National Center for
Pediatric Palliative Care Homes

Children's Respite
Homes of America

Pediatric Palliative Care Centers in the Medicaid Care Continuum

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About this paper

This technical paper is intended to inform and educate policymakers, healthcare leaders, and community stakeholders about the role of Pediatric Palliative Care Centers within the Medicaid care continuum. It examines existing Medicaid spending patterns, care delivery models, and policy alignment considerations relevant to sustainable, family-centered care for children with medical complexity, particularly those with life-limiting and life-threatening conditions.

1. Introduction: The Missing Node in the Pediatric Care Continuum

Children with life-limiting and life-threatening conditions rely on a complex continuum of care that evolves as their medical needs, functional status, and family capacity change over time. For Medicaid-enrolled children with significant medical complexity, this continuum typically includes a combination of family caregiving at home, private duty nursing (PDN), hospital inpatient care, foster care for medically fragile children, and—when families can no longer safely sustain care—institutional or group home placement.

Medicaid policy and financing mechanisms are well developed for many parts of this continuum. States have established licensure categories, reimbursement methodologies, and oversight structures for hospitals, long-term institutional care, and home-based services such as PDN. These settings account for a substantial share of Medicaid spending for children with complex medical needs.

What is largely missing, however, is a clearly defined and consistently reimbursed role for pediatric palliative care respite delivered in community-based, non-institutional settings. Pediatric Palliative Care Centers (PPCCenters)—freestanding pediatric homes that provide planned, overnight respite within a comprehensive pediatric palliative care model—exist in only a handful of communities nationwide and are often sustained almost entirely through philanthropy. Despite serving Medicaid-enrolled children with high medical acuity, these homes frequently operate outside standard Medicaid licensing and reimbursement frameworks.

This paper examines how Pediatric Palliative Care Centers fit within the Medicaid care continuum, and why the absence of appropriate licensure and reimbursement for Pediatric Palliative Care Respite (PPCRespite) has resulted in a system that relies heavily on downstream, crisis-driven care. By examining existing Medicaid spending patterns and comparing them to the capacity and cost of PPCCenters, this paper aims to clarify how better policy alignment could strengthen family-centered care while improving system efficiency.

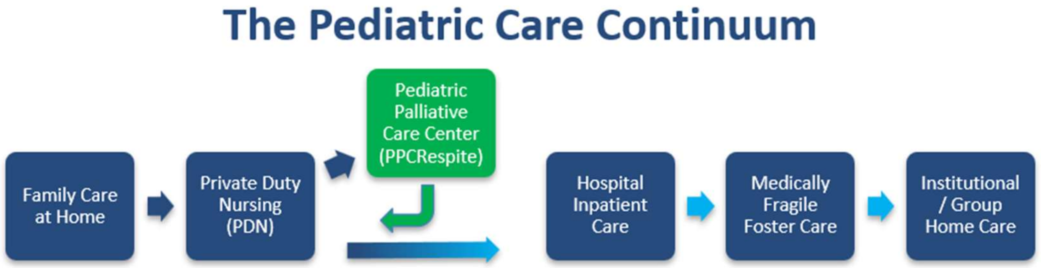


Figure 1. The Pediatric Care Continuum and the Role of Pediatric Palliative Care Centers
This figure illustrates how Pediatric Palliative Care Centers providing PPCRespite function as an upstream, stabilizing node between home-based care and downstream institutional settings.

2. Pediatric Palliative Care Respite (PPCRespite): Definition and Scope

Pediatric Palliative Care Respite (PPCRespite) is a planned, short-term, overnight service designed to support children with life-limiting or life-threatening conditions and the families who care for them. PPCRespite is delivered in a home-like environment by skilled pediatric clinical staff capable of safely caring for children with significant medical complexity, including those who rely on medical technology or intensive nursing support.

PPCRespite is distinct from other forms of respite or residential care. It is not babysitting, custodial care, or long-term placement. Children return home following respite stays, and families remain the primary caregivers. PPCRespite is also not hospital care; it does not involve acute diagnostics or interventions. Instead, it emphasizes continuity, comfort, safety, and caregiver sustainability within a trusted, relationship-based environment.

Figure 2. Pediatric Palliative Care Respite Is More Than Nursing Hours
This figure highlights the interdisciplinary components of Pediatric Palliative Care Respite, demonstrating how PPCRespite extends beyond nursing hours to support the full medical, psychosocial, and emotional needs of children and families.

