

May 12, 2017

Dan Berger

Acting Assistant Secretary for Aging
Acting Administrator, Administration for Community Living
Administration for Community Living
U.S. Department of Health and Human Services
330 C Street, SW
Washington, DC 20201

Electronic submission to AdvancedIllness@acl.hhs.gov

RE: ACL Draft Principles for a Person-Centered Approach to Serious or Advanced Illness

Dear Mr. Berger:

The National Association of Social Workers (NASW) appreciates the opportunity to comment on the *Draft Principles for a Person-Centered Approach to Serious or Advanced Illness* issued by the Administration for Community Living (ACL) on March 21, 2017.

As the largest membership organization of professional social workers in the United States, with 130,000 members, NASW works to enhance the professional growth and development of its members, to create and maintain professional standards, and to advance sound social policies. Working throughout the spectrum of long-term services and supports (LTSS) and health care, social workers play an integral role in supporting individuals and families affected by serious or advanced illness. Thus, a person-centered approach to serious or advanced illness is a high priority for NASW, and the association applauds ACL's work in this area. We submit the following comments for ACL's consideration.

Principle 1. NASW agrees wholeheartedly with this principle. Self-determination is at the core of the NASW *Code of Ethics*¹ and is central to a person-centered approach. We recommend the following change to the end of the sentence: “. . . how to live **meaningfully with** these factors.”

Principle 2. NASW concurs that a person-centered approach requires all service providers to engage individuals with serious or advanced illness in a meaningful way about all aspects of

¹ National Association of Social Workers. (2015). *Code of ethics of the National Association of Social Workers*. Retrieved from <http://www.socialworkers.org/pubs/code/default.asp>

planning and decision making related to health and LTSS. The association offers the following recommendations to enhance this principle.

- Bullet 1: We recommend that ACL elaborate on principles related to person-centered planning and decision making by providing examples, such as treating the individual as an equal partner, eliciting and respecting the values and preferences of each individual, and similar actions. Alternately, ACL could include a footnote linking to a reputable resource for additional information.
- Bullet 2: NASW supports this principle.
- Bullets 3 and 4: NASW promotes the right of people with cognitive, communication, or intellectual disabilities to make decisions that affect their health and well-being. At the same time, we recognize that supports are sometimes needed to facilitate such decision making. We recommend that ACL provide examples of supported decision-making principles and practices. Alternately, ACL could include a footnote linking to a reputable resource for additional information.
- Bullet 5: NASW concurs that ongoing communication about one’s health and LTSS goals and decisions with service providers and loved ones is essential. Optimally, such communication is done both in personal interactions and in writing. At the same time, we recognize that a wide variety of factors may influence planning and decision making. For example, within the United States, the bioethical principle of autonomy often underlies health care and LTSS planning and decision making. However, autonomy is not valued equally by every individual, family, or group. Some people who live with serious or advanced illness prefer to plan and make decisions collectively with their families (a term NASW defines broadly to include legally recognized family and family of choice).^{2,3} Others may express their self-determination by deferring to their families for such planning and decision making.³ Therefore, a person-centered approach to serious or advanced illness requires flexibility in eliciting and expressing an individual’s values, goals, and decisions. Accordingly, NASW recommends that ACL modify bullet 5 in this manner: “People **should be encouraged** to document and communicate . . .”

Principle 3. NASW has long worked to eliminate discrimination based on the cultural factors listed in Principle 3, and we understand the value of referencing antidiscrimination in federal law within the principles. At the same time, the association recognizes that discrimination can be based on many other cultural factors. Consequently, we urge ACL to broaden principle 3 to read, “. . . national origin”;^[footnote] **on ability (behavioral, cognitive, emotional, intellectual, mental,**

² National Association of Social Workers. (2010). *NASW standards for social work practice with family caregivers of older adults*. Retrieved from http://www.socialworkers.org/practice/standards/Family_Caregivers_Older_Adults.asp

³ See, for example, two publications by Karen Bullock:

Bullock, K. (2011). Advance directives from a social work perspective: Influence of culture and family dynamics. In T. Altilio & S. Otis-Green (Eds.), *Oxford textbook of palliative social work* (pp. 625–635). New York: Oxford University Press.

