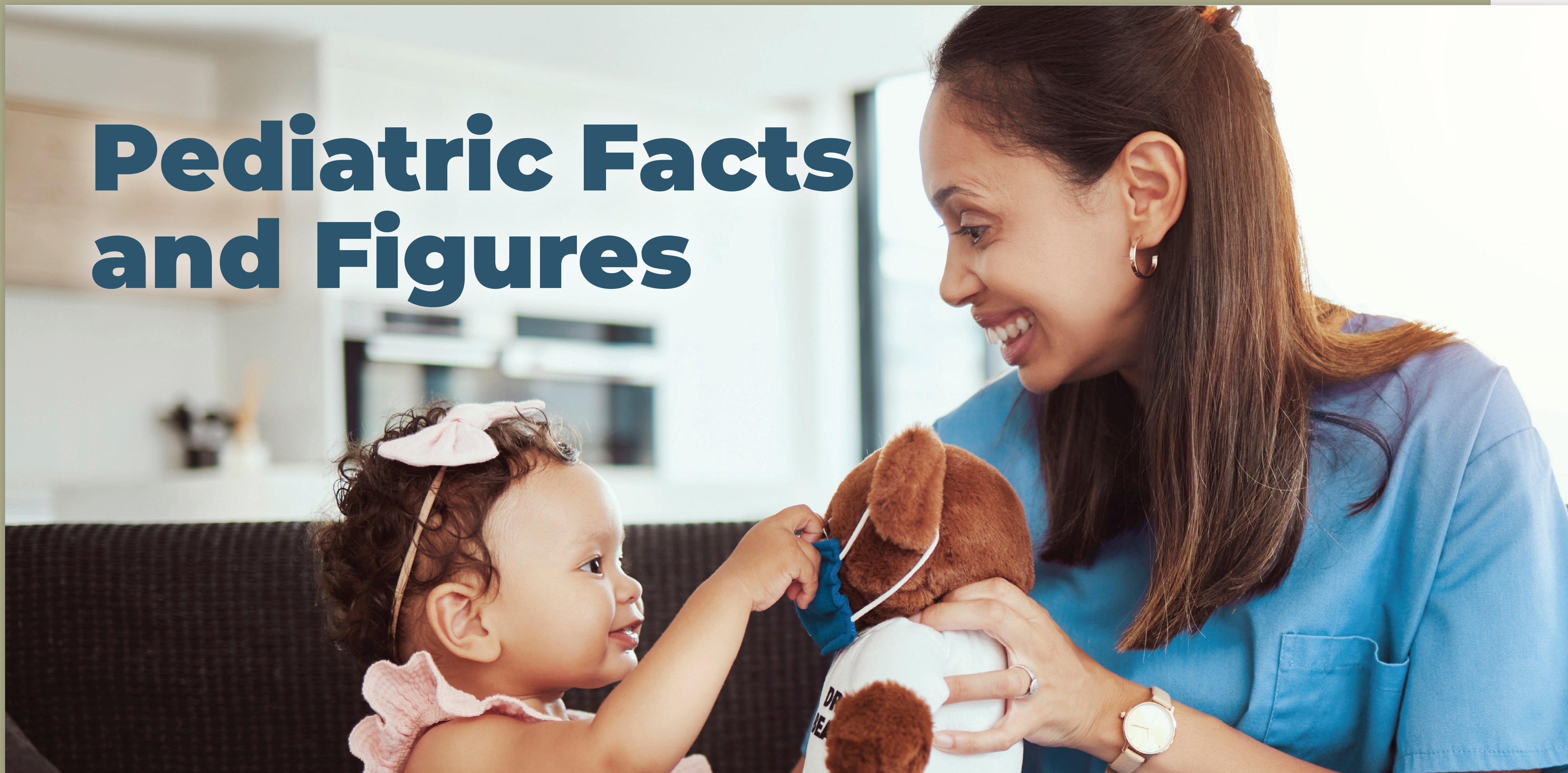
Pediatric Facts and Figures



National Alliance for Care at Home

2025 EDITION

Published July 2026

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Introduction

About this Report

The National Alliance for Care at Home Pediatric Facts and Figures report provides an overview of pediatric palliative care and hospice in the United States and presents the results of a national survey of providers. This survey had a response rate of 56% and yielded 295 entries representing distinct pediatric programs. Responses represent all 50 states and Washington, DC. The survey was active from May through August of 2024.

This overview provides specific information on the following, including a new section focused on concurrent care:

- Pediatric patient characteristics
- Location and access to care
- Reimbursement for care
- Provider characteristics
- Barriers and facilitators to care
- Concurrent care

The tenets of palliative care remain the cornerstone of all care: patient-centered, interdisciplinary approach; expert pain and symptom management; support for all members of the family; and a focus on quality of life as defined by the patient and family. These were articulated in 2013 and reaffirmed in 2019.[1]

The purpose of this report is to highlight the pediatric palliative and hospice care in the U.S. as reported by the agencies responding to the national survey distributed by the Alliance (and formerly the National Hospice and Palliative Care Organization) and by our partner organizations at the National Coalition for Hospice and Palliative Care in 2024.

Section 1: What are Palliative and Hospice Care?

What is palliative care?

"Palliative care is patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering".[2]

Palliative care can be provided from the time of diagnosis of a serious illness, addressing physical, emotional, social, and spiritual needs to facilitate patient autonomy and access to information, and supporting and advocating for the patient and family's goals for care.

Both the National Alliance for Care at Home and the National Consensus Project for Quality Palliative Care[3] list the following precepts of palliative care:

- Appropriate at any stage in a serious illness
- Provided longitudinally over time to patients based on their needs and not their prognosis
- Offered in all care settings and in concert with patients, families, palliative care providers, and non-palliative health care providers, collaborating and communicating about care needs
- Focused on what is most important to the patient, family, and caregiver(s), assessing their goals and preferences and determining how best to achieve them
- Interdisciplinary to address the holistic care needs of the patient and their identified family and caregivers
- Services are available concurrently with, or independent of, curative or life-prolonging care

Pediatric care includes perinatal, neonatal, infancy, childhood, adolescence, and young adulthood. The definitions used in this report are:

Perinatal—before birth
Neonatal—birth to 1 month
Infancy—1 month to one year
Childhood—1 year to 12 years
Adolescence—13 years to 17 years
Young adulthood—18 years+

What is perinatal palliative care?

As defined by the American College of Obstetricians and Gynecologists (ACOG) and endorsed by the American Academy of Pediatrics and the Society of Maternal-Fetal Medicine[4], perinatal palliative care is a coordinated care approach encompassing obstetric and neonatal services that prioritize quality of life and comfort for newborns with a range of conditions that may be life-threatening before birth or early infancy. With dual emphasis on alleviating suffering and respecting patient and family values, perinatal palliative care may be provided alongside life-prolonging therapies.[5] Perinatal palliative care should be a collaborative effort between clinical service lines, encompassing obstetrics, neonatal, and palliative care services.

What are Palliative and Hospice Care? (continued)

What is hospice care?

According to the National Consensus Project for Quality Palliative Care,[6] "hospice is a specific type of palliative care provided to individuals with a life expectancy measured in months, not years. Hospice teams provide patients and families with expert medical care, emotional and spiritual support, focusing on improving patient and family quality of life." Hospice is the model for quality, expert, compassionate care for individuals facing the last months of life with a serious illness. Hospice provides care and support based on the individual patient's and family's needs and wishes. The focus is on care rather than cure.