Critically, PPCRespite is grounded in an interdisciplinary pediatric palliative care approach. Care teams commonly include nurses and nursing assistants experienced in high-acuity pediatric care, as well as child life specialists, social workers, chaplains, and clinicians trained in pediatric palliative care. Together, these professionals support not only the child's medical needs, but also the psychosocial, emotional, and spiritual needs of the entire family. This includes support around anticipatory grief, caregiver stress, and the difficult conversations that often accompany serious childhood illness.

The purpose of PPCRespite is to stabilize families over time. By providing predictable, scheduled overnight support within a comprehensive palliative care framework, PPCRespite helps prevent caregiver exhaustion, reduces the likelihood of unplanned hospital admissions, and supports families' ability to continue caring for their child at home. For children whose conditions may ultimately be life-limiting, PPCRespite also provides continuity across palliative and hospice needs as those needs evolve.

From a policy perspective, however, PPCRespite is often poorly defined or inconsistently categorized within Medicaid programs.

The Human Dimensions of PPCRespite. Beyond its clinical components, PPCRespite derives much of its effectiveness from human and relational factors that are difficult to replicate in other settings. Families consistently emphasize the importance of trust—developed over time through continuity of staff, interdisciplinary presence, and a care environment designed specifically for children with complex needs. Trust in this context is not based solely on credentials or licensure, but on families' confidence that their child is known, understood, and genuinely cared for.

PPCRespite also serves children directly, not only caregivers. Children and adolescents experience respite stays as opportunities for social connection, play, and independence within a medically safe environment. In this way, PPCRespite supports quality of life for children themselves, reinforcing that respite is not simply relief from caregiving duties, but a meaningful intervention for the child.

Finally, PPCRespite allows parents to temporarily step out of constant clinical coordination and return to their role as parents. Families often describe this shift—from managing medical care to simply being present—as one of the most significant benefits of PPCRespite. These human dimensions are integral to why PPCRespite stabilizes families over time and cannot be replicated through episodic or shift-based services alone. In many states, PPCRespite does not fit neatly into existing benefit categories, leaving providers without a clear path to licensure or reimbursement even when the children served are Medicaid eligible and highly medically complex.

3. Pediatric Palliative Care Centers (PPCCenters)

Pediatric Palliative Care Centers are freestanding pediatric homes designed to deliver PPCRespite alongside palliative and, when appropriate, hospice care. These centers are intentionally non-institutional in scale and design, typically serving a small number of children at any given time in a setting that resembles a home rather than a facility.

PPCCenters are not intended to replace hospitals, home health agencies, or family caregiving. Instead, they function as a complementary setting within the care continuum. Children who utilize PPCCenters generally live at home and receive services such as PDN or other home-based supports. PPCRespite provided by a PPCCenter supplements these services by offering families reliable, overnight relief within an interdisciplinary palliative care environment that cannot be replicated through shift-based care alone, particularly in the context of persistent nursing workforce shortages.

Existing PPCCenters demonstrate several common characteristics:

- Short-term stays rather than long-term residence
- High clinical competency to support children with significant medical needs
- Interdisciplinary teams that address medical, psychosocial, emotional, and spiritual needs
- Strong integration with families and local pediatric care systems
- Emphasis on continuity across respite, palliative, and end-of-life care

Despite these shared characteristics, PPCCenters operate under a patchwork of regulatory arrangements. In practice, the PPCCenter setting is uniquely suited to support the human experience of serious childhood illness. Because care is delivered by an interdisciplinary team in a consistent environment, PPCCenters become trusted destinations for families rather than one-time service encounters. Over repeated stays, children build relationships with staff, families develop confidence in the team, and difficult conversations—about uncertainty, progression of illness, or end-of-life preferences—can occur in a setting that is neither the hospital nor the home.

