# How States Can Leverage Existing Medicaid Services To Better Meet Palliative Need in the Community

There are at least 12 million adults,[1] along with roughly 500,000-700,000 children, living with serious illness in the United States. Many experience poor quality of life and poor quality of care from the health care system, and would benefit from **palliative care approaches** to manage symptoms and stressors, and improve shared decision-making**.**

In response, some states are developing programs to expand access to specialty palliative care services. But, while specialty palliative care is essential for high-need patients, the number of people living with serious illness will always exceed the capacity of palliative care specialists to deliver this care. In the meantime, many of these patients' needs could be met by their existing treating providers and extended care team (referred to here as "clinicians;" please see Key Definitions at right) – as long as these professionals are competent in the core tenets of palliative care such as: discussing goals, values, and serious news; pain and symptom management; and family/caregiver support (i.e., "primary palliative care"). **Importantly, many patients with serious illness already receive services from Medicaid-funded support programs, and so some of their palliative needs can be met through existing**

## Key Definitions

**Clinician** is a broad term used to refer to physicians, doctors, advanced practice providers, nurses, social workers, and therapists. Unlike the term "provider," it does not include organizations or agencies.

**Primary palliative care** refers to care delivered by any clinician who does not specialize in palliative care that addresses the symptoms and stresses of serious illness, including assistance with informed decision-making.

**Specialty palliative care** refers to care delivered by palliative-trained specialists that addresses the more complex symptoms, stresses, and decision-making of serious illness. Specialty palliative care is called for when a patient's complexity exceeds what primary palliative care can deliver.

**Serious illness** is a health condition that carries a high risk of mortality AND either negatively affects a person's daily functioning or quality of life, or excessively strains caregivers. Examples of serious illnesses include heart failure, advanced dementia, frailty, COPD, and metastatic cancer (Kelley, Bollens-Lund; 2018).

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[1] This 12 million figure excludes people living with serious illness who do not have documented activities of daily living (ADL) impairments; other published estimates on the size of the adult population go as high as 38 million.

**relationships and resources, without the addition of palliative care specialists**. Given this, palliative care in the context of Medicaid home and community-based services is key area of opportunity that state policymakers should consider to better align payment with quality.

### Consider Maricela

Maricela, dually-eligible for Medicare and Medicaid, was recently hospitalized for uncontrolled neuropsychiatric symptoms of dementia when her community nurse care manager called 911. The floor nurse – who was not a palliative care specialist – considered that her behaviors may be due to constipation, and recommended the addition of over-the-counter Colace. Once her constipation was addressed, her behavior improved dramatically and she was able to return to her home- and community-based services.

Note that this clinical attention to her pain and symptoms was **not** delivered by palliative care specialists, nor was it billed separately as palliative care. As Maricela continues to receive long-term services and supports, the best chance of keeping her stable is ensuring that her nurse care manager has the knowledge and skills to assess for all sources of distress, and respond as warranted.

In the example above, the home and community-based services – with its requisite nurse care management – already had the structures and processes needed to deliver primary palliative care, without having to terminate services and transfer to a different program and care team in order for Maricela to have her physical distress addressed. **However, Medicaid requirements in most states could use further clarification and/or more consistent application to ensure that providers are delivering this primary palliative care effectively,** as described in the pages that follow

Furthermore, **additions to assessment and training requirements could expand the capacity of all clinicians working within existing Medicaid programs** to deliver palliative-informed care that can improve quality of life while reducing the risk of avoidable or unwanted emergency visits and hospitalizations.

### State Variability

There are significant differences in how states have implemented their programs, depending on their target population(s) and program designs. The examples in this paper are meant to illustrate areas in which the complete list of program parameters overlap with palliative care; please see your specific state's program for more information.

This paper explores how two types of Medicaid programs – Home and Community-Based Long-Term Services and Supports, and Health Homes – can better deliver primary palliative care under existing authorities, benefits, and program staff. It also highlights how care delivery can be further improved with selected regulatory changes and/or additional subregulatory guidance.

This is a companion piece to an earlier National Academy for State Health Policy (NASHP) paper highlighting how states are embedding specialty palliative care within existing models and Medicaid authorities, and reflects information gathered from interviews with state policymakers, professional associations, and health care providers.

