NATIONAL COALITION
FOR HOSPICE AND
PALLIATIVE CARE

COALITION MEMBERS

American Academy of Hospice and Palliative Medicine (AAHPM)
Association of Professional Chaplains (APC)
The Catholic Health Association of the United States (CHA)
Center to Advance Palliative Care (CAPC)
HealthCare Chaplaincy Network™ (HCCN)
Hospice and Palliative Nurses Association (HPNA)
National Association for Home Care & Hospice (NAHC)
National Hospice and Palliative Care Organization (NHPCO)
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Palliative Care Quality Collaborative (PCQC)
Physician Assistants in Hospice and Palliative Medicine (PAHPM)
Social Work Hospice & Palliative Care Network (SWHPN)
Society of Pain & Palliative Care Pharmacists (SPPCP)

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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 thirteen organizations that comprise the National Coalition for Hospice and Palliative Care (Coalition) thank you for the opportunity to submit feedback on the discussion draft of the Home and Community Based Services Access Act (HAA). We look forward to collaborating with you and your staff as you work towards your goals of increasing access to, and establishing consistent criteria for these critical home and community-based services (HCBS) for all those eligible, especially those with serious or life-limiting illness.

Our Coalition

The goal of our Coalition is to ensure that all patients (both adults and children), families, and caregivers who need it will have equitable access to quality hospice and palliative care. Our Coalition works to present a united, yet diverse voice to the public and policy makers on behalf of providers, professionals and other organizations that are interested in working together to advocate for equitable health care policies and programs that will improve the care of patients and families living with serious or life-threatening illnesses.

Palliative Care Connection to Home and Community-Based Care

There is significant overlap in the patient population receiving home and community-based services and those who receive or could benefit from receiving palliative care. Palliative care means "…patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice."[1] Palliative care includes use of an inter-disciplinary team to address the wide range of patient care needs.

It is well documented that patients with serious illness benefit from palliative care.[2] Examples of serious illness include (but are not limited to) dementia, malignant cancer or leukemia, chronic pulmonary disease, renal failure/kidney disease, congestive heart failure and pediatric pulmonary, chromosomal, metabolic and neurodegenerative disorders. Without adequate support in the home, these patients often find themselves in the emergency department or hospital as a result of potentially avoidable symptom crises such as pain, shortness of breath, nausea, anxiety and more. This creates unnecessary suffering for patients and family members/caregivers and leads to wasteful health care spending. And while some of these patients will eventually transition to hospice care, many will live for several years with high levels of functional dependency and symptom distress – including pain and depression.[3] With advancements in medical technology, we are also experiencing an increase in the number of children living with complex medical needs. For these patients, access to high quality palliative care, ***paired*** with a robust system of home and community-based services, would both offer a higher quality of life and reduce health care waste.

The HAA can provide a foundation for a home-based palliative care benefit for this population. Through early integration into the care plan of seriously ill people, palliative care improves quality of life for both the patient and the family.[4] By focusing on priorities that matter most to patients and their families, palliative care has been shown to improve quality of care and quality of life, and to generate reductions in avoidable spending.

Interdisciplinary teams, which are a hallmark of palliative care and hospice, manage a wide array of symptoms, facilitate shared decision-making, support family members, coordinate care transitions and help connect patients and families to home and community-based services on a regular basis.

Our Coalition has been working with other stakeholders to demonstrate the value of this person-centered care for people with serious illness in the Medicare program with the goal that there should be seamless integration between federal programs.[5] For instance, we recommended to the Centers for Medicare & Medicaid Services (CMS) that every Medicare beneficiary living with serious illness would benefit from high-quality palliative care at any time during their disease progression and not just at the end of life (hospice).

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[1] 42 C.F.R. § 418.3

[2] http://aahpm.org/uploads/advocacy/The_Evidence_for_High-Quality_Palliative_Care.pdf

[3] Meier DE, Back AL, Berman A, et al. A national strategy for palliative care. *Health Affairs.* 2017 Jul; 36(7). https://www.healthaffairs.org/doi/10.1377/hlthaff.2017.0164

[3] National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care, 4th edition. Richmond, VA: National Coalition for Hospice and Palliative Care; 2018. https://www.nationalcoalitionhpc.org/ncp

[4] https://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2021/04/20/long-haul-covid-renews-push-to-expand-palliative-care

Overall Recommendation: Our Coalition recommends that Medicaid home and community-based services include access to community-based palliative care. Specifically, we request the inclusion of palliative care in the HAA and recommend that the definition of "home and community-based services" include home and community-based palliative care. The remainder of this letter provides more detailed suggestions on how to incorporate palliative care into HCBS using models, programs, and services that are already being tested or have been previously recommended by the Coalition.

