

Perspectives on State Opportunities to Improve Care of the Seriously Ill

In 2021 and 2022, the Center to Advance Palliative Care (CAPC), in partnership with the National Academy for State Health Policy (NASHP) and with generous support from The John A. Hartford Foundation, hosted three conversations with Medicaid-serving organizations. The goal of these sessions was to hear firsthand from attendees about ideas and opportunities for state policymakers to better support the care of residents living with serious illness and expand palliative care access.

Participants in these listening sessions were leaders in:

1. Managed Medicaid plans, including Managed Long-Term Services and Supports and integrated Medicare-Medicaid Plans (May, 2021)
2. Certified Home Health Agencies (September, 2021)
3. Palliative care programs that serve a significant percentage of adult Medicaid-only patients (March, 2022)

Combined, these listening sessions had 40 participants from 16 states. Discussion topics included the ways in which palliative care services are currently provided and paid for, along with the barriers and frustrations therein, the merits of a standalone Medicaid community-based palliative care benefit vs. integration with existing Medicaid programs, the role of non-traditional providers in supporting beneficiaries living with serious illness, and policies that could potentially expand palliative care access.

The following are potentially high-impact opportunities that listening session attendees discussed to expand access to quality palliative care for people living with serious illness.

Clarifying Licensure to Deliver Interdisciplinary Palliative Care in the Home. Currently, there is no single program or facility licensure that allows for all members of an interdisciplinary care team to provide care in the home. There is clarity that patients enrolled in certified home health care or home- and community-based programs may receive professional services in the home, but palliative care delivered under a medical license is a grey area. To comply with all applicable laws, palliative care programs often hold multiple licenses

Therefore, a key opportunity is clarifying licensure so that an interdisciplinary palliative care team can provide care in the home, distinct from the hospice license, the home health license, and any other community-based service operating certificate. For example, in California a new law was created to allow hospices to provide non-hospice palliative care ([SB 294](#)), which allowed the state to collect information on palliative care delivery while solving this issue. If this opportunity is pursued, it might also be beneficial to provide additional definitions for 'serious illness' and 'palliative care' in states that have not already done so.

Guidance on recommended home-based palliative care program requirements can be found [here](#).

Embedding Palliative Care into Existing Programs Serving Dual-Eligible Beneficiaries. The certified home health agency participants were already providing palliative care to many dual-eligible beneficiaries in need, using the Medicare home health benefit and supplementing with licensed and specialty-trained advanced practice providers. However, they acknowledged that this compilation left gaps, and those individuals who need palliative care but do not have a skilled need or meet home-bound criteria simply cannot be served this way.

Opportunities exist to modify Medicaid benefits to fill these gaps, such as through clarifications and tweaks to the home- and community-based services or the Medicaid home health benefit, without duplicating services. As one representative said, “it doesn’t take a full episode with all the skilled services and therapies to keep someone safe in their home.” Modifications suggested include:

- Adding specific diagnoses such as chronic obstructive pulmonary disease (COPD) or congestive heart failure (CHF) to the home- and community based services (HCBS) eligibility criteria, regardless of beneficiaries’ activities of daily living (ADLs).
- Providing specific fee-for-service payment for services and activities that are currently un- or under-funded, such as conducting an initial comprehensive assessment; providing “light touch” ongoing monitoring and care coordination post-discharge from a home health episode; social work encounters for dual-eligible beneficiaries in states where this is disallowed; and chaplaincy and spiritual support services. These fee-for-service solutions are needed until population-based alternative payment arrangements are more widely in use.

Promoting Medicare-Medicaid Integration, Including Inserting Requirements in D-SNP Contracts. It was universally acknowledged that Medicaid Long-Term Services and Supports serve many people with unmet palliative care needs, and while palliative care referrals can be made, these plans do not have control of Medicare benefits or even the information contained in the medical claims to support palliative care access. Yet integrated Medicare-Medicaid plans were able to serve their seriously ill enrollees successfully by combining both sets of benefits.

