



May 12, 2017

Dan Berger, MPA
Acting Administrator, Administration of Community Living
Acting Assistant Secretary of Aging
Department of Health and Human Services
Washington DC

Dear Acting Administrator Berger:

The National Coalition for Hospice and Palliative Care (Coalition) appreciates the opportunity to submit comments on the *Draft Principles for a Person-Centered Approach to Serious or Advanced Illness*. The Coalition commends the Administration for Community Living (ACL) for establishing a core set of principles around serious illness to guide the ACL and the Department of Health and Human Services when developing policies that will impact older adults and persons with disabilities. We fully support the Administration's efforts to establish principles that promote each individual's right to guide and control their care and services, regardless of their age, disability or severity of illness.

The Coalition is composed of the leading national hospice and palliative care organizations dedicated to advancing care of patients, families and caregivers living with serious illness, as well as those facing the end of life. The organizations that form the Coalition represent more than 5,000 physicians, 11,000 nurses, 5,000 professional chaplains, more than 5,000 social workers, researchers, 1,600 palliative care programs, and over 5,300 hospice programs and related personnel, caring for millions of patients and families. Our combined membership represents the interdisciplinary hospice and palliative care team which is person- and caregiver-centered.

In response to the ACL's request for comments, we have attached recommended edits for each specific principle. Additionally, we would like to offer the following general comments for your consideration:

Title of document: We recommend that "Advanced Illness" be removed from the title and within the document. In the field of hospice and palliative care, "advanced illness" and "serious illness" are not interchangeable. Each phrase indicates a different place on the severity scale of illness; those with serious illness may live for several years with their condition (and may recover or eventually transition to end of life), whereas advanced illness typically refers to those in the last year of life. Although we recognize that efforts to include both terms are well-intended, [market research](#) has shown that presenting these phrases together confuses the public and negatively impacts their understanding of and willingness to ask for (and clinicians' willingness to refer to) palliative care. Adjusting the title to "Principles for a Person-Centered Approach to Serious Illness" will increase the likelihood that the target audience can access palliative care, and later on, hospice, when appropriate.

Cultural competency: The Coalition believes strongly that these principles should specify the need to provide culturally sensitive care to seriously ill older Americans and those with disabilities. A "one-size-fits-all" approach to advance care planning, goals of care discussions, palliative care or hospice care

must be culturally appropriate to each community; therefore this should be explicitly noted in the principles.

Anti-discrimination language: We commend the Administration for including basic antidiscrimination language in the principles, but note that a few groups were omitted. Antidiscrimination principles should reflect the discrimination, abuse/neglect, and stigma older Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, and Asexual (LGBTQIA) adults have encountered in receiving services. According to the groundbreaking report published in 2011, [LGBT Older Adults in Long-Term Care Facilities](#), LGBTQIA elders are more likely to be single, childless, estranged from their biological family, and reliant on families of choice, such as friends and other loved ones. The Coalition supports adding language explicitly adding antidiscrimination protections for this community, as well as a few others.

Improved definitions of palliative care and hospice: The Coalition fully supports the inclusion of access to palliative care and hospice care for older adults and those with disabilities, as those with serious illness would greatly benefit from these services. Within this set of principles, we have provided a more comprehensive definition of palliative care and hospice and would appreciate the inclusion of this language.

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The National Coalition for Hospice and Palliative Care, and our member organizations, thank the ACL for your willingness to engage with the broad stakeholder community and your dedication to improving the health and well-being of older Americans and those with disabilities. We look forward to future stakeholder engagement opportunities as the ACL continues to refine these principles. If you have any questions, please do not hesitate to contact me, Amy Melnick, MPA, Executive Director of the Coalition at amym@nationalcoalitionhpc.org or 202.306.3590. I would be happy to set up an additional time with you or your staff and our Coalition leadership to discuss these comments in more detail.

Sincerely,



Amy Melnick, MPA
Executive Director

Current National Coalition for Hospice and Palliative Care member organizations are:

- [American Academy of Hospice and Palliative Medicine](#) (AAHPM)
- [Association for Professional Chaplains](#) (APC)
- [Center to Advance Palliative Care](#) (CAPC)
- [Health Care Chaplaincy Network](#) (HCCN)
- [Hospice and Palliative Nurses Association](#) (HPNA)
- [National Hospice and Palliative Care Organization](#) (NHPCO)
- [National Palliative Care Research Center](#) (NPCRC)
- [Social Work Hospice and Palliative Care Network](#) (SWHPN)