List of Services

Relative to services offered under HCBS, we applaud inclusion of hospice as among those services that would be offered to eligible patients. However, we note that in the proposed Section 1905 (hh)(2)(A), a list of services is included by reference to current provisions with sections 1905 and 1915. Section 1905(a)(18) on hospice services is not included while "hospice services" is referenced in the proposed section 1905(hh)(2)(A)(x).

Recommendation: In the interest of clarity, we recommend that section 1905(a)(18) be included in those provisions referenced in (A) to avoid any confusion regarding the intent to include hospice services within the scope of covered HCBS services.

Learn from and Expand the Medicare Care Choices Model and Pediatric Palliative Care Medicaid Waiver Programs

The Medicare Care Choices Model (MCCM), operated by the Center for Medicare and Medicaid Innovation (CMMI), has provided an important opportunity to test community-based palliative care in a limited and targeted fashion (beneficiaries must be hospice-eligible), with outcomes demonstrating the effectiveness of "supported care services" and concurrent curative care in improving quality and reducing costs.[6] According to the most recent CMMI evaluation report for MCCM, it was found that the supported care services in MCCM "led to a 25 percent decrease in total Medicare expenditures" and resulted in earlier hospice elections.[7]

Pediatric Palliative Care Medicaid Waivers (PPCW) have demonstrated benefit to children with a wide range of disease progression - with even greater efficacy for children with less severe disease progression, offering further evidence of the benefits of introducing pediatric palliative care in-home services earlier on within the continuum of care[8]. Children eligible for PPCW services are not required to meet the hospice eligibility requirements. A study conducted by the UCLA Center for Health Policy Research noted success in reducing caregivers' stress and worry related to their child's care, in building the confidence of the caregiver in their ability to provide care in the home, and in reducing children's pain as observed by their caregiver. The same study demonstrated a significant reduction in health care costs due to a reduction in hospital admissions and length of stay on the part of children enrolled in California's PPCW program.[9]

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[6] https://innovation.cms.gov/innovation-models/medicare-care-choices

[7] https://innovation.cms.gov/data-and-reports/2020/mccm-fg-thirdannrpt

[8] Gans D, Hadler MW, Chen X, et al. Impact of a Pediatric Palliative Care Program on the Caregiver Experience. Journal of Hospice & Palliative Care Nursing, 2015; 17(6)

[9] Gans D, Hadler MW, Chen X, et al. Cost Analysis and Policy Implications of a Pediatric Palliative Care Program. Journal of Palliative Care and Symptom Management, 2016; 52(3)

Recommendation: To build on the success of MCCM and the PPCW, the Coalition recommends that Congress modify Medicare and Medicaid such that an MCCM and PPCW type bundle of services is available to Medicare patients upstream from hospice (which will help to facilitate more timely entry to hospice care where appropriate) and to establish access to a similar package of services under HCBS and elsewhere for Medicaid patients in need palliative care.

Create a New Community-Based Palliative Care Benefit

Adults and children with serious illness and their families and caregivers require high-quality, interdisciplinary care that is provided in the communities where they live and work. Hospice and palliative care (HPC) providers have expertise in patient and family education, advance care planning, pain and symptom management, support for functional needs, enhanced telehealth services, interdisciplinary care, psychological, social and spiritual support, care coordination, and co-management with other medical providers – making them ideal to support these patients and families. Yet, while HPC providers can deliver these services in homes and communities (although access for non-hospice patients remains variable),[10] they are not broadly covered by Medicaid and Medicare outside of demonstrations.

In response to this gap, the Coalition has drafted a framework for a Community-Based Palliative Care (CBPC) model aimed at improving patient outcomes and experience of care and reducing avoidable and potentially harmful emergency department visits and hospitalizations for high-risk patients.[11]

Recommendation: Our Coalition recommends Congress consider the inclusion of CBPC for people of all ages with serious illness, as an essential component of home and community-based services and interdisciplinary care in the home.[12] We believe the time is right for a CBPC demonstration to be carried out under the authority of the Centers for Medicare and Medicaid Services Innovation Center (CMMI), either as a new model or as a second-generation Medicare Care Choices Model (MCCM).

HCBS Standards

Given the heterogeneity of HCBS services across the country, it is critically important that there be standard expectations for minimum services delivered under this program. The proposed legislation would go a long way towards that; pending passage, we urge that there be sufficient resources allocated to enable detailed regulatory and subregulatory guidance to inform how these services should be implemented.