Given this, states are encouraged to pursue strategies which better integrate Medicare and Medicaid benefits for dual-eligible beneficiaries. While ensuring access to palliative care may not be the main motivation for doing so, beneficiaries with seriously ill will especially benefit from integration. More information on strategies can be found [here](#).

Additionally, there are opportunities to include impactful palliative care-related requirements in the state contract with Dual-Eligible Special Needs Plans (D-SNPs). Some suggestions included:

- Required assessments for enrollees with specific diagnoses (such as COPD, heart failure, cancer, and advanced dementia) for symptom distress, declining function, and caregiver burden on a regular basis
- Network requirement to include palliative care in some way. Given the shortage of palliative care specialists (see below), formal network adequacy requirements for palliative care specialists is infeasible at this time. Instead, D-SNPs should demonstrate capacity to connect enrollees with a clinician trained in serious illness communication skills, such as through palliative care telehealth organizations or their own nurse care managers.

- Reported quality measures that are relevant to the population with serious illness (or better yet, include such measures in value-based payment and financial incentive arrangements)
- Requiring training and competency in function, symptom, and caregiver burden assessments for all care managers in D-SNP plans.

Growing the Primary and Specialty Palliative Care Workforce. Currently, there are [significant shortages](#) of both palliative care specialists and other clinicians trained in core communication and symptom management skills. Therefore, ensuring essential skills are available across providers, as well as encouraging palliative care specialists to practice in a state, were opportunities that participants felt should be pursued.

States can help bolster palliative care skills and capabilities by establishing requirements for Medicaid providers and Medicaid care managers to be trained in serious illness communication skills and pain/symptom assessment and management. A few states have used [medical continuing education requirements](#) for licensure as a vehicle to improve capabilities statewide. Furthermore, states can take action to expand the specialty palliative care workforce in the state, such as loan forgiveness programs for these specialists or establishing scholarships for palliative care nurses, social workers, pharmacists, physician assistants, and other professionals. Current [availability of palliative care specialists by state](#) can be found here.

Increasing Public and Provider Awareness of Palliative Care. There are significant misconceptions of what palliative care is and who is eligible; often, it is confused with hospice (which is a defined benefit for individuals who have a confirmed prognosis of under six months and who agree to stop curative treatment), and this can have a chilling effect on provider referrals and patients' willingness to accept palliative care services. Furthermore, many Medicaid beneficiaries have experienced neglect from the health care system, and may therefore have concerns about any service that is perceived as withholding care.

Yet we know that quality of life is significantly improved when palliative care is received, and [benefits accrue](#) not only to the patient, but also to their family caregivers, and often to their clinicians. Therefore, improving professional and public perceptions through orchestrated public awareness initiatives can be quite impactful. Guidance on messaging palliative care can be found [here](#).

Ancillary Opportunities to Support More Seamless Palliative Care Delivery. Palliative care is unique in that it is appropriate for people living with serious illness, regardless of age, diagnosis, prognosis, setting of care, etc. Therefore, listening session attendees raised a few other opportunities that, if pursued, could create a more conducive environment to palliative care delivery. These include:

- preserving and expanding access to telehealth, including all the surrounding considerations (e.g., increase broadband access, provision of devices, supporting interstate practice of medicine – as long as there are appropriate patient protections) that are being championed outside of specialty palliative care;
- growing investment in direct care and community health workers; and
- updating state opioid/controlled substance prescribing policies that preserve appropriate access for people living with serious illness, which are accompanied by better education requirements for providers and clearer guidance around telehealth prescribing.

In closing, there are still significant gaps in care for people living with serious illness and their caregivers. States – as regulators, payers, communicators, and program administrators – have numerous tools to explore and implement the ideas generated from these listening sessions. For more information and resources on how to expand palliative care access at the state level, please visit NASHP’s website [State Strategies to Build and Support Palliative Care](#).