In the U.S., hospice is typically provided in a home setting but can also be delivered in hospitals, freestanding hospice facilities, and other care facilities. For pediatric patients, hospice is usually covered by Medicaid, Tricare, or private insurance. Although adults generally must forego any curative or life-sustaining treatments when electing hospice care, children are eligible for concurrent care. Concurrent care allows children to continue curative and life-sustaining treatment; however, children must still meet the 6-month prognosis in most states.

Hospices promote inclusiveness in the community by ensuring all people, regardless of race, ethnicity, color, religion, gender, disability, sexual orientation, age, disease, or other characteristics, have access to the hospice's programs and services. More on this later in this report.

What is concurrent care?

Concurrent care is a benefit under the Patient Protection and Affordable Care Act (ACA) for children with serious illness who meet the hospice 6-month prognosis eligibility criteria. Concurrent care entitles all children enrolled in Medicaid or the Children's Health Insurance Program (CHIP) to receive curative and life-sustaining treatment with hospice care, avoiding the impossible choice between life-prolonging and hospice care for children and their families.[7,8,9] Tricare adopted concurrent care in 2018 through the National Defense Authorization Act. Tricare is the largest and first major third-party payor to provide this benefit to all beneficiaries. To date, most other third-party insurers offer concurrent care on a case-by-case basis.[10,11]

Section 2: Who Receives Pediatric Hospice and Palliative Care?

What are the characteristics of patients who received home-based palliative care and hospice care?

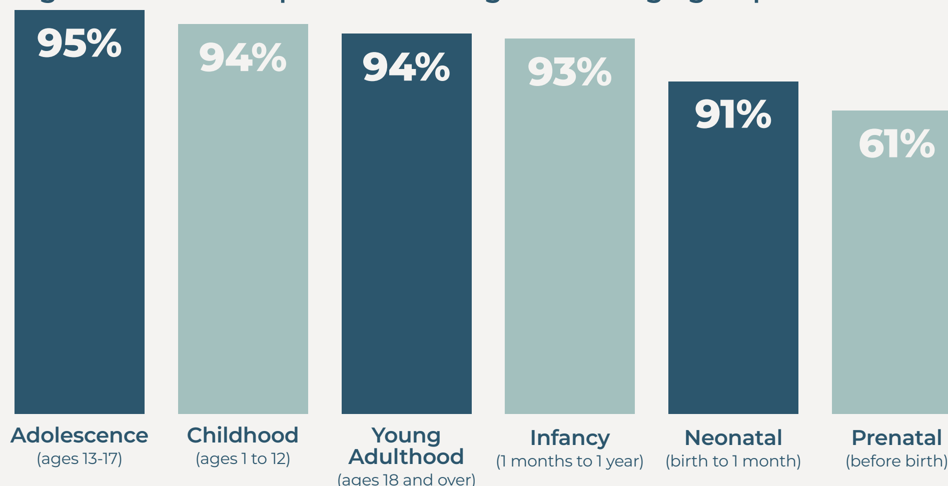
Since the 2023 report, there have been additional studies demonstrating national data regarding demographics, including gender, race, and ethnicity, though in our review, there do not appear to be any studies specifically analyzing national trends from an equity lens.[12] Children and young adults more frequently have technology dependence, continued pursuit of life-sustaining interventions, and higher utilization of inpatient resources compared to adult hospice recipients. Additionally, a majority of patients continue to utilize their primary care providers, reflecting the ongoing involvement of non-hospice clinicians in their medical care.[13,14] Furthermore, much of the data in the past two years shows children and young adults often have longer lengths of stay in hospice compared to adults[15,16,17] Length of admission is related to multiple factors, including prognostic uncertainty, continued ability to pursue life-prolonging medical care, and continued access to curative interventions. There remains limited national analysis related to differences between those who receive hospice and home-based palliative care. Some single-site data suggest oncologic diagnoses may be more common in hospice, while neurologic diagnoses may be more common in home-based palliative care.[18]

What age groups are served?

Pediatric hospice and palliative care serve a wide variety of ages. Children and young adults who have met eligibility criteria have benefited from hospice and palliative care. The most common pediatric age groups are 1 to 5 years old and 6 to 14 years old, accounting for approximately 69% of patients. A growing cohort is those who receive perinatal palliative care and hospice, which provides individuals and families expecting a child with a life-threatening condition with the appropriate support. It is important to note that at age 21, individuals are no longer eligible for concurrent care hospice, as the Patient Protection and Affordable Care Act (ACA) mandates this for those under the age of 21 with Medicaid or the Children's Health Insurance Program (CHIP).[20,21]

Hospices and palliative care programs surveyed provided fairly consistent with 91-94% providing coverage across pediatric age groups, with the exception of perinatal, which was provided by 61% of respondents.[22]

Figure 1: Portion of providers caring for each age group



Source: *Analysis of 2024 Pediatrics Palliative and Hospice Needs Survey, National Alliance for Care at Home*

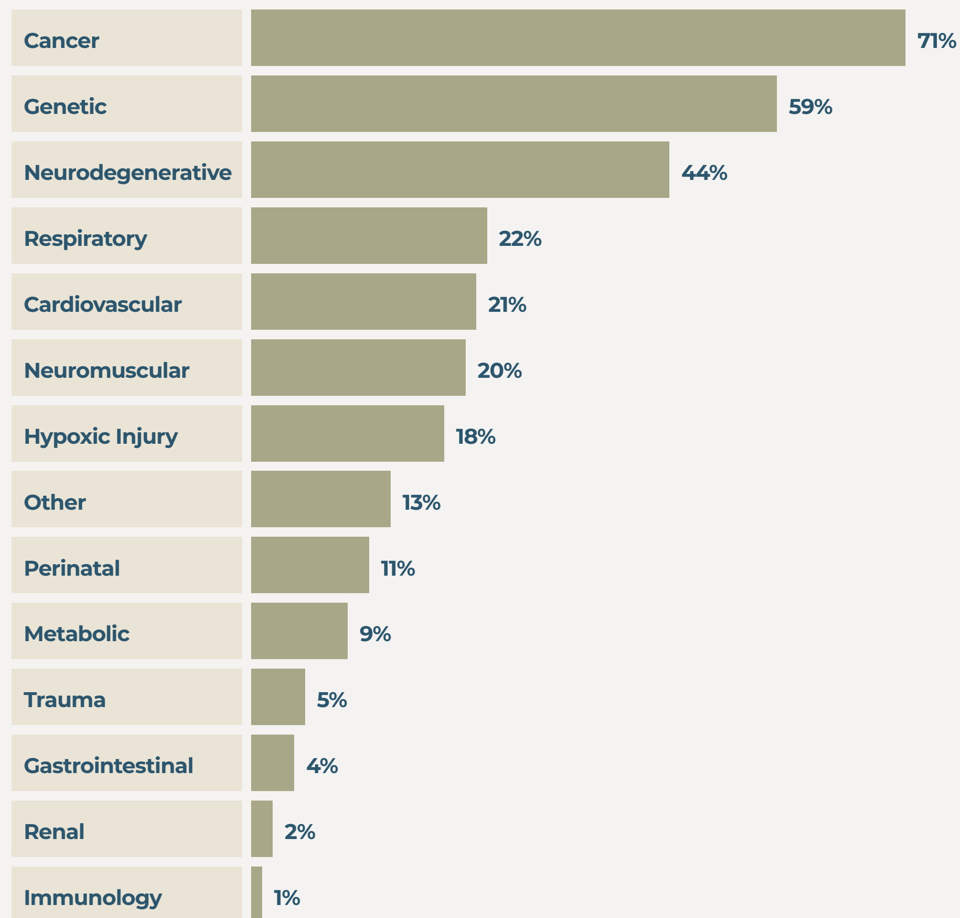
Who Receives Pediatric Hospice and Palliative Care? (continued)

What are the most common conditions experienced by patients receiving palliative care services?

