



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

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

1. People should receive full information about their health, conditions, disabilities, available services, and about how to live successfully regardless of these factors.
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.
3. Discrimination based on “age, race, sex, disability, color, national origin,”¹ or number and type of conditions a person has should not occur during planning for or treatment of serious or advanced illness.
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.
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.
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.
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.

¹ These are anti-discrimination terms in federal law. Please see Title VI of the Civil Rights Act of 1964 (Title VI), [42 U.S.C. 2000d et seq.](#) (race, color, national origin), Title IX of the Education Amendments of 1972 (Title IX), [20 U.S.C. 1681 et seq.](#) (sex), the Age Discrimination Act of 1975 (Age Act), [42 U.S.C. 6101 et seq.](#) (age), or Section 504 of the Rehabilitation Act of 1973 (Section 504), [29 U.S.C. 794](#) (disability).

8. Family caregivers need services like one care coordinator they can rely on, access to a 24/7 helpline, respite, and grief counseling.
9. Health and LTSS providers should be encouraged to include older persons and individuals with disabilities on their boards and committees, particularly ethics committees.