May 12, 2017

Edwin Walker, Deputy Assistance Secretary for Aging
Bob Williams, Acting Commissioner
Administration on Disabilities Director
Independent Living Administration

Administration for Community Living
Sent Via Email: AdvancedIllness@acl.hhs.gov

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

Dear Mr. Walker and Mr. Williams:

We are writing on behalf of the National POLST Paradigm; the National POLST Paradigm improves the quality of care for patients who are seriously ill or frail by creating a system that elicits, documents and honors patient medical treatment preferences through portable medical orders. It is part of advance care planning, a process that includes conversations between patients and health care professionals about goals of care and quality of life. We encourage involving a patient’s surrogate in the conversation as well as any family, loved ones, friends and faith leaders as may be appropriate for the specific patient. Attached is additional information about our work.

We’d like to emphasize that the POLST Paradigm is not appropriate for individuals with stable disabilities. It is appropriate to consider for anyone- with or without disabilities- who are nearing the end of their lives.

Like the Administration for Community Living, the National POLST Paradigm believes everyone should have the right to control their own decisions, particularly regarding choice of treatment for serious ill or frail patients whose health care professionals wouldn’t be surprised if they died within a year. We appreciate ACL’s efforts in drafting Principles for a Person-Centered Approach to Serious or Advanced Illness.

Overall, we think these principles are well drafted. We have attached a tracked-changes version of the principles with our recommended edits; the key edits are highlighted here:

**Recommendation 1:** We recommend changing the title to “Principles for a Person-Centered Approach to Serious Advanced Illness.”

**Rationale:** This removes the “and” between “serious” and “advanced” and represents the preferred language of the Center to Advance Palliative Care.
**Recommendation 2:** In Section 1, we recommend adding “status” after “health” and including “illness” and “prognosis” in the list provided.

**Rationale:** We felt the addition of “illness” emphasized that some people are ill and use that term to describe their “condition”. Additionally, prognosis is key information necessary for making treatment decisions.

**Recommendation 3:** We recommend adding the following language to the second bullet under Section 2. “Advance care planning should begin as soon as individuals reach the age of majority with a priority place on appointing an appropriate health care proxy or surrogate and clarifying values and goals of care should be renewed at each transition stage of life and health.”

**Rationale:** This language supports the recommendation that decision-making and advance care planning should occur when someone is of the appropriate legal age in their state to execute legal documents and that these documents should be periodically reviewed. Early familiarity with these documents can ease the stress and burden of revising them later - as opposed to being introduced to them at the same time of a diagnosis.

**Recommendation 4:** We recommend rephrasing the third bullet under Section 2 to “A person is presumed to have decision-making capacity regardless of the level of impairment or disability. If it has been determined that the person’s decision-making capacity is diminished, the level of decision-making capacity the person has shall be honored for specific tasks or decisions, working with health care proxies or surrogates as appropriate.”

**Rationale:** While we agree removing bias of assuming people with impairment or disabilities lack decision-making capacity is important, we thought the original draft language could be misinterpreted. We are proposing language acknowledging that, when in doubt, there should be an evaluation by a physician or mental health professional - and reinforcing that surrogates or health care proxies have a role for patients lacking decision-making capacity.

**Recommendation 5:** We recommend changing the following language in the fifth bullet under Section 2 to add “and document their wishes in a meaningful manner” at the end of the first sentence and to add “any authentic expression of one’s” in the second sentence, prior to “goals.”

**Rationale:** These additions emphasize that it isn’t enough to have a conversation - advance directives and possibly POLST Forms need to be completed to ensure that person’s treatment wishes are honored.

**Recommendation 6:** We recommend adding this statement as a sixth bullet under Section 2: “Health care professionals should make eliciting, documenting and honoring individual care and treatment decisions and goals a priority. Health care professionals, individuals, and those who are helping individuals who need assistance should periodically review these decisions and revise them as appropriate.”

**Rationale:** This statement is directed towards health care professionals to further advocate for patient-centered care. Fundamentally, care and treatment plans should not be decided without first knowing a patient’s values, goals and thoughts on treatment options. Unfortunately, this is not always the case and including a statement, like our suggested one, is a step towards encouraging a shift in how we deliver care.

**Recommendation 7:** We recommend adding “sexual orientation” and “gender identity” to the list in Section 3.

**Rationale:** It is important to recognize and include these as potential traits for discrimination.
Recommendation 8: We recommend changing the first part of Section 4 to read “Individuals need access to long term services, resources and supports...” (underlined language to be added)

**Rationale:** “Long term services” is a term of art that includes things like psychosocial support, which everyone should have access to and “resources and support” expands the language to include other sources of support beyond just services.

Recommendation 9: We recommend adding “independent” prior to “advocacy services” in Section 6.

**Rationale:** Adding “independent” reinforces the need to avoid corporate of conflicts of interest; this is particularly necessary for patients having problems with current services.

Recommendation 10: We recommend adding “effectively coordinated” before “services” in Section 8, as well as replacing “like one” with “with a”.

**Rationale:** This language reinforces the need for effective coordination of the various services and support available to patient’s and the need for a reliable care coordinator.

Recommendation 11: We recommend adding “shared” prior to “decision-making” in several places.