Based on Medicaid and private insurance data, children and young adults with neurologic, cardiovascular, gastrointestinal diagnoses, and malignancies make a large percentage of the cohort of children enrolled in hospice and concurrent hospice care.[23] Children with medical complexity (CMC), an important but at times challenging group to describe, are also a significant cohort who benefit from pediatric hospice and palliative care programs. This group overlaps with the previously mentioned diagnoses but is further defined by the presence of chronic medical conditions associated with significant functional impairment, technology dependence (e.g., tracheostomy, ventilator support, feeding tube), and impact on multiple organ systems.[24,25] Data continues to demonstrate the importance of palliative and hospice care in these individuals' medical care.

Prior to the ACA, continuation of life-sustaining interventions was a barrier to pediatric enrollment in hospice, especially for CMC. With the ACA requirement in place, enrollment has improved. Prognostic uncertainty in children and young adults continues to serve as a common barrier to enrollment in both hospice and home-based palliative services. Enrollment patterns, however, may not perfectly reflect the population of those who should qualify and would benefit from hospice enrollment. The characteristics of patients in home-based palliative care are less well-defined, though some data has been presented in the literature on differences between these populations.[26] Patients receiving inpatient pediatric palliative care, as well those in the community or home-based care, have similar results compared to those receiving hospice services.[27,28]

Figure 2: Conditions most commonly referred to pediatric palliative care



Source: *Analysis of 2024 Pediatrics Palliative and Hospice Needs Survey, National Alliance for Care at Home*

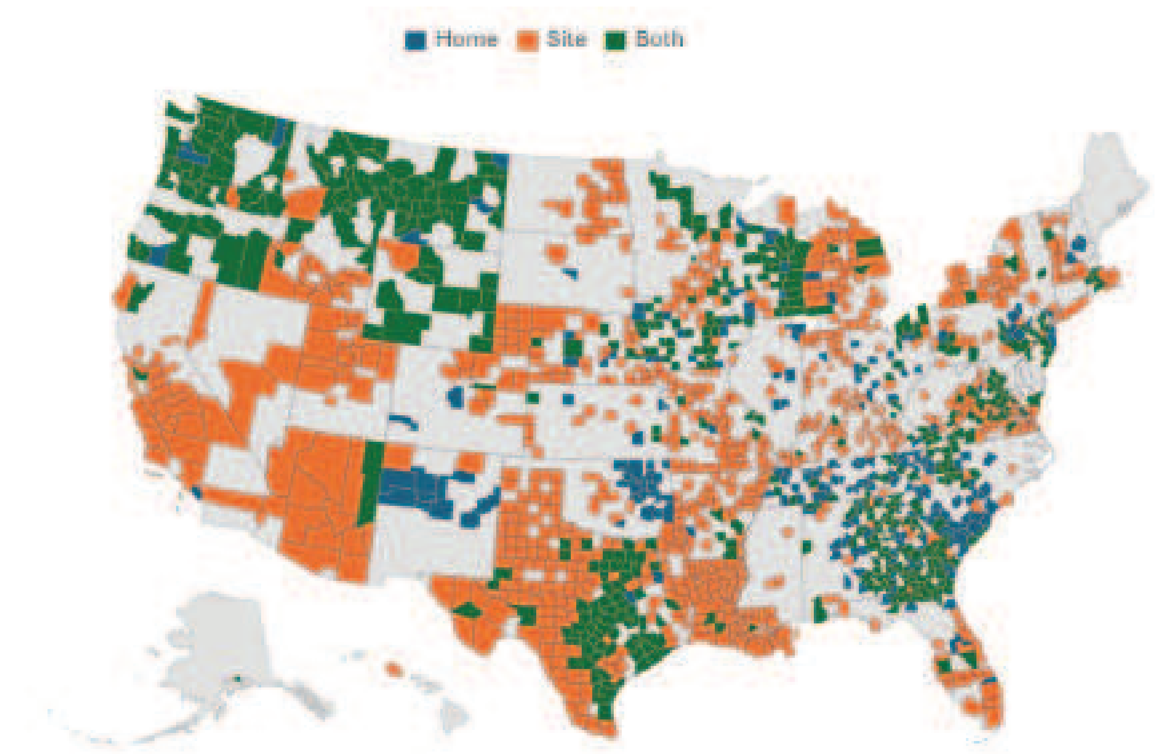
Section 3: Where Services are Provided?

Where are palliative care providers located?

Pediatric hospice and palliative care are provided throughout the U.S. in a variety of settings (Home-Based, Clinic, Hospital, Inpatient Hospice, Respite, etc.). There is no reliable or accurate single source of information on which adult palliative and hospice providers serve pediatrics. While some states do make lists available publicly, audits have found these lists to be inaccurate, and most providers incidentally support pediatric patients rather than hold it as a core component of their service offerings.[29]

Service availability was measured by setting type (non-metropolitan, metropolitan) and county type (non-metropolitan, metropolitan). In the 2024 survey, organizations were asked to identify which counties they offered services in, as well as the type(s) of settings in which they provided services. County data is taken from the 2023 RUCC County report[30,31] which identifies and classifies 3,236 U.S. counties.

Figure 3: Counties with reported pediatric services in the United States by Setting



Source: *Analysis of 2024 Pediatrics Palliative and Hospice Needs Survey, National Alliance for Care at Home*

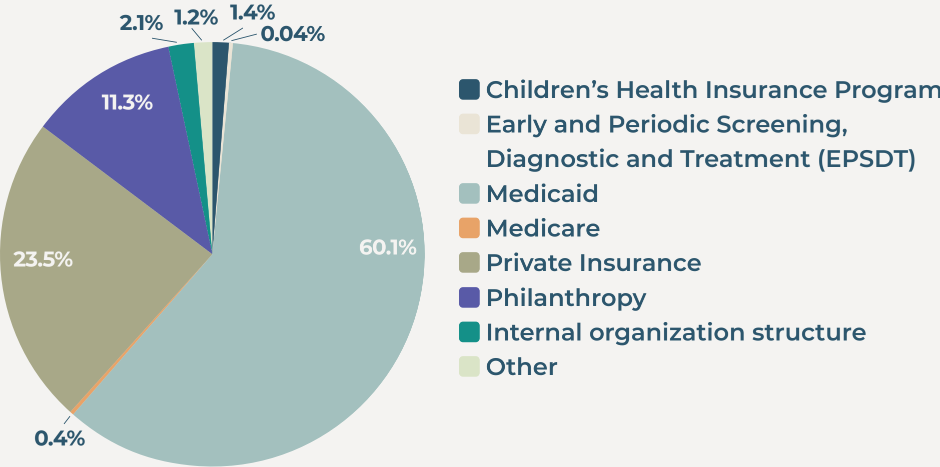
Section 4: How is Care Reimbursed and Who Provides the Care?

How Much Does Pediatric Hospice and Palliative Care Cost?

Children with serious illnesses compose the top 10% of U.S. healthcare expenditures with an average annual cost of $82,000 per year per child.[32]

Hospice and palliative care costs vary significantly depending on the type and level of care provided.[33,34,35] Pediatric hospice care averages approximately $54,540 per year, while pediatric concurrent hospice care averages about $76,452 per year. Pediatric palliative care costs are substantially higher, averaging approximately $200,000 per year.