Bullock, K. (2011b). The influence of culture on end-of-life decision making. *Journal of Social Work in End-of-Life & Palliative Care*, 7, 83–98. doi:10.1080/15524256.2011.548048

and physical), documentation status, family status, genetic information, sexual orientation, religious or spiritual belief or affiliation, gender identity and expression, or other cultural factors; or on number and type of conditions . . .” Such language is in keeping not only with NASW standards⁴ and with social justice and human rights principles, but also—to a great degree—with the regulations and standards of many health care and LTSS settings.

Principle 4. NASW recommends revising this principle both to reflect that affordability is integral to accessibility and to highlight the wide array of applicable services, including psychosocial support services: “Individuals need access to **a comprehensive array of affordable services, including psychosocial support services and spiritual care,** that enable them to manage their conditions and symptoms, live in the setting of their choice, and be integrated in the community.”

Principle 5. NASW supports access to palliative care throughout the course of serious or advanced illness. We are concerned, however, that the definition of *palliative care* is limited. In its *Clinical Practice Guidelines for Quality Palliative Care* (3rd ed.),⁵ the National Consensus Project for Quality Palliative Care (NCP) supported the definition put forward by both the Centers for Medicare & Medicaid Services (CMS) and the National Quality Forum (NQF):

Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.^{6, 7}

The NCP guidelines go on to note:

The following features characterize palliative care philosophy and delivery:

- Care is provided and services are coordinated by an interdisciplinary team;
- Patients, families, palliative and non-palliative health care providers collaborate and communicate about care needs;
- Services are available concurrently with or independent of curative or life-prolonging care;
- Patient and family hopes for peace and dignity are supported throughout the course of illness, during the dying process, and after death.⁵

⁴ National Association of Social Workers. (2015). *Standards and indicators for cultural competence in social work practice*. Retrieved from

http://www.socialworkers.org/practice/standards/Standards_and_Indicators_for_Cultural_Competence.asp

⁵ National Consensus Project for Quality Palliative Care. (2013). *Clinical practice guidelines for quality palliative care* (3rd ed.). Retrieved from http://www.nationalconsensusproject.org/Guidelines_Download2.aspx [Quote appears on p. 9.]

⁶ Medicare and Medicaid Programs: Hospice Conditions of Participation Rule, 42 C.F.R. § 418 (2008). [Quote appears on p. 202.]

⁷ National Quality Forum. (2006). *A national framework and preferred practices for palliative and hospice care quality: A consensus report*. Retrieved from www.qualityforum.org/WorkArea/linkit.aspx?LinkIdentifier=id&ItemID=22041 [Quote appears on p. VI.]

The preceding text was supported by all six NCP members: American Academy of Hospice and Palliative Medicine, Center to Advance Palliative Care, Hospice and Palliative Nurses Association, National Hospice and Palliative Care Organization, National Palliative Care Research Center, and NASW. Although the guidelines are voluntary, they are recognized widely as the gold standard for palliative care. Yet, understanding of palliative care remains limited, both among service providers and among people affected by serious or life-limiting illness. To address this gap, and for consistency with both the NCP guidelines and the U.S. Department of Health and Human Services (HHS), NASW recommends incorporation of the entire CMS–NQF definition. Should such a change not be feasible within the brief context of the ACL principles, NASW recommends use of a phrase that is more in keeping with the CMS–NQF–NCP definition, such as “interdisciplinary health care that optimizes quality of life by addressing physical, emotional, social, and spiritual needs, thereby preventing or decreasing suffering,” with a footnote to linking to the NCP guidelines.⁵

Moreover, NASW recommends that the remainder of principle 5 be amended as follows: “. . . throughout a serious illness. **Timely** access to hospice (which **is a specific palliative care delivery system for people with limited life expectancy**) is also critical for people **at the end of life.**” Rationale for these proposed changes follow.

