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

Dear Assistant Secretary Walker and Acting Commissioner Williams,

The Alzheimer’s Association appreciates the opportunity to comment on the Administration for Community Living’s (ACL) Draft Principles for a Person-Centered Approach to Serious or Advanced Illness.

The Alzheimer’s Association is the world’s leading voluntary health organization in Alzheimer’s disease care, support, and research. Today, there are more than 5 million Americans living with Alzheimer’s disease, and more than 15 million Americans providing unpaid care for them. Alzheimer’s is the only cause of death among the top 10 without a way to prevent, cure, or even slow its progression. As the size and proportion of the United States population age 65 and older continue to increase, the number of Americans with Alzheimer’s and other dementias will grow. Given this growing population and the unique needs and challenges that dementia presents to individuals and caregivers, we commend ACL for its focus on person-centered approaches.

1. **People should receive full information about their health, conditions, disabilities, available services, and about how to live successfully regardless of these factors.**

The Alzheimer's Association supports this principle. Alzheimer's and related dementias are underdiagnosed and when diagnoses are made, they are too often undisclosed by clinicians: studies suggest that fewer than half of individuals report being told of their diagnoses. Care cannot be person-centered without a thorough understanding of conditions. However, we respectfully request that ACL change “successfully” to “well.” While we understand ACL’s underlying intent, many people with degenerative conditions like dementia think in terms of living well for as long as possible with their diseases rather than “succeeding,” which suggests achievement.

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2 Ibid.
2. Principles related to planning and decision-making:

- Person-centered planning principles and practices should guide health and long-term services and supports (LTSS) planning and provision.
- Decision-making and advance planning should occur as early in the disease process as possible, especially for people with progressive illnesses like dementia or ALS, which can make clear expression of choices increasingly difficult during the course of the illness.
- All parties should presume that people with real or perceived cognitive, communication, or intellectual disabilities are able to make decisions.
- Supported decision-making principles and practices should guide those who are helping individuals who need assistance with planning and decision-making. Individual goals, decisions, and known views should take priority.
- People have a responsibility to document and communicate with loved ones and health and LTSS providers about their goals and decisions. All parties should respect these goals and decisions. Since circumstances may change over time, there should be regular opportunities to update planning and communicate goals and decisions.

The Alzheimer’s Association suggests that ACL define or expand on its understanding of “person-centered planning,” as the concept can extend to individuals with a wide range of conditions and across the care continuum.

Because Alzheimer’s and related dementias are degenerative and lack effective treatments, care planning is essential to affected persons and caregivers. It allows persons living with dementia to participate in decision-making while they are still able, and it can reduce stress and confusion for those individuals and for family and friends. And because needs and preferences can vary drastically between affected individuals and even day to day, it is all the more important that planning be tailored and updated regularly.

We respectfully request that ACL rephrase its principle related to the presumption that “people with real or perceived cognitive, communication, or intellectual disabilities are able to make decisions.” Again, we understand and support ACL’s underlying intent, but the unfortunate reality is that most individuals in the middle and late stages of dementia simply cannot make decisions. This statement fails to account for the support these individuals need.

3. Discrimination based on “age, race, sex, disability, color, national origin,” or number and type of conditions a person has should not occur during planning for or treatment of serious or advanced illness.

The Alzheimer’s Association supports this principle.

4. Individuals need access to services that enable them to manage their conditions and symptoms, live in the setting of their choice, and be integrated into the community. Spiritual care providers can be critical to community integration.

We support this principle and take this opportunity to thank ACL and the Centers for Medicare & Medicaid Services for issuing the FAQs on Wandering and Exit-Seeking Behavior in HCBS Settings in
December 2016. The guidance is clear and helpful in its examples of promising practices related to choice, integration, and safety while emphasizing a person-centered approach.

5. **Individuals should have access to palliative care (which provides symptom relief and comfort) throughout a serious illness, not just when they are dying. Access to hospice, which uses palliative care principles, is critical during the dying process.**
The Alzheimer’s Association fully supports this principle. Nearly half of all people with Alzheimer’s and other dementias are in hospice care at the time of death, yet less than half of surveyed nursing homes have some sort of palliative care program. For people with advanced dementia, such care improves quality of life, controls costs, and enhances patient and family satisfaction.

6. **Individuals should have access to advocacy services to assist them in resolving problems with services or benefits or when their choices are not honored.**
The Alzheimer’s Association supports this principle.

7. **Health and LTSS providers, including both paid and family caregivers, need education about health conditions and disabilities, living well with advanced age and/or disability, and evidence-based information and training about how to help individuals with serious or advanced illness.**
We fully support this principle and appreciate ACL’s emphasis on quality of life. As noted above, this is key to living with degenerative conditions like dementia. We also note for ACL, providers, and caregivers the many resources available through [www.alz.org](http://www.alz.org) and the Alzheimer’s Association 24/7 Helpline: 1.800.272.3900. Finally, we encourage clinicians to use the new G0505 Medicare billing code, which provides reimbursement for physicians and other practitioners to assess and develop care plans for persons with cognitive impairment. To assist primary care providers in integrating this code into their practices, the Association developed a Cognitive Impairment Care Planning Toolkit which can be found at [http://www.alz.org/careplanning/](http://www.alz.org/careplanning/). The toolkit contains a variety of educational and assessment resources.

8. **Family caregivers need services like one care coordinator they can rely on, access to a 24/7 helpline, respite, and grief counseling.**
The Alzheimer’s Association fully supports this principle and notes the 24/7 Helpline and the Caregiver Center section of our website, [http://www.alz.org/care/overview.asp](http://www.alz.org/care/overview.asp). The Cognitive Impairment Care Planning Toolkit also contains a list of resources specifically for patients and caregivers.

9. **Health and LTSS providers should be encouraged to include older persons and individuals with disabilities on their boards and committees, particularly ethics committees.**
The Alzheimer’s Association supports this principle. Since 2006, we have received advice and guidance from our National Early-Stage Advisory Group. Composed of people in the early stages of Alzheimer’s and other dementias, these advisors highlight needs and advocate on issues unique to individuals in the early stages of the disease, including younger-onset dementia. This group has helped the Association to shape better policies and services and we encourage other providers to include their patients and constituents on their advisory bodies.
Thank you for the opportunity to comment. The Alzheimer’s Association would be glad to serve as a resource to ACL as it considers these important issues and how they relate to individuals living with Alzheimer’s and related dementias. Please contact Laura Thornhill, Manager of Regulatory Affairs, at 202-638-7042 or lthornhill@alz.org if you have questions or if we can be of additional assistance.

Sincerely,

Robert Egge
Executive Vice President, Government Affairs