Figure 4: Census-Weighted Average Payer Mix for Responding Pediatric Hospice and Palliative Care Providers



Source: *Analysis of 2024 Pediatrics Palliative and Hospice Needs Survey, National Alliance for Care at Home*

Who Pays for Pediatric Hospice and Palliative Care?

Medicaid, Children's Health Insurance Program (CHIP), private insurance, TRICARE, and other mechanisms pay for pediatric hospice, concurrent, and palliative care. It is common for children to be covered by multiple payers.[34]

Medicaid and CHIP

Medicaid and CHIP are the most common payers of pediatric care. More than 90% of children are Medicaid and CHIP beneficiaries due to a serious health condition while not meeting federal poverty level (FPL).[35]

Hospice Care. Medicaid and CHIP hospice payment is a per-diem based on add-on rates and level of care (i.e., routine home care, continuous home care, inpatient respite care, general inpatient care). Children most often receive routine home care.[36]

Concurrent Care. The Concurrent Care for Children benefit is available for all eligible Medicaid and CHIP beneficiaries (i.e., under 21 years old with a six-month prognosis) per section 2302 of the Patient Protection and Affordable Care Act (ACA). Children enrolled in managed care plans, prepaid inpatient health plans, prepaid ambulatory health plans, and primary care case management systems are entitled to the same Concurrent Care for Children benefit as children receiving the fee-for-service Medicaid. Medicaid and CHIP pay for non-hospice care separately from hospice services.

How is Care Reimbursed and Who Provides the Care? (continued)

Palliative Care. Inpatient and community-based pediatric palliative care payment is limited under state Medicaid and CHIP plans. Payments are typically made only for clinician services, not for interdisciplinary services such as chaplaincy and social work.

Private Insurance

Less than half of children are covered by private insurance.[37] The most common plan types are Preferred Provider Organizations (PPO) (49%) and Point of Service Plans (POS) (37%).[38]

Hospice Care. Hospice payment by private insurance is similar to Medicaid and CHIP with per-diems, add-ons, and level of care rates. Each insurer has its own payment structure.

Concurrent Care. Section 2302 of the ACA does not require private insurance to pay for pediatric concurrent hospice care. To date, there are no Federal or State regulations requiring private payers to cover the benefit. Very few national private insurance companies provide coverage of concurrent care.

Palliative Care. Payment for pediatric palliative care by private insurers is dependent on the insurer. Some plans fully or partially cover the service, while others do not. Each provider has a unique definition of palliative care. Children and their families may incur out-of-pocket costs including premiums, deductibles, copayments, and coinsurance for palliative care services.

TRICARE

TRICARE is the healthcare program of the U.S. Department of Defense Military Health System and is managed by the Defense Health Agency. TRICARE provides civilian healthcare benefits to military personnel, military retirees, and their dependents, including children.[39]

Hospice Care. TRICARE pays for hospice services for children of active military personnel in the U.S., District of Columbia, and U.S. territories. It does not cover hospice services overseas. The four levels of care apply to TRICARE hospice payment.

Concurrent Care. Concurrent care is available for children under 21 years covered by TRICARE since 2017. Payment for hospice and medically necessary curative care services is allowed when children are referred to hospice by their provider. Concurrent care must be pre-authorized, payments are plan restrictions and provisions, and case management is required.

Palliative Care. TRICARE does not pay for community-based pediatric palliative care services.

How is Care Reimbursed and Who Provides the Care? (continued)

Other Mechanisms

Other organizational, Federal, and State mechanisms are used to pay for pediatric hospice, concurrent, and palliative care, this includes.[40,41,42,43]

- Philanthropic support (e.g., donations, gifts, write-offs, and organizational support)
- Foundation grants
- Medicaid Waivers (e.g., 1915, 1115, 2703)
- Medicaid Targeted Case Management
- Medicaid State Plan Amendments
- Medicaid Early & Periodic Screening, Diagnostic, and Treatment
- Title V Children and Youth with Special Health Care Needs Programs
- 2019 ACE Kids Act
- 2005 Family Opportunity Act
- 1982 Tax Equity & Responsibility Act

Staffing for Pediatric Palliative and Hospice Care

The 2024 data indicate that an average of 2 (median 1) team members on staff hold certifications in pediatric or hospice care. Representative disciplines cited as having formal pediatric certification and/or training include physicians, nurses, advanced practice providers, child life specialists, social workers, integrative therapists, spiritual care providers, certified nurse assistants, and grief counselors. Prior data from 2020 indicated that less than half (48%) of responding agencies had a team dedicated solely to pediatric care. Now, more than half (62%) of responding agencies report having a dedicated pediatric palliative care or hospice team. In 2020, 71% of respondents cited a lack of pediatric-trained personnel as a main challenge, while 50% cited access to pediatric-trained personnel as a main concern.

Pediatric-specific education and even formalized credentials in pediatrics have been recognized as a top-cited need by care teams.[44,45] Nurses and staff accustomed to caring for adults benefit from training in pediatric-specific principles not only for professional competence and quality of care, but also for personal comfort and job sustainability.[46,47,48]

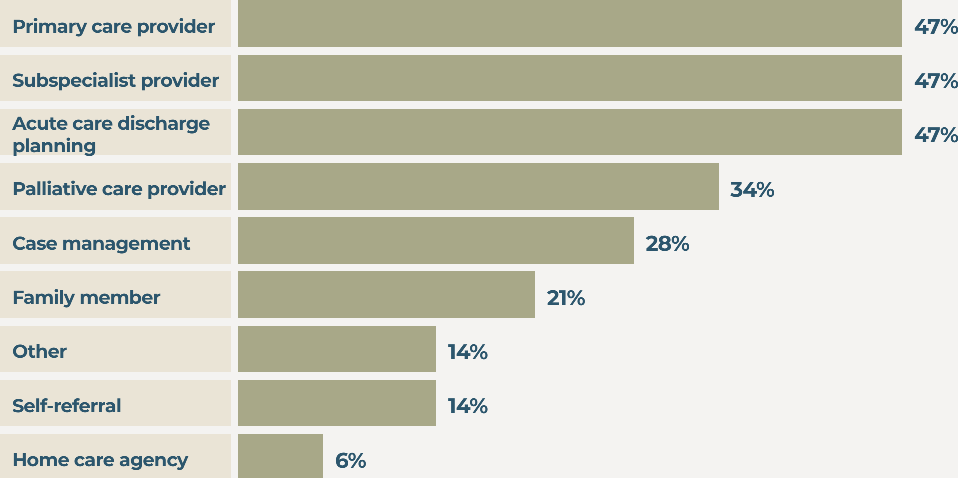
Section 5: Referral Sources for Pediatric Palliative Care

Where are patients referred from?

Common referral sources include consultative pediatric palliative care teams, subspecialty clinics, and other clinicians who care for children with serious, life-limiting conditions. Referrals are commonly placed upon discharge from the acute care . Specific data on the clinical context of the source of referral are poorly characterized. One study looking at inpatient pediatric palliative care found that 45% of patients seen by inpatient pediatric palliative care in one year were referred to home-based palliative care or hospice.

Based on the 2024 National Alliance for Care at Home Pediatric Needs Assessment.[40]

Figure 5: Most Common Referral Sources (proportion of respondents selecting each)



Source: *Analysis of 2024 Pediatrics Palliative and Hospice Needs Survey, National Alliance for Care at Home*

Important trends to watch include whether a decentralized referral system meets the needs of children and families and improves referral timeliness.[41,42,43] Self-referral and family referral patterns will be additional patterns to monitor longitudinally as community-based services increase direct-to-consumer and patient-directed outreach.