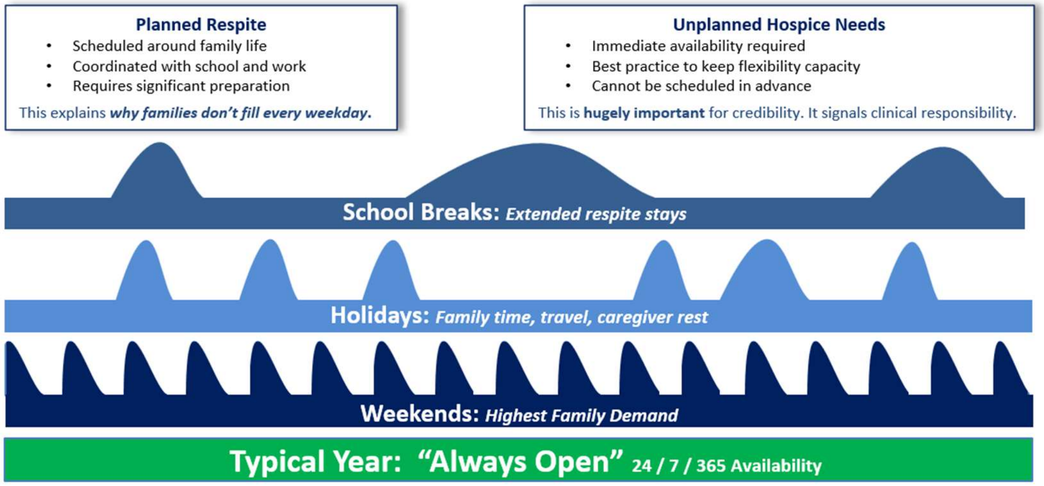
This relational continuity is a defining feature of PPCCenters and helps explain family utilization patterns. Demand for PPCRespite often peaks on weekends, holidays, and school breaks, when parents and siblings are more likely to be off work or school and able to fully benefit from time together. These periods of high demand reflect not only caregiver exhaustion, but families' desire to live as families—traveling together, attending important events, or simply resting—while knowing their child is safe and supported. Some rely on combinations of charitable funding, limited Medicaid waiver reimbursement, and local support. Others operate entirely outside Medicaid financing. This variability reflects not differences in care delivery, but differences in state-level policy recognition and alignment.

4. The Financial Equivalency: Philanthropy Versus Medicaid Alignment

The sustainability challenge facing many Pediatric Palliative Care Centers is often framed as a funding problem. In practice, it is more accurately understood as a financing alignment problem.

To illustrate this distinction, consider a representative PPCCenter operating an eight-bed pediatric home. Assuming 365 days per year, this equates to 2,920 potential bed-days annually. A Pediatric Palliative Care

Center is open and available 24 hours a day, 365 days a year to meet the flowing and often unpredictable needs of families. During peak periods such as weekends, holidays, and school breaks, demand frequently exceeds available capacity and waitlists are common. At other times—such as weekdays during the school year—families may schedule respite less frequently due to school attendance, transportation logistics, and the significant coordination required to prepare for a stay.



Planned Respite

- Scheduled around family life
- Coordinated with school and work
- Requires significant preparation

This explains ***why families don't fill every weekday.***

Unplanned Hospice Needs

- Immediate availability required
- Best practice to keep flexibility capacity
- Cannot be scheduled in advance

This is **hugely important** for credibility. It signals clinical responsibility.

Figure 3. Real-World Utilization Patterns in a Pediatric Palliative Care Center
This figure illustrates typical demand patterns and operational realities that explain why conservative occupancy assumptions reflect family-centered care rather than lack of need.

Preparing for a respite stay can involve coordinating medical orders with a child's primary care team, packing medications and supplies, transporting durable medical equipment such as wheelchairs or adaptive devices, and arranging travel—sometimes over long distances. Best practice also requires maintaining flexibility to accommodate unplanned hospice needs, where immediate access to a room may be essential. These realities contribute to natural variability in occupancy, even in the presence of strong and consistent demand.

Applying a conservative average occupancy rate of 60 percent yields approximately 1,752 billable bed-days per year. This assumption reflects real-world operations while intentionally erring on the side of caution.

In Minnesota, Crescent Cove—a pediatric palliative care home operating under Medicaid waiver authority—receives reimbursement on the order of $2,000 per 24-hour day for children with high medical acuity. Applying this rate to 1,752 bed-days results in approximately $3.5 million in annual revenue.

This figure closely mirrors the annual philanthropic fundraising requirement of Ryan House in Phoenix, Arizona, which raises approximately $3.5 million each year to deliver comparable Pediatric Palliative Care Respite services. Importantly, the children served, the clinical model, and the scope of services do not materially change between these two examples. What differs is not the care delivered, but the financing mechanism that supports it.

