBT patients and families, we urge CMS to issue nondiscrimination guidance. Pursuant to its authority under 42 C.F.R. 482.13 and 42 C.F.R. 489.102, CMS should issue the following guidance to hospitals and CAHs for determining medical decision-makers:

- 1) For the purposes of determining a surrogate decision-maker where there is no validly executed advance directive, providers may not discriminate against otherwise eligible family members on the basis of the actual or perceived marital status, biological or legally recognized relationship, sexual orientation, or gender identity. For example:
 - a. Where a “spouse” would become the medical decision-maker for a patient, this category must include any adult who shares a committed, emotional, physical and financial relationship with the patient that shares characteristics that include those that are similar to that of a spouse, regardless of whether or not their relationship is legally recognized.
 - b. Where an “adult child” would become the medical decision-maker for a patient, this category must include adult biological or adopted children, stepchildren, foster children, and children for whom anyone in the family stood *in locoparentis*, regardless of whether the relationship is based on a biological or legally recognized tie.
 - c. Where a “parent” would become the medical decision-maker for a minor child, this category must include any adult who is related to the child through biology, adoption, a step-parental/child relationship, and anyone who has stood *in loco parentis* for the child, regardless of whether the relationship is based on a biological or legally recognized tie.

D. Conclusion

In conclusion, we would like to reiterate our appreciation for the willingness of CMS to engage in this issue. We are grateful that CMS is aware of the seriousness and importance of the right of LGBT patients to have access to the correct surrogate decision-makers and those who

⁷Me. Rev. Stat. Ann. § 5-805; N.M. Stat. Ann. §§ 24-7A-5.

⁸*Id.*



know them best in a time of such vulnerability. We look forward to continuing to work with CMS to ensure that the wishes of all patients, regardless of sexual orientation or gender identity, are respected when they are unable to speak on their own behalf.

Thank you,

American Civil Liberties Union
Center for LGBT Social Science & Public Policy Roosevelt House Public Policy Institute at Hunter College
Family Equality Council
Gay and Lesbian Medical Association
Human Rights Campaign
National Black Justice Coalition
National Center for Lesbian Rights
National Center for Transgender Equality
National Coalition for LGBT Health
National Gay and Lesbian Task Force
Services and Advocacy for GLBT Elders (SAGE)
Transgender Law Center