Section 6: Services Provided?

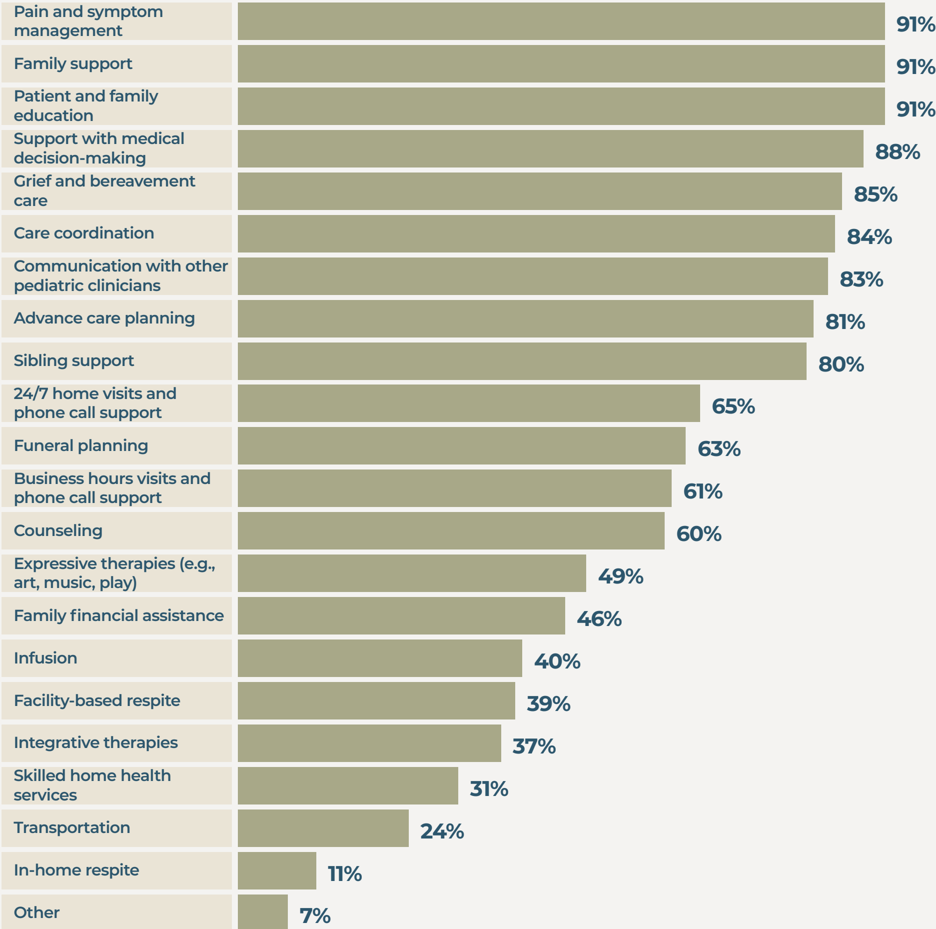
The services provided to pediatric hospice and palliative care patients are often similar and include pain and symptom management, medication management, care coordination, education, patient and family support, integrative therapies, advanced care planning, and goal setting; as well as the support provided by the interdisciplinary team social work, spiritual care and for pediatric child life. However, the intensity and frequency of services vary based on the child's and family's needs and acuity level. Regardless of whether the child is enrolled in a palliative or hospice program, quality of life for the child and family is central to the care and services provided.

Services are provided by an interdisciplinary team for both hospice and palliative care. While hospice guidelines outline core disciplines (physician, registered nurse, social worker, and chaplain) and services (such as bereavement support) involved in the delivery of hospice care to the child and family, palliative care programs have flexibility in the design and services provided to the child and family.[44]

Services cited most often include pain and symptom management, patient and family education and support, grief and bereavement care, care coordination and collaboration with other providers, advanced care planning, and sibling support. Other services frequently provided include 24/7 phone and home-visit support, funeral planning, counseling, expressive therapies, and financial assistance.

While services may vary based on program design, the focus of all pediatric hospice and palliative care programs is to provide the right level of care, at the right time, for each child and their family based on their unique personal, cultural, religious, and spiritual values and beliefs.

Figure 6: Services Provided by Respondent Pediatric Palliative and Hospice Organizations



Source: *Analysis of 2024 Pediatrics Palliative and Hospice Needs Survey, National Alliance for Care at Home*

Services Provided (continued)

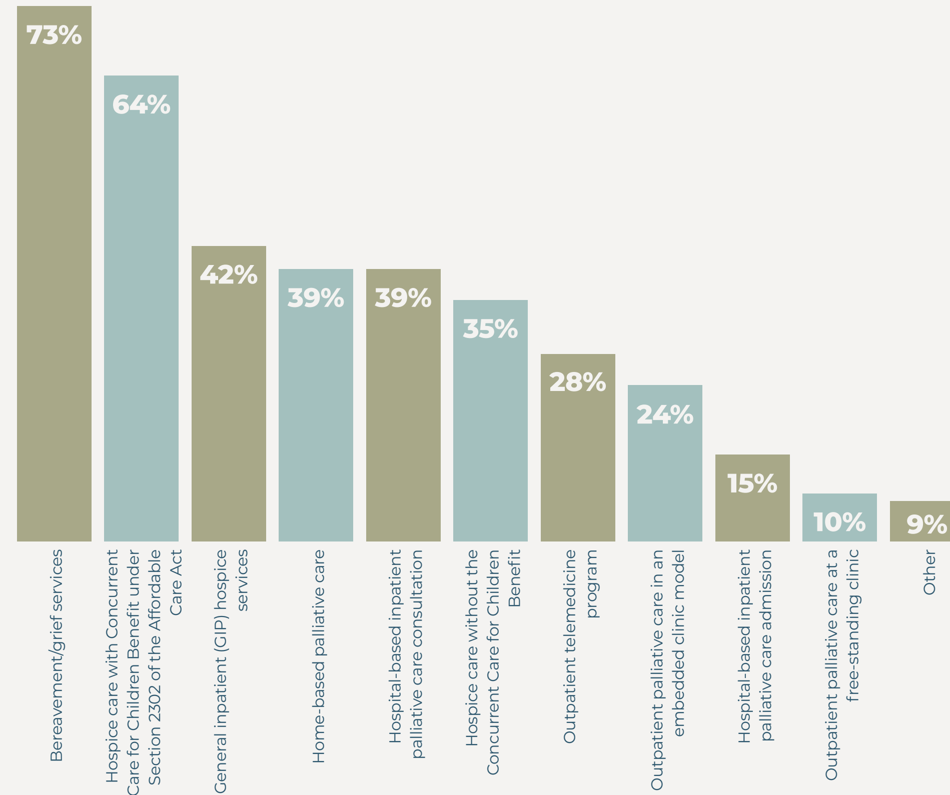
Additional services offered include (but are not limited to) the following:

Figure 7: Additional Services Provided

Source: *Analysis of 2024 Pediatrics Palliative and Hospice Needs Survey, National Alliance for Care at Home*

Services are provided to pediatric patients and their families. Care models are similar to adult-focused models of care. The following table shows the categories of care models and the percentage of respondents who provide services in each model of care. Bereavement/grief support was identified by 73% of the respondents as a model of care, primarily for families whose child was no longer on service.