- Within the palliative care content, we have suggested deleting the phrase *not just when they are dying*; stating myths reinforces them, even if the goal is to refute them.
- The addition of *timely* to the hospice content reflects that, although use of hospice care has increased steadily over time, length of service tends to be quite short: Although Medicare and many other payers use a six-month prognosis for hospice eligibility, more than half of individuals enrolled in hospice die within two weeks of enrollment, and just more than one-third have a length of service of one month or longer.⁸
- Modification of the brief hospice definition is consistent with conceptualization used in both the NCP guidelines⁵ and the NQF report.⁷
- Use of the phrases *for people with limited life expectancy* and *at the end of life* are consistent with the NQF report,⁷ and the latter phrase is consistent with the NCP guidelines.⁵ Both phrases convey a broader span than the phrase *during the dying process*, which many people interpret to mean the final days—or, at most, weeks—of life.

Principle 6. Advocacy is an integral role and responsibility of all social workers, and NASW supports the integration of this concept in the principles. We recommend modifying the final phrase slightly: “. . . or when their **values, goals, or** choices are not honored.” Because choices are rooted in values and goals, lack of respect for a person’s values or goals can decrease self-determination in decision making.

Principle 7. NASW concurs with this principle and recommends the following changes: “Health and LTSS providers **need to engage** family caregivers in education about health conditions . . .

⁸ National Hospice and Palliative Care Organization. (2015). *NHPCO’s facts and figures: Hospice care in America*. Retrieved from <https://www.nhpc.org/hospice-statistics-research-press-room/facts-hospice-and-palliative-care>

with serious or advanced illness. **Such education and training are also essential for other members of health and LTSS teams, such as direct care workers and professionals.**” We have listed the rationale for these changes below.

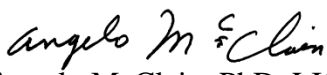
- We have substituted the strengths-based concept of engagement for the deficit-based concept of need.
- We have separated family caregivers from other members of the care team, reserving the term *caregivers* for family members (broadly defined, as previously noted). This terminology is consistent with the usage promulgated by family caregiving advocacy organizations and, furthermore, can prevent confusion. Moreover, given the existence of programs that remunerate family caregivers, the term *paid* no longer distinguishes family caregivers and other people who care for people living with serious or advanced illness.
- We have delineated direct care workers and professionals to make clear that education and training benefit *all* members of the care team. An alternate term for *direct care workers* could be *paraprofessionals*, which would include community health workers, paraprofessional social service providers, and other important groups.

NASW supports draft principles 8 and 9. Furthermore, the association encourages ACL to add two additional principles to the document:

- We recommend incorporation of a principle urging health and LTSS providers to demonstrate cultural and linguistic competence in working with individuals and families affected by serious or advanced illness. This recommendation is consistent not only with the NASW standards and indicators for cultural competence,⁴ but also with the *Advanced Care, Hospice, and End-of-Life Principles* developed by the Leadership Council of Aging Organizations⁹ and with HHS’s *National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care*.¹⁰
- We also recommend incorporation of a principle noting that a person-centered approach to serious or advanced illness requires that services be coordinated and integrated.

Thank you for your consideration of NASW’s comments. Should you have questions about the association’s comments, please contact my office at naswceo@naswdc.org or (202) 408-8200.

Sincerely,


Angelo McClain, PhD, LICSW
Chief Executive Officer

⁹ Leadership Council of Aging Organizations. (2016). *Advanced care, hospice, and end-of-life principles*. Retrieved from <http://www.lcao.org/lcao-advanced-care-hospice-end-life-principles/>

¹⁰ U.S. Department of Health and Human Services, Office of Minority Health. (2013). *National standards for culturally and linguistically appropriate services in health and health care*. Retrieved from <https://www.thinkculturalhealth.hhs.gov/clas>