

Principles for Person-directed Services and Supports during Serious Illness

Introduction

The Administration for Community Living (ACL) supports the ability of people with a serious illness to make their own choices about how they want to live. Age, disability, type or stage of illness, and other unique personal characteristics and circumstances should not diminish people's choices or ability to live life on their own terms. ACL also supports the ability of people with serious illness to communicate their choices so that families, family caregivers,* and service providers can honor these choices. ACL's work in this area is consistent with its mission to "maximize the independence, well-being and health of older adults, people with disabilities, and their families and caregivers."

Unfortunately, people may face obstacles in making choices during serious illness. People with disabilities often have had few chances to control their own lives and make choices. Older adults often face progressive loss of control over their own lives and the chance to make choices as they age. Even if these groups make choices, those choices may not be honored during serious illness.

To address these problems, ACL listened to its aging and disability stakeholders and developed a set of person-directed* principles, which describe how our stakeholders believe health care and the long-term services and supports systems would work best for them when they are seriously ill. ACL used several sources of information to develop these principles, including:

1. Relevant literature published from 2010-2015 from the perspectives of aging and disability stakeholders.
2. Informal conversations among aging, dementia, and disability stakeholders.
3. Public comments received on the draft principles.

ACL found many commonalities among stakeholders' views, including an emphasis on a person-directed approach to services and supports during serious illness. This approach promotes choice and control by informing people about their conditions; supporting reflection on goals, values, and priorities; honoring their choices, managing symptoms; and providing individualized supports to them and others important in their lives. This can include any relative, partner, friend, neighbor, or caregiver, related or not, who has a significant personal relationship with, and who provides a broad range of assistance for a person with a chronic, disabling, or serious health condition.

The following principles are designed to:

1. Promote choice and control for people with serious illness, while taking into account their unique life circumstances.
2. Help people plan for serious illness.
3. Help families, family caregivers, and service providers honor the choices of people with serious illness.
4. Assist people with serious illness in choosing and controlling services according to personal values, priorities, and goals.

* Please see glossary for definitions.

Principles

The following principles are grounded in several assumptions about older adults and people with disabilities. These individuals need to plan for life with and without serious illness, and they are the only ones who know how and where they want to live, given their own unique circumstances. Older adults and people with disabilities need to communicate their decisions to others, and some may need supports in doing so. Families, family caregivers, and service providers should honor people's choices. In doing so, no one should make assumptions about "quality of life." For example, families, medical professionals, and service providers should not presume to know "what is best" for the person and should never assume someone would not want to live under certain circumstances, such as very old age, isolation, or significant disability or illness. In addition, communication, care, and other support during serious illness should occur in a culturally competent manner, using methods and language that the person with serious illness and those important to them understand and use.

1. **Live with serious illness according to personal values and goals.** People should be able to live according to their own values, goals, priorities, and choices, including those related to health care and long-term services and supports,* and place where they live.
2. **Enable choice of services.** People with serious illness should be able to choose or decline services. To make the best decisions, people should receive from their providers and other supports full information about: 1) their health status, conditions, illnesses, prognosis, and disabilities; 2) available services and supports, including those that are person-directed; 3) risks associated with choices; 4) rights; and 5) options for independent living in an integrated community setting. The focus for services should be on enabling people to live according to their personal values and goals and choices regarding acceptable risks. Information should be provided in a way that people can understand, taking into consideration language, preferred method of communication, culture, and health literacy. If people choose not to have information about their conditions, this choice should also be honored.
3. **Avoid discrimination.** Discrimination¹ based on a person's unique circumstances, including values, goals, conditions, and characteristics should not occur during planning for or treatment of serious illness.
4. **Enable choice of representative.** People should be able to choose whether, under what circumstances, and who they want assist them in making choices about health care and long-term services and supports that are consistent with the values, goals, and priorities of the person with serious illness. Depending upon their circumstances and cultures, people with serious illness may choose family, family caregivers, friends or others to assist them. Educating people with serious illness and those assisting them about decision-making may be necessary. Those involved in decision-making should have access to information and services available to the person with serious illness. If a person with serious illness chooses a representative, the representative should be included in all person-directed planning, and decisions about health care and long-term services and

¹ 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); Section 504 of the Rehabilitation Act of 1973 (Section 504), [29 U.S.C. 794](#) (disability); or the Americans with Disabilities Act, [42 U.S.C. 12101 et seq.](#) (disability).

supports.

5. Carry out person-directed planning and decision-making:

- Person-directed planning principles and practices should guide goal-setting and decision-making, including planning for and provision of health care and long-term services and supports.
- Providers should ask people with serious illness if they want to engage in planning for their priorities, goals, and needs.
- Advance planning for health care, long-term services and supports, and financial matters is a process, not an event. It should occur at appropriate times, especially for people with progressive illnesses, such as a dementia or Amyotrophic Lateral Sclerosis (ALS), because these illnesses make it increasingly difficult for a person to express their choices. The person with serious illness should have frequent opportunities to update their choices because a person's perspectives, values, priorities, and goals may change over time.
- The person with serious illness should take an active, leading role in the planning process and the process should occur when and where it is convenient for that person.
- People with serious illness should be encouraged and assisted to document their values, goals, priorities, and decisions and communicate them to family, friends, family caregivers and providers of health care and long-term services and supports.
- Service providers should ensure that all parties clearly understand, respect and adhere to the values, goals, priorities, and decisions of the person with serious illness.
- People with serious illness, their families, family caregivers or their service providers should receive information, explanations, or communication in a manner they can understand. When needed, communication aids should be used to facilitate discussions around planning and decisions.
- All parties should presume that people with real or perceived cognitive, communication, or intellectual disabilities are able to make and change decisions, even if supports are needed, and until proven otherwise.
- Supported decision-making* principles and practices should guide those who are providing support to people who need assistance with planning and decision-making. Supporters should be aware of and examine their motives and biases when providing supported decision making and record the decisions of the person with serious illness appropriately.²
- Alternatives to guardianship, including supported decision making, should be identified and used whenever possible prior to the commencement of guardianship proceedings.