Figure 8: Portion of Respondent Programs Offering Service to Pediatric Patients and Families



Source: *Analysis of 2024 Pediatrics Palliative and Hospice Needs Survey, National Alliance for Care at Home*

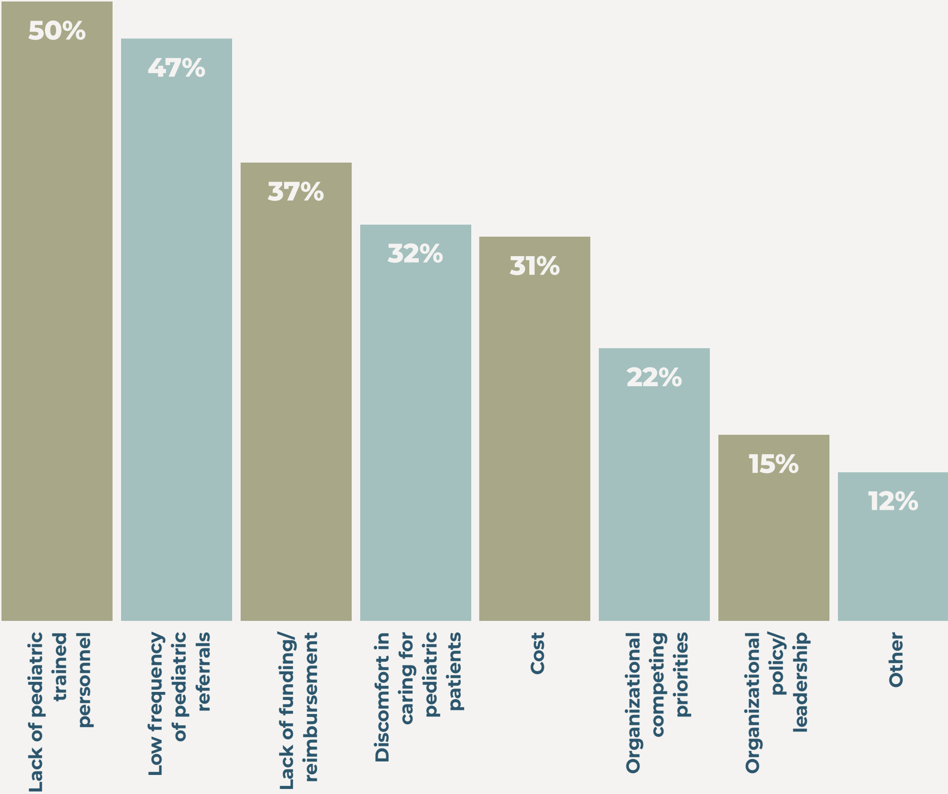
Section 7: Barriers

What barriers do patients and families face accessing pediatric care?

Survey respondents face a range of barriers in delivering pediatric hospice and palliative care, with the most prominent being a lack of pediatric-trained personnel and infrequent referrals, both of which were cited by nearly half of the respondents. Financial challenges, including inadequate reimbursement and high costs, can further complicate service provision. Many respondents reported discomfort in caring for pediatric patients, highlighting the need for specialty training, and cited organizational issues such as competing priorities and limited leadership support. Additional obstacles include difficulties with concurrent care—especially with private insurance—and geographic separation from pediatric specialists. Misunderstandings around disease criteria, limited community resources, and staff juggling multiple roles also contribute to the complexity of providing consistent and comprehensive pediatric care.

Comparison to 2023 report: While the lack of pediatric-trained personnel remained the highest-cited barrier in both 2023 and 2025, lack of funding/ reimbursement and discomfort in caring for pediatric patients were both cited more frequently in 2025.[45]

Figure 9: Barriers and Challenges in Providing Pediatric Services (proportion of respondents selecting each)



Source: *Analysis of 2024 Pediatrics Palliative and Hospice Needs Survey, National Alliance for Care at Home*

Barriers (continued)

In Figure 9, “other” includes:

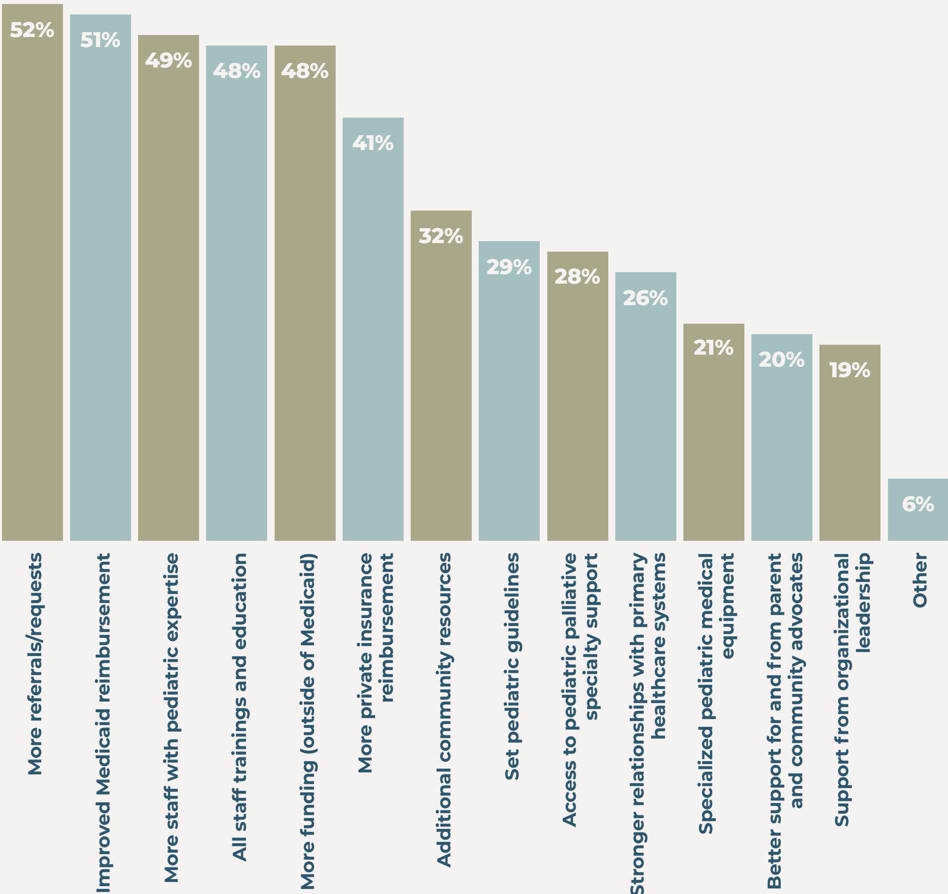
- Prognosis and limited /defined 6-month benefit
- Challenges with negotiating concurrent care
- Private insurance is not required to offer concurrent care.
- Pediatric staff holding added roles that divide their time
- Misunderstanding of appropriate disease criteria
- Lack of resources in the community for therapies

What factors facilitate access to pediatric care?

To improve and expand pediatric hospice and palliative care services, respondents identified several key facilitators. The most frequently cited needs were increased referrals and improved Medicaid reimbursement, both of which were mentioned by over half of the participants. Enhancing staff expertise through pediatric-specific training and education was also emphasized, as was securing additional funding beyond Medicaid sources. Respondents highlighted the importance of better private insurance reimbursement, additional community resources, and clearer pediatric care guidelines. Access to pediatric palliative specialty support and stronger relationships with primary healthcare systems were also seen as critical. Other suggestions included Increased awareness and advocacy, availability of pediatric supplies and sub-specialists, and expanding eligibility criteria, such as prognostic timelines. These facilitators reflect a strong desire for systemic support, education, and resource development to meet the growing needs of pediatric patients and their families.

