

August 13, 2019

Secretary Alex Azar
U.S. Department of Health and Human Services
Herbert H. Humphrey Building, Room 509 F
200 Independence Ave. SW
Washington, DC 20201

Re: Docket ID HHS-OCR-2019-0007, RIN 0945-AA11, Nondiscrimination in Health and Health Education Programs or Activities (Section 1557 NPRM)

Dear Secretary Azar:

The National Partnership for Hospice Innovation (NPHI) is writing to comment on the notice of proposed rulemaking (NPRM) on Section 1557 of the Patient Protection and Affordable Care Act (ACA) issued by the Office for Civil Rights (OCR) at the U.S. Department of Health and Human Services (HHS). NPHI is a collaborative of many of the nation's most innovative, community-based, not-for-profit hospice and palliative care providers that serve as a critical safety net in communities across the United States. In coming together, we work to identify, enhance, and spread the best practices in which our members are engaged.

NPHI members have decades of experience in providing the highest quality hospice and palliative care to those facing the final stages of their lives. Of the almost 4,500 hospice providers in the United States, only 27 percent are not-for-profit, but they serve the sickest and most vulnerable patients in our communities and refuse to turn any patient away regardless of their terminal condition or ability to pay, while still providing a comprehensive scope of care to meet each patient's goals, values, and wishes during their last stage of life. Our programs serve thousands of individuals every year, including those who are on the LGBT-spectrum and those who require services in languages other than English.

The Health Care Rights Law (Section 1557 of the ACA) prohibits discrimination in health care based on race, color, national origin, sex, age, and disability. We strongly oppose the NPRM provisions which seek to eliminate and limit the law's protections for individuals who are limited English proficient, LGBTQ persons, persons with disabilities and chronic conditions, and persons needing reproductive health services, as well as individuals whose identities intersect multiple protected classes. If finalized, the proposed rule would severely threaten our member organizations' patients' access to health care.

Because of the harmful effects of these proposed rules on the individuals we serve, we urge HHS to withdraw this NPRM in its entirety.

The Proposed Rule Would Harm Individuals' Meaningful Access to Care and Nondiscrimination Protections

We oppose the proposed repeal of the requirement that covered entities provide a notice of nondiscrimination that informs individuals of their legal rights. Without the notice, patients and their caregivers of all backgrounds and identities will be less likely to know what to do if they experience discrimination, including that they have the right to file a complaint and how to file such a complaint. Those who need language services and auxiliary aids have less reason to know that language services and auxiliary aids and services are available and how to request them.

The Proposed Rule Would Greatly Harm Patients and their Families Who Are Limited English Proficient

We strongly oppose the proposal to eliminate the 1557 rule’s nondiscrimination notice, taglines, and language access plan provisions. These provisions are key to ensuring that those considering palliative or hospice care and their caregivers, can a) access care and services, b) receive important health care information in a language they understand, and c) are informed of their rights and how to enforce them.

It is especially critical that those facing the end of their lives have robust language access resources and protections from discrimination. It is unrealistic to expect LEP individuals to attain full English proficiency at the end of their lives. Specifically, in the health care context, four million Medicare beneficiaries—older adults and people with disabilities—are limited English proficient, and 12% of Medicare beneficiaries living in the community report that English is not their primary language.

Hospice and palliative care organizations provide a comprehensive scope of care that meets each patient’s goals, values, and wishes during the last stages of their lives. This necessarily translates into everything from treatment for the terminal condition and comorbidities to pain and symptom management, as well as psychosocial and spiritual care. Due to the complex nature of hospice and palliative care, this information must necessarily be communicated in the primary language of the individual and their caregiver(s). A prime example of this comes up often with Spanish-speaking patients and families. In Spanish, “el hospicio” translates to concept not at all affiliated with the English word “hospice” – it can mean “asylum” as in mental health institution or “poorhouse.” Thus, it is crucial to be able to communicate in an individual’s primary language and use the correct words or phrases to translate the concept of “hospice.”