This comparison highlights a critical insight: Pediatric Palliative Care Centers are already operating at a scale that Medicaid routinely finances elsewhere in the care continuum. When PPCRespite is recognized as medically necessary and supported through appropriate licensure and reimbursement pathways, a PPCCenter can function as sustainable Medicaid infrastructure rather than relying exclusively on philanthropy.

The sections that follow examine how this level of spending compares to what Medicaid already pays for downstream services, and how PPCCenters can alter the trajectory of care for children with medical complexity.

5. What Medicaid Already Pays For: Downstream Spending Patterns

Medicaid already invests significant resources to support children with medical complexity, particularly when families reach points of crisis or can no longer safely sustain care at home. These investments are concentrated in downstream settings that are well defined within Medicaid policy and reimbursement structures, including institutional or group home care, high-intensity private duty nursing, extended hospital stays, and medically fragile foster care. Examining these spending patterns provides essential context for understanding where Pediatric Palliative Care Centers fit within the broader care continuum.

5.1 Institutional and Group Home Care

All states maintain licensure and reimbursement pathways for institutional or congregate care settings, particularly for individuals with intellectual and developmental disabilities. While these frameworks are often designed with adults in mind, children with significant medical complexity may also be served in group home or institutional settings when family caregiving is no longer feasible.

Although reimbursement rates vary by state and facility type, pediatric group home or medically fragile residential care commonly ranges from approximately $500 to $800 per child per day. At the upper end of this range, annual Medicaid spending approaches $292,000 per child. At this scale, an annual investment of approximately $3.5 million supports care for roughly 12 children in full-time, long-term placement.

These settings play an important role when no other safe options exist. However, they represent a downstream point in the care continuum, typically reached only after families have exhausted available home- and community-based supports. Once children enter institutional care, Medicaid assumes full responsibility for ongoing daily care, often for years.

5.2 Private Duty Nursing (PDN)

Private duty nursing is a cornerstone of home-based care for children with high medical acuity. Medicaid programs authorize PDN to support children who require continuous or near-continuous skilled nursing oversight in the home. Authorized hours may range widely, from overnight coverage several nights per week to as much as 112 hours per week for children with the highest needs, and even to a maximum of 168 hours, which is full 24/7 care.

Medicaid reimbursement rates for PDN typically fall between $45 and $60 per hour, depending on state policy and provider type. At these rates, an annual investment of $3.5 million supports approximately 58,000 to 77,000 nursing hours. Depending on authorized intensity, this level of funding may fully support PDN for roughly 10 to 25 children annually.

While PDN is essential, it is also constrained by persistent workforce shortages. Many families receive fewer hours than authorized, experience frequent staffing gaps, or rely on informal caregiving to fill unmet needs. PDN alone cannot provide the relational continuity, interdisciplinary support, or planned relief that PPCRespite offers within a PPCCenter setting.

5.3 Hospital Inpatient Care as De Facto Respite

In the absence of adequate community-based supports, hospitals sometimes function as an unintentional source of respite for families in crisis. Extended inpatient stays may occur when caregivers are exhausted or unable to safely continue care at home, even when acute medical treatment is no longer required.

Pediatric inpatient care is among the most expensive settings within the Medicaid system. Overnight hospital stays for medically complex children can cost several thousand dollars per night, often ranging from $3,000 to $5,000 or more when room, board, and basic nursing care are included. These costs increase substantially when diagnostic testing, specialty consultations, or procedures are added.

Although hospitals provide critical services, they are not designed to meet ongoing family support or respite needs. Reliance on inpatient care for non-medical reasons is costly, disruptive for families, and often avoidable with appropriate upstream alternatives.

5.4 Medically Fragile Foster Care

When families can no longer safely care for a child at home and institutional placement is not immediately available or appropriate, medically fragile foster care may serve as an intermediate option. Foster families receive enhanced reimbursement to account for the child's medical needs, and Medicaid typically covers additional services such as PDN, therapies, and medical equipment.

While medically fragile foster care provides safety and stability, it also represents a full-time substitute caregiving arrangement and separation from the child's family of origin. From a system perspective, it remains a downstream intervention that carries significant public cost and long-term implications for children and families alike.

6. Comparative Impact: Pediatric Palliative Care Centers as an Upstream Investment

When examined side by side, Medicaid spending patterns reveal a striking contrast in reach and impact. An annual investment on the order of $3.5 million can support a small number of children in high-cost, downstream settings, or it can be leveraged to support a far larger number of families earlier in the care continuum through PPCRespite delivered in a PPCCenter.