In essence, the facilitators directly address the barriers, suggesting that with targeted investment in staffing, education, funding, and systemic support, many of the current challenges could be significantly reduced.

Figure 10: Factors that Could Support Continued or Expanded Access (proportion of respondents selecting each)



Source: *Analysis of 2024 Pediatrics Palliative and Hospice Needs Survey, National Alliance for Care at Home*

Barriers (continued)

Other aids needed:

- Increased awareness/advocacy
- Pediatric supplies and feedings
- Expand prognosis to 1 year vs. 6 months

Care was denied to patients requesting it in rare circumstances. The reasons given by survey respondents typically indicated 1) a mismatch between communicated prognosis and allowable use under state or federal regulations or 2) a mismatch between expectations and what the facility was able to provide. Reasons for service denials included:

- Inappropriate palliative diagnosis
- Child did not meet criteria for 6-month prognosis
- Significant behavioral needs
- Was beyond our scope
- Unable to provide palliative care due to lack of funding
- Parents had conflicting expectations from palliative care
- Did not provide outpatient visits
- Did not meet medical complexity criteria
- Private insurance did not honor concurrent care

These responses brought more questions and highlight more inequities across programs. It brings to light the many factors involved in the decision to take a pediatric patient and the challenges in access to care for pediatric patients. These statements are the reasons from the needs assessment survey and could be indications of situation specific, skill or liability concerns by the agency.

Section 8: Concurrent Hospice Care

How commonly is Concurrent Hospice Care covered by insurance?

Based on recent national survey data,[46] a majority of US hospice organizations admit youth under the pediatric concurrent hospice care Medicaid or TRICARE benefit (74%). However, there is low utilization of the key government programs,[47] such as the Children's Health Insurance Program (CHIP) (3%) and the Early and Periodic Screening Diagnostic and Treatment (EPSDT) (0.2%). Concurrent care can be confusing from a regulatory compliance standpoint as Medicare – the primary payer for adult hospice – explicitly denies concurrent care for adults.

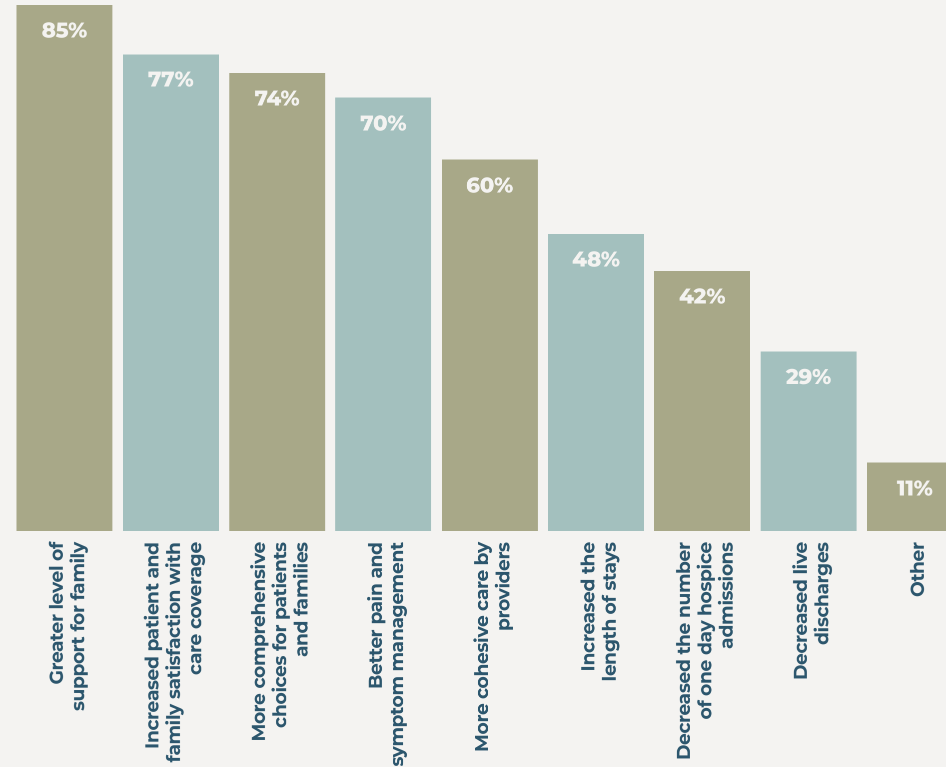
What is concurrent care?

There is variation in how organizations define pediatric concurrent hospice care.[48,49]

Fifty percent of organizations either did not know or declined to provide a working definition of concurrent care. Those that did define its common use as direct reference to the ACA and/or the Concurrent Care for Children Requirement (CCCR) or state guidelines. Features of the definition include age under 21 years (3%); 6-month life prognosis (3%); with reference to the financial source (8%); and not having to choose between life-prolonging, curative care, and hospice (42%). Definitions focused on the care location, including less stringent hospice discharge requirements during inpatient hospitalization. For example, the child could still be hospitalized/inpatient and remain enrolled in hospice with concurrent care. Life-prolonging treatments in the concurrent care definitions (e.g., chemotherapy, radiation) are rarely included. The patient or family's values/goals and teamwork or care coordination across care teams are also absent.

Concurrent Care Successes and Challenges

Figure 11: Concurrent Care Successes (proportion of respondents selecting each)



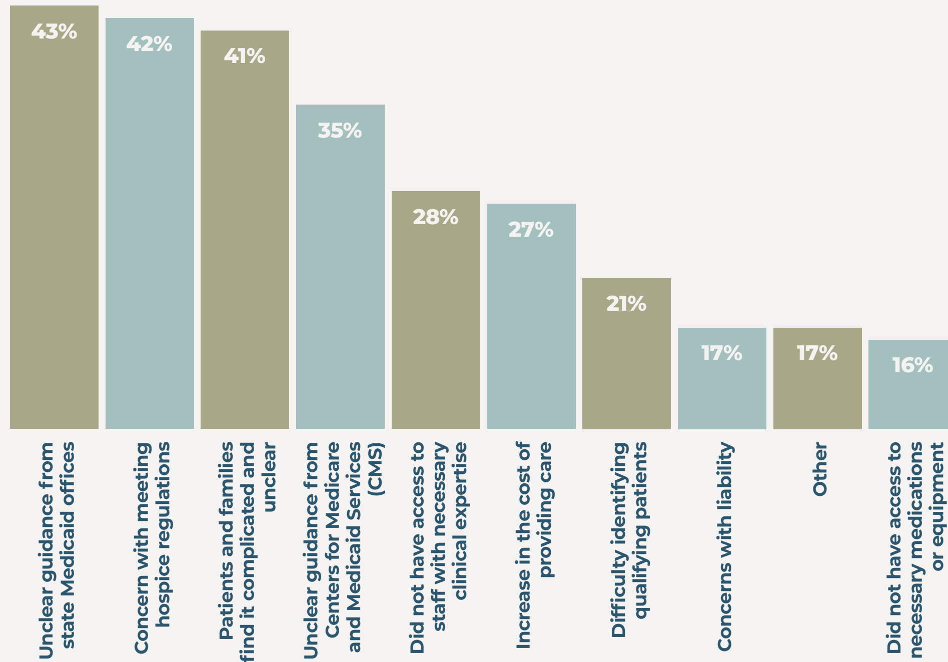
Source: *Analysis of 2024 Pediatrics Palliative and Hospice Needs Survey, National Alliance for Care at Home*

Concurrent Hospice Care (continued)

There are several notable successes in the provision of pediatric concurrent hospice care.[50,51,52] The most common concurrent care successes include a greater level of support for families, increased patient and family satisfaction with care coverage, and more comprehensive choices for patients and families. In addition, concurrent care improves the potential for home discharges, quality of life, service access, family stress reduction, relationship continuity, care utilization, and symptom management.

