

United States Senate

WASHINGTON, DC 20510-0609

June 30, 2021

The Honorable Xavier Becerra
Secretary of Health and Human Services
Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

The Honorable Chiquita Brooks-LaSure
Administrator
Centers for Medicare and Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

Dear Secretary Becerra and Administrator Brooks-LaSure:

We write to request review of issues facing the Lesbian, Gay, Bisexual, and Transgender (LGBT) older adult population, including those who are seriously ill or at the end-of-life, to improve high-quality, culturally competent care and request a briefing on the subject. We urge you to use all appropriate authority to improve data collection and issue guidance for providers, specifically to support LGBT older Americans receiving palliative and hospice care.

At this time, there are well over one million LGBT persons 65 and older in the United States. With a growing aging population, there is greater urgency to address the palliative and end-of-life care needs among this population. LGBT persons have unique health needs and have experienced disparate health care due to discrimination based on their sexual minority status and associated fear of disclosure of their sexual orientation or gender identity to health care providers.^{1,2} These fears are steeped in historical discriminatory trauma as LGBT persons have been persecuted. At times, individuals have experienced harassment and violence in their communities, and for decades, it was a crime to be a member of the LGBT community in America. This is especially true for older LGBT adults and these specific fears pose as a barrier to their accessing and receiving high-quality, culturally competent care. Over a third of LGBT older adults are fearful that they will not receive treatment with dignity and respect by medical providers.³ Moreover, specific to Palliative and end-of –life care, over 60 percent of interprofessional palliative care and hospice providers report that family members and friends of LGBT patients were more likely to experience discrimination than heterosexual patients.³ Many of these providers noted observing discriminatory actions including inadequate and disrespectful

¹ Carey Candrian, PhD, Kristin G Cloyes, PhD, MN, RN, “She’s Dying and I Can’t Say We’re Married?”: End-of-Life Care for LGBT Older Adults, *The Gerontologist*, 2020;, gnaa186, <https://doi.org/10.1093/geront/gnaa186>

² Claire Cleveland, “Many LGBTQ Seniors Don’t Get The Health And End-Of-Life Care They Need. Some Coloradans Are Working To Change That.” CPR News January 22, 2021 [Link](#)

³ Gary L. Stein, Cathy Berkman, Sean O'Mahony, David Godfrey, Noelle Marie Javier, and Shail Maingi. Transgender Patients and Families in Hospice and Palliative Care: Perspectives of the Palliative Care Team, *Journal of Palliative Medicine*. Jun 2020.817-824.<http://doi.org/10.1089/jpm.2019.0542>

care of the patient. Family, friends, and surrogates have had their treatment decisions disregarded or minimized and been treated disrespectfully, as well.

The previous administration eliminated the sexual orientation and gender identity (SOGI) questions once included in the National Survey of Older American Act Participants (NSOAAP). It is critically important that you reincorporate these questions. Going forward, we also request inclusion of a sexual orientation category and a transgender identity field in the national disability survey, as was planned prior to the previous administration.^{3,4,5}

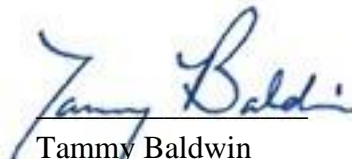
In addition, we request guidance for hospitals, long-term-care facilities, and agencies in the provision of palliative and hospice care for LGBT older adults. Guidance developed based on the work of SAGE, a national organization serving LGBT older adults, or similar organizations that provides a model for training staff to identify abuse of LGBT patients, will encourage respectful and competent treatment.^{6,7,8} This manualized training may assist long-term-care facilities and agencies in palliative and hospice care provision through a cultural humility lens, allowing for greater acceptance and comfort while ill and at the end-of-life.

We look forward to your response confirming these actions and to schedule a briefing with our staff. You may reach them at Santiago_Gonzalez@bennet.senate.gov.

Sincerely,



Michael F. Bennet
United States Senator



Tammy Baldwin
United States Senator

⁴ U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services: Protecting statutory conscience rights in health delegations of authority. 84 FR 23170. Rockville, MD, May 21, 2019. [Google Scholar](#)

⁵ SR. Cahill and Harvey J. Makadon. If they don't count us, we don't count: Trump rolls back sexual orientation and gender identity data collection. *LGBT Health*. June 2017.171-173. <http://doi.org/10.1089/lgbt.2017.0073>

⁶ Kimberly D. Acquaviva *LGBTQ-Inclusive Hospice and Palliative Care: A Practical Guide to Transforming Professional Practice*. New York: Harrington Park Press, 2017.

⁷ SAGE National Resource Center on LGBT Aging: *Age-Friendly Inclusive Services: A Practical Guide to Creating Welcoming LGBT Organizations*. New York, SAGE National Resource Center on LGBT Aging, 2017.

⁸ National Hospice and Palliative Care Organization Diversity Advisory Council. 2019. <https://www.nhpco.org/about-nhpco/committees-and-councils/diversity-advisory-council>