Hospice and palliative care treatment plans are necessarily developed in consultation with the individual and their families. If an LEP patient or their caregiver does not understand a statement they receive, is not told or has no notice of how to get help in their primary language, they may not ask for an interpreter or there may be a catastrophic misunderstanding in the development of a treatment plan. Misunderstandings could range from a failure to disclose all of the patient’s medications at the point of intake, to developing care plans that are not in accordance with the patient’s goals, values, and wishes, or crafting treatment plans that the family does not understand and is thus unable to help carry out. This is especially important when there is an expectation for care to be administered in the home by caregivers or family members. The consequences of a patient and their caregiver not receiving this information in their primary language and in a timely manner are nothing short of catastrophic.

Another example of how eliminating Sec 1557 protections will have dire consequences relates to the data collected by the government to inform quality and value-based payment. Published studies indicate that Chinese speakers are culturally less likely to choose extremes (low or high) on surveys.ⁱ Additionally, the way the rating question is worded (“what number would you give this hospice” rather than a more explicit question indicating what that rating means) makes it more likely that a Chinese-speaking person will give a hospice a rating of an 8 rather than a 9 or a 10. One of our member hospices found that those Chinese speaking patients and families who rated the hospice an 8 were very satisfied with our care. Upon further inquiry, they found that “8” is a lucky number in Chinese culture and that those who reported 8s were likely intending to indicate a high level of satisfaction. This example serves to highlight that a result of eliminating Sec 1557 protections could profoundly impact the data that HHS uses to move toward a value-based payment system.

The Proposed Rule Would Greatly Harm LGBTQ Patients

We strongly oppose the proposed rule's elimination of the definitions of sex, gender identity, and references to sex stereotyping.ⁱⁱ The current regulations make clear that the law's prohibition on discrimination based on sex includes discrimination on the basis of gender identity and sex stereotyping. The rules' protections for transgender older adults include requiring providers to treat individuals consistent with their gender identity.

Moreover, the rollback of these protections will increase health disparities. LGBTQ older adults experience pronounced health disparities and higher poverty rates compared to their heterosexual and cisgender peers due in large part to historical and ongoing discrimination.

Research has consistently shown that older LGBT individuals are less likely than heterosexual peers to reach out to providers or utilize social support programs because they fear sexual orientation- or gender-based discrimination and harassment, because they have already experiences with receiving inferior or neglectful care, or because they already have experiences with being denied health care.ⁱⁱⁱ This means that individuals who may otherwise need palliative care or treatment through hospices are less likely to seek services while they face advanced illness or at the end of their lives.

Furthermore, recent research has shown that older LGBT individuals are twice as likely to be single and live alone and are four times less likely to have children.^{iv} As a result, LGBT individuals are more likely to turn to others for care, including in assisted living centers, nursing homes, and hospice settings—leaving them especially vulnerable to discriminatory treatment at the end of their lives.

NPHI member organizations see this on a routine basis, as many of our programs have their own inpatient units, serving patients who have no caregivers themselves and have a multitude of special programming all of which play a critical role at the end-of-life for those who have no alternative supports and who could otherwise go without care during this vulnerable time. Even with the promise of specific programming, patients will not seek out care if they are afraid of discrimination.

Nondiscrimination protections, like those in the Health Care Rights Law (Section 1557) ensure that patients can access the same care provided to other patients—no matter who they are.

Conclusion

Thank you for the opportunity to comment on the nondiscrimination NPRM. Because of the harms it would cause older adults, particularly those at the end-of-life, we strongly urge HHS to withdraw this NPRM in its entirety. Please contact John Richardson at jrichardson@hospiceinnovations.org or Cate Bonacini at cbonacini@hospiceinnovations.org with any further questions.

Sincerely,



Tom Koutsoumpas
President and CEO
National Partnership for Hospice Innovation

ⁱ Rui Wang, Brian Hempton, John P Dugan, Susan R Komives. Cultural Differences: Why Do Asians Avoid Extreme Responses? Survey Practice, Vol. 1, Issue 3 (September 30, 2008). [10.29115/SP-2008-0011](https://doi.org/10.29115/SP-2008-0011).

ⁱⁱ **45 C.F.R. § 92.4**

ⁱⁱⁱ <https://www.sageusa.org/wp-content/uploads/2018/05/sageusa-the-facts-on-lgbt-aging.pdf>

^{iv} <https://www.sageusa.org/wp-content/uploads/2018/05/sageusa-the-facts-on-lgbt-aging.pdf>