## Home and Community Based Long-term Services and Supports

Home and Community Based Services (HCBS) waiver programs, such as Medicaid 1915(c) and other waivers, enable beneficiaries who meet criteria for nursing home admission to be served in the community. Services include assessment and coordination services, personal care, and social supports to people with impairments in daily functioning and nursing needs. Often, people who meet institutional level of care overlap with those considered as "living with serious illness" because of the functional impact. **Additionally, recent updates to the HCBS quality measure set increasingly hold states accountable for aspects of care that primary palliative care can positively impact (e.g., person-centered goals, comprehensive assessment, or communication).** Therefore, embedding enhanced attention to their palliative needs and quality of life can improve quality of life for HCBS participants while improving program performance.

While there is significant variation across state HCBS offerings, providers, and services, the overall intention of HCBS programs has significant overlap with primary palliative care. The following table highlights the universal elements of patient eligibility, as well as the most relevant options for clinicians and services within HCBS waiver parameters.

| | Existing HCBS Parameters | How HCBS Overlaps with Primary Palliative Care |
|---|---|---|
| **Patient Population** | • Eligible individuals must demonstrate the need for a Level of Care that would meet the state's eligibility requirements for services in an institutional setting (based on an assessment of activities of daily living and other factors)<br>• Health care needs may also be considered | • Impairment in activities of daily living<br>• Health care needs related to the serious illness<br>• Experts have estimated that the majority of individuals eligible for nursing home-level care in the United States have palliative care needs |
| **Care Team** | • Nurse care managers<br>• Direct care workers (homemaker, home health aide, and personal care)<br>• Therapists<br>• Social workers | • Nurse care managers<br>• Direct care workers<br>• Therapists as warranted<br>• Social workers |
| **Services** | Standard services include, but are not limited to:<br>• Assessment and person-centered care planning (currently the assessment domains are not uniform across states)<br>• Care management (i.e., supports and service coordination)<br>• Homemaker, home health aide, personal care<br>• Adult day health services<br>• Habilitation (both day and residential)<br>• Respite care | • Comprehensive assessment of function, cognition, medication risks, as well as other areas, resulting in a person-centered care plan<br>• Care management<br>• Skilled and unskilled nursing services<br>• Therapy as warranted<br>• Personal care as warranted<br>• Caregiver support (usually short of respite) |

|  | Existing HCBS Parameters | How HCBS Overlaps with Primary Palliative Care |
|---|---|---|
|  | States can choose to provide optional services that may assist in diverting and/or transitioning individuals from institutional settings into their homes and community. |  |

The **greatest challenge to meeting palliative needs in home- and community-based long-term services and supports is ensuring strong coordination with medical services**, so that medication risks can be managed and pain and other symptoms can be addressed. Because home- and community-based services already provide assessment and support to meet beneficiaries' needs, the opportunity to improve primary palliative care lies in directing the care manager's attention to physical distress, caregiver distress, potentially harmful medications, and supporting decision-making consistent with values, goals, and preferences.

**Care Team Considerations**. States can more closely align the HCBS care team with primary palliative care in two ways:

- → First, the state could encourage providers to have a formal linkage agreement with a medical provider (who would bill separately for any medical services). In this way, symptoms can be more seamlessly addressed. A more comprehensive contract requirement might similarly include a formal linkage agreement with spiritual care and mental/behavioral health professionals.
- → Second, states can require serious illness communication training for nurse care managers. Nurse care managers equipped with goals of care conversation skills can support patients and families in finding comprehensive care to meet their needs, values, and preferences.
    - ○ In fact, Arizona has incorporated such training into its managed care organization contracts under the 1115 Waiver, requiring contractors to ensure that all providers and their staff are educated in concepts of end-of-life care and advance care planning.

### From the Provider Perspective

"I would venture to say that we *are* doing elements of palliative care – we are just not calling it that. Person-centered care planning is such a large component of what we do, and a lot of care plans are built around patient quality of life goals, not rehabilitation goals."

