February 10, 2015

Ms. Marilyn Tavenner
Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS–3302–P
P.O. Box 8013
Baltimore, MD 21244–8013

Re: Medicare and Medicaid Program; Revisions to Certain Patient’s Rights
Conditions of Participation and Conditions of Coverage (CMS-3302-P/RIN 0938-AS29)

Dear Administrator Tavenner,

American Psychological Association, Center for Medicare Advocacy, AIDS Community Research Initiative of America, Medicare Rights Center, Gay and Lesbian Advocates and Defenders, Lambda Legal, National Center for Transgender Equality, National LGBTQ Task Force, Services and Advocacy for GLBT Elders, Consumer Voice, National Senior Citizens Law Center, National Center for Lesbian Rights, and Human Rights Campaign appreciate the opportunity to provide comments related to the proposed regulations by the Centers for Medicare and Medicaid Services (“CMS”), which would revise the applicable conditions of participation (“CoPs”) for providers, conditions for coverage (“CfCs”) for suppliers, and requirements for long-term care facilities, to ensure that the agency’s regulations are consistent with the Supreme Court decision in United States v. Windsor

1 570 U.S. 12, 133 S.Ct. 2675 (2013).
2 American Psychological Association, Center for Medicare Advocacy, AIDS Community Research Initiative of America, Medicare Rights Center, Gay and Lesbian Advocates and Defenders, Lambda Legal, National Center for Transgender Equality, National LGBTQ Task Force, Services and Advocacy for GLBT Elders, Consumer Voice, National Senior Citizens Law Center, National Center for Lesbian Rights, and Human Rights Campaign appreciate CMS’s clarification
We commend CMS for its efforts to revise the agency’s regulations to ensure that all same-sex spouses in legally-valid marriages are recognized and afforded equal rights in Medicare and Medicaid participating facilities. As such, we strongly support the proposed regulations (“celebration rule”) and encourage CMS to adopt a final rule that provides the same commonsense fixes, which aim to ensure that the agency will treat same-sex spouses the same as opposite-sex spouses. Additionally, to avoid the unintended consequence of continued discrimination, we request that CMS consider implementing several revisions (outlined below) so that the proposed regulations would rely less on state law. Without such protections, and their vigorous enforcement, long-term care facilities may create disparate rules and practices that violate the rights of LGBT people.

I. RECOMMENDATIONS

1. The “Celebration Rule” Appropriately Updates CMS’s Regulations, Is Consistent with Windsor and HHS Policy, and Should Be Adopted

A. Changes in Regulations Are Needed to Afford Equal Treatment to Same-Sex Spouses.

As indicated by CMS in its request for comment, the Supreme Court has held that prohibiting Federal recognition of same-sex spouses who were lawfully married “undermines both the public and private significance of state-sanctioned same-sex marriages.” As a result of the ruling in the Windsor case, the Federal government now must recognize the valid marriages of same-sex couples. Notably for these circumstances, HHS has already adopted a department policy calling for the equal treatment of same-sex spouses in all allowable circumstances. Therefore, it is particularly appropriate that the regulations proposed by CMS – a division of HHS – would update the agency’s regulations and bring them in line with department policy.

B. The Proposed Regulations Will Affect a Large Number of People.

While estimates of the size of the lesbian, gay, bisexual, and transgender (“LGBT”) community vary, a conservative estimate puts the number of LGBT individuals in the United States at around 10,000,000. Thus, should CMS fail to adopt the “celebration rule,” a significant portion of American citizens would be left potentially unprotected at a critical time in their lives. In addition, while more than 70% of the United States now lives in states in which same-sex couples may legally marry, these simple updates to CMS’s regulations would provide those lawfully married same-sex spouses with much needed certainty and dignity on a nationwide basis, as there are still a number of states that refuse to recognize a marriage celebrated by a same-sex couple in another jurisdiction. Simply put, the “celebration rule” is sound policy that provides a simple fix to a significant problem.

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3 For background information on each of our organizations, please see Appendix A.
4 This proposed rule would revise certain regulations governing Medicare and Medicaid participating providers and suppliers by proposing to clarify that where state law or facility policy provides or allows certain rights or privileges to a patient’s opposite-sex spouse under certain provisions, a patient’s same-sex spouse must be afforded equal treatment if the marriage is valid in the jurisdiction in which it was celebrated.
5 Id. at 2694-94.
C. The Proposed Regulations Will Protect a Vulnerable Population.

i. LGBT Patients Experience Greater Discrimination in Health Care.

In addition to being sound policy, the “celebration rule” will provide much needed protections to already vulnerable populations and potentially improve these populations’ health and welfare. For example, studies have shown that more than half of gay individuals and nearly three-quarters of transgender individuals report some form of discrimination, harassment, or substandard care when attempting to access quality health care services. Given the heightened level of discrimination the LGBT community faces in a medical setting, it is clear why ensuring same-sex spouses have equal rights in Medicare and Medicaid participating facilities is necessary.