**Rationale:** We understand “supported decision-making” and appreciate it as a core principle in the disability community. The term “shared decision-making” is used in advance care planning, advocating for a healthy dialogue between the patient and his/her health care professional; the term includes all elements of informed consent (information about diagnosis prognosis, treatment options, risks and benefits and opportunities to ask questions) and a nuanced discussion that includes a deeper conversation about a patient’s goals of care and values. A shared decision-making process leads to consent for treatment that is well-informed, collaborative and thoughtful. Recognizing “shared decision-making” within this document may help bridge aging principles and terminology with language conventions within disability community.

The National POLST Paradigm applauds this effort and supports the proposed principles. If you have any questions about our proposed language, please contact Amy at (202) 780-5738 or amy@polst.org.

Sincerely,

Judy Thomas, JD
Chair
National POLST Paradigm

Amy Vandenbroucke, JD
Executive Director
National POLST Paradigm
Draft Principles for a Person-Centered Approach to Serious Advanced Illness

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

2. Principles related to planning and shared decision-making:
   - Person-centered planning principles and practices should guide health and long-term services and supports (LTSS) planning and provision.
   - Shared 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. Advance care planning should begin as soon as individuals reach the age of majority with a priority placed on appointing an appropriate health care proxy or surrogate and clarifying values and goals of care and should be renewed at each transition stage of life and health.
   - A person is presumed to have decision-making capacity regardless of the level of impairment or disability. If it has been determined that the person’s decision-making capacity is diminished, the level of decision-making capacity the person has shall be honored for specific tasks or decisions, working with health care proxies or surrogates as appropriate.
   - Supported decision-making principles and practices should guide those who are helping individuals who need assistance with planning and shared decision-making. Individual goals, values, decisions, and known views should take priority.
   - People have a responsibility to communicate with loved ones as well as health and LTSS providers about their goals and decisions and document their wishes in a meaningful manner. All parties should respect any authentic expression of one’s goals and decisions. Since circumstances may change over time, there should be regular opportunities to update planning and communicate goals and decisions.
   - Health care professionals should make eliciting, documenting, and honoring individual care and treatment decisions and goals a priority. Health care professionals, individuals, and those who are helping individuals who need assistance should periodically review these decisions and revise them as appropriate.

3. Discrimination based on “age, race, sex, disability, color, national origin,” sexual orientation, gender identity, 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 long term services, resources and supports that enable them to manage their conditions and symptoms, live in the setting of their choice, and be integrated into the community. Spiritual care 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 independent 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.
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 **effectively coordinated** services with a 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.
About the National POLST Paradigm

The National POLST Paradigm is an approach to end-of-life planning that helps elicit, document and honor patient treatment wishes. The POLST Paradigm emphasizes:

(i) advance care planning conversations between patients, health care professionals and loved ones;
(ii) shared decision-making between a patient and his/her health care professional about the treatment the patient would like to receive at the end of his/her life; and
(iii) ensuring patient wishes are honored.

As a result of these conversations, patient treatment wishes may be documented on a POLST Form, which translates the shared decisions into actionable medical orders. The POLST Form assures patients that health care professionals will provide only the treatments that patients themselves wish to receive, and not the treatments they wish to avoid.

The POLST Paradigm is not for everyone. Only patients with serious illness or frailty whose health care professional would not be surprised if they died within one year should have a POLST Form. For these patients, their current health status indicates the need for standing medical orders. Another way to look at it: patients appropriate for a POLST conversation are those who are most likely to have a medical crisis (predictable based on diagnosis) but who may not want our current standard of care, which is to do everything possible in an attempt to save someone’s life. A health care professional determines if a patient is appropriate for a POLST conversation. For healthy patients, an advance directive is an appropriate tool for making future end-of-life treatment wishes known.

The National POLST Paradigm embodies and promotes the essential elements of a POLST Paradigm Program; individual states and regions implement POLST programs. As a result, state programs vary in name (e.g. MOLST, MOST, and POST), how their programs are implemented, and in the appearance of their forms. Although these programs may be identified by the National POLST Paradigm Task Force (Task Force) as “Developing Programs” and use the term “POLST” or a similar term, they do not represent the POLST Paradigm until they have been endorsed by the Task Force. Only state programs that have demonstrated to the Task Force that their POLST Paradigm Program and Form meet Task Force standards can be endorsed. 21 states have Task Force endorsed programs, 24 states have developing programs, and 3 states have no programs and 3 have programs that don’t conform to POLST requirements.

To learn more please visit www.polst.org
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<thead>
<tr>
<th><strong>POLST Paradigm Form</strong></th>
<th><strong>Advance Directive</strong></th>
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<tbody>
<tr>
<td><strong>Type of Document</strong></td>
<td>Medical Order</td>
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<tr>
<td><strong>Who Completes</strong></td>
<td>Health Care Professional</td>
</tr>
<tr>
<td><strong>Who Needs One</strong></td>
<td>Seriously ill or frail (any age) for whom healthcare professional wouldn’t be surprised if died within year</td>
</tr>
<tr>
<td><strong>Appoints a Surrogate</strong></td>
<td>No</td>
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<tr>
<td><strong>What is Communicated</strong></td>
<td>Specific medical orders for treatment wishes.</td>
</tr>
<tr>
<td><strong>Can EMS Use</strong></td>
<td>Yes</td>
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<tr>
<td><strong>Ease in locating</strong></td>
<td>Very easy to find. Patient has original. Copy is in medical record. Copy may be in a Registry (if your state has a Registry).</td>
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