-- HCBS Service Agency/Managed Long-Term Services and Supports Plan CEO

**Assessment Considerations**. States can help HCBS program operate more holistically by reviewing and revising guidance on the comprehensive assessment to ensure that it covers symptom distress and caregiver burden. States could either provide resources or formalize the expectation that care managers receive training in assessing for symptom distress, caregiver distress (and psycho-social needs if such training is not already required).

Further guidance can include the evidence-based assessment tools (such as the Revised Edmonton Symptom Assessment System for pain and other physical symptoms, the Karnofsky Performance Status Scale for functional abilities, and the Zarit Burden Interview for caregiver distress).

## Health Homes

Health Homes already provide coordination and assistance for patients living with "chronic conditions" to ensure comprehensive, person-centered care that addresses medical, behavioral, and social needs. Medicaid Health Home services are typically delivered by an interdisciplinary care team, and focus on care management and coordination, regular outreach and problem-solving through care plan development to improve the continuity of care and support optimal well-being. Furthermore, Health Home teams can, if elected by the state, be community-based, hospital-based (outpatient, professional services), or provider based. This aligns with the principal that palliative care services should be community-based and transcend the four walls of the provider's office to improve access and facilitate more person-centered care.

### State Variability

As noted in the previous section, there are significant differences in how states have implemented their programs, depending on their target population(s) and program designs.

Similar to HCBS programs, there is significant heterogeneity among the states' Health Homes, depending on the model type they have chosen to implement (chronic conditions, serious mental illness [SMI], substance use disorder, intellectual or developmental disabilities) and implementation variation. Some of the following recommendations may be more feasible for those Health Homes concentrating on chronic conditions; that said, Health Homes that focus on other areas are still responsible for coordinating physical health and long-term care services along with behavioral health – and could therefore benefit from integrating primary palliative care into their models.

The following table demonstrates the extent to which existing Health Home parameters could overlap with primary palliative care, depending on what states have selected to pursue within Health Home program parameters.

| | Existing Health Home Parameters | How Health Homes Overlap with Primary Palliative Care |
|---|---|---|
| **Patient Population** | • States select from the following: Patients with 2+ chronic conditions; "chronic conditions" are statutorily defined as mental health, substance abuse, asthma, diabetes, heart disease, and being overweight; and CMS may consider additional conditions such as HIV/AIDS for approval<br>• Patients with 1 chronic condition and are at risk for a second<br>• Patients with 1 serious and persistent mental health condition | Depending on what the state selected for the population, these are particular populations with common palliative needs:<br>• Heart disease<br>• Diabetes (advanced)<br>• Cancer<br>• COPD<br>• Dementia<br>• HIV/AIDS<br>• Neurological conditions<br>• Renal disease<br>• Sickle cell<br>In addition, people with serious mental illness also can become seriously ill with cancer, heart disease and other illnesses. Therefore, even Health Homes focused on mental illness are serving some patients with serious illness. |

| | Existing Health Home Parameters | How Health Homes Overlap with Primary Palliative Care |
|---|---|---|
| **Care Team**[2] | - Prescribers (physicians or nurse practitioners[3]<br>- Nurse care coordinators<br>- Specialists (e.g., pediatricians, gynecologists, cardiologists)<br>- Behavioral health professionals<br>- Nutritionists<br>- Social workers<br>- Navigators<br>- Any other professionals the state deems appropriate for its model, such as pharmacists | - Prescribers (physicians or nurse practitioners)<br>- Nurse care coordinators<br>- Social workers<br>- Sometimes: behavioral health professionals, nutritionists, navigators |
| **Services (and Provider Qualifications)**[4] | - Comprehensive care management<br>- Care coordination<br>- Health promotion<br>- Comprehensive transitional care/follow-up<br>- Patient and family support<br>- Referral to community and social support services | - Comprehensive assessment, care planning, and management<br>- Care coordination<br>- Health education, with a focus on what to expect as the disease progresses and making informed decisions<br>- Comprehensive transitional care and follow-up<br>- Patient and family support<br>- Referral to community and social services |

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[2] Each state defines the care team as part of its state plan amendment (SPA); some are defined at the practice/organization/agency level, while others specify the types of clinicians and other workers that should be involved in the care. The list of care team members under “Health Home Parameters” represents the kinds of clinicians that may feasibly be included in the various models.

[3] Core Health Home interdisciplinary team clarified in Health Home FAQ 1-21.