6. Access to care coordination: People with serious illness, and their families and family caregivers should have access to a primary contact on a care coordination team that knows them, and respects their values, goals, priorities, and choices, including those concerning health care and long-term services and supports.

7. Choose among services and supports. People should have to be able to choose among services and supports that enable them to maximize their independence and integration in the community; manage their conditions and symptoms; and live in the setting of their choice. In addition to health care and long-term services and supports, many people identify other support systems, such as spiritual care* providers, as being important to their well-being and community integration.

² Please see the [National Resource Center for Supported Decision-Making](#).

8. **Deliver palliative care.*** Providers should offer, and deliver when requested, palliative care throughout a person's illness, not just during end of life. Palliative care provides an added layer of support for the relief of a wide array of symptoms associated with serious illness.
9. **Provide hospice care.*** Access to hospice, which uses palliative care principles, is often critical during end of life for people with serious illness and their families and family caregivers. The person with a prognosis of death within 6 months would receive palliative care and caregivers would receive training, education, and counseling on what to expect during the dying process and how to provide care. Timely access to hospice is critical to maximizing its benefits of pain relief for the person with illness and because support is provided to the caregivers/family members throughout the dying process and up to 12 months thereafter. Home hospice appears to be a first choice when possible.
10. **Provide independent advocacy services.** People with serious illness and their families, family caregivers or other supporters should have access to independent advocacy services to assist them in: 1) planning for their goals, including decisions about health care and long-term services and supports; 2) resolving problems with services or benefits, including when their values, goals, priorities, or choices are not honored; and 3) addressing other legal matters that affect their lives. Advocacy and supportive services may also be needed if abuse, neglect, or exploitation of the person with serious illness is suspected.
11. **Educate and support providers.** Health care and long-term services and supports providers, including family caregivers, should have education, resources, support, and incentives to provide person-directed services. Service providers should know about health conditions, the aging process and disabilities, and to have evidence-based information and training about how to serve people with serious illness. Education in effective communication and basic pain and symptom management is important. Service providers also should understand that the person with serious illness defines their values, goals, and priorities for their lives and services. When service providers understand these values, goals, and priorities, they can help the person with serious illness live their lives independently, with dignity, and in the manner and place in which they choose.
12. **Support family caregivers.** Family caregivers should receive services that support them in avoiding isolation and providing the care that they are able and choose to provide. Family caregiver services could include a consistent care coordination team they can rely on, access to a 24 hour/7 day a week helpline, emergency back-up, respite care, grief counseling, and information about and referral to community services.
13. **Address the concerns of older adults; people with disabilities, including those with developmental disabilities; and their family caregivers.** These people should have a strong voice in the structure and delivery of health and long-term services and supports to help ensure that services address their needs and provide resources tailored to them. One method of doing this is to ensure that representatives of these populations serve on providers' boards and committees and are able to engage in and vote during discussions about policies of concern to them. Ethics and patients' rights committees are particularly important because they often deliberate on issues related to treatment and services for older adults and people with disabilities.

Glossary

Advance planning: Making plans now for the care a person wants when they have a serious illness and for any financial decisions that may be necessary. Part of planning could include giving instructions or guidance about how decisions should be made and choosing a representative(s) to make decisions if the person loses the ability to do so.

Family caregiver: any relative, partner, friend or neighbor, related or not, who has a significant personal relationship with, and who provides a broad range of assistance for a person with a chronic, disabling, or serious health condition.

Hospice: Care that focuses on providing the person with serious illness and their family with comfort, pain relief, support services, and spiritual care when they are expected to live six months or less.

Long-term services and supports: A range of health care and social services that support older adults or people with disabilities who need help with daily living tasks.

Palliative care: Care to help people get relief from pain, distress, psycho-social and spiritual distress, and other symptoms that can occur during an illness. Palliative care requires person and family-directed care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout an illness involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitating a person's autonomy, access to information, and choice. A person can receive palliative care at any stage of a serious illness, including when getting treatment.

Person-directed planning: A process that the person directs, which may also include a representative who the person has freely chosen, or who is authorized to make personal or health decisions for the person. This type of planning identifies the person's strengths, preferences, priorities, service and support needs, and desired life outcomes. Agency workers' role in this type of planning is to enable and assist the person to identify and access the desired services. The person takes an active, leading role in the planning process. The planning process occurs at times and locations of convenience to the person and includes supporters the person chooses, including a representative or advocate if desired. The person's values, goals, priorities, and desired outcomes should be honored and given priority.

Supported decision-making: This involves a framework for assisting people with cognitive or other types of disabilities in making decisions and exercising their legal capacity. The person with disabilities considers and makes specific decisions while drawing on the support of others. Supported decision-making is an alternative to guardianship or other legal tools that rely on a surrogate to take over responsibility for a person's decision-making.

Spiritual care: Care that responds to the needs of the human spirit when faced with trauma, ill health, or sadness. It can include the need for meaning, to express oneself, for faith support, or for a compassionate listener.