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[10] https://www.capc.org/mapping-community-palliative-care/

[11] https://www.nationalcoalitionhpc.org/wp-content/uploads/2021/01/Coalition-NHPCO-CBPC-Demo_One-Pager_-2020-F.pdf

[12] https://www.nationalcoalitionhpc.org/wp-content/uploads/2020/09/CBPC_sign-onz-letters.pdf

Medicaid Rates

Our Coalition supports appropriate payment rates to cover the costs of providing HCBS, including home and community-based palliative care. Expanding access to these services will be of limited use if providers are not adequately reimbursed.

Workforce and Training

To ensure quality care, all home and community-based care providers should have the knowledge and skills to provide person-centered care for adults and children with serious illness. The Coalition and Congress have a long history of calling for health care workforce training initiatives that address the nation's evolving health care and social service needs, including efforts to close the large gap between the number of health professionals with palliative care training and the number required to care for the expanding population of patients with serious illness. Additionally, the National Academy of Sciences, Engineering and Medicine (NASEM) and the Medicare Payment Advisory Commission (MedPAC) have highlighted the need to increase education and training opportunities for those caring for patients with serious illness.[13] However, narrowing the current and projected health care workforce gap will require an increase in the number of interdisciplinary clinicians graduated each year, as well as an increase in the number of providers trained to teach future health professionals in palliative care.[14]

To that end, the House passed the Palliative Care and Hospice Training and Education Act (PCHETA) (H.R. 647) in the 116th Congress. This bill addresses workforce gaps by:

- Expanding opportunities for interdisciplinary education and training in palliative care and end-of-life care through the establishment of education centers and career incentive awards for physicians, nurses, advanced practice nurses, social workers, and other health professionals.
- Enhancing existing health professions education programs by providing incentives to incorporate palliative care and hospice training.

While it did not pass the Senate in 2020, the bill has strong bipartisan support and will be reintroduced in the 117th Congress in the coming months.

Additionally, more training is needed for care managers and direct care workers who provide a significant portion of home and community-based services to patients/clients with serious illness. These health care professionals are well-positioned to recognize poorly managed symptoms, yet few have received sufficient training to identify suffering and respond appropriately. For instance, care managers should be trained to conduct a comprehensive assessment of the patient/client and connect them to the right supports (including palliative care) as needed;[15] and direct care workers – who are essentially the "eyes and ears" in the home – must be trained to be able to recognize signs of distress and notify the right party. Examples include knowing what pain looks like in a non-verbal patient, or how to identify caregiver distress. Beyond that, all HCBS providers should be able to conduct a basic assessment, be trained in communication skills, and recognize common symptoms affecting this population and know how to respond (within their scope).

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[13] https://www.nap.edu/catalog/25789/building-the-workforce-we-need-to-care-for-people-with-serious-illness

[14] https://www.healthaffairs.org/doi/10.1377/hlthaff.2019.00018

[15] See Care Manager Training Recommendations at https://www.capc.org/documents/download/909/

Recommendation: As a complement to the HAA, we encourage Congress to pass PCHETA expeditiously when it is introduced later this year, and/or incorporate its provisions into related workforce legislation. Additionally, we urge Congress to set minimum competency standards for all HCBS providers' – particularly care managers and direct care workers – to ensure the unmet needs of patients living with serious illness and their families/caregivers are addressed.

Family Caregivers

In many instances, HCBS providers caring for people with cognitive and physical impairments must provide as much support to the family/caregiver as they do the patient. Caregivers assist with daily activities over many years, and the success of any care plan is dependent upon the caregiver's well-being. Yet fewer than half of caregivers receive counseling or other support, and only about a quarter report a clinician ever asking them about their own self-care needs.[16] Caregivers also have a much higher risk of getting sick themselves, with the additional strain often resulting in increased utilization of hospital services and ED visits as their health deteriorates over the caregiving period.[17] To address this issue, HCBS providers should be attuned to caregiver capabilities and current burden, and support the development of care plans that include: caregiver education on all potential task responsibilities; counseling and support for their emotional needs; training and skill building (such as how to understand and respond to behavioral symptoms of dementia); and linkage to supports in the community for practical needs and respite support.

The Coalition also strongly supports your inclusion of respite services as part of your proposal. Understanding the demand placed upon caregivers, "respite care" can be used for a loved one to be temporarily transferred to a professional care facility, such as a hospital, hospice inpatient care facility, or nursing home. This allows the caregiver to get some much-needed rest and time away from the rigorous demands of daily caregiving and avoid caregiving burn-out and other complications. The Coalition has previously supported policies and initiatives such as those established under the RAISE Family Caregivers Act.