The proposed regulations strive to ensure recognition of all same-sex spouses. Non-recognition of same-sex spouses is a form of stigma that can be harmful. For example, stigma gives rise to prejudice, discrimination, and violence against people based on their sexual orientation. Research indicates that the experience of stigma and discrimination is associated with heightened psychological distress among LGBT individuals, which has negative implications for health, including mental and behavioral health. It is especially noteworthy that these proposed regulations would cover Community Mental Health Centers, which provide services that can mitigate the impact of stigma.

Moreover, as we know you are aware, LGBT older adults also experience other forms of discrimination in health care settings beyond the issue of marriage recognition. We note that CMS already plans to propose a regulation to explicitly add sexual orientation and gender identity nondiscrimination protections in the CoPs for hospitals. We urge CMS to adopt similar protections across all of its programs. Without such protections, and their vigorous enforcement, many facilities may create disparate rules and practices that violate the rights of LGBT people. Similarly, we ask that protections extend to the special health services and needs of transgender persons who have undergone transition-related procedures, surgeries, and/or rehabilitation and reside in long-term care facilities.

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10 I.H. Meyer, *Prejudice, Social Stress, and Mental Health in Lesbian, Gay, and Bisexual Populations: Conceptual Issues and Research Evidence*, 129 Psychol. Bull. 674, 690 (2003); see also I.H. Meyer, *Minority Stress and Mental Health in Gay Men*, 36 J. Health & Soc. Behav. 38 (1995) (finding that gay men who experienced high levels stress related to their minority status were also two to three times more likely than other gay men to suffer from high levels of psychological distress); V.M. Mays & S.D. Cochran, *Mental Health Correlates of Perceived Discrimination Among Lesbian, Gay, and Bisexual Adults in the United States*, 91 Am. J. Pub. Health 1869 (2001) (finding disparities in psychological symptomatology between heterosexuals and gay/bisexual people but also finding that disparities were explained to significant degree by respondents’ experiences with discrimination and prejudice).

ii. **LGBT Patients Are at a Greater Risk to Experience a Disability or Poverty.**

What’s more, there are certain subsets of the LGBT community that are faced with particular circumstances that make it more likely that these individuals will need to access services from Medicare and Medicaid participating facilities, thus further necessitating that CMS adopt the “celebration rule.” For example, according to some studies, LGBT older adults experience higher rates of physical disabilities than their straight counterparts.\(^\text{12}\) Moreover, statistics show that approximately 24% of lesbians and 15% of gay and bisexual men live in poverty, compared with only 19% and 13% of heterosexual women and men, respectively.\(^\text{13}\) These statistics, when taken together, suggest there is an elevated likelihood that LGBT adults, older adults, and same-sex families will access health services through Medicare and Medicaid participating facilities. By adopting the “celebration rule,” the CMS is striving to ensure that these LGBT individuals, spouses, and families are treated the same as opposite-sex spouses.

iii. **Older Gay Men Are Disproportionately Affected by HIV.**

Also of note, by 2015, half of those living with HIV in the U.S. will be age 50 or older.\(^\text{14}\) Gay and bisexual men remain disproportionately affected by the virus, with 60% of infections among men 50 and older attributed to male-to-male sexual contact.\(^\text{15}\) While the aging of the HIV/AIDS population is a tribute to the success of current HIV treatments, older adults with HIV are experiencing high rates of multimorbidity decades earlier than their non-infected peers.\(^\text{16}\) These high rates of multimorbidity portend a heavy reliance on a variety of healthcare services, including long-term care services, as many in this population lack the informal supports that are typically relied on for caregiving assistance. Thus, they use a high volume of non-HIV services, including community-based and institutional long-term care.\(^\text{17}\) CMS’s “celebration rule” will help insure that older gay and bisexual men with HIV and their spouses receive equal treatment and support in Medicare and Medicaid participating facilities.

### 2. **In Adopting the “Celebration Rule,” CMS Should Rely Less on State Law**

While the proposed regulations will certainly help ensure that same-sex spouses in legally-valid marriages are recognized and afforded equal rights in Medicare and Medicaid participating facilities,

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we are concerned that the regulations incorporate or rely on state law to such an extent that they do not fully achieve their intended goal. Unfortunately, as written, the proposed regulations appear to allow discrimination to continue, but based on state, rather than federal law. For example, § 482.13(a)(1) of the proposed regulations states:

A hospital must inform each patient, or when appropriate, the patient’s representative (as allowed under State law), of the patient’s rights, in advance of furnishing or discontinuing patient care whenever possible. The same-sex spouse of a patient must be afforded treatment equal to that afforded to an opposite-sex spouse if the marriage was valid in the jurisdiction in which it was celebrated.

