August 13, 2019

The Honorable Alex Azar, Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Re: Nondiscrimination in Health and Health Education Programs or Activities

Dear Secretary Azar,

On behalf of the Coalition to Transform Advanced Care (C-TAC), we appreciate the opportunity to provide comments on this proposed rule in regard to its effects on those living with advanced illness.

C-TAC is a national non-partisan, not-for-profit organization dedicated to ensuring that all those living with advanced illness, especially the sickest and most vulnerable, receive comprehensive, high-quality, person- and family-centered care that is consistent with their goals and values and honors their dignity. C-TAC is made up of over 140 diverse national and regional organizations including patient and consumer advocacy groups, practitioners, health plans, faith-based and community organizations, and others. While they all share a common vision of improving advanced illness care in the U.S, C-TAC’s members represent many different perspectives.

C-TAC’s definition of advanced illness is when one or more conditions becomes serious enough that general health and functioning begin to decline, treatment may no longer lead to preferred outcomes, and care oriented toward comfort may take precedence over attempts to cure – a process that extends to the end of life and that for some individuals and their families may lead to transition to hospice. This population is large and growing and increasingly diverse in regard to ethnicity, spiritual practices, culture, and gender identity.

While we support the Administration’s efforts to reduce regulatory burden and cost, we fear that some of the proposed changes may have negative unintended consequences. These could include potentially eliminating the general prohibition on discrimination based on gender identity, as well as specific health insurance coverage protections for transgender individuals; eliminating the provision preventing health insurers from varying benefits in ways that discriminate against certain groups, such as people with HIV or LGBTQ people; and weakening protections that provide access to interpretation and translation services for individuals with limited English proficiency.
Those with advanced illness already represent a vulnerable population and they require all the legal and regulatory support possible. Individuals that identify as LGBTQ and their caregivers often experience challenges in accessing high-quality palliative and advanced illness care\(^1\), including hurdles related to provider communication, perceptions of safety and acceptance, and assessing and respecting patients’ definitions of family and spirituality\(^2\). Additionally, people from culturally and linguistically diverse backgrounds and their caregivers are often confronted with difficult language barriers and unfamiliar customs that frustrate their ability to access palliative care and benefit most fully from its interventions\(^3\). We therefore suggest you revise the proposed rule to ensure that those with advanced illness, and their families, continue to receive all the protections and opportunities possible to achieve their personal goals, live their values, and attain their best health and quality of life.

Thank you for the opportunity to comment on this proposed rule. If you have any questions, please contact me, Marian Grant, Senior Regulatory Advisor, C-TAC, at 443-742-8872 or mgrant@thectac.org.

Sincerely,

*Marian Grant*

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\(^1\) Stein, GL, Berkman, C, et al., "Experiences of LGBT Patients and Families in Hospice and Palliative Care," 2019, unpublished manuscript