The most common barriers to providing pediatric concurrent hospice care include benefit complexity, perceived cost, low pediatric patient volume, lack of state implementation, and perception of cumbersome cross-provider collaboration.[53,54,55] Lack of knowledge/understanding among families and clinicians, lack of consistency across settings, programmatic and staffing challenges, frustration with the six-month prognostic timeframe in pediatrics, family reluctance, and philosophical differences were additional challenges.

Figure 12: Concurrent Care Challenges (proportion of respondents selecting each)



Source: *Analysis of 2024 Pediatrics Palliative and Hospice Needs Survey, National Alliance for Care at Home*

Section 9: Landscape

Overview of the Current Pediatric Hospice and Palliative Care Environment

Pediatric hospice and palliative care in the United States continues to expand in visibility and perceived value, driven by increasing recognition that children with serious illness and their families benefit from early, coordinated symptom management, communication support, psychosocial, and spiritual care. The findings summarized in this report reflect a field that is simultaneously advancing, through interdisciplinary models and broader service offerings, while still facing persistent challenges related to reimbursement, workforce capacity, variable access, and inconsistent payer policies.

Within this landscape, pediatric palliative care and pediatric hospice care remain distinct yet with overlapping services. Palliative care is commonly positioned as appropriate at any stage of illness and may be provided alongside disease-directed treatment, while hospice care is more often aligned with end-of-life care needs and eligibility rules. In pediatric settings, these distinctions are frequently complicated by prognostic uncertainty, family goals that may change over time, and the ongoing need for high-intensity supportive services.

Population Need and Complexity

Children with serious illness represent a relatively small proportion of the pediatric population but often require extensive clinical and supportive resources. The report highlights that these children can account for disproportionate health care utilization and costs (e.g., reference to the highest-cost segment and an average annual cost of $82,000 per child). This level of complexity reinforces the importance of coordinated care models that reduce avoidable suffering, support families, and help align care with patient/family goals.

The patient population spans the full pediatric age range, including perinatal and neonatal needs. However, specialized capacity is not uniform; for example, the report notes variability in perinatal service availability despite 61% of surveyed programs reporting perinatal care services.

Service Delivery Models and Settings of Care

Across the field, pediatric hospice and palliative care are often delivered through an interdisciplinary team approach, emphasizing:

- Pain and symptom assessment and management
- Communication and goals-of-care support
- Emotional, social, and spiritual support for the patient and family
- Care coordination across settings and providers

Care is commonly delivered across multiple settings (home, hospital, outpatient/clinic, and community-based environments), with program capabilities shaped by local workforce availability, regional partnerships, and payer policy. As a result, the “right” model is frequently community-dependent, and access can vary substantially by geography and health system infrastructure.

Landscape (continued)

Reimbursement and Coverage Realities

Reimbursement remains a defining factor in the pediatric hospice and palliative care landscape. Medicaid/CHIP frequently plays a central role in coverage for pediatric populations, while private insurance coverage may be inconsistent or require extensive navigation. The report's payer-related findings underscore that private insurance plan types and coverage structures vary (examples cited include PPO (49%) and POS (37%) among respondents referencing private coverage arrangements), contributing to differences in authorization requirements, covered services, and family financial burden.

Sustainable reimbursement is closely tied to a program's ability to staff interdisciplinary services (including social work, spiritual care, and other supportive roles) and provide timely access to symptom management and care coordination.

Workforce Capacity and Pediatric Expertise

A persistent landscape issue is the limited supply of clinicians with pediatric palliative/hospice expertise. Programs often require staff who are comfortable managing:

- Complex symptom burden
- High-acuity clinical needs in home and community settings
- Family-centered communication under emotionally difficult circumstances
- Coordination across multiple specialty teams and care sites

Workforce constraints can affect timeliness of visits, service intensity, geographic coverage, and the ability to offer specialized services (including perinatal support or advanced care planning across developmental stages).

Concurrent Care as a Central Landscape Issue

Concurrent hospice care, supporting hospice services while disease-directed treatment continues, is a critical feature of pediatric end-of-life care access and impacts decisions to enroll in hospice services. The report notes that many hospice organizations indicate concurrent care is covered (e.g., 74%), yet implementation is uneven. Common landscape-level challenges include:

- Variability in payer interpretation and operational rules
- Administrative and documentation complexity
- Coordination barriers among hospice providers, specialty teams, and payers
- Philosophical differences about the role of hospice alongside ongoing treatment

At the same time, the report identifies meaningful successes associated with concurrent care, including improved continuity, symptom management, and family support when coordination is effective.

Barriers, Facilitators, and the Direction of the Field

The broader landscape described in this report is defined by a tension between increasing demand for services and constraints in funding, staffing, and policy consistency. Common barriers include reimbursement limitations, workforce

Landscape (continued)

shortages, uneven access in rural/underserved regions, and variable payer policies, especially affecting concurrent care and interdisciplinary service delivery.

Facilitators that may strengthen the landscape include:

- Clearer payer guidance and standardized operational definitions (especially for concurrent care)
- More consistent reimbursement models that support interdisciplinary care
- Investment in pediatric palliative/hospice education and workforce development
- Regional partnerships that extend access and reduce fragmentation
- Increased awareness among clinicians and communities to support timely referrals

Implications for Programs and Stakeholders

Overall, the pediatric hospice and palliative care landscape is moving toward greater normalization and integration across care settings, but progress depends on aligning policy, reimbursement, and workforce capacity with the real-world needs of children with serious illness and their families. Stakeholders, including providers, payers, policymakers, and community partners, have shared opportunities to reduce access gaps, strengthen interdisciplinary care, and ensure families can receive appropriate support regardless of diagnosis, geography, or payer type.

Key Takeaways:

- **Pediatric hospice and palliative care is growing, but unevenly.** Programs are expanding services and visibility, yet access and program capacity vary by geography, setting, and payer environment.
- **Need is high and resource intensity is substantial.** Children with serious illness can require extensive, ongoing support; the report underscores the disproportionate cost and utilization burden (including the cited $82,000 average annual cost figure).
- **Interdisciplinary care is the backbone of effective pediatric support.** Strong programs integrate symptom management, communication, psychosocial/spiritual care, and care coordination across settings.
- **Reimbursement is a primary driver of what care can be delivered.** Medicaid/CHIP is central, while private insurance coverage may be inconsistent and administratively complex, shaping staffing and service availability.
- **Workforce constraints limit scalability.** Shortages of pediatric-experienced hospice/palliative clinicians affect service reach, intensity, and specialized offerings (including perinatal supports).
- **Concurrent care is pivotal—and complicated.** Even where coverage exists (e.g., 74% reporting coverage), real-world implementation is hindered by variability in definitions, payer rules, and coordination demands.
- **Progress depends on alignment across stakeholders.** Clearer policies, sustainable reimbursement, workforce development, and cross-system partnerships are key to improving access and continuity for children and families.

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Suggested Citation:

2026 Edition: Pediatric Facts and Figures. Alexandria, VA: National Alliance for Care at Home

Acknowledgement:

Facts and Figures are made available by the National Alliance for Care at Home Pediatric Workgroup. The following individuals are recognized for their effort in the development of this resource:

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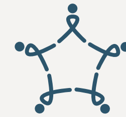

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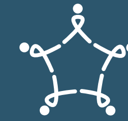

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