At comparable levels of spending, approximately $3.5 million may fund:

- Full-time institutional or group home care for roughly 12 children;
- High-intensity private duty nursing for approximately 10 to 25 children, depending on authorized hours;
- A limited number of extended hospital stays used as de facto respite;
- Or Pediatric Palliative Care Respite through a PPCCenter serving approximately 300 children annually.

This comparison is not intended to diminish the importance of downstream services, which remain essential when families reach points of crisis or when no other safe options exist. Rather, it highlights the opportunity to rebalance Medicaid investments toward upstream, preventive infrastructure that stabilizes families before such crises occur.

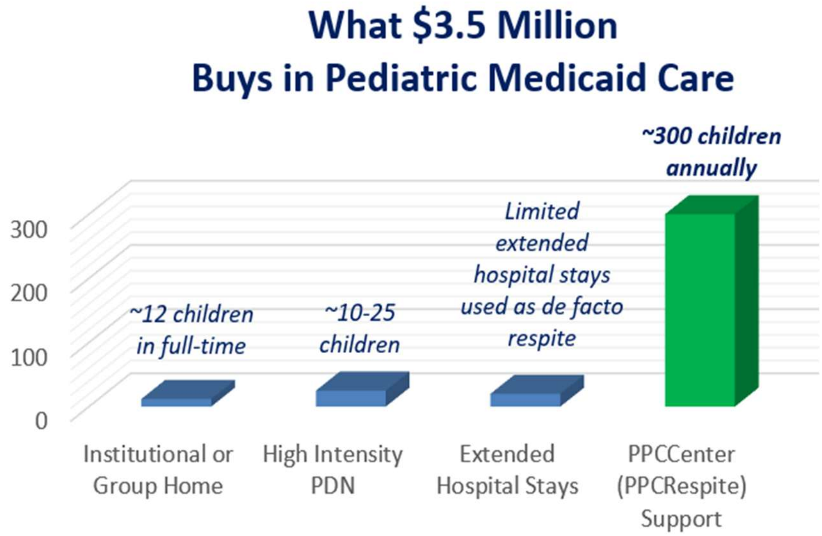


Figure 4. What $3.5 Million Buys in Medicaid Care

This figure compares how a similar annual Medicaid investment supports a small number of children in downstream settings versus hundreds of children through Pediatric Palliative Care Respite delivered in a Pediatric Palliative Care Center.

Pediatric Palliative Care Centers function as a stabilizing node within the care continuum. By providing trusted, planned, and interdisciplinary respite, PPCCenters help families sustain home-based care longer, reduce avoidable hospital utilization, and delay or prevent transitions into institutional or substitute caregiving settings. In doing so, they extend the impact of Medicaid dollars while aligning with longstanding policy goals related to home- and community-based care, family preservation, and cost containment.

The following sections explore the policy implications of this comparison and describe how improved licensing and reimbursement alignment can enable PPCCenters to operate as sustainable components of state Medicaid systems.

7. The Policy Gap: Licensing and Reimbursement Misalignment

Despite the demonstrated clinical value and growing demand for Pediatric Palliative Care Centers, most state Medicaid systems lack a clear and coherent policy framework to support them. This gap is not the result of uncertainty about need or effectiveness, but rather the absence of licensure and reimbursement pathways that reflect how PPCRespite is delivered in practice.

States have well-established mechanisms to license and reimburse hospitals, nursing facilities, institutional group homes, and home-based services such as private duty nursing. These categories are embedded in Medicaid state plans, waiver programs, and regulatory structures that have evolved over decades. Pediatric Palliative Care Centers, however, do not fit neatly into these existing categories. They are neither hospitals nor long-term residential facilities, and their interdisciplinary model extends beyond what is typically contemplated in home health or respite benefits.

As a result, PPCCenters are often forced to operate under fragmented or ill-suited regulatory arrangements, or entirely outside Medicaid reimbursement. In many cases, philanthropic funding is used to fill this policy gap, even though the children served are Medicaid-enrolled and would otherwise qualify for high-cost services in downstream settings. This misalignment places sustainability risk on community-based providers and limits the ability of PPCRespite to scale.

The policy challenge, therefore, is not whether PPCRespite should exist, but how Medicaid frameworks can be updated to appropriately recognize and support it.