Thus, if state law does not recognize the spouse, then a spouse of the same sex may not be the patient’s representative.

Similarly, § 482.13(b)(2) of the proposed regulations provides:

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 same-sex spouse of a patient must be afforded treatment equal to that afforded to an opposite-sex spouse if the marriage was valid in the jurisdiction in which it was celebrated. 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. This right must not be construed as a mechanism to demand the provision of treatment or services deemed medically unnecessary or inappropriate.

In all such places, the regulation could state that the patient, his or her designated medical power of attorney, health care proxy, or, in the absence of such a person, his or her spouse. Moreover, not only should married couples be recognized as spouses for these purpose, but so too should those persons who have entered into a civil union or registered domestic partnership that was valid in the jurisdiction in which it was celebrated.

Moreover, the proposed regulations in some instances potentially create two decision makers. For example, proposed § 418.3 provides:

Representative means an individual who has the authority under State law (whether by statute or pursuant to an appointment by the courts of the State) to authorize or terminate medical care or to elect or revoke the election of hospice care on behalf of a terminally ill patient who is mentally or physically incapacitated. This may include a legal guardian. The same-sex spouse of a patient must be afforded treatment equal to that afforded to an opposite-sex spouse if the marriage was valid in the jurisdiction in which it was celebrated. If a state court has appointed a representative, that person is the representative for these purposes.

This proposed language could make both the spouse a representative and a court-appointed person a representative. Or worse, it may allow a state court to disregard a marriage between spouses of the same sex, as state law requires. In other words, discrimination might continue, albeit through a new mechanism, potentially leaving parties in lengthy litigation while decisions need to be made.

A more effective regulation might read:

Representative means a medical power of attorney, health care proxy or legal guardian or, in the absence of such a designated person, a lawful spouse (in the case of a spouse of the same
sex, as determined if the marriage, civil union, or registered domestic partnership was valid in the jurisdiction in which it was celebrated).

The proposed regulations are also often phrased in the passive voice, making it less than clear what person or entity must afford equal treatment. For example, § 418.52 of the proposed regulations states:

(3) If a state court has not adjudged a patient incompetent, any legal representative designated by the patient in accordance with state law may exercise the patient’s rights to the extent allowed by state law. The same-sex spouse of a patient must be afforded treatment equal to that afforded to an opposite-sex spouse if the marriage was valid in the jurisdiction in which it was celebrated.

This regulation presumably means the hospice provider must afford the same-sex spouse of a patient equal treatment to an opposite-sex spouse if the marriage is valid in the jurisdiction in which it was celebrated. But it does not say that, and state law may also impose limits on who may be designated.

A more effective regulation might read:

(3) If a state court has not adjudged a patient incompetent, any legal representative designated by the patient may exercise the patient’s rights, including the same-sex spouse of a patient if the marriage was valid in the jurisdiction in which it was celebrated.

There is also just some language in the proposed regulations that is less than clear. § 482.27 of the proposed regulations states:

*Notification to legal representative or relative.* If the patient has been adjudged incompetent by a State court, the physician or hospital must notify a legal representative designated in accordance with State law. If the patient is competent, but State law permits a legal representative or relative to receive the information on the patient’s behalf, the physician or hospital must notify the patient or his or her legal representative or relative. The same-sex spouse of a patient must be afforded treatment equal to that afforded to an opposite-sex spouse if the marriage was valid in the jurisdiction in which it was celebrated. For possible HIV infectious transfusion beneficiaries that are deceased, the physician or hospital must inform the deceased patient’s legal representative or relative. If the patient is a minor, the parents or legal guardian must be notified.

It is not clear to whom the proposed regulations are referring when they reference “HIV infectious transfusion beneficiaries.” Presumably this means someone who received a transfusion that was infected with HIV. Regardless, whatever it means, it does not ensure that the deceased’s spouse is informed of the HIV infection. It would be more effective to provide:

For possible HIV infectious transfusion beneficiaries that are deceased, the physician or hospital must inform the deceased patient’s spouse (in the case of a spouse of the same sex, as determined if the marriage, civil union, or registered domestic partnership was valid in the jurisdiction in which it was celebrated) and legal representative or relative. If the patient is a minor, the parents or legal guardian must be notified.
II. CONCLUSION

We appreciate the opportunity to comment on CMS’s “celebration rule” proposal and look forward to working with the agency to ensure the proposed rule is ultimately adopted, but with less of a reliance on state law. We would welcome efforts to collaborate with CMS to ensure the provision of quality care. Please feel free to contact us with any questions you may have on our comments at madams@sageusa.org or (212) 741-2247.

Sincerely,

Michael Adams
Executive Director, SAGE