[4] Core Health Home services clarified in Health Homes FAQ 5-3-12.

Health Homes are structurally prepared to meet the palliative needs of beneficiaries, given their reliance on interdisciplinary care and assessment-driven care planning and management. That said, there are three opportunities to strengthen the palliative care capabilities of Health Homes.

**Assessment Clarifications**. A key way that states can improve primary palliative care delivery in Health Home programs is to specify that functional impairment, symptom burden, medication risks, and caregiver burden should be included in the comprehensive assessment – either reiterating this in the requirements as they currently exist, or adding them if they don't. Further guidance can include the evidence-based assessment tools (listed on page 6, and also the Anticholinergic Burden calculator for patients over 65 to screen for potential adverse events).

It is important to note that these assessments are equally appropriate for Health Homes that focus on supporting beneficiaries living with SMI, in addition to those supporting people with chronic conditions, because there is a disproportionate overlap between serious illness and serious mental illness. Assessment for physical care needs and proactively conveying these responses to members of the extended care team meets the intention of comprehensive, coordinated care for high-need beneficiaries.

**Care Team Clarifications**. States can also improve the primary palliative care alignment of the Health Home care team by creating expectations for team member training. This includes how to hold meaningful conversations with patients and families about what to expect and choosing among their treatment options.

For example, in California's Health Home Program, which is administered through Medi-Cal managed care plans, the plans regularly provide training to the community-based care management entities on operational, care coordination, and communication best practices (the latter including Motivational Interviewing, a significant palliative care practice). Further, the Health Action Plan (comprehensive

## Sharing Resources

Washington State has taken the additional step of certifying patient decision aids (PDAs) to assist Health Homes and other types of providers with standardized advance care planning resources, from ACP Decisions and Respecting Choices.

care plan) is shared across all providers so that medical providers can be aware of assessment findings and care plan specifics.

**Patient Population Considerations**. While Medicaid Health Homes already serve a significant number of people living with serious illness, additional beneficiaries could benefit from the support that these programs provide, and the primary palliative care that can be delivered. This includes patients living with cancer, certain neurological diseases such as dementia or Parkinson’s, COPD, as well as HIV/AIDS (if not already included). States must submit expanded eligibility to CMS for consideration.

There are also Health Homes that target pediatric beneficiaries. For example, the New York Health Homes Serving Children (HHSC) makes available a suite of services for Medicaid beneficiaries under the age of 21 with medically complex conditions, developmental delays, and life-limiting illness that includes pain management, massage therapy, and other services to reduce suffering and address palliative needs.

Lastly, states could establish referral parameters (i.e., eligibility criteria) for referral to specialty palliative care for those patients whose palliative needs cannot be met with primary palliative care from the Health Home care team.

## Other Promising Programs

People living with serious illness often require services and supports to assess their holistic needs, provide anticipatory guidance and decision-making support, and assist with social and other services. At the same time, **many seriously ill people already receive some similar services and supports from Medicaid programs for people with chronic and/or disabling conditions.** For instance, the following programs – managed long-term services and supports, special needs plans for people who are eligible for both Medicare and Medicaid, and patient-centered medical homes – already incorporate components of primary palliative care and could be similarly adapted to meet beneficiaries’ needs using existing services and care teams.
As demonstrated by the HCBS and Health Home examples above, targeted policy changes could better support the delivery of primary palliative services through these programs. Some of the ways that states have advanced attention to palliative care needs in these programs are noted in NASHP’s March 2023 Brief How States Can Embed Palliative Care in Health Care Reform Initiatives.

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In closing, significant population, care team, and service overlap between Medicaid programs like Home- and Community-Based Services and Health Homes and the core services of palliative care. For many patients and families whose needs do not necessitate specialty-level palliative care, their existing relationships with the clinicians and caregivers in these programs can be leveraged, and further improved with the addition of specific skills and processes. Enhancing the capabilities of existing programs may reach many more beneficiaries in need of basic palliative care, and in turn, should improve patient quality of life while reducing the risk of avoidable emergency visits and hospitalizations. Further, it will preserve specialty palliative care access for patients with intractable symptoms, high levels of burden and impairment, and/or complex social dynamics.

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