8. What Policy Alignment Enables

When Medicaid policy is aligned with the realities of Pediatric Palliative Care Centers, several system-level benefits become possible.

First, appropriate licensure and reimbursement enable PPCCenters to operate as stable, community-based infrastructure rather than as philanthropic exceptions. This stability allows communities to plan capacity, invest in workforce development, and integrate PPCCenters more fully with hospitals, home health agencies, and pediatric specialty providers.

Second, policy alignment supports earlier, preventive engagement with families. By making PPCRespite reliably available, states can reduce reliance on crisis-driven hospital admissions, mitigate caregiver burnout, and delay or prevent transitions into institutional or substitute caregiving settings. These effects align with longstanding Medicaid goals related to home- and community-based care, family preservation, and cost containment.

Third, aligned policy creates consistency across funding streams. Rather than requiring families and providers to navigate multiple waivers or patchwork reimbursement approaches, a coherent framework allows PPCRespite to be supported through Medicaid in a manner that reflects its interdisciplinary scope and medical necessity.

Importantly, policy alignment does not eliminate the need for hospitals, private duty nursing, foster care, or institutional services. Instead, it allows these components of the care continuum to function more effectively by ensuring that families have access to appropriate support earlier in their journey.

9. Conclusion: Reframing Pediatric Palliative Care Respite in the Care Continuum

Pediatric Palliative Care Centers occupy a distinct and currently underdeveloped position within the Medicaid care continuum. They provide trusted, interdisciplinary PPCRespite that stabilizes families, supports quality of life for children, and complements existing home- and facility-based services.

As this paper demonstrates, the level of investment required to sustain a PPCCenter is comparable to what Medicaid already spends on downstream services for a far smaller number of children. The question facing policymakers is not whether resources exist, but whether current policy structures allow those resources to be used in the most effective and family-centered way.

By recognizing Pediatric Palliative Care Centers and PPCRespite within Medicaid licensing and reimbursement frameworks, states have the opportunity to strengthen community-based infrastructure, improve continuity of care, and better align spending with the needs of children and families. In doing so, PPCRespite can move from the margins of the system to its appropriate place as a stabilizing, upstream component of pediatric care.

Acknowledgment of Lived Experience

This paper is informed by the lived experiences of families caring for children with life-limiting and life-threatening conditions, as well as by the operational experience of community-based Pediatric Palliative Care Centers across the United States. These perspectives provide essential context for understanding how policy design and reimbursement structures affect real families and care delivery in practice.

Selected References & Context

The concepts and comparisons presented in this paper are informed by publicly available Medicaid policy guidance, peer-reviewed literature, and established practice frameworks related to pediatric complex care, palliative care, and home- and community-based services. Key reference areas include:

- **Medicaid Home- and Community-Based Services (HCBS) Authorities**
  Centers for Medicare & Medicaid Services (CMS). *1915(c) Home and Community-Based Services Waivers.* CMS guidance describing state authority to design HCBS benefits for individuals with complex needs, including children with medical fragility.
- **Private Duty Nursing (PDN) in Medicaid**
  State Medicaid provider manuals and CMS guidance describing authorization ranges for pediatric private duty nursing, including high-acuity cases requiring extensive weekly coverage. Persistent workforce shortages affecting PDN availability are documented across multiple states and national analyses.
- **Institutional and Congregate Care Spending**
  Medicaid reimbursement frameworks for Intermediate Care Facilities and medically fragile group home settings, including per-diem cost ranges for pediatric residential care. These frameworks demonstrate that Medicaid routinely supports high per-child expenditures when families can no longer sustain care at home.
- **Pediatric Palliative Care Principles**
  National consensus statements and professional guidance describing pediatric palliative care as an interdisciplinary model addressing medical, psychosocial, emotional, and spiritual needs of children and families across the illness trajectory.
- **Caregiver Burden and Avoidable Hospital Utilization**
  Peer-reviewed research documenting the relationship between caregiver strain, gaps in community-based supports, and increased reliance on hospital inpatient care for children with medical complexity.

This paper synthesizes these sources with real-world operational experience to examine how Pediatric Palliative Care Centers and Pediatric Palliative Care Respite can function as stabilizing, upstream components within the Medicaid care continuum.

This paper is issued by the National Center for Pediatric Palliative Care Homes (NCPPCH) as an educational resource. It does not advocate for specific legislation, but seeks to clarify policy considerations relevant to sustainable, family-centered pediatric care.