



April 26, 2021

The Honorable Bob Casey
Chair, Senate Committee on Aging
G31 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Maggie Hassan
United States Senator
324 Hart Senate Office Building
Washington, DC 20510

The Honorable Sherrod Brown
United States Senator
503 Hart Senate Office Building
Washington, DC 20510

The Honorable Debbie Dingell
United States Representative
116 Cannon House Office Building
Washington, DC 20515

Via HCBSComments@aging.senate.gov

Re: *Home and Community-Based Services Access Act* discussion draft

Dear Chairman Casey, Senator Hassan, Senator Brown, and Representative Dingell,

The undersigned members of the Patient Quality of Life Coalition (PQLC) appreciate the opportunity to comment on the *Home and Community-Based Services Access Act* (HAA) discussion draft. PQLC was created to advance the interests of patients and families facing serious illness. The coalition includes over 40 organizations dedicated to improving quality of care and quality of life for all patients from pediatrics to geriatrics, as well as supporting public policies that improve and expand access to quality palliative care and appropriate pain management. PQLC members represent patients, caregivers, health professionals, and health care systems.

We appreciate your efforts to develop and seek stakeholder input on the HAA discussion draft, and we strongly support your goals of increased access to home and community-based services for Medicaid beneficiaries. Specifically, we have the following recommendations, which we detail further in our comments below:

- The definition of “home and community-based services” should include palliative care services;
- The definition of “functional impairment” should be expanded to include impairments which would require palliative care;
- Any “face to face” evaluation requirement should allow for such evaluation to be conducted via telehealth; *and*
- Issues concerning network adequacy must be considered and addressed.

Palliative Care Background

Palliative care is an interdisciplinary model of care that focuses on people living with serious or complex chronic illness, including cancer, cardiac disease, respiratory disease, kidney failure, Alzheimer’s, AIDS, ALS, and MS. It provides relief from the symptoms and stress of a serious illness, whatever the diagnosis. Palliative care is provided by a team of doctors, nurses, social workers, and other providers working together with a patient’s other doctors to provide an extra layer of support.

Palliative care is appropriate at any age and any stage in a serious illness. Palliative care services can be provided at the point of diagnosis of a serious illness and be used alongside curative treatment. Key

components of palliative care include care planning based on open, honest communication about the patient's condition and treatment options; effective control of pain, symptoms and side effects; and highly coordinated care that addresses physical, neurological, psychosocial, and spiritual needs and family/caregiver support. Given its focus on the patient and the patient's family, palliative care improves a patient's ability to tolerate medical treatments and carry on with daily life. It also empowers patients to play a greater role in their own care by facilitating communication between patients, caregivers, and providers across the care continuum.

Definition of "Home and Community-Based Services"

We urge the drafters to amend the HAA discussion draft definition of "home and community-based services" to explicitly include palliative care services. Many patients who suffer from serious illness experience debilitating symptom, which palliative care can help to manage. Palliative care can be offered simultaneously with life-prolonging and curative therapies for persons living with serious, complex, and eventually terminal illness and includes hospice care. By its very nature, palliative care is patient-centered care — translating patient goals to appropriate treatments. While one of the goals of palliative care is to enable the patient to continue their daily life, many patients unfortunately do not have access to palliative care in home and community settings. By explicitly including palliative care services on the list of home and community-based services in this legislation, we hope this bill would expand access to these services outside of the hospital settings and in patients' homes and communities.

Definition of "Functional Impairment"

To meet the drafters' goal of providing greater access to home-based care, the definition of "functional impairment" should be expanded to include impairments which would require palliative care. As drafted, a patient must have functional impairment in order to be eligible for the services provided for in the draft. While some patients undergoing treatment for serious illness and aided by palliative care may not be experiencing permanent or prolonged functional impairment per se, those patients nonetheless are typically severely limited by their medical condition and practically impaired from physically taking on activities such as visits to healthcare facilities or clinics. We ask that you review this section to ensure that it is sufficiently broad to include patients receiving palliative care.

Face-to-face Evaluation Requirement

Any "face to face" evaluation requirement should allow for such evaluation to be conducted via telehealth, whenever clinically appropriate. We have seen face-to-face requirements waived as part of the COVID-19 pandemic and, even prior to 2020, as new technologies such as telehealth have allowed providers and patients to engage in a meaningful way via remote modalities. While we understand the need to create guardrails to prevent fraud and abuse for the Medicaid program, absent an option to complete this evaluation via telehealth, we believe that a face-to-face requirement would lend unnecessary regulatory burden to patients and providers. Instead, we encourage you to think flexibly about how this requirement or others could be conducted virtually, allowing the patient to participate from their home setting.

Network Adequacy

As you continue work on the HAA discussion draft, we ask that you consider how issues concerning network adequacy can be addressed. For the expanded services provided under the bill to truly deliver

for patients, there must be an adequate number of providers within the network to provide the care detailed therein. This already has been a challenge for palliative care patients, and we worry that their care options could continue to be limited in spite of the expanded coverage provided under the HAA if palliative care providers and clinicians are not accessible as part of the network. We ask that you pay particular attention to patients who live in rural areas, have highly specialized conditions, or who do not have easy access to large hospital systems. These are patients who could most benefit from home- or community-based palliative care but are also the most likely to have challenges finding providers in-network.

Pediatric Patients with Medically Complex Conditions

Survivorship among pediatric patients has increased for several conditions that were once thought to be untreatable. This is an excellent development; however, current home and community-based services (HCBS) for children and young adults with medically complex conditions do not meet the medical needs of many patients. This is largely due to the patchwork nature of policies and programs and to workforce and coverage gaps. Mandating HCBS in Medicaid addresses this by helping to alleviate workforce gaps in addition to expanding access to HCBS. Improving training and workforce opportunities, payment reforms to ensure coverage, and expanding access through telehealth can drastically improve the current system for patients and providers.

Conclusion

We look forward to working with you and members of the Working Group as you develop ideas to improve home and community-based services in the Medicaid program. If you have any questions or would like to discuss these comments further, please contact Keysha Brooks-Coley, Vice President of Federal Advocacy at the American Cancer Society Cancer Action Network and Chair of the Patient Quality of Life Coalition, at 202-661-5720 or Keysha.Brooks-Coley@cancer.org.

Sincerely,

Alzheimer's Association
Alzheimer's Impact Movement
American Academy of Hospice and Palliative
Medicine
American Cancer Society Cancer Action
Network
Association for Clinical Oncology
Association of Pediatric Hematology/Oncology
Nurses
Cancer Support Community
Catholic Health Association of the United States
Center to Advance Palliative Care
Children's National Hospital
Coalition for Compassionate Care of California

GO2 Foundation for Lung Cancer
National Alliance for Caregiving
National Brain Tumor Society
National Coalition for Hospice and Palliative
Care
National Hospice and Palliative Care
Organization
National Patient Advocate Foundation
Oncology Nursing Society
Pediatric Palliative Care Coalition
Physician Assistants in Hospice and Palliative
Medicine
ResolutionCare Network
Social Work Hospice & Palliative Care Network