Recommendation: The Coalition recommends that HCBS entities complete a comprehensive assessment of caregiver capabilities and of current burden and develop care plans that address the findings.[18] Furthermore, as Congress works to advance the HAA, we urge you to consider the provisions in existing laws such as the RAISE Family Caregivers Act that would go a long way towards supporting families/caregivers but may have not necessarily received the implementation support they need.

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[16] Belmin, J., Min, L., Roth, C., Reuben, D., Wenger, N. "Assessment and Management of Patients with Cognitive Impairment and Dementia in Primary Care," J Nutr Health Aging, 2012; 16(5): 462-7 & National Alliance for Caregiving. Dementia Caregiving in the U.S.: National Alliance for Caregiving and Alzheimer's Association. February 2017. Web Access: http://www.caregiving.org/wp-content/uploads/2017/02/ DementiaCaregivingFINAL_WEB.pdf

[17] Schulz, R., Cook, T. Caregiving Costs: Declining Health in the Alzheimer's Caregiver as Dementia Increases in the Care Recipient. National Alliance for Caregiving; Bethesda, Maryland, 2011; 7p

[18] National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care, 4th edition. Richmond, VA: National Coalition for Hospice and Palliative Care; 2018. https://www.nationalcoalitionhpc.org/ncp

Network Adequacy

The Coalition encourages you and your staff to explore the development of federal standards for network adequacy for states and geographic areas that have made the decision to deliver HCBS through managed care, so that patients and families are ensured a choice of providers for all essential services. Specifically, we are concerned about rural access to care, access to a variety of providers that offer culturally competent services, and access to quality providers. Patients will have limited access and choice if provider access is arbitrarily limited.

Quality Measures-Establishing a Federal HCBS Quality Committee

The Coalition appreciates that the HAA discussion draft introduces a process for developing standardized HCBS metrics that requires public and beneficiary involvement. For the past 2 years, our Coalition has helped lead a CMS funded project to develop patient-reported outcome-based performance measures (PRO-PMs) that assess how well health care providers help patients with serious illness get the care they want and need.[19] The PRO-PM, "How Much Patients Feel Heard and Understood" is particularly relevant to the HCBS population.[20]

To develop these measures, the project team is working closely with an advisory group of doctors, nurses, social workers, chaplains, pharmacists, patients, family members, and others to ensure the measures focus on what matters most to patients. One unique example of this CMS funded project was the inclusion from the very beginning - and throughout - of patients and caregivers through the establishment of the unique Technical Expert Clinical User **Patient** Panel (emphasis added).[21] Our patient and caregiver members were not afterthoughts or "tokens" to the process but were integral to the entire process from measure conception, interviews, testing and evaluation to presentation before the National Quality Forum (NQF) later this year.

Recommendation: We encourage the future development of HCBS measures that consider related existing measures such as "How Much Patients Feel Heard and Understood." Furthermore, given our demonstrated expertise in meaningful engagement with interdisciplinary providers and patients, families, and caregivers, we urge the inclusion of home health, hospice, and palliative care stakeholders in the proposed Federal HCBS Quality Committee and the development of a minimum data set for HCBS.

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[19] https://www.nationalcoalitionhpc.org/macra/

[20] For more information, see:
https://www.nationalcoalitionhpc.org/wp-content/uploads/2021/01/Abbreviated-Survey-Instrument_Public-Comment-Version.pdf
https://www.nationalcoalitionhpc.org/wp-content/uploads/2021/01/Abbreviated-Survey-Instrument_Public-Comment-Version.pdf
https://www.nationalcoalitionhpc.org/wp-content/uploads/2021/01/HU_MIF_Public-Comment-Version_V2.pdf

[21] https://www.nationalcoalitionhpc.org/wp-content/uploads/2021/03/1.14.2021-Blueprint-TEP-Membership-List-Template-Update-2.25.2021.pdf

Thank you for the opportunity to provide feedback on the HAA discussion draft. Our Coalition, including members from our National Pediatric Palliative Care Task Force,[22] is pleased to offer the expertise of our members and we look forward to collaborating with you and your staff as you continue to work on improving the care of adults and children who can be better served with increased access to home and community services. If you have any questions, please contact Amy Melnick, Executive Director, at 202-306-3590 or amym@nationalcoalitionhpc.org.

Signed,

American Academy of Hospice and Palliative Medicine
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National Hospice and Palliative Care Organization
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[22] https://www.nationalcoalitionhpc.org/pediatric/